‘WHAT CAN WE DO? WE HAVE TO LIVE THIS LIFE!’

The lived experiences of elderly Palestinian refugees living in Lebanon, how do those experiences influence health and the refugees’ ability to manage health as they age?

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March 2017

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SUMMARY

The Palestinian refugees in Lebanon have lived there since they fled the Israeli war of independence in 1948. In the more than sixty years following this episode the situation of these refugees has not been resolved — they remain stateless and legally discriminated against by their host country. This study looks at how these life experiences of being long-term refugees have adversely affected their health as they age.

While there is limited research into the health status of the Palestinian refugees, what there is indicates that their health outcomes are poorer, including areas such as self-assessed health and incidence of mental health problems and chronic illnesses and disability in old age. However there has been little research to identify why this has been observed.

Several ecological and social theories of health attempt to model health in a way which identifies why certain patterns of health appear in communities; for example, Nancy Krieger's Ecosocial Model. This model considers both life experiences and societal levels to disentangle social and ecological factors, helping to identify where power to make changes to health outcomes lies. However Krieger's model has been used principally in western countries, and its flexibility could be tested by using it to study an Arab refugee community.

The thrust of this research questions why certain health patterns occur among the Palestinian older refugees in Lebanon, and so, in keeping with that aim, the methodology chosen was qualitative: it included in-depth interviews with elderly refugees, managers of service providers, focus groups with employees of service providers and collecting relevant photographic data from refugee participants. This methodology considers both the lay knowledge within the community and the technical knowledge of service providers. Data analysis involved developing a narrative of behaviours considered important indicators for health, such as diet, smoking and exercise, over the lifetime of the older refugees combined with a thematic analysis that focused on why behaviours had changed over time. The methodology was approved by the Social and Behavioural Research Ethics Committee of Flinders University.

I identified changes in the three behaviours analysed, including increases in smoking, eating a less healthy diet and reduction in some refugees' exercise levels. These changes were linked to environmental conditions, including overcrowding and poor housing safety, and to attempts to maintain emotional and psychological wellbeing through personal stress management and maintenance of social cohesion.

These themes, when further analysed within the Ecosocial model, were related to the underlying problems of war, refugee status and poverty. This indicates a divergence from Krieger's original model which identified underlying problems as racial/ethnic inequality, gender inequality, and class inequality.

Informants also reported their feelings of powerlessness in changing their situation. I reviewed the literature on empowerment, and found a model identifying five societal levels of empowerment, from personal to political and social action, which reflected community empowerment. Using this framework I developed a narrative of attempts to empower the refugee community, finding that the PLO and the NGOs working in the community had made several attempts to empower the community with limited success.

Laverack has examined nine factors which support empowerment, and starting with this analytical framework I looked at both literature and data to understand these attempts at empowerment. The analysis found that the power to make changes in this community existed at national and international levels with bodies like the United Nations, Israel and its allies, the Lebanese government and international donor organisations. However, these same groups resist the empowerment of the refugee community. While the refugees have attempted to influence these powerful bodies, some internal factors have limited their success, including the existence of factionalisation and internal conflict. A more structured attempt to empower the community, based on Laverack's work, modified by the findings of this analysis may, in the long term, provide strength to this community.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed.....

Date.....

ACKNOWLEDGEMENTS

I wish to thank my supervisors, Colin MacDougall, George Tsourtos, Pat Dorsett, Kris Ryan and Frank Tesoriero for their support and advice in this endeavour.

I also thank my support team in Lebanon, Kholoud, who acted as gatekeeper to the camp community, PEER interviewer, co-leader in focus groups and interpreter in Arabic interviews; the other PEER interviewers, Hiba and Suhaila; friends who agreed to advised on security matters, Olfat, Mahmoud and Sabaa; and my landlady in Lebanon, Um Rabia, who shared her home so graciously. And for their help with travel expenses, through the F. Watson Coleman Bequest, I would like to thank the Adelaide Local Meeting of the Religious Society of Friends. Without the support of these people I would not have been able to undertake this research.

For assisting in the technicalities of preparation of the thesis I would also thank Valerie Mobley, my editor, and Jason Lange, who provided computer support.

For permission to use photographs from the UNRWA archives, I thank Amani Shaltout, Photo Librarian.

I would also like to thank the scholars studying the Palestinian diaspora who have encouraged me to increase our understanding of Palestinian and refugee health; they are Maria Holt, Laleh Khalili, Rebeka Roberts, and Rosemary Sayigh.

Finally, I would like to thank the Palestinian and Lebanese informants who so willingly showed me how they lived.

1. INTRODUCTION

This chapter begins by outlining my personal reasons for being interested in the health of Palestinian refugees, and particularly the health of the refugees over their entire lifetime. I then review the history of the Palestinian refugee population in Lebanon, supplying a historical context for the life experiences of these people. Finally, I pose some research questions and summarise the content which will be included in the remaining chapters.

1.1 Why study the health of Palestinian Refugees?

Palestinian refugees left their country of origin over sixty years ago, in 1948 (Sayigh 2007, pp. 62–97). Globally, they are among the longest displaced people for whom there has been no enduring resolution to their situation. However, there are other refugee communities who have also been (or are also being) displaced for long periods, and for whom there is no foreseeable enduring resolution to their situation. These include those in the Western Sahara, refugees since mid-1970s (discussed by an international aid worker in the data, 403, p.4[1]) and Tibetan diaspora, starting with the Chinese occupation in 1950, and increasing again following the revolt in 1959 (Hess 2006, p.80). While each community of refugees will have different life experiences, and thus different health outcomes, my clinical observations suggest that the health professionals and other service providers in these communities may need to start to consider refugee health problems in terms of the effects of living in unresolved exile due to forced migration.

1.1.1 Experiences as a service provider in Palestinian refugee camps

I first saw Palestinian refugee camps in December 2001 when I worked as a volunteer physiotherapist in the Bourj el-Barajneh refugee camp, to help develop home rehabilitation (my professional specialisation) and nursing services run by a local non-government organisation (NGO). Shortly after completing this volunteer contract, I returned to Lebanon as technical advisor to a program providing holistic healthcare to elderly refugees across a number of camps and gatherings. As a volunteer I shared a three-roomed apartment with other volunteers in the camp, earning similar wages to my local colleagues, and making many friends in this camp among neighbours, colleagues and patients. Through these friendships I started to gain a fuller understanding of residents' concerns, including the problems caused by chronic illness among residents, many of whom were ageing. On my return to Lebanon I lived outside the camps, but saw most camps and many 'gatherings' (the term used for areas populated principally by

[1] References to specific pieces of data include the number of the interview and the page number where the reference can be found. See Appendix 2 for further details of the system of numbering items of data.

Palestinians, but not formally recognised as refugee camps). I was also involved with local and international NGOs in meetings where we discussed the problems that we were trying to alleviate.

These experiences gave me a general understanding of local medical services, the concerns of service providers, and specific medical problems experienced by older refugees. These included a perceived increase in chronic diseases, such as hypertension and type 2-diabetes, and I observed that many had difficulty controlling these diseases, leading to complications such as heart disease, stroke and amputation. Some people suggested to me that these patients' problems could be linked to their situation as refugees but I found little literature on the incidence or prevalence of such illnesses among refugee communities.

1.2 Historical experiences of Palestinians in Lebanon

During my time in Lebanon I became familiar with the history of the Palestinians in the twentieth century from listening to friends describing their experiences, reading the published histories and reading academic papers. This section briefly describes the main historical events, and, where possible, the social contexts in which these events took place.

1.2.1 Life in Mandate Palestine (1920-1948)

Most of the camp refugees came originally from the rural villages of Palestine. Those who had more portable assets, usually urban upper and middle classes moved to cities , but those whose assets were not portable, ie farms and homes, eventually settled in camps (Peteet 2005, p. 6). In her 1979 oral history study of the Palestinians in Lebanon, Rosemary Sayigh, an anthropologist, notes that the people themselves recall the time of the British Mandate (a League of Nations mandate from 1920 to 1948 held by the British, to govern Palestine, previously part of the Ottoman Empire) as idyllic (Sayigh 2007, p. 1). She refers to their memories of close family and village bonds, a stable environment, and sense of belonging. Despite these idyllic memories of life during the Mandate, Sayigh acknowledges and goes on to describe the difficulties for Palestinians living under that regime. Specifically, she highlights the already-changing economic situation, whereby there was insufficient wealth generated from the land to support all villagers, so that many had to leave to find work in the coastal cities (p. 33). The size of rural landholdings was usually insufficient to support a family (p. 35) and many were in debt for sums of approximately one year's income (p. 25). Jewish migration and some policies of Jewish organisations, for example, that Arab labour should not be employed on Jewish land, caused dissatisfaction among both the peasants and urban upper classes (who generally did not become part of the refugee camp communities following their forced migration). This period of unrest culminated in the Arab Revolt of 1936–1939 (Sayigh 2007, pp. 1–61).

Fleischmann (2003 p. 24), in her history of feminist politics during the Mandate, also reports that her informants remember this period as one of stability, despite the massive social changes which the country was experiencing. Education services varied in quality and availability because each village had to finance the infrastructure of its own schools. Female education was given a low priority by both the government and the villagers. When girls were educated at all, the focus of the curriculum was on domestic science (Fleischmann 2003, pp. 38–39). Fleischmann also reviews health policy during the Mandate, which was primarily aimed at improving the overall health and hygiene of the population. Initiatives included the establishment of 36 infant welfare clinics for Palestinian communities, funded by both private charities and the government, and also the regulation of midwifery. The focus of child welfare was on maternal education and hygiene, similar to that offered in middle-class Europe. For example, bathing daily was encouraged — a practice that was difficult in a village environment without a piped water supply. Regulating midwifery services had the side-effects of undermining the authority and use of traditional midwives, and imposing Western concepts of healthcare on the village communities. The general focus was on modifying the behaviour of the individual rather than providing the infrastructure that would make healthy behaviours possible (Fleischmann 2003, pp. 49–51). In summary, the Mandate was a period of gradual change, shifting towards a cash economy, and exposing the Palestinian peasants to sometimes inappropriate European concepts of health, education and other social services. However, the people were supported by strong community cohesion in their villages, and close family bonds.

1.2.2 The Nakba: becoming refugees (1948)

The status of the Mandate came into question at the end of World War II. The Palestinian community wanted an Arab state, the Jewish population a Jewish state. The British were unable to negotiate a compromise and referred the problem to the newly created United Nations (Morris 2001, pp. 167–90). The United Nations voted to partition Palestine into two states: one primarily Jewish and one primarily Palestinian Arab. However, fighting started as soon as partition took effect (Said 1992, pp. 99–102; Morris 2001, pp. 191–252). The details of this conflict are not relevant to this study other than in relation to the exodus of Palestinian Arabs from their homes and villages, so we will now focus on that forced migration and its consequences.

Contemporary official Israeli publicity said that the Palestinians fled ‘voluntarily’, urged by their own political leaders, in order to leave certain areas clear for battle. However, Morris identifies documentary evidence of a long-standing Jewish policy to force the Palestinians to leave their ancestral towns and villages and settle outside the borders of the new state of Israel (Morris 2001, pp. 252–58). Sayigh (2007) offers several reasons for Palestinians to flee, including poor military organisation, poor communication, and poor supplies of weapons amongst the villagers, who were facing a well-disciplined and well-armed Israeli force (Sayigh 2007, pp. 65–84). Massacres in some Arab villages prompted others to leave before suffering the same fate

(Sayigh 2007, pp. 90–97). Many Palestinians were physically and forcibly expelled: they were driven to the borders and told to leave Israel (as their homeland was now called), and not return (Sayigh 2007, pp. 90–94, p. 105).

Lebanon's history has been dominated by the conflicts between religious sects. It was part of the Syrian Mandate, under the control of the French, at the collapse of the Ottoman Empire. The French separated their Mandate into a closely governed area, with boarders similar to modern Syria, and Lebanon, which had a semi-autonomous status (Traboulsi 2007, p. 77). In World War 2, after the fall of France to Nazi Germany, the Vichy government ruled Lebanon, but in in 1942 the British and Free French retook both Syria and Lebanon (Traboulis 2007, p.104). In 1943 the Lebanese leadership declared independence, and while it was not initially accepted by all nations, by the end of the war, 1945, the great powers accepted this independence (Traboulsi 2007, pp. 107-112)

The Government was structured along 'confessional' lines (meaning linked to religion). Leaders of the various religious sects, Druze, Sunni Muslim, Shia Muslim, Maronite (the dominant Christian sect) and a range of smaller Christian sects, were each worried that they would be dominated by another sect, so in establishing the independent state of Lebanon there was a 'National Pact' which established a balance of power between the various sects. Thus the Christians and Muslims would hold a ration of seats in the Parliament of 6:5, ensuring Christian control. The President and head of the Army, would likewise be Maronite Christians, but the Prime Minister would be Sunnie. (Salibi 1988, p. 169). The economy was structured along monopolistic lasses-faire principles. (Traboulis 2007, p. 156). This was the Lebanon which in 1948 received the Palestinian refugees.

In the immediate aftermath of fighting there was little organised support for the refugees. It was summer and the conditions were hot and dry. Although many of the local peasants in South Lebanon were generous, others were less supportive, refusing requests for food and drink unless they were paid (Sayigh 2007, p. 107). In the confusion of the flight from Palestine many families were split up, (Sayigh 2007, p. 89). Most refugees gathered together in 'camps', near Sidon and Tyre, the cities closest to the border with Palestine. Later, the Lebanese government set up refugee camps further from the border, in the Bekaa Valley, on the outskirts of Beirut, and north of Tripoli. Conditions were difficult, with several families crowded into each tent. There were inadequate hygiene facilities and so people suffered with dirt and lice. Sayigh's informants reported that they found these conditions 'shameful' (2007, p. 108). In addition to the hardships of refugee life there was the psychological trauma of separation from home and property. Sayigh's informants, in her 1979 study, used terms such as 'death', 'paralysis' and 'non-existence' to describe their feelings at this time (Sayigh 2007, pp. 109–10). While the period of the Mandate had brought gradual changes, this period, known as the *Nakba* (from the Arabic word for

catastrophe), forced massive changes over the space of a few months. People lost most of their property, their land, and often family members. They also lost something more fundamental, their social structure. There was little support during this time.

1.2.3 Establishing the camps: the early years (1948–1975)

The fleeing Palestinians initially expected to return to their homes quite soon, once the violence had subsided (Khalili 2007, p. 43). The host countries, Lebanon, Syria and Jordan, had also assumed the refugees would be returning home once the conflict was over (Sayigh 2007, pp. 110–11). However, it was soon apparent that the Palestinian Arabs had lost that most fundamental human right: nationality (United Nations 1948,Article 15a). When it became obvious that Israel would not take back the Palestinian refugees, the Arab world brought pressure to bear on the international community to assume financial responsibility for them. The United Nations' initial involvement in the problem made this relatively easy to achieve (Sayigh 2007, p. 111).

In the interim, support and care of the refugees was undertaken by local and international charities, including the Red Cross (Roberts 1999, p. 36; Khalili 2007, p. 45). Many refugees had used up whatever resources they had brought with them in surviving through the early years (Sayigh 1978, pp. 106–07). The United Nations Relief and Works Agency for Palestinian Refugees in the Near East (UNRWA) was established in December 1949, with the aim of carrying out direct relief and works programs to assist the Palestinian refugees (United Nations 1949). Functionally, UNRWA directly offered (and still offers) relief services in the areas of social services, education, and health (United Nations 1949). Host governments provided land for camps and currently UNRWA manages twelve camps in Lebanon (Fig.1)

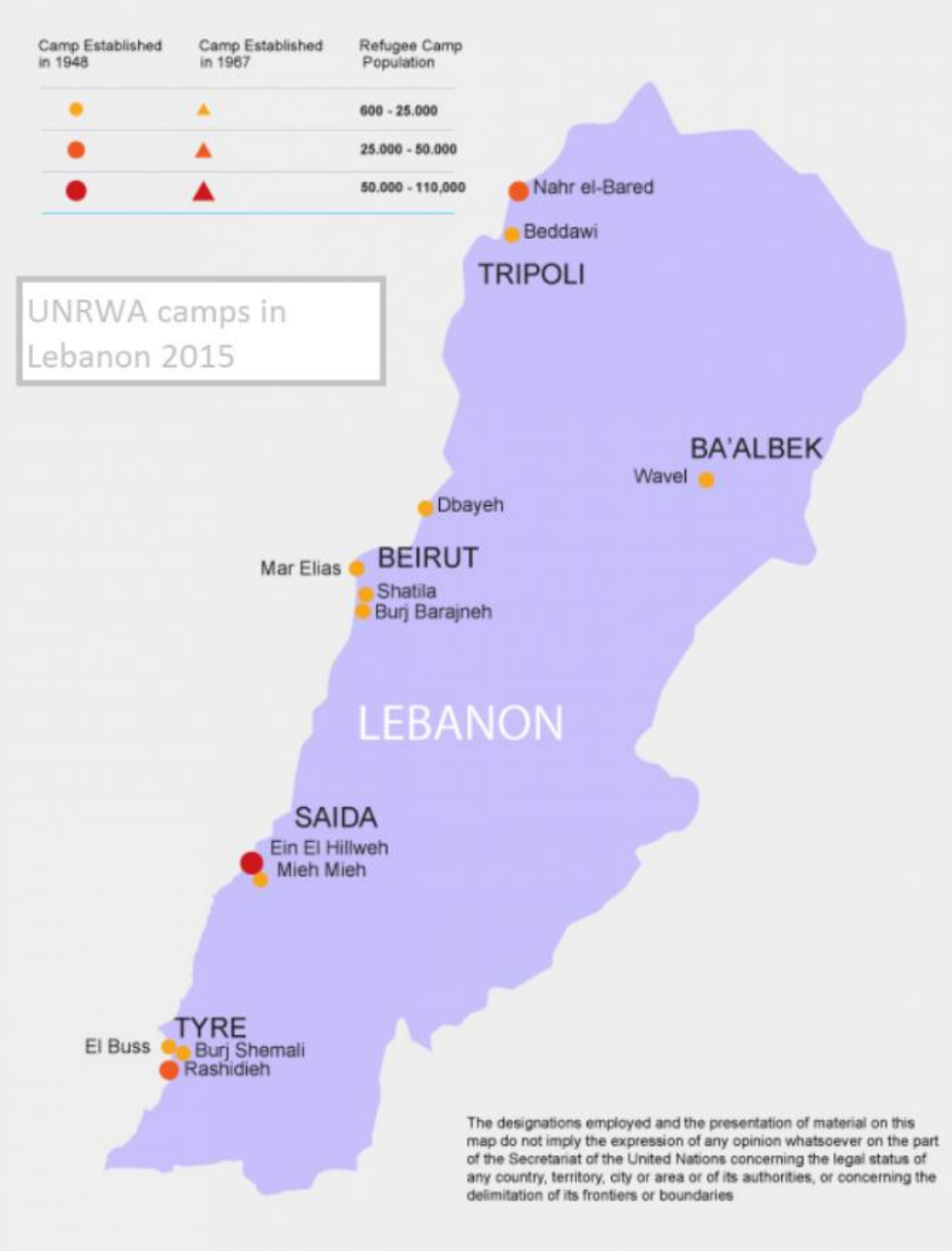

Figure 1: Map of Lebanon showing current camps (http://www.unrwa.org/where-we-work)

Meanwhile, the government in Lebanon had concerns that the presence of 100,000 Palestinian refugees would destabilise the nation. The Lebanese government is organised along 'confessional' lines, meaning that there is a balance within the government and public service between the various religious denominations, specific positions being reserved for members of specific religions. It was feared that the arrival of the Palestinians, most of whom were Sunni Muslims, would upset this delicate balance of political power (Sayigh 2007, p. 115). This fear is considered to be responsible for the strict level of government control that has been exercised over Palestinian refugees in Lebanon since 1948. Palestinians were not (and are not) allowed to work in the public sector, nor in many private sector areas (Sayigh 2007, pp. 115–18); nor were the camps provided with access to Lebanese utilities (water and electricity) until the mid-1970s (Sayigh 1994, p. 9; Khalili 2007, p. 45).

Following the civil unrest of 1958 in Lebanon, the government placed the camps under the control of the Deuxieme Bureau, a branch of the Lebanese army responsible for internal security. This French term is used in Lebanon, which was a French Mandate (as Palestine was a British Mandate), following the collapse of the Ottoman Empire in 1919 — Lebanon was thus one of the *Francophonie* nations. The Bureau set up stations outside each camp and controlled all activities inside the camps, including water usage, bathing times and building activities. Camp residents who opposed the control of the Deuxieme Bureau risked imprisonment, deportation, torture or execution (Khalili 2007, p. 46; Sayigh 2007, pp. 140–47).

Initially most camps consisted of tents. The tents were gradually made more weatherproof, for example, by stealing paving stones to hold them down in storms. Later, flattened petrol tins and sheets of galvanised corrugated iron (zinco) were purchased to construct huts. Sanitary facilities consisted of communal toilets, but there were no bathing facilities, (Roberts 1999, p. 37). Women carried household water from water tanks provided by UNRWA (Sayigh 1994, p. 39). Although cement and cinder blocks were forbidden (Sayigh 1994, pp. 38–39; Roberts 1999, p. 37) by the end of the 1960s many homes were constructed of cement blocks, with zinco roofs (Khalili 2007, p. 45).

Family structure had been severely damaged during the *Nakba*. Some families were split between the Arab countries and Israel; people were killed or had died during the flight, and some families had been separated. However, during the initial years people searched out family members or people from the same village. Sayigh, in her study of Chatilla camp, describes how the camp leader searched for people from his village in Palestine, and encouraged them to settle in Chatilla camp (Sayigh 1994, pp. 35–37). Roberts, in her study of Bourj el-Barajneh, concluded that this process was less formal in that camp, but people still encouraged family and friends to join them (Roberts 1999, p. 59 and p. 93).

The Palestinian peasants had been subsistence farmers, growing a few cash crops to buy items not produced in the villages and to help them pay taxes. However, in Lebanon they became farm labourers or building labourers (Sayigh 2007, p. 118). Later, camps were set up in the industrial area of Mkallis (in Christian East Beirut), where the inhabitants could provide cheap factory labour (Sayigh 2007, p. 129). Peasant women had worked in Palestine in family homes or on family farms; however, in Lebanon poverty forced them to work in factories, on farms, as servants, or selling fruit and vegetables in the street (Sayigh 1994, pp. 45–47; Sayigh 2007, p. 129).

UNRWA offered basic education to children in the camps, and for children from some villages this was their first chance to attend school. Schools were severely under-resourced. For example, the first school in Chatilla camp, in 1951, consisted of three large hospital tents with three teachers per tent (Sayigh 1994, p. 53). Ugland, in his 1999 survey, found that those refugees over 44 years

old (i.e. the cohort born in Palestine or born in the six years following the *Nakba*), had literacy rates of approximately 35% for women and 75% for men. Among those aged 30 to 44 years literacy had risen to more than 85% among women and more than 90% among men, suggesting that the camp Palestinians were taking advantage of the free education provided by UNRWA schools (Ugland 2003, p. 115). Thus, the refugees who grew up in the camps were better educated than their parents.

Sayigh found it difficult to find workers from the health (i.e. curative) services who had operated during the period when the camps were under direct Lebanese control, but suggests that the main causes of ill health at this time were malnutrition, poor housing and inadequate clothing. Tuberculosis was quite common, and was one of the few illnesses which the Lebanese medical services would treat. Men often suffered from work injuries and war injuries (from trying to infiltrate Israel) (Sayigh 1994, pp. 55–56). UNRWA clinics were operating and people used a combination of traditional medicine and the services provided by the clinics. However, one of Sayigh's Chatilla respondents asserted that their health had been better in the villages, despite the lack of clinics and doctors (Sayigh 1994, p. 58).

The period following the *Nakba* was characterised by the need for basic survival — learning to survive in a market economy far removed from villages and country of birth. Sayigh describes this period as the time when Palestinians changed from peasant land owners and sharecroppers to urban proletariat (Sayigh 2007, p. xxv). However, in the late 1960s the political and social picture in the camps changed. These changes were local reflection of the political activism of the Palestinian diaspora, which developed in the 1960s, with a range of political parties and 'liberation' groups. These organisations came together in coalition to form the Palestine Liberation Organisation (PLO) in 1964. This organisation attempted to form a Palestinian proto state (Y. Sayigh, 1997, p. 19)

The Six-Day War in 1967, waged between Israel and several Arab countries, ended in defeat of those Arab countries. Following the war the Palestinians began to assert their national identity (Mansfield 1991, p. 280). In the Lebanese camps there was unrest in 1969 when the refugees rebelled against the Lebanese authorities. Sayigh reports these rebellions as being popular in nature, though organised and coordinated by political parties (Sayigh 2007, pp. 169–82). Roberts' informants remember a feeling of freedom to do what they wanted inside the camp during this period (Roberts 1999, p. 38). The resolution of this political activism came with the Cairo Accords, a treaty agreed to in November 1969 between the Lebanese Government and the PLO. The first four items in the Accords gave the Palestinians in Lebanon the right to work, reside and move freely, and to form local committees which would manage the camps in cooperation with the Lebanese government. Moreover, Palestinians would have the right to participate in the 'Palestinian Revolution' (Cairo Accords 1969). Sayigh, who collected data during this period,

found that most people in the camps were affiliated with a political party. She reports that camp leadership was mainly composed of ‘revolutionary intellectuals’, but notes also that the middle-level cadres were often from the camps.

Services in the camps were improved following the Cairo Accords, with the Popular Committees (politically-appointed committees who managed the running of camps following the withdrawal of the Lebanese authorities) arranging the supply of electricity and water to homes (Roberts 1999, pp. 85–86). More substantial housing was built with money from the PLO (Roberts 1999, p. 38). The PLO also ‘poured money’ into health and education services, as well as providing many jobs within its bureaucracy. This raised the standard of living in the camps enormously (Khalili 2007, p. 48). This period saw a rising level of self-determination and self-management in the Palestinian community, with service provision by UNRWA supplemented by initiatives of the political parties.

1.2.4 The Lebanese Civil War (1975-1990)

In 1975 the Lebanese Civil War (1975–1990) started. Neither the causes of the war, nor the political alignments of the protagonists are relevant to the health of Palestinian refugees. However, because many of the refugees in the camps were directly involved in the war, there were some health implications. For example, Roberts found that Bourj el-Barajneh camp ‘was attacked on numerous occasions and most people lost family and friends’ (Roberts 1999, p. 39). There were several massacres of Palestinian civilians (and likewise massacres of Lebanese civilians by Palestinian militias) in the period from 1975. For example, the camps of Tel-az-Zaatar, Jisr-al-Basha and Maslakh-Karantena in East (Christian) Beirut were besieged and when they surrendered thousands were killed. The survivors moved to other camps in West (Muslim) Beirut (Khalili 2007, p. 51). These massacres are commemorated in both written material and in the oral traditions of the camp Palestinians (Khalili 2007, p. 68).

The Israeli invasion of Lebanon in June 1982 culminated in the siege of West Beirut during July and August (Jansen 1982, pp. 1–87); this siege was aimed at the defeat of the PLO in Lebanon. Although it did not succeed in destroying the PLO, in the negotiated peace the leadership and all Palestinians who were not originally displaced into Lebanon withdrew from Lebanon (Jansen 1982, pp. 39–63). The Israelis believed that some fighters had stayed in Beirut and its forces supported a Lebanese militia which entered the refugee camp of Chatilla and the neighbouring suburb of Sabra. The militia perpetrated a well-documented massacre, killing an unknown number of civilians (estimates vary from 800 to 3,000) (Jansen 1982, pp. 91–109; Swee 1989, pp. 100–118). These events have been transmitted to the next generation of Palestinians through storytelling and songs (Khalili 2005, pp. 207–08).

Following this traumatic episode, the camps were left with reduced political leadership in the

middle of the ongoing civil war. The international leadership of the PLO fragmented following its withdrawal from Beirut. There were two groupings: those who supported Syria, and those who followed Yasser Arafat, chairman of the PLO, and leader of *Fatah*. These two factional groups feuded from 1983 to 1987 (Sayigh 1997, pp. 29–30). Consequences of this factionalisation were felt through many levels of camp society, by the remaining political parties, by popular committees, and by families (Giannou 1990, pp. 41–42; Khalili 2007, p. 53) and will be discussed further in Chapter 8. These struggles in Lebanon led to sieges of several refugee camps. From 1985 to 1988 camps were surrounded by fighters from a Syrian-backed Shi'a militia several times, with the final sieges lasting for eight to nine months (Giannou 1990, pp. 247–49). In the besieged camps starvation and associated diseases were rife; many residents sustained injuries or were killed in the bombardments (Giannou 1990, pp. 51–219; Sayigh 1994, pp. 231–320). Death rates from injury were high; moreover, when undertaking a needs analysis for an NGO, McCue also found a direct relationship between war casualties and deaths from heart attacks, (McCue 1994, ES1 and Appendix 3 Illustration 1). The people themselves told Roberts that they were able to survive because of community cohesion, though others claimed that they had only survived because the physical structure of the camps made invasion impossible (Roberts 1999, p. 39).
During the years of the Civil War, the Palestinian camps were heavily involved in the conflict. The increased facilities and infrastructure that had come from hosting the international headquarters of the PLO were lost. However, the community remained 'steadfast' and was able to overcome many internal and external problems. There is some evidence that the war had far-reaching health consequences, other than deaths from wounds, starvation and acute illness. For example, as mentioned above, there was an increase in the incidence of heart disease.

1.2.5 Oslo and afterwards (1991–2008)

After the conclusion of the Civil War in 1990 and following the Oslo Accords in 1993, which attempted to resolve the Palestinian–Israeli conflict, violence against Palestinians died down, and consequently the PLO militia groups became almost invisible (Khalili 2007, p. 54). The focus of Palestinian and international politics at this time moved from the diaspora refugees to setting up the new Palestinian proto-state (McCue 1994, p. ES4).

There have since been changes in funding for service provision over a wide range of areas. In terms of medical services, UNRWA continues to provide clinics and partial funding for hospital services, though these are over-extended (Soweid and Al Khalidi 2004, p. 19). For example, in 2006 medical officers saw an average of 95 people per day, and in 2005 they saw 110 (UNRWA 2008). These numbers permit the doctors on duty to spend less than five minutes with each patient. In the early 1990s McCue described the Palestinian Red Crescent Society (PRCS) services (hospitals and clinics in the camps) as 'diminishing and increasingly costly' (McCue 1994, p. ES4). The unmet service needs were being partially met by programs run by NGOs and funded

by donors. Much funding was obtained by describing the suffering of the Palestinian people in the camps, both during the *Nakba* and throughout the years spent in Lebanon, often emphasising massacres and sieges. This perspective focused the attention of the people away from their future prospects as their memories and attitudes remained fixed on the traumatic past (Khalili 2007, p. 110). Any focus on human rights or political activism was avoided both by the camp populations and the NGOs; the displaced Palestinians were encouraged to see themselves passive victims (Khalili 2007, p. 204).

The physical environment of the camps has improved over time; for example, in 1995 UNRWA undertook to provide underground sewers to replace the existing open drains in the streets of most camps (Davey & Maziliauskas 2003, p. 1). However, the overall conditions in the camps remain poor. There is overcrowding, lack of privacy and lack of natural light. There are few open spaces, and pathways between the houses are often barely wide enough to walk along (Roberts 2004, p. 189). These environmental problems expose people to risk of injury, indoor air pollution, and gastro-intestinal infections (Makhoul, Ghanem et al. 2003, p. 257).

Roberts identifies mutually supportive family networks as a positive element within the camp community, and notes that families with larger social networks tend to be more prosperous (Roberts 2004, p. 249). Social solidarity, based on common ethnic background and shared history, is seen by Makhoul and colleagues to counter the negative effects of the challenging conditions found in the camps, and she sees this as adding to the resilience of the community (Makhoul, Ghanem et al. 2003, p. 259). Khalili found that this social cohesion partly comes from a sense of collective national identity, which is referred to in Arabic as *sumud* (generally translated as ‘steadfastness’). She identifies both organised and informal commemorative practices which support *sumud.*

1.3 Aims of research and outline of thesis

My overarching purpose in undertaking this this research is to understand how these lived experiences, briefly outlined above, have contributed to the health in old age among Palestinian refugees living in Lebanon, and what are the implications for addressing these health issues. To guide my research I pose the following questions:
In relation to the Palestinian refugees in Lebanon;

1. What aspects of their lived experiences impact upon health in old age?
2. How do their life experiences interact with each other to support or detract from good health in old age?
3. Where does the power to change these life experiences to promote better health in old age lie?
4. How do these lived experiences, the interactions between experiences and the power to

control the lived experiences impact on health services in this community?

Over the time the study was conducted these questions have been refined and modified by a greater understanding of the nature of health, the nature of qualitative research and the data itself.

Having briefly reviewed the history of the Palestinian refugees in Lebanon, and my own experiences with these communities, Chapter 2 will present a review of the literature on the health of Palestinian refugees in Lebanon. Chapter 3 will continue the review of literature by exploring the concept of health, and suggesting ways of operationalising it which will help to answer the research questions; I will also examine an inclusive ecosocial model of health which will be useful in addressing the research questions. Chapter 4 will explore the literature of community empowerment and the role of empowerment in improving health outcomes. This will conclude the review of literature. Chapter 5 will outline the epistemological and methodological problems in researching this community; it will outline the methods used and justify the reasons for their use. Chapter 6 will examine health issues from a behavioural perspective, identifying healthy and unhealthy behaviours and the lived experiences which drive these behaviours. Chapter 7 will examine the societal links to health, and identify the underlying reasons for health problems within an ecosocial model. Chapter 8 will analyse the power structure of the camp and discuss the problems that the community has had in controlling its own health outcomes. Finally, Chapter 9 will link the problems of health in this community with the power to make changes.

2
HEALTH AMONG PALESTINIAN REFUGEES IN LEBANON

This chapter examines knowledge of the health of Palestinians living in Lebanon, with a focus on those living in camps and gatherings (informal camp-like communities of Palestinian refugees). Peer reviewed literature is sparse in the area of health. It comes principally from the Department of Health Promotion and Community Health of the American University of Beirut. However, I was aware of several studies, commissioned by a donor and undertaken by international NGOs and a research institute, which examined health and other areas of life in the camps and gatherings. While not peer reviewed, this grey literature provided a second strand of information in an area not previously widely researched, and as Jones suggests, it may include cutting edge research (Jones 2007, p. 42). I have therefore read this material critically, bearing in mind it lacks peer review.

2.1 Available literature on Palestinian health

I conducted a systematic literature search using key terms including 'health' or 'chronic illness' and 'Palestinian' or 'refugee and Lebanon' in the databases Medline and CINAHL. Results were few, with work primarily coming from the The Urban Health Study (UHS), a large survey of three poor communities in Beirut, including Bourj-el-Barajneh camp, in the southern suburbs of Beirut. This study has provided some useful factual information. The researchers, from the American University of Beirut's (AUB) Centre for Research and Population Health, surveyed 3,300 households across three poor suburbs in 2002–03. The survey included subsections of respondents from households in several categories, including elderly people and youth. Several papers have been published based on this study (Saab, Salem et al. 2005; Chaaya, Mehio-Sibai et al. 2006; Afifi, Yeretzian et al. 2009). Its methodology permits comparisons of Palestinian health with health in similar, poor Lebanese communities. Several smaller studies of Palestinian communities have also investigated health among the refugees.

My experiences as an NGO technical advisor made me aware of several studies commissioned by donors, some by individual academics, and others by research institutes. With a paucity of peer reviewed literature, I turned to this source of information. While these have not been peer-reviewed, their authors are trained researchers. This grey literature included a survey of camps and gatherings undertaken by the Fafo Research Institute (Fafo), for the Norwegian Ministry of Foreign Affairs, which has been a donor to both the Palestinian and Lebanese communities in Lebanon. This survey conducted interviews with almost 4,000 households in the period from 1999 to 2001. It used a survey tool that they had developed and which had been previously used in camps in Jordan and the Occupied Palestinian Territories, referred to as LIPRIL, to gain a better understanding of living conditions in the camps. The results were published in 2003

(Ugland 2003; Tiltnes 2005). This methodology thus allows comparison with Palestinian refugees in other neighbouring countries.

Another survey, undertaken by Handicap International for the European Union Humanitarian Aid and Civil Protection (ECHO), a large donor that funds a range of programs in the Palestinian community of Lebanon, looked at the problems of disability among elderly Palestinian refugees living in Lebanon. It used interviews based on several standardised and validated instruments appropriately modified for an Arab community, to assess medical issues, psychological difficulties, physical disability, environmental issues and carer issues. (Lemire, Dubois-Rondon et al. 2004).

A further strand of information comes from the NGO needs analyses. These tend to answer less complex questions, and focus on service needs within specific geographic areas, but some have gone further to look at identified health issues as well as service needs. Some service providers have also provided access to their internal evaluations; among these are the annual health reports from UNRWA.

A final source of information has been peer-reviewed studies of other refugee communities, some of which cast light on the experiences of the Palestinians in Lebanon. Though each refugee community has different experiences, there are common threads which helped me to identify potential directions for this research. For example, studies of refugees from the break-up of Yugoslavia highlight the impact of war on mental health.

Thus, while there is a paucity of peer-reviewed research this particular community, there is a range of published literature which adds to the understanding of community issues, if read with care and consideration of the aims of the work in question.

2.2 Health of Palestinian refugees in Lebanon

I have reviewed the literature under several headings, grouping information from the literature on similar subject matter together. However, there are several significant gaps in the literature, including limited information on both social and behavioural determinants of health.

2.2.1 General health status

A frequently used measure of health in a community is self-reported health. This measure has been validated as a measure of potential morbidity and mortality by several researchers and is now used in standardised health questionnaires such as the SF36 (Ware, Kosinski et al. 1994). Several surveys have used versions of self-reported health when considering Palestinian wellness.

In a UHS examination of smoking among informants aged sixty years and over (sample size 760) found that the informants in Bourj-el-Barajneh camp had significantly more self-reported bad health than residents of Lebanese suburbs, with 43.4% saying they suffered bad health (Chaaya, Mehio-Sibai et al. 2006, p. 919). However, the Fafo study found the self-reported health status of the over 60s, was bad or very bad for 60% of men and women, while those who reported very good health was almost 0%. (Ugland 2003, pp. 62–64, and Fig. 3.2). Lemire and colleagues also considered self-reported health in their survey of disability among Palestinian refugees, and found as many as 76% of their sample of refugees aged 60 and over reported their health status as bad or very bad (2004, pp. 21–22).

The UHS compared its result with other poor urban communities and found statistically significant poorer health in Bourj-el-Barajneh, 43.4% having 'poor' self-rated health (with Nabaa having 21.2% and Hay-el-Sullum having 42.2%). The other two studies appear to report even worse self-related health. The differences between study results may have several explanations. Firstly, the studies were undertaken at different seasons of the year. The UHS collected data in early summer 2002 and winter 2003 (Saab, Salem et al. 2005, p. 654); data for Lemire's disability study was collected in autumn 2004; and the Fafo study collected data in 1999 (no time of year given). The poor housing in the camps (Section 2.2.4) may result in some seasonal differences to self-rated health; for example, colder or warmer weather may make people more or less aware of symptoms, or more or less likely to suffer from transient illnesses. The sample population may also have some influence on responses: the UHS looked only at one urban camp, while the two other studies were undertaken within the Palestinian camps and gatherings, some of which are urban and others rural. Finally, some reports do not provide details of the actual questions or the range of possible responses.

However, while the actual measures of self-reported health show some fluctuations, all researchers state that health of older residents is generally poor in the Palestinian community, and that it is worse than other similar communities, such as the poorer Lebanese communities, the Jordanian Palestinian camp residents, or other poor communities.

2.2.2 Chronic illnesses and functional impairment

The Fafo study and the Lemire research both asked questions about chronic illnesses. Fafo asked if the informant suffered from 'any physical or psychological illness of a prolonged nature, or any affliction due to injury, a handicap or age.' They found that 19% had such a chronic health problem and, on further questioning, found that 9% were 'disabled'— defined as difficulty going outside without assistance (Ugland 2003, p. 67). When examined by age group, more than 70% of informants over 70 years of age had a chronic illness, and 40% of men and 50% of women in the 50 to 59 year old cohort reported chronic illnesses. The study investigated disability further, by asking people if they could perform five basic activities of daily living. They

found that 53% could perform all these activities of daily living, while 10% could perform none or only one of the activities (Ugland 2003, pp. 70–71). These responses were clustered among the lower-income informants and the less well-educated groups, but disability and chronic illness were not exclusive to these groups. (Ugland 2003, pp. 68–69). This number of refugees with disability conflicts with an international NGO publication, based on both the NGO's needs analysis and their final reports about their interventions to their donors. This organisation found that only 1.7% of people living in Palestinian camps and gatherings were disabled, based on information from the Palestinian Disability Forum, using a definition based on the 1980 International Classification of Impairment, Disability and Handicap (Dominguez & Saint-Esteban 2002, pp. 6–7 and p. 11). However, the authors of the report do suggest that they may have underestimated the prevalence of disability because they had focused on physical and mental disability.

Lemire and colleagues were studying informants over 60 years of age, with different strands of their research looking at function, dependency and chronic illnesses. When they asked about current illnesses, they found that 97% of respondents had a current illness, with 95% taking medication and 57% having ancillary treatment, such as nursing or physiotherapy. They identified the main chronic illnesses as diabetes, hypertension, cardiac problems, hemiplegia, sciatica and back pain (Lemire, Dubois-Rondon et al. 2004, p. 22). When asking about disability and dependency, using a standard measure of autonomy, dependency and physical disability (GIR), they found that of the 260 informants, 105 were autonomous (40.4%), and 81 needed some level of assistance from a carer (31.2%), and that dependency increased with age (Lemire, Dubois-Rondon et al. 2004, pp. 23–24). This suggests that the elderly refugees in the camps and gatherings faced serious difficulties in managing their lives independently.

The literature reports considerable differences in levels of chronic illness and of disability, depending on the research methods used and the rationale for the research in question. For example, Fafo was aiming to investigate the living conditions of the community as a whole (Ugland 2003, p. 13) while Lemire's research was focused on health among the aged, specifically in terms of medical, psychological, dependency, environmental and social factors. (2004, p. 10). Dominguez and colleagues, on the other hand, were reporting on their activities as service providers (2002, p. 5). However, in general all the reports suggest both high levels of chronic illness and high levels of disability in the refugee communities.

2.2.3 Mental health problems

Mental health problems cover a wide range of illnesses, and conditions, and as will be discussed in Chapter 3 (section 3.2.2.2) some of these will have an effect on physical health. Peer-reviewed research and also other studies have considered aspects of mental health. In addition, some peer-reviewed research has specifically looked into the effects of war on mental

health in other locations.

The UHS compared psychological distress with perceptions of health among women in the Lebanese and Palestinian communities (Saab, Salem et al. 2005). Psychological distress was determined using a validated survey instrument and found a high prevalence of psychological distress, with an overall level of 46.6% of the women and 49.9% of women living in Bourj-el-Barajneh camp reporting psychological distress. Using the same validated instrument, Saab and colleagues compare this to other groups, such as people living in a more affluent Lebanese community (27%), or prisoners tortured and released from Israeli prisons (42%). They also note it is double the level of psychological distress found in England, Scotland or urban Pakistan.

Another paper from the UHS looked at depression and religiosity among older people in the three communities (Chaaya, Mehio-Sibai et al. 2007). Their discussion of depression in the Bourj-el-Barajneh community found that the Palestinian community showed higher levels of depression, compared to the two Lebanese communities (31% among Palestinians, compared to 21% and 12% among the Lebanese communities (p. 5)). Both these peer-reviewed studies show a higher level of mental health problems in Bourj-el-Barajneh Palestinian camp, which is the focus of this research.

Both the Fafo study and the study of dependency in old age (research projects not peer-reviewed) assessed mental health problems. Lemire et al. (2004) assessed self-reported mental health as 'bad' or 'very bad' in 65% of the older population, compared with other Beirut respondents where 42% reported very bad mental health. Like Saab and colleagues, the Fafo researchers assessed psychological distress but used a different instrument from the UHS; this allowed them to focus on anxiety and depression, which they argue is a good proxy for overall mental health. They found that the Palestinian refugees had significantly higher scores than Jordanian refugees. Among the Palestinians in Lebanon there was little difference between men and women, but that psychological distress increased with age and with worsening physical health. The Fafo researchers did not suggest a causal link with poor physical health, nor does their data make it possible to suggest the nature of links between these variables.

This literature suggests that there is a high level of depression and anxiety in the Palestinian community in Lebanon — probably significantly more than in the Lebanese community, even though both shared the experiences of the Civil War, or for the Palestinian camp communities in Jordan, who share the experiences of being refugees. There have been studies of the mental health problems of refugees in the Balkan wars of the 1990s. Hunt and Gakeny (2005) studied Bosnian refugees and internally displaced people. They found that ten years after the war the refugees had higher psychological symptomatology than the people who had been internally displaced. This study focuses on post-traumatic stress disorder (PTSD), and the authors suggest this could be related to the prolonged asylum process, loss of cultural support, and

language barriers. While the latter two reasons are less likely to apply to camp-residing Palestinians, who speak a similar dialect of Arabic to the Lebanese host country, and live in a camp community made up of people of similar cultural background, the first reason is very relevant, since the Palestinians have not had their refugee situation resolved in more than 60 years.

Mollica et al. (2001) also studied mental health among Bosnian refugees, following their initial study with comparisons three years later. They found that depression (with or without PTSD) was much more likely to become chronic among the refugees, with 43% remaining depressed on follow-up, (compared to 10% to 20% in the general population). Additionally, 16% of people who had not been depressed had become depressed in the three years between data collections. PTSD was usually found to co-exist with depression in this population, at both baseline and follow-up data collections.

Thus, there is a body of research which identifies high levels of depression and anxiety among the Palestinians. This is consistent with research in the former Yugoslavian states, where refugees have high levels of depression. In the latter research there is evidence that suggests PTSD is co-morbid with depression, and that both conditions become chronic.

2.2.4 Health and the environments?

There has been limited peer-reviewed research on the physical environment that the refugees live in, though not all studies have linked their research findings to the health of the refugees. For example, the engineers involved in retrofitting closed sewage systems into the some camps outside Beirut published their work without linking the value of it to health outcomes (Davey and Maziliauskas 2003); however, another study specifically considered how the physical environment of a gathering (informal camp) in Beirut did link health outcomes to the quality of the physical environment (Zabaneh, Watt et al. 2008). Davey and colleagues (2003) described the provision of drinking water, sewage and stormwater infrastructure in the eight camps outside Beirut, a contract which commenced in 1997. Their description of infrastructure prior to that date gives a picture of unchlorinated water which was intermittently contaminated by sewage. Sewage disposal was a mixture of open drains and underground pipes, often leaking into the ground and usually emptying untreated into the sea, or used as irrigation water. Stormwater was managed either through open drains or underground systems shared with greywater clearance. These various systems had not been well-maintained and homes often flooded either with stormwater, grey sewage or foul sewage. The project described, funded by UNRWA, aimed to provide a safe and reliable water supply, an effective sewage system, and separate stormwater management until 2020. The projects in the eight camps overcame a range of logistical problems to achieve these goals, including working in narrow alleyways without vehicular access, gaining adequate fall to achieve suitable water flows, accessing manholes

inside homes, and negotiating linkages to the local municipal sewage systems.

The Fafo report, with data collected in 1999 (probably towards completion of the work described by Davey and colleagues) found both water supply and sewage disposal was unreliable in some camps and gatherings. This study found that UNRWA was the sewage provider in 70% of camps, but noted that 11% of camps had no sewage provider (Ugland 2003, p. 194). However the Fafo researchers did not consider the ultimate destination of sewage — released to the open sea, used for irrigation water, or sent to treatment plants — all choices which have implications for public health. The Fafo researchers considered water in terms of whether it was piped into houses and how safe it was as drinking water. They found that 65% of houses had piped water, but only 50% of it was of drinkable quality. This last figure is considerably lower than Lebanese government figures which suggest that 97% of residents have access to safe drinking water. Problems of poor drinking water was worse in the city camps and gatherings (Ugland 2003, pp. 195–96). Lack of potable water and unsafe sewage disposal in the camps and gatherings are both serious potential public health hazards; however, UNRWA is currently addressing this problem.

Another area addressed in both the Fafo study and the peer-reviewed literature is the quality of the buildings in the camps, with problems identified such as overcrowding, lack of heating or cooling, and lack of recreational space. Zabaneh et al. (2008) investigated the living conditions of the Gaza Buildings, a Beirut gathering since the 1985–88 internecine conflict in the camps, and prior to that a PRCS hospital. They found that half the people living in this gathering had only one room. The median floor space per person was six to seven square metres. The authors compared this to two different standards of overcrowding: the WHO (Europe) definition found 28% of homes overcrowded, while a second measure (LIPRIL, the tool developed by the Fafo institute) suggested that 49% of homes were overcrowded. Fafo reports that, in general, dwellings have three rooms in either a traditional courtyard home (called a *dar*) or an apartment. Most houses are constructed out of cement or blocks, with a few being made from substandard materials, such as clay, asbestos, wood or zinc. This research found that there was less overcrowding than in refugee camps in Jordan or the West Bank, and that camps were less overcrowded than gatherings.

Both the Fafo study (Ugland 2003) and Zabaneh et al. (2008) study found the conditions inside the dwellings of concern. Within the Gaza buildings gathering there was a lack of heating, with half the homes relying on blankets and extra clothing to keep warm in winter. Those with heating relied on wood, charcoal, electricity, kerosene or gas. The presence of heating was associated with internal mould and dampness, as was a lack of ventilation, because the rooms often lacked doors and windows to admit outside air and light (p. 94). The Fafo study (Ugland 2003, p. 202) considered a wider range of housing, taking in gatherings and camps in a variety

of rural and urban settings. They too found that cold and damp were problems, as was dust, air pollution and heat in summer. These problems were reported by between two-thirds and three-quarters of the informants (for each problem). Lack of natural light and ventilation were also mentioned in regard to internal environments. However, Zabaneh et al. did not find that these environmental problems were associated with chronic illness (p. 95).

Thus, it is clear that the standard of housing is most unsatisfactory, with problems including poor water and sanitation supplies, overcrowding, presence of damp and mould, dust and poor temperature control. However, from these reports there is little evidence to link these factors specifically to poor health outcomes.

2.2.5 Health and lifestyle behaviours

While a range of behaviours have been associated with health and chronic illnesses, previous literature on health among Palestinians in the refugee camps has focused mainly on smoking behaviours. This has been the subject of two UHS reports, and is also discussed by the Fafo researchers. However, other substance abuse is not discussed, nor is diet or exercise.

Chaaya and colleagues (2006), as part of the UHS, studied older smokers and their smoking patterns. The informants in Bourj-el-Barajneh were more likely to smoke than the informants in the two primarily Lebanese communities: 34.3% camp residents smoked compared to 25.1% and 20.4% in the other communities studied. Despite starting to smoke later in life than informants in the Lebanese communities, camp smokers had smoked the same number of 'pack years' (a measure of total amount smoked) suggesting that they were heavier smokers. (p. 919). The study also looked at smoking cessation figures, which were also higher in the Bourj-el-Barajneh camp. The reasons given for stopping smoking across all communities were personal decision (44.5%), health reasons (32.8%), advice of a health professional (13.2%) and finally, cost or some other reason (9.5%) (p. 919). In their discussion Chaaya et al. suggest that the known links between smoking and depression, combined with the poor living environment in the camps, may explain the higher smoking rates there (p. 921). Their conclusions include the suggestion that UNRWA should provide more education on the link between health and smoking cessation (p. 922). While this suggestion may well be beneficial, there is no indication in the research findings that smoking is linked to lack of knowledge about the health problems of smoking, and survey data is not an ideal research design to understand why people follow particular behaviour patterns.

A second UHS paper considered the use of *nargeleh* (water pipe), and why adolescents between 13 and 20 in the poorer suburbs of Beirut take up this form of smoking (Afifi, Yeretzian et al. 2009). They found that a similar number of adolescents had tried the *nargeleh* across the three communities studied, (54% to 59%); however, those living in the Bourj-el-Barajneh camp

were more likely to continue (45% in Bourj-el-Barajneh, compared to 35% and 33% in the other communities (p.459). In Bourj-el-Barajneh the influence of friends encouraging a person to use the *nargeleh* was stronger than in the other communities, though peer pressure was a significant factor in all the communities (pp. 459–60). Looking at the factors specific to the Bourj-el-Barajneh community, they found religiosity and being female tended to protect against *nargeleh* smoking. Smokers of cigarettes were less likely to continue to smoke the *nargeleh*, and the belief that it was more harmful than cigarettes was also a common deterrent (pp. 460–61).

The Fafo Study (Ugland 2003) reviewed smoking habits in the camps and gatherings, and found that 29% of respondents were daily smokers (44% of men and 16% of women) with a further 5% being occasional smokers. They compared this to a study undertaken of the Beirut population in 1992–93, and also with studies of the Jordanian and Palestinian refugee populations, using the same questionnaires. They found a similar incidence of smoking across all these studies. The bulk of smokers belonged to the age groups 30 to 44 years (using five-year cohorts) where smoking incidence for men reached 70% and for women 30% (pp. 99–101). This study also asked informants about their ability to undertake physical activities, such as walking briskly or climbing stairs, and compared the responses between smokers and non-smokers; there was a slight positive relationship between smoking and exercise tolerance among the 15 to 29-year-old cohort, and the 30 to 44-year-old cohort, but among the over 45 cohort a significantly higher number of smokers reported good exercise tolerance (pp. 103–04). The report does not speculate on reasons for this unexpected result.

Within the camp community both cigarette smoking and *nargeleh* smoking are common, despite some level of knowledge that it is harmful to health. The reasons so far identified suggest this is to do with social pressure among adolescents (particularly in relation to *nargeleh* smoking), though other possible influences have not been fully explored. Research on other behaviours, such as diet, exercise or substance abuse has not been reported in relationship to the elderly.

2.3 What the literature describes; what it fails to describe

The literature reviewed indicated a higher prevalence of poor health and disability in the Palestinian camp communities This body of literature consists of surveys and quantitative studies, and as such has presented answers to such questions as ‘what?’, and ‘how much?’, as well as looking for connections between a range of predetermined factors. However, there appears to have been no attempt to ask why health problems are unusually prevalent among the Palestinians, though the UHS has confirmed that the Palestinians do have higher levels of poor health, both physical and psychological than comparable Lebanese communities.

Answers to questions about ‘why’ and ‘how’ tend to be better answered with qualitative data,

which can be more nuanced and interpretive of the informant's own experiences (Liamputtong and Ezzy 2005, pp. 2–3). While other researchers, including political scientists, sociologists and anthropologists, have long used qualitative data, the health sciences to date have used this approach less often. While there are many areas of health that could be examined to better understand 'what' and 'how much', I believe that it is time to start studying and understanding 'why' and 'how' emerging health patterns have developed.

2.4 How this literature refined the research questions

As this research has progressed, I have refined and modified the research questions that I initially posed, as I gained a greater understanding of the determinants of health, the nuances of epistemology and the nature of the data I had collected. In my initial approach to universities I discussed the aims of my research as a desire 'to improve our understanding of the effects of loss of country, exposure to long-term war, and loss of human rights on the health of refugees, as well as exploring the more obvious problems of poverty and inequality'. This general aim assumed that I understood the principal losses of this refugee community, and had predicted that these losses would have affected their health.

At this stage I had completed a review of what was known about Palestinian refugee health in Lebanon and improved my understanding of a range of ways of studying health; I felt ready to identify the overarching aim of my proposed research: 'What is the nature and extent of the social, psychological, physical and environmental factors which have contributed to the development of chronic illness among elderly Palestinian people who live in the refugee camps of Lebanon'. This research aim was then expanded into five specific research questions:

1. What do Palestinian refugees themselves understand by the terms usually translated as 'health' and 'chronic illness'?
2. What chronic illnesses do the Palestinians have?
3. What are the factors which influence the development of those chronic illnesses?
4. How significant are these factors to the Palestinian refugees?
5. How do these factors inter-relate with each other and contribute to the development of chronic illness?

These questions assume that the principal health problems in old age will be derived from chronic illness, which both the Urban Health Survey and the various NGO studies had identified as one of the health problems in the camp communities — and so I built my research questions around this concept. I was aware of some problems in defining chronic illness, and planned to explore

ideas underpinning the concept with Palestinian informants.

One problem with these questions lies in their focus on factors which contributed to the development of a specific list of illnesses. Having returned to Beirut and collected data, I began to better understand the nature of qualitative data and the similarities and differences between lay knowledge and academic knowledge (Frankel, Davison & Smith, 1991). People may have a sound grasp of the factors which contribute to their health and/or illness, but they do not express them in neat lists, linking a cause to an effect, nor in modern clinical or scientific language. The refugees tend to think in terms of their own personal and lived experiences. In the light of these realisations.

A second problem with the initial research questions was that I did not address appropriate solutions to the problems of refugee health. While I had started to consider this before data collection it was while in the field this point was highlighted as both a social and a political problem, and suggested the need to extend research questions to address the philosophical underpinning of service provision.

I therefore modified the questions after, the data collection and initial analysis, to allow discussion to bring out the richness and depth of the data collected. The overarching aim now became:

> **To understand how the lived experiences have contributed to the health in old age among Palestinian refugees living in Lebanon, and what the implications for addressing these health issues are**

The specific research questions became:

In relation to the Palestinian refugees in Lebanon

1. **What aspects of their lived experiences impact upon health in old age?**
2. **How do their life experiences interact with each other to support or detract from good health in old age?**
3. **Where does the power to change these life experiences to promote better health in old age lie?**
4. **How do these lived experiences, the interactions between experiences and the power to control the lived experiences impact on health services in this community?**

Re-stating the research questions has enabled me to move away from consideration of specific chronic illnesses and return to the concept of overall health: those questions relating to people's understanding of chronic illness could then be removed. In the words of the Alma Ata declaration, health '[…] is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity' (World Health Organisation 1978, Article 1). Considering health in this way, rather than focusing on a specific group of diseases would, I believed, meet my aims more closely as initially conceived.

With a background in service provision, I had hoped that the results of my research would help future service providers. I had naively assumed that a greater understanding of factors affecting health would automatically lead to improved services. However, when I began to understand the complexity of the interrelationships that were emerging from the data, I realised that I had to consider the problem in terms of where did the power lie — this was an essential precursor to facilitate health-enhancing changes to the lives of the refugees and also to improving health services provided for the community. These last two questions emerged strongly from my initial data analysis, impelling me to consider who had the power to improve health outcomes for the community being investigated. Responses to the first two questions indicated that the refugees felt powerless to change their lifestyles to support healthier outcomes. Thus the second two research questions needed to probe where did that power lie, and how could the community access it to gain some level of control over their own lives. This shift in my thinking required a second analysis of the data and related literature to explore the nature of sociopolitical power and community empowerment.

3
UNDERSTANDING HEALTH

In this chapter I will be considering a wide range of past and present models used to conceptualise health and its influencing factors. I propose to consider these models as they relate to an inclusive model of health developed by Nancy Krieger, an American epidemiologist. Krieger's model, which she describes as 'ecosocial', includes a range of biological, social and behavioural determinants (Krieger 1994). Having examined this model, and the underlying models to which she refers, I will discuss why Krieger's model is more appropriate to answer my research questions than others. While Krieger's model was developed in the 1990s, and so developed from literature prior to that date, I have included appropriate literature since that time, as well as Krieger's work on her theoretical model. Finally, I will review the similarities and differences between the conceptualisation of health, illness and causation as understood by key actors: the lay person, the epidemiologist and health professionals

3.1 Defining health

In 1978 the World Health Organisation (WHO) defined health in the Alma Ata Declaration as 'A state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity' (World Health Organisation paragraph one), thus suggesting a dialogue in which some define health as the absence of disease while others consider it a more positive state of wellbeing. The WHO definition was reiterated in the 1986 Ottawa Charter for Health Promotion as part of a statement on the requirements for health (paragraph 3). Both the Ottawa Charter and the subsequent Bangkok Charter (2005) focus primarily on health promotion, or in the words of the Ottawa Charter, 'the process of enabling people to increase control over, and to improve, their health' (paragraph 3).

In undertaking this research, I needed a comprehensive understanding of all facets of health, to enable me to operationalise the concept. I conducted a systematic search of the literature in order to identify an appropriate approach to studying the health of a community. I used several databases, including Medline, CINAHL Psychinfo and Sociological abstracts. Search terms used included, 'public health', 'health behaviours', 'health status' and 'social determinants'. . The aim was to cover a broad range of public health literature in my search for an appropriate health model. Once I had identified ecosocial theory as a useful model of health for this research I also used 'ecosocial' and 'public health' as search terms. In addition I reviewed a wide range of references from articles identified by the search, and throughout the analysis stage I conducted relevant searches to widen my understanding.

3.1.1 Development of models of health

Several theories of health and illness have dominated the literature of public health in the past. There has been a basic understanding of social and environmental determinants of disease since as early as the 1840s (Susser & Susser 1996, p. 669; MacDonald 2004, p. 382, Engels 2005, p. 108). However, the emergence of germ theory in the late nineteenth century overshadowed this work (Susser & Susser 1996, p. 670; MacDonald 2004, pp. 382–83). The decline of infectious diseases in the mid-twentieth century then refocused research onto chronic non-infectious illnesses, such as coronary heart disease, diabetes and the cancers (Susser & Susser 1996, p. 670; MacDonald 2004, p. 383). Initially, research focused on behaviours and how they were linked to chronic illness, but the study of social determinants of health made it apparent that behaviour alone could not account for all chronic illness (Syme 1994, p. 81). Many theories developed in parallel; for example, around neonatal and prenatal maternal health (Notkola, Punsar et al. 1985; Barker 1991; Barker, Forsen et al. 2001); social gradients and their effects on health (Wilkinson 1997; Wilkinson 2005); and workplace effects on health (Rose & Marmot 1981; Griffin, Fuhrer et al. 2002; Chandola, Britton et al. 2008). These developed in an attempt to explain the prevalence of chronic non-infectious diseases which could not be accounted for by individuals' behaviours.

While research usually focused on one or more social or behavioural determinants, researchers linked the various theories by suggesting that illnesses had multiple causation, often referred to as a 'web of causation' (Krieger 1994; Susser & Susser 1996, p. 670; MacDonald 2004, p. 383). Susser and Susser (1996) suggested a model which could be described by a metaphor of concentric boxes (Chinese boxes), each representing a level of societal structure and organisation, with interconnections between the nested boxes. Krieger (1994), on the other hand, uses the metaphor of a biological bush growing upon a scaffolding of societal structures. These paradigms link the biological person to the social structure, and permit consideration of the interactions of the social to the biological.

3.2 Ecosocial theory: health as a complex system

Nancy Krieger's ecosocial model is one researcher's attempt to combine theories of illness and health in a way which gives better insight into the complexity which is health. In her attempt to incorporate the theories of health and illness which had supportive evidence, Krieger proposed a complex, ecosocial model of health. Levin et al. (1999), in using this approach to evaluate the health of the population of the state of Kansas (USA), suggested that the ecosocial framework embraces previous theories of health and illness. However, while other theorists have tended to suggest their theories are exclusively correct and other theories are less correct, ecosocial theory integrates health, society and environment as a complex and dynamic system (p. 226).

According to Krieger's theory, societal relationships, such those based on race, class or gender inequality, should be considered alongside biological determinants, such as genetic predisposition, physical susceptibility and resistance. Inequality refer to a hierarchy based on a feature. Krieger's hierarchies place men above women, people of darker skin below those of lighter skin and those with better finances in a higher social class.

These are considered within political, economic and ecological perspectives. Within these spheres the inequalities can be maximised or minimised, through equity of access to services and facilities. For example financial inequality can be minimised by progressive taxation, or alternatively providing quality facilities such as social housing or recreational facilities, so that all people on the hierarchy have similar (or equitable) access to services (Popey, 2003, p. 7)

Historical and generational considerations must be considered, because illness is embodied over the whole lifetime. Multiple levels of social and ecological structure are encapsulated in this model, from the individual to the global (2008, p. 224). Krieger explains these concepts in several ways. For example, she uses the double metaphor of the 'continually-constructed scaffolding of society' and the 'ever-growing bush of evolution' which are entwined at all levels from the sub-cellular level to the global level. (Krieger 1994, p. 896). She compares this concept to mathematical fractals which repeat themselves infinitely. The overall theory is explained diagrammatically in her 2008 article and reproduced below (Figure 2).

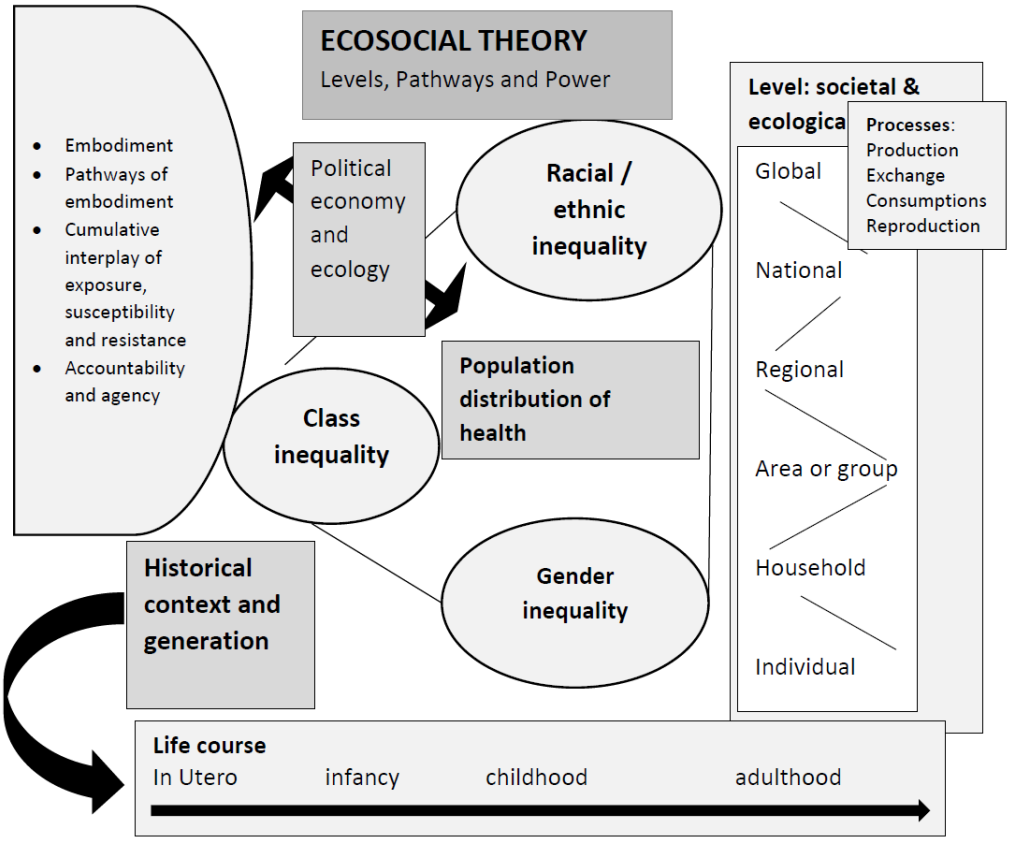

Figure 2: Krieger's representation of ecosocial theory (Krieger 2008, p. 224)

Krieger, when discussing her ecosocial model, links the model to a 'scale of biological organisation' in which the molecular biologists study health at the molecular level, while epidemiologists study health at the levels of the individual, family, community and society. Between these extremes there are overlapping disciplines which encompass increasingly complex biological structures (Krieger 1994, p. 893). Thus, this model emphasises the integration of a wide range of studies into the single concept of health. This present study is principally a public health study and as such the details of work done by physiologists, molecular and cellular biologists is beyond the scope of this review of the literature. However, I should stress that, consistent with this ecosocial model, researchers from many disciplines have contributed findings which link people's lived experiences to biological, environmental and social determinants of health.

While this model is complex, it permits a wide range of data, including social, biological, historical and behavioural to be integrated to provide an overview of population health for a community. Because it considers both the biological and social aspects of health it can be used to understand why health failures occur and also to identify where changes can be applied, in both the biological and the societal domains. It identifies the pathways in which power is applied in the community to either improve health or damage it, intentionally or otherwise. It can be combined with other

concepts, for example, human rights theory (Chilton 2006; Teti, Chilton et al. 2006) and race discrimination (Krieger 2005; Godette, Headen et al. 2006). Thus its very complexity provides a flexible model with which to analyse specific communities and situations.

3.2.1 Equity and inequity — how this relates to health

A central tenet within the social determinants of health is that indicators of health among communities with greater social gradients are worse than those with lesser social gradients. Thus more inequitable communities have more illness and poorer health than communities that are more equitable. Research in this area has contributed to understanding of health and inequity which contributes to the parts of Krieger's ecosocial model included in the 'population distribution of health'. Krieger represents this in her diagram which shows the three specific inequalities of gender, class and race (Figure 3).

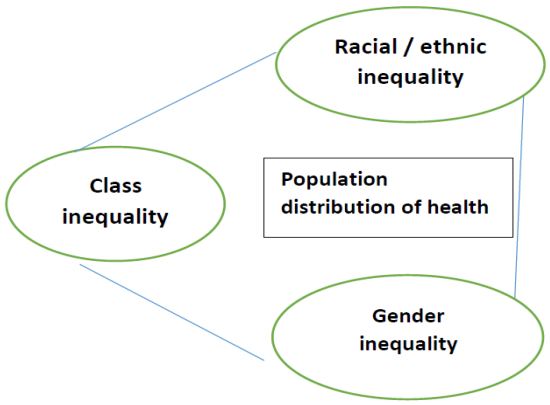

Figure 3: From Krieger's diagram, showing the linked inequities of raced, class and gender (Krieger 2008, p. 224)

Wilkinson, in his 2005 book, discusses the topic of inequity in detail, considering multiple pathways by which inequity in itself could cause poor health outcomes. He considers both behavioural determinants — i.e. individual behaviours that are healthy or otherwise (p. 60) — and psychosocial determinants — i.e. determinants which act on the biological and behavioural aspects of life and which are driven by societal forces (pp. 60–66).

Evidence from the initial Whitehall study (a cross-sectional study which led to the longitudinal Whitehall 2 study) has linked employment grade (used as an indicator for social gradient among the employees) within the Civil Service to chronic heart disease. This study, from 1968, looked at cardio-respiratory disease among 17,530 middle-aged male London civil servants and found that, contrary to previous medical thinking, the more senior a person was the less likely they were to suffer from coronary artery disease. More than half the differences in health status could not be explained by known behavioural health determinants, but could be positively linked to civil service grades and therefore the individual's place on the social gradient (Rose &

Marmot 1981). Subsequent studies have confirmed this finding (Notkola, Punsar et al. 1985; Blane, Hart et al. 1996; Wilkinson 1997; Kaila-Kangas, Keskimaki et al. 2006; Sacker, Head et al. 2008).

While this type of research has mainly been conducted in wealthier countries, similar trends can be seen in the mortality and morbidity statistics of low- and middle-income countries, where more equitable countries, such as Cuba, Sri Lanka and Costa Rica, have better health outcomes than less equitable countries, such as Indonesia, or Kenya (Baum 2008, pp. 228–29). Moreover, within any one country, areas that have less differentiation between rich and poor citizens tend to have better health outcomes than those areas which have wider equity gaps. For example, the state of Kerala in India achieved significantly greater life expectancy than other Indian states, while being less wealthy than other Indian states (Franke & Chasin 2000, p.17-18). Similarly, in the US, states which have greater income disparity also have worse health outcomes (Wilkinson 2005, p. 41). However, within a neighbourhood, the relationship between health and wealth tends to be more closely related to absolute wealth, rather than to a person's place on a gradient from the most wealthy to the least wealthy (Wilkinson 1997, p.1505).

There is some discussion in the literature on the relative significance of inequity and poverty. The latter has been considered an important health determinant since the work of social researchers such as Engals (2005, p. 108) and Virchow (Laverack 2004, pp. 1–5). Froehlich and Polvin, in their review of health models, refer to 'vulnerable populations' or 'populations that share social characteristics that put them at higher risk of risks' (Frohlich & Potvin 2008, p. 218). These are populations also referred to by some authors as those who experience social exclusion. People at risk, or socially excluded, vulnerable populations, share social characteristics that make it difficult for them to avoid risks (p. 216). The socially excluded are those disadvantaged as an outcome of social processes, rather than as a result of group traits; they may include women (in patriarchal societies), racial minorities (where there has been institutional racism in the recent past), and disabled people (Labonte 2004, p. 117). People who live in absolute poverty (inability to access essentials, such as food and water) and basic poverty (inability to access health services, education and housing) are among the socially excluded, and will generally have poorer health outcomes (Labonte 1992, p. 123).

Froehlich and Potvin suggest that people at risk will tend to be overlooked by programs aiming to improve the health of the general population. While population measures of disease will often show a decline in the morbidity of the total population, there will be a socially excluded group within the overall population who are not improving in terms of health outcomes (Frohlich & Potvin 2008, p. 218). For example, black Americans, who have been socially excluded by institutional racism in their past, have tended to be poor, and to have had worse health outcomes than white Americans (McCord & Freeman 1990).

Social exclusion tends to be related to poverty, but there is a body of research that looks at the health problems of groups who have suffered explicitly from social discrimination: these include indigenous minorities, ethnic minorities and others (McCord & Freeman 1990, Williams, Labonte et al. 2003).

Therefore, ecosocial theory considers both differences between most wealthy and least wealthy, and also absolute levels of wealth. Within Krieger's ecosocial model, inequities that result from social exclusion of those at the lower extreme of the gradient, whether due to class, gender or race, are highlighted as critical societal relationships which always affect health; however, these divisions and histories may vary from community to community (Krieger 2009, personal communication) Therefore, ecosocial theory posits that identifying the societal and historical factors that have shaped a society gives us insight into the determinants of health for that society.

3.2.2 How to organise complex systems: are special descriptions appropriate?

The Krieger ecosocial model includes a range of societal levels at which a social or ecological determinant of health can be identified (Fig. 6). This part of the model considers at which levels of society the processes of production, exchange, consumption and reproduction occur. This concept has been drawn from the social determinants of health, which says that health determinants of person's health stem from the society in which an individual lives, and that society can be shaped at all levels from the family to the global. However, Krieger views the relationship between levels differently from most proponents of social determinants. For any researcher looking at the relationships between determinants of health it is vital to understand the various ways they have been considered.

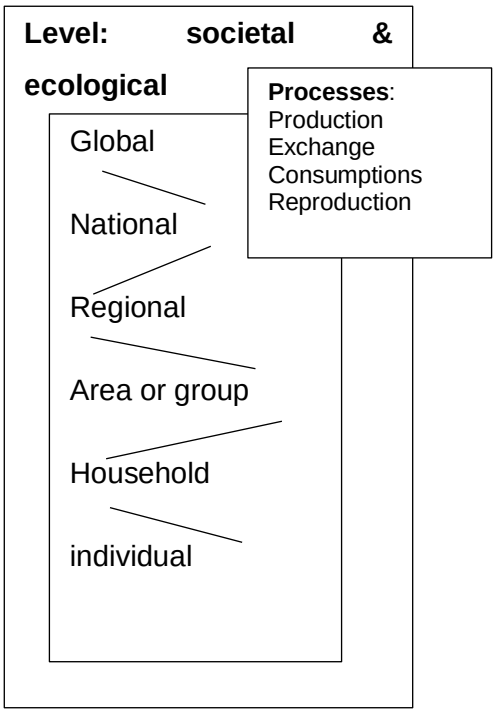

Figure 4: Societal and ecological levels

As public health and epidemiology researchers refocused on chronic non-infectious illness in the years following improved control of infectious diseases, the range of determinants widened, and it became important to consider how they related to each other. The term ‘web of causation’ was commonly used, although the perceived nature of the web varied. For example, Labonte (1992, p. 122), looking at cardiovascular disease, suggested causal links, which included risk conditions, psychosocial factors, risk behaviours, and physiological risks. These all related to each other, as well as to the onset of cardiovascular disease and other causes of death. McMahon (as reproduced by Krieger 1994, p. 889), linked contraction of Hepatitis B (a chronic infectious disease) to a wide range of factors, including the nature of the virus involved, lack of education among drug users, syringe availability for drug users and other factors that linked to form a large and complex web.

In attempts to organise the web of causation, its various elements have been categorised as either close to or distant from the individual experiencing the illness (Oldenburg, McGuffog et al. 2000, pp. 4–5; Jackson 2003, p. 26–27; Godette, Headen et al. 2006, p. 381; Buffardi, Thomas et al. 2008, p. 1129; Krieger 2008, pp. 222–23). There is a tendency to use spatiotemporal descriptors, such as ’distal and proximal’, or ‘upstream and downstream’. As seen in the Krieger model, multiple levels are considered as follows: **international factors**, such as relative affluence of a country compared with its neighbours and ability to generate wealth in a global marketplace; **national factors** (from both private and public sectors), such as methods of providing curative services when people become ill, methods of supporting people who are socially disadvantaged,

distribution of economic wealth, and cultural mores of the nation; **community factors**, including availability of transport, recreation facilities, safe water and sewage, shopping and work; and finally **personal factors**, such as health behaviours, education, employability, genetic inheritance and past health experience.

However, Krieger has suggested that the use of spatiotemporal terms to describe the various levels of health determinants has encouraged some researchers, policy makers and practitioners to give priority to one level or another of the web (Krieger 2008, p. 227), suggesting that the intervention focus should be either proximal (e.g. Tohme, Jurjus et al. 2005, p. 866) or distal (e.g. Eskin 1994, p. 39; Buffardi, Thomas et al. 2008, pp. 1133–34). Krieger also suggests that interactions of the individual with the phenomenon of societal structures (e.g. economic or political systems) do not necessarily link sequentially, either in time or space (Krieger 2008, p. 223). . The concept of distal and proximal helps us to understand the various levels of society which are involved in the process of determining health outcomes. However, within the ecosocial model it is important to avoid placing value judgements on the spatiotemporal relationships between the various 'levels'. It is the interplay of biological, behavioural and social determinants over a range of different societal levels which determines outcomes of health and disease.

This concept is best seen be considering examples. In a hypothetical example, the effects of a national action, such as war, may impact directly on the village community, by forced evacuation, on the family, by having their home bombed, or on the individual, by being injured. None of these effects is linked through the intermediate societal levels, but rather each is directly linked to the national societal level, making war. In considering examples from the literature the clean water supply and safe sewage disposal, which is important to health of a community and was an overarching aim of early public health workers (Baum 2008, pp.156–57). Such amenity is expected among wealthier countries but it remains a significant problem for many communities in middle- and low-income countries (Giacaman 1988, pp.132–33; Özkan, Tüzün et al. 2007, p.108). This public health deficiency in low-income countries can be attributed to action or inaction at a range of societal levels. For example Giacaman (1988, pp. 45–46), in her case study of health in three Palestinian villages, explained that one village was linked to municipal water supplies while the other two 'are still in the process of struggling with the military government for permission to connect themselves to a neighbouring communality's water supply'. The village government needed permission from a central bureaucracy before they could install an adequate water supply, and thus reduce the incidence of water-borne infection (one of Giacaman's research interests). Ozkan and colleagues (2007) looked at water and sewage services in four Turkish villages. They found that many people had a less than safe distance between septic tanks and wells, and the closer the well was to the septic tank the more likely the family were to experience diarrhoea (p. 5). They also noted that low monthly income was linked to increased incidence of diarrhoea (p. 5). The article goes on to say that the village government had not provided a sewerage system,

and although there was a reticulated water supply, it provided insufficient water for the community. The problem can be considered as an educational one — people putting their septic tanks too close to drinking water supplies because they know no better. However, it could also be that lower-income families do not have enough land to separate the two utilities adequately. Their available sources of income may be inadequate for many reasons — because of Turkey's role in global trade, or perhaps because taxes are a greater burden on the poor than the rich. These are all possibilities, which place accountability, or agency at a different level of the community: global, national, local or individual. Understanding the nature of agency can be facilitated when examined under the lens of the ecosocial model.

These two examples illustrate the interconnections between the social and the ecological: the social policies that provide utilities and the ecology of how two such utilities interact to facilitate or conversely, to minimise illness. They also demonstrate Krieger's argument that that health determinants do not move from the international (distal or upstream) to the personal (proximal or downstream) in a simple level-by-level jump — in fact, international or national actions may have a direct impact on people at the family or community level.

3.2.3 Advantages and disadvantages of using the ecosocial model

The ecosocial model emerged in the 1990s as a response to problems researchers had identified in the existing models, including those connected with the biological, social and behavioural determinants of health. There was a move to review the various competing models of health in a holistic way. While Krieger was developing the ecosocial model (1994), Susser and Susser developed a model which they called a 'Chinese boxes' model (1996). The similarities of the two models included multiple levels of involvement from the microscopic to the global. Susser and Susser saw this concept as a series of Chinese boxes where levels were 'nested' within each other. Both Krieger and Susser and Susser sought to treat health as a complex system, rather than as a single cause to a single effect-type mechanism — a concept which Susser and Susser refer to as 'universalism vs. ecologism'.

I have chosen to use Krieger's ecosocial model over the Chinese boxes model for the following reasons: Firstly, Krieger's ecosocial model accommodates the accumulation of exposure, as well as the psychology of susceptibility and resistance and how these may be embodied into the health of the individual over the lifetime of that individual (Krieger 1994). Secondly, the societal and ecological levels which Krieger describes do not lead automatically from one level to the next; rather, in her model, all societal levels interact with each other as well as with biological factors (Krieger 2008). Thirdly, the model acknowledges that the historical roots of social systems will affect the development of a population, creating inequities and social pressures that shape both the society and the health of the people in that society (Krieger 2005). Fourthly, by considering the individual within a societal context it is possible to identify power structures

and pathways which may affect health (Krieger 2001, pp. 673–74). Finally, accountability and agency are considered in the model; thus, if change is needed, this model can assist in identifying where effective interventions can be implemented. (Levins & Lopez 1999).

The research questions I have posed seek not only to find out what were the influences on the health of a refugee community, but also to understand how these influences related to each other. This demanded a holistic lens through which to view the data I collected. My final two questions consider where the agency or power-to-change the health outcomes of the refugees is located. Because the model scans the entire experience over time, examining both the lives of individuals and the community's historical development, agency and accountability for health problems may be identified.

The principal challenge of working with the ecosocial model is its complexity. The researcher needs to consider the lives of the people living in the community, the history of that community and what has shaped the societal structures which exist today, and the interactions that the society and its individuals have had with various levels of society outside the community. Having gathered this information, the researcher must connect the information into a cohesive whole in such a way that it tells the story of how patterns of health and illness were formed. While some simplification may be necessary, it should be minimised to avoid overlooking critical facets of the health status of the community.

While the ecosocial model may help to identify the agencies which influence health and illness, the model does not provide solutions to change the health outcomes of the community. Having mapped out the story of health and illness in a community, the implications for addressing the needs of the community may then be linked with other theoretical approaches. This has been accomplished by reference to other researchers; for example, Chilton (2006) combines the ecosocial model with a human rights perspective in her study of dignity, stress and health outcomes, and Levins and Lopez link their ecosocial analysis of Kansas with urban–rural differences. In this study a dominant theme emerging from the health analysis of data was the respondents' feeling of helplessness and inability to control many aspects of their lives. Therefore, having completed my analysis of health, I returned to the literature to gain an understanding of power and empowerment (Chapter 4). This concept links well with an ecosocial model, which has examined the accountability and agency of health at multiple societal and ecological levels and over the lifetime of the members of the community.

3.2.4 Embodying health and illness over a lifetime

Working according to Krieger's model, the researcher needs to consider the history of a community and the factors which affect health in each generation (Fig. 5). Krieger considers that the term 'embodiment', as used by epidemiologists, refers to how we and other living

organisms literally incorporate the world in which we live, including societal and ecological circumstances of our lives, into our bodies (Krieger 2005, p. 351). The ecosocial theory considers both the embodiment of the various health determinants and the pathways through which they are embodied.

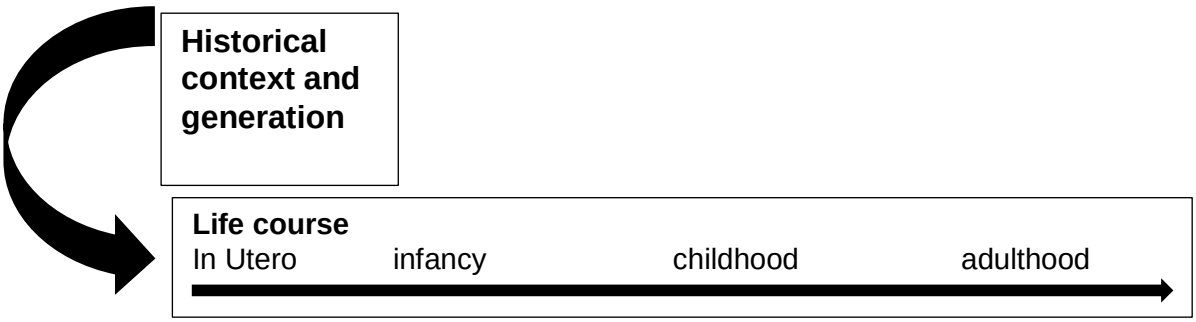

Figure 5: From Krieger's diagram of her Ecossocial model which relates to embodiment (Krieger 2008, p. 224)

3.2.4.1 Healthy behaviours

There have been studies of how an individual's behaviour can be embodied to the benefit or detriment of that individual's health. There is a strong body of evidence which links behaviours to health, and while not accepting the premise of Lalonde (1974, p. 8) that behaviour which promotes ill health is always within the control of the individual, there is compelling evidence that certain behaviours are embodied.

For example, smoking was identified as being linked to lung cancer in 1950, and has been the subject of both national and community-based health promotion projects since then (Berridge & Loughlin 2005, Berlivet 2008). A second area of behaviour, identified in a longitudinal study, generally referred to as the Seven Countries Study, involved the links between diet and heart disease. Keys and his colleagues found that high serum cholesterol, diets high in saturated fat, and heart disease were linked, and proposed that a diet low in saturated fats would produce better health outcomes (Keys, Mienotti et al. 1986). Other dietary factors have also been identified, including childhood obesity (Summerbell, Waters et al. 2001, Stice, Shaw et al. 2006) and adult obesity (Norris, Zhang et al. 2008). A further line of behavioural research identified exercise as a significant behavioural factor affecting health (Taylor, Klepetar et al. 1962, Batty, Shipley et al. 2002).

A major aim of health promotion over the past 40 years has been to encourage individuals to change behaviours. This concept has found expression in major policy documents (Lalonde 1974, MacDonald 2004, p. 384). While the bulk of health promotion programs show some benefit to overall health outcomes, they rarely achieve more than 30 to 40 percent reductions in harmful

behaviours (Stice, Shaw et al. 2006, Brunner, Rees et al. 2007, Nield L, Moore HJ et al. 2007, Norris, Zhang et al. 2008).

A critical limitation of the behavioural approach to health promotion has been its focus on the individual's behaviour (Pearce 1996, p. 680; Jackson 2003, p. 42; Frohlich & Potvin 2008, p. 217). This is best expressed in a 1974 Canadian report on health promotion, 'Most Canadians are not prepared to forgo all self-indulgence nor to tolerate all inconvenience in the interest of preventing illness' (Lalonde 1974, p. 8). Though policies acknowledged that social and physical environments did impact on health, interventions were focused at the individual level in terms of behaviour (Frohlich & Potvin 2008, p. 216). Within an ecosocial analysis of health and illness, the questions go further than what behaviours cause illness, to ask: '*Why* do people exhibit these behaviours?'; '*Which* behaviours support health?'; and '*How* do they all interact?'

3.2.4.2 Mental health, emotions and stress

Another body of research has looked at the mental health of the individual to see how that is embodied. Mental health problems cover a wide range of conditions, some of which constitute illnesses while others do not, though they may influence overall health, as pathways of embodiment. The concept of mental health is considered in several components of Krieger's ecosocial model. It is an important aspect of people's historical and generational life courses, and can be one of the pathways whereby experiences which affect emotions are embodied into the physical health of members of the community.

One condition which is not usually considered a mental illness, but which has been studied and found to have a role in embodying physical illnesses, is stress. According to McEwen (2004), the complex physiological activities of hormones and neurotransmitters 'are essential for our adaptation to the challenges of daily life' (p. 1).

These challenges may include a range of stress-inducing situations, such as danger, infections, living in crowded or unpleasant neighbourhoods, or even undertaking public speaking (McEwen 1998, p. 172). McEwen describes situations when physiological responses behave abnormally; for example, they do not switch off when the perceived danger has gone, or do not turn on adequately when they are needed, or when they have been overused by multiple stressors. This situation is referred to as 'allostatic overload', or as 'chronic stress'. McEwen explains the physiological processes that are involved in normal stress responses and in allostatic overload; for example, the immune system, when stressed, facilitates the movement of immune cells to the parts of the body where they will be most needed, but in chronic stress, or allostatic overload, the immune system can be suppressed. He goes on to discuss similar changes in the

cardiovascular, metabolic and nervous systems (McEwen 1998, pp.175–76, McEwen 2004, pp .2–3).

Using data from the Whitehall II study, specific links have been made between work-related stress and coronary heart disease. Chandola and colleagues found that among the younger (under 50 years) participants in this longitudinal study there was a demonstrable link between work-related stress and coronary heart disease, through both direct neuro-endocrine stress pathways and through indirect behavioural pathways (Chandola, Britton et al. 2008). This study attributed around one-third of the observed effect to behaviour and the metabolic syndrome, suggesting that the incidence of the coronary heart disease was partially and causally linked to stress. The Whitehall II study has also suggested that stress may have a direct link to the development of type 2 diabetes, via pathways involving stressful life experiences, low educational levels, low emotional support and sleeping disorders (Abraham, Brunner et al. 2007, p. 265).

When considering individuals and their social networks, an understanding of the stressors in their life experiences will provide insight into the pathways by which social determinants of health may be embodied in the individuals of a population. Hence, there is a body of research on the stresses endured by those who have experienced both war and forced migration. In the context of the life experiences of Palestinians, discussed in chapters 1 and 2, this body of work is highly relevant. In their review of the literature on stressors and mental health in conflict and post-conflict situations, Miller and Rasmussen (2010) identify studies which focus on two sources of stress: the stressors generated by exposure to war, violence and loss, and the stressful material and social conditions which may or may not have been exacerbated by the conflict (Fig. 6). They suggest that researchers have focused on one or the other cause of stress. However, Miller and Rasmussen (2010) suggest that a model which combines all of these stressors presents a more realistic understanding of the stresses created by the experience of war.

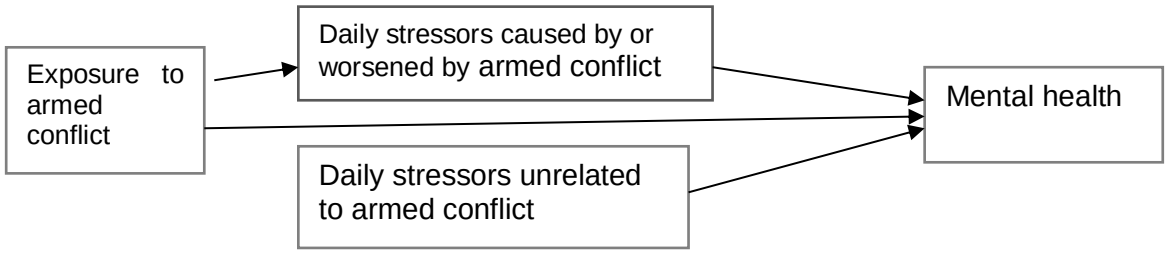

Figure 6: Daily stresses

Another mental health problem which is frequently identified in war and post-conflict situations is post-traumatic stress disorder (PTSD). This ‘develops following a stressful event or situation of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone’. PTSD sufferers involuntarily re-experience aspects of the traumatic event in a

vivid and distressing way, including flashbacks where they act or feel as if the event was recurring (NICE 2005, p. 6).This diagnosis has been questioned by some humanitarian workers and researchers, who suggest that PTSD is a Western socio-political diagnosis which does not sit well outside of its original cultural context (Summerfield 1999). However, PTSD has been studied both immediately following conflicts (Mollica, Sarajlic et al. 2001; Mollica, Henderson et al. 2002; Saab, Chaaya et al. 2003; Hunt & Gakenyi 2005; Marshall, Schell et al. 2005; Muhtz, Godemann et al. 2011) and long after the resolution of the conflict (Mollica, Sarajlic et al. 2001; Muhtz, Godemann et al. 2011). Muhtz and colleagues, studying elderly people who had been refugees in childhood, during World War II, concluded that PTSD among these refugees did not show associations between the endocrine or metabolic parameters examined, but did affect the refugees' quality of life and depression (Muhtz, Godemann et al. 2011, p. 650). This conflicts with findings reported in McEwan's review of acute and chronic stress (2005, p. 4), when he claims that there are changes in various parts of the brain in animal models. Therefore, the role of PTSD as a possible pathway of embodiment is not currently well understood, with conflicting explanations between neurological researchers, psychologists and anthropologists.

Depression is considered to be a mental illness, and it includes 'a wide range of mental health problems characterised by the absence of a positive affect (a loss of interest and enjoyment in ordinary things and experiences), persistent low mood and a range of associated emotional, cognitive, physical and behavioural symptoms' (NICE 2009, p. 2). McEwen (2004, pp. 4–5) discusses a link between chronic stress and depression, suggesting that one of the impacts of allostatic overload can be depression. Several studies of mental health in post-conflict situations found depression, either co-morbid with PTSD (Mollica, Sarajlic et al. 2001; Mollica, Henderson et al. 2002; Hunt & Gakenyi 2005) or alone (Salama, Spiegel et al. 2000; Chaaya, Mehio-Sibai et al. 2006; Chaaya, Mehio-Sibai et al. 2007). Griffin and her colleagues, using data from the Whitehall II study, found that lack of control over home and work environments predicted a later development of depression (Griffin, Fuhrer et al. 2002, p. 796). Also, using the Whitehall II data, Kumari and colleagues (2004, p. 1878) found there was a weak relationship between depression, impaired glucose tolerance and diabetes, although effort–reward imbalance was a stronger predictor. Thus there is a possible embodiment pathway from various life experiences to depression (itself an illness) and other chronic illnesses, though the evidence remains tentative. Additionally, the life experiences of war and being a refugee increase the risks of emotional and psychological problems, such as stress, depression and PTSD, which may have an impact on chronic ill-health in later years.

While some researchers have looked at the present status of the target population to identify social determinants of health, there has been a parallel body of research which has studied the determinants of health, both biological and social, over the individual's lifetime (Power & Matthews 1997). Barker (1991, p. 67) and his colleagues focused on the in-utero and neonatal

periods and found that low-birthweight babies were more susceptible to chronic illness in adulthood. His findings suggest that the nutritional status of mothers and the socioeconomic status of the childhood family were both significant factors. Although his findings were initially based on British studies, they have subsequently been confirmed in other communities (Barker, Forsen et al. 2001, p. 1275).

Blane and colleagues found that both adult and childhood socioeconomic status was related to the development of chronic illness in adulthood, concluding that both adult and childhood socioeconomic circumstances related to the development of physiological risk factors for cardiac disease (such as serum cholesterol or high blood pressure) while behavioural determinants (such as smoking or exercise) were more closely related to adult socioeconomic circumstances (Blane, Hart et al. 1996, p. 1437). The Whitehall II study also found links between childhood socioeconomic status and chronic illness, but considered the causal pathway was probably related to the way early life experiences affect transition into adulthood (Marmot, Shipley et al. 2001, p. 306). Other authors working with the Whitehall II data conclude that fibrinogen levels (high fibrinogen increases the risk of arterial disease, which may lead to heart disease and stroke) were related to past and present socioeconomic circumstances (Brunner, Smith et al. 1996, p. 1012).

There is obviously more work needed to investigate the role of childhood social and biological factors before we can fully understand the relationship between childhood experience and adult health. Studies have relied heavily on either audits of extant records or indirect indicators, such as leg length, when evaluating childhood status.

While causal pathways are still debated in the literature, there is strong evidence to support Krieger's concept that there is 'literal embodiment of adverse social, physical and biological exposures from conception to death' (Krieger 2007, paragraph 3). The literature suggests that both behavioural and the psychological aspects of a person's life will be embodied, influencing health outcomes over the lifetime of the individual. Ecosocial theory includes acknowledgment of the cumulative interplay of susceptibility and resistance to health determinants over the lifetime (Krieger 2008, p. 224) it permits and encourages analysis of the pathways by which the social is embodied in the biology of the individual as susceptibility or resistance to ill health.

3.3 Lay knowledge as it relates to health and illness

One of the advantages of Krieger's ecosocial theory is that it makes clear connections between the biological and the social determinants of health. While the biological determinants can be examined through the biological sciences (Krieger 1994, pp. 892–94), the social determinants fall into the realm of the social sciences (Krieger 1994; Ward, Tsourtos et al. 2008). One area of social research has examined the knowledge of the general population on matters of health, the

way such knowledge is gained, and its accuracy (Popay & Williams 1996; Popay, Rogers et al. 1998; Kangas 2002; Williams & Popay 2006).

Popay and Williams (1996, 1997) suggest that the lay person makes a valuable contribution to the understanding of their disease processes, although this has only recently been granted the status of 'knowledge', rather than 'beliefs'. They suggest that this occurs through a more or less systematic checking of life events, and historical circumstances against their experiences of illness (Popay & Williams 1996, p. 760). They further suggest that lay knowledge provides unique insights into the relationships between individual behaviour and life circumstances, lay theories of aetiology of disease, and into the prediction of health outcomes. The validity of this view has been demonstrated — for example when people living in a particularly depressed part of Salford, an urban community in the north-west of England, linked to health outcomes concepts such as stress related to poverty, economic decline, and experience of crime. They were also able to link illness to a serious industrial accident in the area (Williams & Popay 1997, pp. 64–67). These ideas have also been addressed by Brown, who argues that lay people, with the support of some scientists, have helped to identify environmental contaminants impacting on their health. The cases he cites are principally in the United States, such as Woburn, Massachusetts, where local people identified a leukaemia cluster and took legal action against companies they considered to be responsible. Brown identifies a set of stages by which lay people take action in communities. The first stage is access to data otherwise inaccessible to scientists, usually based on their experimental knowledge. They then make assumptions linking data, followed by organising this knowledge coherently, thus in effect mapping the data (Brown 1995, pp. 92–95). Further stages consider a range of potential actions which can be undertaken by the community, based on lay knowledge and lay hypothesis, suggesting that in some situations communities have power to make changes based on their attainment of first-hand epidemiological knowledge.

Popay and colleagues theorise that lay knowledge is at least in part related to a deep understanding of the effect of place on health (Popay, Williams et al. 1998). Popay and her colleagues suggest that lay knowledge not only involves an understanding of the physical environment, as discussed by Brown, but also to the social aspects of place. Specifically, they theorise that that a deeper understanding of the relationship between the individual and their social environment could be gained through studying lay knowledge (Popay, Williams et al. 1998, p. 640). In a later paper, where this theoretical concept was tested both quantitatively and qualitatively, Popay and colleagues studied four locations to understand lay knowledge of the effects of inequity on health: these were two advantaged areas and two disadvantaged areas. In the survey they found that only 20 percent of respondents focused on a single category of causes for poor health in disadvantaged areas (coded as place-based factors, individual factors,

macro-structural factors and others). Others identified more than one causal category and discussed the complex relationships between them (Popay, Bennett et al. 2003, pp. 8–9).

In the subsequent qualitative phase of the study, a more nuanced understanding of lay knowledge of inequity and health emerged. Those people living in the disadvantaged areas tended to disbelieve the data presented or to find it illogical and contrary to their understanding of health (Popay, Bennett et al. 2003, pp. 10–11). Popay and her colleagues suggest that this is a reflection of people's unwillingness to accept the suggestion that illness is inevitable for people living in disadvantaged areas. When interviews explored the ideas further, there were examples of understanding of the complex and changing nature of society, such as the changing nature of the class system and the differences between levels of poverty and social gradients. As the interviews progressed, people began to consider the lives lived in particular places, and the power of the individual to operate as an agent of change. These ideas were then linked to the causal significance of stress and social comparison (Popay, Bennett et al. 2003, pp.13–14).

Popay and Williams (1996, p. 759) also suggest that lay knowledge has a critical place in the research of chronic disease, focusing on the 'upstream' factors which influence their development, while the biological sciences focus on the 'downstream' factors. Thompson and Gifford (2000) illustrated this concept in their study of an urban Australian Aboriginal community. The community demonstrated an understanding of the complex nature of the factors influencing their diabetes, delineating causal factors within the family, in the local neighbourhood, and at a national level. They were describing interactions between these levels in a similar way to the ecosocial model suggested by Krieger (p. 1468).

Frankle and colleagues (1991) suggest that lay knowledge is more nuanced than the knowledge provided by health educators, which tends to focus on behaviours which will improve health (p. 430). They question why people respond to different health messages differently: for example, when advised that there was a risk of contracting salmonella from eggs the consumption of eggs dropped significantly; however, when advised that consumption of eggs increased cholesterol and hence the risk of coronary artery disease, the effect on egg consumption was less significant (p. 429). The complex and changing methods by which people come to conclusions relating to their understanding of any specific health issue includes advertising, government media campaigns, routine observations of their community, and discussion of cases of illness (pp. 428–29). Whether people utilise this knowledge depends upon their perception of the degree of risk and the desirability of the activity to be curtailed.

Popay and colleagues suggest that lay people use biographical narratives through which they can articulate ideas on the experiences of chronic illness, also through which the researcher can understand these experiences (Popay, Williams et al. 1998, pp. 636–37). This was

discussed further in considering qualitative data of their study on inequity, health and lay knowledge. The informants were reluctant to link health problems with living in socially disadvantaged areas; however, in discussing their biographical experiences they 'provided commentaries on inequalities in health' and 'drew attention to the complex causal pathways lay people "construct" to make sense of their experiences' (Popay, Bennett et al. 2003, pp. 13–14). In his discussion on considering health behaviours and their relationship to perceived risks, Zinn (2005) argues that a biographical approach will help to illuminate how people understand their health and gauge the risks to which they are exposed.

Thus when considering the lived experiences of a community, one option for the researcher is to examine the knowledge held by community members, particularly by asking them to discuss their lives and activities. While the terminology will not be that of the social or physical scientist, their understanding of their experiences and the effect these experiences have on their health may provide insights which cannot be seen by the outsider.

3.4 In conclusion

In choosing Nancy Krieger's ecosocial model of health to inform this health study of a community I have been able to incorporate other theories of health in a way in order to identify links between the social, behavioural, biological and environmental determinants of health. In considering these linkages through the model I will be able to identify pathways of embodiment of health or illness. In studying the community through the experiences of its members, the study data, managed through Krieger's ecosocial model, will be will reflect the reality as experienced by this refugee community. Thus, these theoretical lenses support the answering of the first two questions,

1. **What aspects of their lived experiences impact upon health in old age?**
2. **How do their life experiences interact with each other to support or detract from good health in old age?**

It will also contribute to answering the third question, because the model identifies agency and accountability

3. **Where does the power to change these life experiences to promote better health in old age lie?**

However a further theoretical lens is needed to understand fully where the power lies to change life experiences, and to answer the fourth question by considering service provision.

4
POWER AND EMPOWERMENT

Following an analysis of data according to Krieger's ecosocial model, which will be discussed further in chapters 5 and 8, I considered what further analysis was needed to understand how the Palestinian community I chose to study could improve their health outcomes. I decided to use an empowerment perspective, because firstly, as I have discussed in Section 4.2, empowered communities tend to have better health outcomes; and secondly, the study data suggested that the community felt disempowered (Chapter 8). Finally, Krieger's ecosocial model considers agency and accountability for health outcomes, thus facilitating the identification of where the power lies to make societal changes affecting health. A deeper consideration of community empowerment theory may open opportunities' for the community to seize power over health outcomes.

Therefore in this chapter I will firstly review literature which defines empowerment, focusing on community empowerment and secondly, literature which links empowerment to positive health outcomes. As I had already identified a feeling of disempowerment among my informants, in my reading I sought to understand the various concepts of empowerment, along with methods to analyse processes of empowerment in the community, especially empowerment specific to health outcomes. I undertook a systematic literature search using the general term 'empowerment' in the databases Psychinfo and Sociological Abstracts. Having grasped the essential concepts of empowerment, I narrowed my search to 'community empowerment' both alone, and linked to the search term 'health'. In the latter search I added the databases Medline and CINAHL. I extended my reading by following up related literature cited in the articles found.

I identified two models from my reading, which could assist in my aim: firstly, an often-used concept of a 'continuum of empowerment', a dynamic that considers empowerment from the 'individual' to the level of 'political and social action'; secondly, Laverack identified a range of at least nine factors which underpin the process of community empowerment. These tools will provided a framework for an analysis of empowerment within the community.

4.1 Defining power and empowerment

The concepts of power and empowerment are used across several disciplines, including health, education, community development and community psychology. This inevitably means that there is a plethora of associated definitions that seek to encapsulate some complex concepts. Before attempting to operationalise the idea of empowerment appropriately for this study, it is important to define what the term might mean within the particular context of a Palestinian refugee community.

4.1.1 Power

The concept of power is intrinsically linked to the concept of empowerment; however, power can mean many things. I have already noted (section 3.2.4) that Krieger's ecosocial model facilitates understanding of power and pathways of power; however, Krieger's model focuses on the interactions between agency and outcomes. While this may help to understand where power resides in a community and how that power affects health, it does not identify the processes that empower people and communities to make changes to improve their health outcomes.

This discussion focuses principally on power as it relates to empowerment and disempowerment, and does not aim to be a comprehensive overview of the social theories of power. Laverack (2009, p. 1), who works in development and health promotion, describes power and empowerment as 'key concepts….that seek to redress inequities in health and to change determinants of health through collective and community based action'. Later, Laverack asserts 'Power cannot be given to people but must be gained or seized by those who want it' Laverack (2009, p. 3). Thus he claims that the process of empowerment involves a community gaining power over its destiny — but what kind of power are we talking about?

Firstly, power can be considered as an internal characteristic involving the inner strength to make changes in one's circumstances — described as 'power-from-within'. In a second meaning, it can mean the power to make others do as the powerful person wants — described as 'power-over'. There is a third concept of power, where people who have 'power-over' choose to help those over whom they have power to attain 'power-within'; in this scenario, those who were previously powerless achieve a level of self-determination they had not previously had. (Laverack 1999, pp. 72–77).

Laverack describes power-over as a relationship in which one party is made to do what another party wishes them to. This may be against the wishes of the subservient party, though it may be well-intentioned and ultimately for the good of the community — for example, quarantine laws are designed to manage the spread of contagious disease (Laverack 2004, pp. 37–38). Laverack goes on to suggest that while the most obvious form of power-over is that which is backed by force, he goes on to split power-over into three subgroups. Firstly, there is sheer dominance or direct power to control people's choices; secondly, there is exploitation, an indirect control over people's choices through economics; and thirdly, there is hegemonic power — the power to control through intense persuasion (Laverack 2004, p. 38).

Power-from-within, in contrast, comes when an individual gains control over their own life. Laverack suggests that power-from-within is the same as psychological empowerment, also known as personal or individual empowerment. Labonte, when discussing psychological empowerment, describes it as 'the experience of a potent sense of self, enhancing self-esteem'

(1990, p. 64). Rissel considers it important to distinguish between this subjective experience of psychological empowerment and the objective reality of modified structural conditions (Rissel 1994, p. 41). Zimmerman argues that psychological empowerment includes a belief about one's competence, efforts to exert control, and an understanding of the sociopolitical environment (Zimmerman 2000, p. 47), Cattaneo and Chapman, when looking at the process of psychological empowerment, include concepts such as self-efficacy, competence and knowledge, linked to goal setting, taking action, and reflection on the outcomes of actions (Cattaneo & Chapman 2010, p. 647) I will discuss the processes of psychological empowerment in further detail in section 4.3.1; however, while power-from-within is an essential component of psychological empowerment, it is not synonymous with it. Rather, power-from-within is that sense of mastery which, when linked with knowledge and resources, helps an individual to achieve their goals.

The term 'power-with' describes the interrelationship where a person or group of people with power-over a subservient person or group chooses to exercise that power with care and deliberation in such a way as to encourage the person or community to increase their power-from-within (Laverack 2004, p. 39). Laverack discusses this form of power in relation to health promotion, suggesting techniques whereby health educators can work *with* communities, to increase their sense of power-from-within as a means of community empowerment (Laverack 2004; Laverack 2007; Laverack 2009). Labonte raises the difficulty of whether the professional worker can exercise 'power-with', suggesting that professionalism represents control over people by the very nature of the professional–client relationship, and by the role of the professional in defining both the problem and the solution. He suggests that this protects professional privilege and disempowers clients (Labonte 1990, p. 65). This is similar to a problem identified by Freire when discussing the 'banking' concept of teaching in adult education. This term describes the process of 'depositing' facts in the brain of the student with little or no discussion, and with little control on the part of the student. His alternative teaching method, called 'problem-posing', involves a mutual process of understanding of a situation through discussion. The teacher, who would, in the banking method of teaching, have power over the students, has become a fellow student who is trying to explore the topic with the students (Freire 1996, ch. 2). This model identifies ways in which those who traditionally have power-over can develop power-with. Freire's work has been used by health promotors (Wallerstein & Bernstein 1988), and social workers (Lee 2001), as well as adult educators who initially pioneered the idea. The concept of power-with is important when an outsider works with a community to try to improve their situation, and I discuss this further when considering how professionals can work with communities to facilitate community empowerment (Section 4.4.8).

Power can be seen as an internal personal characteristic which becomes psychological empowerment when linked to appropriate goals and resources to achieve those goals: it then

becomes power-from-within. Another way of seeing power is the ability of one person or group to exert its will over another person or group; either to the advantage or disadvantage of the subservient group, but without their control. This is known as power-over. A third concept is power-with, when those with power-over choose to share their power to encourage increased power-from-within. It should be remembered that these concepts were originally applied to Anglo communities, and in other cultural and language contexts there may be differences.

4.1.2 What is empowerment?

The idea of empowerment is recognised across several disciplines, and there is no single agreed-upon definition. For example, Wallenstein, working in public health, refers to Rappaport's definition: 'Empowerment is a process by which people, organisations and communities gain mastery over issues which concern them' (Rappaport 1987, p. 122); or in a World Bank definition: 'Empowerment is the process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes' (Wallerstein 2006, p. 17), (World Bank). Laverack, another public health and development researcher, defines empowerment as 'a process by which people are able to gain or seize power (control) over decisions and resources that influence their lives' (2009, p. 4). Zimmerman, a community psychologist, uses Rappaport's 1987 definition (Zimmerman 1995, p. 581).

These definitions, while subtly different, encapsulate the main paradigm of empowerment. People, or groups of people acting together, may be empowered. The individual or the group takes control over some aspects of their lives. Both resources and knowledge are needed to do this. The direction and drive comes from within the individual or the group, not from outside, though outsiders may facilitate this process. Psychologists refer to the empowerment of individual people as 'psychological empowerment', while that of groups is described as community or organisational empowerment, depending on the nature of the group (Maton & Salem 1995, p. 632; Zimmerman 2000). These concepts are linked, but distinct, and a closer examination of the strands that make up this complex idea is needed.

4.1.2.1 Empowerment and its relationship to power

Rappaport (1987, p. 129) discusses two dictionary meanings of empowerment, stating that empowerment refers to a process of *becoming* or *being allowed* to do some[thing], [my italics] .Labonte (1990, pp. 64–65), expands on these two definitions, using the dictionary definition of power. He firstly discusses empowerment as a transitive verb (where the action is done by something onto something) — a person or organisation gives power or authority to another person or organisation, a delegation of power, or a transfer of some part of that person or organisation's power to another. He follows with a second, preferred, dictionary meaning, that people take action, themselves, to acquire power. Here power becomes an intransitive verb,

whereby the subject acts. The person or organisation empowered is in this case actively achieving empowerment rather than being passively given a level of power that another thinks is appropriate. This latter concept is applicable to both community and individual empowerment; the individual, organisation or community 'takes power' (Labonte) or 'becomes more powerful' (Rappaport). Thus empowerment does not involve a person or community being given some control over their situation by a person or group with power-over them, but rather empowerment requires the taking of power over, or control of, aspects of life of a community or person.

Rappaport's (1987, p. 122) widely used definition of empowerment is also cited by other researchers (Zimmerman 1995; Wallerstein 2006; Cattaneo & Chapman 2010). The focus of his definition is on the outcome of being empowered rather than a process which led to empowerment. It also highlights the multi-layered nature of empowerment, which can occur equally within individuals, organisations or communities.

More recently, Cattaneo and Chapman (2010, p. 647) defined empowerment as 'an iterative process in which a person who lacks power sets a personally meaningful goal oriented towards increasing power, takes actions towards that goal, observes and reflects upon the impact of that action, drawing on his or her evolving self-efficacy, knowledge, and competence related to the goal. This process-driven definition of empowerment summarises a model of the process of individual empowerment, and implies that the outcome is achievement of power-oriented goals. While discussing individual empowerment, the model sees the person as embedded in a social context. The strength of this model is that it focuses on power: empowerment involves the taking of power, and as such there is a need to analyse who has power in a given situation, and how that power can be redistributed to achieve people's defined goals.

From these definitions several components of empowerment theory can be extrapolated. It is a complex theory because empowerment occurs at several levels of society, from the individual to the community level. The term is used to discuss both the outcomes of empowerment and the processes which have to be undertaken to achieve these outcomes. At the heart of empowerment theory is the concept that people or groups of people take control of their lives for the betterment of their lives.

4.1.2.2 Process and outcome

As discussed, empowerment it is a concept which includes both processes involved in empowerment and the outcomes of those processes. Zimmerman, a community psychologist, (1995, pp. 583–85; 2000, p. 46) distinguishes between the processes of empowerment and their outcomes. Processes, according to Zimmerman, are actions where people create or are given opportunities to control their own destiny and influence the decisions affecting their lives Outcomes on the other hand are 'specific measurement operations (whether qualitative or

quantitative in nature) that may be used to study the effects of interventions designed to empower participants', these measurements being used to 'generate a body of empirical literature that will help' (Zimmerman 1995, p. 583).

4.1.2.3 Culture and how it affects the concept of empowerment

Much of the research on empowerment theory has come from Europe or North America. However, the concepts have been transferred to other cultures, particularly by development workers and researchers. Concepts which are similar, if not identical to the Western term 'empowerment' have developed in other communities, but under different names. As this study is considering empowerment or disempowerment of Palestinian refugees, it is important to consider how empowerment theory should be conceptualised and operationalised outside of Anglo or Western settings.

Cultural context is basic to understanding empowerment, because 'cultural values influence both the importance of particular goals and the choice of avenues to reach them' (Cattaneo & Chapman 2010, p. 651). Lee (2001, p. 44) also emphasises the importance of understanding both the people and their environment when practising social work from a theoretical perspective of empowerment.

Labonte (1990, p. 65) contrasts two culturally different applications of empowerment theory: that described by Freire in his work with illiterate South American people (Cox 1990; Freire 1996), where Freire uses educational methods which raise consciousness of their life situation within a complex social structure (calling this process *conscientizacao*); and that of Lerner, who worked with Californian industrial workers and used group training programs to increase critical understanding of a complex situation which had disempowered workers. Both these models had the same outcome — a community gained increased skills with which to make changes in their lives, hence improving their wellbeing. However, the cultural differences of poor industrial workers in a wealthy country and illiterate poor of a developing country mean that the processes applied must inevitably be different.

Laverack and Brown (2003) highlighted the need to take into account culturally different approaches to time management. In working with a Fijian community, Laverack and Brown found that Fijians have a more 'casual pace' where time is concerned. They attribute this to the prioritising of social and cultural ceremonies that can take precedence over the task which the group have gathered to consider. They also discussed the problems people had with travelling long distances to attend activities and with finding time to continue to do their normal activities, such as domestic duties, as well as participate in activities related to the research. Laverack and Brown emphasise that culturally-based attitudes to time and punctuality within a community need to be understood, as well as the practicalities relating to the physical environment and

services available to the community. All of these factors need to be taken into account when developing processes to facilitate empowerment.

Erzinger (1994, p. 418), working with Spanish-speaking South American communities, found that Latin-American people can only achieve empowerment through community action, as they do not perceive themselves as standing alone, but as part of a community. Other cultural differences have been identified when developing projects. Laverack and Brown when working with Fijians, identified a strong hierarchy within the culture, which they felt could result in the exclusion of lower-status people; however, they did not observe this in practice, as lower-status women actively participated in their workshops (2003 pp. 337–38). Lai, when comparing projects which aimed to reduce violence in Asian-American and Pacific Islander youth, identified strategies which work within those cultural strengths, including reliance on extended family, and reinforcing traditional beliefs and world-views to minimise violence in the communities (Lai 2009, p. 458). She went on to suggest that processes which empower the community, such as community mobilisation and youth activism, have been adopted by several of these communities. For example, she describes the community mobilising in Oakland to convene a state-wide dialogue on Asian-American and Pacific Islander youth violence. This included meetings between local communities, law enforcement organisations, policy makers, and the media, which facilitated greater understanding of actions already taken and helped to form ideas for more actions (p. 458). A community seeking empowerment may find that some cultural traditions support their endeavours, and in that way an understanding of the culture and its traditions may help a community to achieve its goals.

As well as problems with the process of empowerment across cultures, there can be problems with the fundamental concepts of empowerment, particularly when working in languages other than English. Erzinger (1994, p. 418) highlights this problem. The Spanish word for ‘power’ refers to ‘authority over’, analogous to ‘power-over’ and has no meaning of ‘power-from-within’. Thus to use ‘power’ and ‘empowerment’ together in Spanish would appear contradictory. Freire, writing in Portuguese about empowering poor and illiterate people, uses the term *conscientizacao* to describe the raised awareness he found in his students, and the use of this awareness to change the community. (Cox 1990, p. 78). His discussion of the process of *conscientizacao* indicates that the activity is a form of empowerment (Freire 1996; Cox 1990).

While the outcome of empowerment crosses cultures, both the language and the processes used to encourage empowerment are culturally specific, and this needs to be considered by a researcher when working outside their own culture.

4.1.3 Empowerment as an ecological concept: how individual, organisational, and community empowerment support each other

Until now I have considered a range of concepts under the general heading of empowerment. However, the topic of this study is the empowerment of a specific community, Palestinian refugees in Lebanon. Empowerment can relate to individuals and to groups of people and ways of studying it fall into two general areas: Some researchers, including Zimmerman (2000), consider these are distinct and separate concepts, while others (Labonte 1990; Rissel 1994; Laverack 2009) consider that there is a continuum from individual empowerment to political and social action, and that empowerment can occur at one or more points on the continuum.

Zimmerman (1995, 2000) suggests three levels: psychological empowerment, or empowerment at a personal level; organisational empowerment that enhances an organisation's or its members' skills and provides them with mutual support to effect community level change; and community empowerment, where individuals work together to improve their collective lives (Zimmerman 1995, pp. 581–82). While he describes these levels separately, Zimmerman claims that the individual who is achieving psychological improvement will display (among other things) enhanced community involvement or participation in organisations (1995, p. 588 and p. 590). This concept is examined in greater detail by Maton and Salem (1995) when they look at the factors within three organisations which encourage psychological empowerment in their individual members. Organisations can be structured to either enhance members' empowerment, or to limit it. However, we cannot assume that all those working within empowering organisations will themselves be empowered. As with organisations, communities can be empowering, or not. Zimmerman states that 'An empowered community is one which initiates efforts to improve the community, responds to threats to quality of life and provides opportunities for citizen participation' (2000, p. 54). Again, although citizens are encouraged to become more empowered, not all citizens of a community will achieve this.

As we examine various methods to operationalise levels of empowerment, the divisions become less clear. For example, Manton and Salem discuss the common factors they found in three organisations which set out to empower their members via their programs (Maton & Salem 1995). Saegert and Winkel found that the distinction between individual empowerment and collective empowerment is not clear-cut (Saegert & Winkel 1996, p. 519). Several researchers have resolved this problem by suggesting the use of a continuum which incorporates individual empowerment and moves through various stages of group empowerment (Labonte 1990; Rissel 1994, Laverack 1999). This concept resolves the ambiguities of Zimmerman's three levels of empowerment.

Labonte (1990, p. 67), has developed an integrated model, showing how personal empowerment can be linked to political action originating from the empowered community (Fig. 7). He describes a continuum of five stages of increasingly more collective action towards empowerment of an entire community.

Figure 7: Continuum of community empowerment, adapted from Labonte 1990, Rissel 1994, and Laverack 2004

Labonte suggests that these levels are not a hierarchy with a progression from one level to another, but rather a continuum within which services can be provided to support the development of empowerment in the individual, group, or the community. Other authors have used this concept with minor variations (Laverack 2009, p. 64; Rissel 1994, p. 42).

Labonte's continuum has the potential to identify multiple pathways towards community empowerment, and it offers multiple points for intervention by concerned professionals wishing to share power with the community. As its starting point is personal empowerment it also encompasses the work of psychologists in this area. Power-with can be exercised with individuals, small groups, organisations or coalitions, whichever is most appropriate to the social and cultural norms of a community.

4.2 Health and empowerment

The theories which link behaviour to health outcomes, which were discussed in Section 3.2.2.1 are dependent on the individual having the power to modify their behaviour, and the will to modify their behaviour. Lalonde, as discussed in that section, suggests that self-control is the principal factor governing the modification of behaviour (Lalonde 1974, p. 8). However, those who support the concepts of social determinants are aware that people may not have the power to control all their behaviours.

4.2.1 Research on the effects of empowerment on health

The importance of active participation, both of individuals and of the community as a whole has been recognised since at least 1978, when the Alma Atta declaration, in Paragraph 4, identified participation as both a right and a duty of individuals and the community (World Health Organisation 1978). This concept of community participation was expanded upon in the Ottawa charter of 1986 when, in the section on strengthening community actions, it specifically discusses empowering communities, and the importance of community participation in prioritising and decision making (World Health Organisation 1986). Since then many projects based on these concepts have taken place, and research has measured their validity.

Research into the efficacy of empowerment to improve health is wide-ranging and has been carried out by health educators, nurses, professionals managing chronic illnesses and people involved in community development. It is not always clear what the researcher may mean by empowerment, nor can research projects always be compared. However, the study of projects, including elements of empowerment, can reveal certain patterns.

In the management of chronic illnesses, empowerment may be a key part of educational programs which help the patient to manage their illness and maximise quality of life. A Taiwanese project studying patients with end-stage renal failure helped them to manage the lifestyle changes needed when undergoing haemodialysis (Tsay & Hung 2004). The researchers used normal education processes with half the participants, and applied principles of empowerment with the other half. It was found that the empowerment group had better outcomes, a positive attitude to self-care and greater likelihood of complying with requirements, while experiencing less stress and anxiety. Having choices in how to manage their illness also reduced their depression — itself a chronic illness and also a precursor to other chronic diseases.

The Cochran collaboration, in its review of group-based training for self-management strategies for people with type 2 diabetes, reviewed 11 studies (Deakin, McShane et al. 2005). They found that control of blood glucose and knowledge of the condition were improved. They found some evidence for improved self-empowerment, although only one study looked at this variable (p. 15), but there was not sufficient evidence to be conclusive. This suggests that management of diabetes In the countries surveyed may be better controlled by people with good knowledge of their condition, with the possible addition of empowering strategies, as mentioned in the report. However all these countries are either European or North American, and so do not take into account the problems of living in less developed communities (P. 20).

Education also has a vital role to play in projects to change health-related behaviours more generally. A US study of youth who participated in a multi-state youth-led, youth-directed anti-

smoking program, looked at the psychological empowerment aspects of this program rather than just the outcomes in terms of reduced smoking (Holden, Crankshaw et al. 2004; Holden, Evans et al. 2005). Holden and her colleagues found that the level of participation in this program remained high because the young participants had control over the program. However, relinquishing their decision-making authority may have been difficult for the adults involved.

An intervention in Norway's Arctic north used community empowerment to make significant changes to cardiac health in a small (population about 2,500) community (Lupton, Fonnebo et al. 2003; Lupton, Fonnebo et al. 2005). Two similar communities not subject to the intervention were also observed as controls. The intervention included community-based participation of NGOs and people at high risk of cardiac disease and the wider community. Health improved as indicated by participants' significantly reduced systolic and diastolic blood pressure readings. Healthy behaviours showed increased use of low-fat milk, and increased physical activity. Mental health and self-rated health were found to have improved in some groups within the community. The researchers consider that their interventions were significantly different from previous studies because they used multiple strategies, including local empowerment, mass media and individual programs with high-risk members of the community. Both the nature of the interventions and the empowerment principles used in developing them were considered important in achieving outcomes.

There have been several evaluations of projects aiming to alleviate illnesses by modifying environmental risk factors. As suggested by Zabaneh and colleagues (2008), the environment can have consequences for health, and some studies have looked at the use of empowerment to manage the environment. A program in Ghana (Nsowah-Nuamah, Mensah et al. 2001), sought to manage the increasing prevalence of urinary schistosomiasis, a parasitic disease. An integrated community-based control program was undertaken, including chemotherapy and health education, to encourage community participation in the provision of safe water supply, sanitation and sound environmental management. The interventions followed three protocols: all eight of the participating villages received appropriate drug treatment; however, one group of villages received no health education, another group of villages received 'passive education' implemented by local leaders who received little prior training, and a third group of villages received 'active health education' conducted by specially trained health-educators. The active education villages undertook extensive work to reduce reinfection. In the 'active' villages more church and youth groups were formed than in the other villages. In the other two groups of villages there were only minor changes. Two years after the interventions, the prevalence of illness was reduced in all villages, but in those villages which had received health education there was significantly less, and those with the active education had the lowest prevalence.

As several authors have reported, the emotional and psychological wellbeing of the Palestinian refugees is poor (Saab, Salem et al. 2005). We can hypothesise that psychological empowerment of previously disempowered members of a community may have an impact on the health status of that community. Gala (1997) studied three Indian villages which had elected all-women village councils, something which the author calls ‘a revolutionary move in the patriarchal system of India. The author discusses the difficulties these women had to overcome to be elected and then to function as the village council (pp. 32–41). She outlines the actions of these women once in office, saying how they focused on issues relating to water, fodder and fuel (Gala 1997). While the paper does not consider health directly, the issues addressed by the village councils are those which pertain to environmental health and family needs of the poorer members of the community, and so it may be assumed that the overall health of these villages will probably improve.

These examples demonstrate a range of empowering programs which can have a positive impact on health. By encouraging a deeper understanding of the behavioural and environmental aspects of health, people and communities can participate in the planning and implementation of changes which facilitate better health outcomes. Some studies show that the effect of being part of decision-making processes appears to have a positive effect on mental health. One final supporting example looks not at the empowerment of people, but rather at the situation where people lack control over aspects of their lives. In their paper reporting on the first Whitehall study, Rose and Marmot (1981) found that the social service grade was inversely related to incidence of coronary heart disease, and that then-known factors could not explain the link. The Whitehall 2 study went on to examine the health differences of the various grades of the civil service over time. Two papers have examined the Whitehall 2 data from the perspective of levels of control. Bosma and colleagues (1997) found that men and women with low job control had a higher risk of coronary heart disease, and subsequently Griffin and colleagues (2002) found that low control at either work or home contributed to levels of depression and anxiety. These two studies suggest that both mental health and physical health may be impaired when people are not empowered in their work or their home environments. Zimmerman suggests that organisations, including workplaces, can be empowering, in that they can provide an opportunity to gain control of aspects of life through their structures and leadership styles (Zimmerman 2000, pp. 52–53).

Though widely scattered across health and development, there is a body of literature suggesting that the use of empowerment strategies will positively influence health. Strategies can operate at individual or community levels and be applied in both developed and developing communities. Wallerstein suggests that empowerment strategies are particularly effective in socially excluded populations (Wallerstein 2006, p. 15). However, the literature suggests that

empowerment principles can be integrated into a wide range of programs, across a wide range of communities, leading to improved outcomes for these programs.

4.2.2 The effect of participation on health

Participation and community involvement are similar concepts and are closely linked to empowerment. For example, Wallerstein (2006), in her literature review of empowerment and its effects on health, states that '[…] while participation forms the backbone of empowering strategies, participation alone is insufficient (p. 9). She distinguishes between participation that is active and based on community control, and that which is manipulative or passive — only the former being empowering. Attree and colleagues (2011) quote a widely used definition of community engagement as 'Involvement in decision making and in design, governance and delivery of initiatives which aim to address the wider social determinants of population health and health inequities' (p. 251). These definitions are similar in that they require the members of a community to be actively involved at all levels in a given project. Attree and colleagues reviewed 22 community-based projects, and in general found that participation in them had provided psychological benefits, such as bolstering self-confidence, self-esteem and perceptions of personal empowerment. Their review found evidence, in three case studies, that participation may have actually had negative consequences to physical and emotional wellbeing. On closer examination, however, these three examples did not meet the definitions of community engagement formed by the researchers. One involved Chinese older people living in English communities (Chau 2007). While participation was active and participants had control of the projects, the wider community did not fully understand the process, highlighting the importance of involving the entire community rather than just a section who actively manage the project. This may be particularly important when the population is socially excluded for some reason, in this example for cultural and linguistic reasons.

A second UK study evaluated two consultative processes linked to changes in local public transport systems. Both consultative processes generated tensions that were not fully resolved. The researchers identified two problems contributing to these unresolved tensions: first, unequal power balance between the local authorities, and the participants; and second, consultative fatigue, as the same community groups were the subjects of other projects. This latter factor also suggests that only a small section of the community was actively involved. (Bickerstaff & Walker 2005). These examples highlight the twin issues of passive and manipulative participation with regard to power sharing in the consultative process.

The final study reviewed by Attree and colleagues was based in Australia and this explored whether participation in civil society groups, including volunteer associations, groups, clubs and associations had an effect on the health of participants. This study used both survey and in-depth interview techniques. In the surveys it was found that older people experienced worse

physical health with greater involvement in civil society organisations. The researchers suggest that the nature of the civil society organisation may affect health outcomes differently, with civic action or political groups being more stressful than social groups (Ziersch & Baum 2004). This study highlights various health problems which may be associated with higher rates of participation.

Attree's meta-analysis suggests that it is critical to consider both the costs and the quality of participation. Consultation alone, without control, does not lead to empowerment, though some may associate the two concepts. However, even when participation is of the ideal nature described by Wallerstein, there will be costs to the individual in terms of effort, time and money. The outcomes need to be worth that expenditure.

4.2.3 Power, health and empowerment

The ecosocial theory of health outlined in Chapter 3 helps us to define accountability and agency. Analysis is needed to identify exactly where the power to effect change is situated. In trying to answer the question 'What are the implications of these interrelated life experiences', when addressing health issues, it is necessary to understand where the power-to-effect-change lies. With that understanding, the application of empowerment theory allows a community to develop programs which will help it to gain authority over a particular situation, or to acquire or seize power over the situation.

4.3 Community empowerment as a continuum

I found no existing discussion or research on empowerment among either Palestinian communities or more generally among Arab communities. Therefore, I reviewed theories of empowerment commonly used to guide researchers and practitioners in their fieldwork in a range of different situations, particularly looking at how they have operationalised empowerment. From the outset I considered empowerment as a continuum, as Labonte, Rissel and Laverack have done, looking at how community empowerment plays out across different societal levels (Fig. 8).

Figure 8: Continuum of community empowerment, adapted from Labonte 1990, Rissel 1994, and Laverack 2004

Within the continuum of empowerment there is some discussion as to whether a community progresses from individual empowerment through to the final stage of social or political action. Lavarack says that 'community empowerment can begin at any point along the continuum, but for persons experiencing a high degree of "relative powerlessness" it often starts with a personal action that builds a greater sense of power-from-within' (Laverack 2004, p. 48). However, he also views community empowerment as progressing from one level to the next, or failing to progress, in which case a period of stasis ensues. While acknowledging the potentially conflicting ideas thus expressed by Laverack, it is sufficient to note that he also describes the continuum as a 'simple linear interpretation of what is a dynamic and complex concept' and it is necessary to examine differing cultural and social settings to consider how this complexity is demonstrated in any community. For example, Erzinger, in her work within Latin-American communities, suggests that for the Latin American the concept of individual empowerment would be difficult to envisage — the family or social group is the smallest group which can be empowered because the individual is an isolated and lonely being without context or power (Erzinger 1994, p. 418). I would suggest that within communities empowerment could possibly arise from small group actions which can progress in both directions along the continuum. Therefore, regarding the process of empowerment from individual to community to political action, analysis of any situation must take into account that the process may not follow a simple linear progression.

4.3.1 Psychological or individual empowerment

Personal or psychological empowerment has been operationalised in many different ways, with authors reporting varying emphases and related factors. For example, Lee (2001, p .34), when discussing empowerment as a part of social work practice, discusses the development of a positive sense of self, cultivation of knowledge, and capacity for critical comprehension of one's social and political environment, cultivation of resources and development of strategic goals. On the other hand, Cattaneo and Chapman (2010, p. 647, and pp. 652–53) consider that processes supporting empowerment include self-efficacy (belief that one has the ability to achieve), knowledge (especially of the social context and power dynamics) and competence (the skills

needed to achieve). Both models include belief in the ability to succeed (stemming from power-from-within), and the acquisition of knowledge as essential to achieving the desired outcomes. Lee also adds the need to access appropriate resources (she lists these separately from knowledge, so by implication resources are funds or artefacts which help to achieve), while Cattaneo and Chapman include the need to acquire skills. Both studies argue persuasively and so a comprehensive list of requirements could include both of these additions.

The concept that empowerment occurs in one area of one's life, and that an individual should develop strategies to achieve control or power over this area is implicit in some theories. For example, Laverack discusses prioritising key health issues (2009, p. 54). Cattaneo and Chapman (2010, pp. 651–52) regard the activity of goal setting as central to the process of empowerment. They stress that the process of empowerment is driven by personal aims, and therefore the iterative process of defining goals, taking actions towards achieving them, and then reflecting upon the effectiveness of these actions are critical steps in the empowerment process. Cattaneo and Chapman also maintain that goals supporting the process of empowerment should be 'personally meaningful' and 'oriented toward increasing power'.

Having reviewed the literature on personal or psychological empowerment, I concluded that there are many contributory factors to personal empowerment, sometimes named differently by different authors. I have summarised these factors in Table 1.

Table 1: Factors contributing to individual or psychological empowerment

1. Self-efficacy, positive sense of self, power-from-within
2. Personal aims and goals which are set, reviewed and refined in an iterative process
3. Knowledge of social context and power dynamics
4. Skills to implement the plans made
5. Resources, including funds and materials

4.3.2 Small, informal groups and empowerment

Small groups may form for a range of reasons, some of which contribute to empowering the community as a whole. Labonte, in discussing small group facilitation, suggests that the small group avoids isolation and the resulting tendency to self-blame. He discussed ways in which groups can form, including professionally led groups, such as therapy and education groups, informal social networks, or informal groups with a common need.

In more formal networks there is usually an identified leader. However, groups with an outside professional facilitator may have difficulty in switching from outside leadership to leadership from within the group (Labonte 1990, p. 68). Freire discusses the nature of the group dynamics, which can either facilitate or block the path to internal leadership. In the small literacy classes he forms, 'learners are empowered by the knowledge they are learning' (Cox 1990, p. 76). In his groups formed to improve literacy, Freire's problem-posing teaching methods encouraged the development of analytical skills and critical thinking. In this atmosphere group members begin to question the status quo and this leads to the process that will ultimately empower them. Thus, the original purpose of the group is less important than the way it operates.

In addition to issues of group leadership, Labonte discusses conflict resolution within small groups, suggesting that they are 'often fraught with their own internal issues of power and cohesion'. Some of these problems may arise because the group focuses on problem solving, rather than on the development of group identity and community building within the group (Labonte 1990, p. 68). However, as small groups often come together because they have an identified problem, it is understandable that their priority will be that problem.

In reading the experiences of both researchers and fieldworkers, it seems that the distinction between small informal groups and organisations can be blurred, and the development from one to another can be gradual. Small groups organise around problems unique to the group members, while community organisations organise people around larger concerns, (Labonte 1990, p. 69). In practice distinctions are often unclear and this can be a difficult line to determine.

4.3.3 Organisations and empowerment

Community organisations form around issues or problems that are larger than the immediate concerns of the individuals in the group (Labonte 1990, p. 69). The literature considers empowerment and organisations in two distinct ways. One focuses on organisations which encourage their clients and/or their employees to increase their psychological empowerment; for example, Spence-Laschinger and colleagues investigated the links between nurses' empowerment within the workplace and their patients' empowerment (Spence-Laschinger, Gilbert et al. 2010). More relevant to this study are those researchers and practitioners who consider the empowerment of organisations to make changes within an entire community. This process may also include the psychological empowerment of individuals — but this should be seen as a first stage of the continuum leading to lasting political and social changes, rather than being an end in itself.

Some researchers have attempted to identify the domains or factors within organisations that lead to organisational structures that will support community empowerment. Labonte, (1990,

p. 66), adapts Kindervatter's (1976) seven criteria for empowerment, four of which focus on personal empowerment and three on organisational empowerment. Maton and Salem (1995) reviewed the features of three organisations and identified four factors which supported empowerment within the organisation. Laverack, in his work in health education and development, identifies nine key domains of empowerment, which he uses during strategic planning of programs (Laverack & Wallerstein 2001, p. 181; Laverack 2004, ch. 7; Laverack 2007, ch. 5). Our understanding of the domains or factors which affect the ability of organisations to encourage empowerment in their related communities is gradually increasing. Laverack has identified nine important domains but acknowledges that there may be others. However, while acknowledging the possibility that other domains may be relevant in any particular organisation, Laverack's nine domains provide a sound basis for developing empowering processes within organisations.

4.3.4 Empowerment and coalitions of organisations

Several organisations within a community may have identified similar problems, and in order to influence policy at higher levels they can join forces to advocate collectively (Laverack 2004, pp. 52–53). Coalitions may come together for a range of reasons, not all relevant to the empowerment of their communities or their organisations. For example, Labonte discusses coalitions of service providers which come together to better manage services and resource allocation in a process which may not in itself be empowering (Labonte 1990, p. 72). Another form of coalition may be formed as part of community consultations; these may seek to empower the organisations being consulted, but there is a risk that the consultative process dissipates activists' energies without achieving the goals of the organisations (Labonte 1990, p. 72). Bickerstaff and Walker (2005) discuss two such community consultation processes in developing public transport services in two English local government areas. They highlight the top-down nature of the consultation, with financial control always held by the local government, while community organisations were focused on minor details. Laverack (2004, p. 53) also discusses the problems where one partner dominates, quoting the situation when a service provider and housing rights groups formed a coalition to improve housing. While extensive work was undertaken by the coalition, the final recommendations, were reviewed and rewritten by the service provider into a non-challenging and non-committal form.

While there are pitfalls such as those discussed, coalitions can encourage broadening of the community's issues and politicising of their endeavours to bring about change (Labonte 1990, p. 73). Coalitions may enable the voice of the community to be heard when negotiating with those who hold power.

4.3.5 Political and social action

The final point on the continuum considers action which generates change, either through political changes, changes to social norms or a combination of both. Laverack (2004, pp. 127–31) discusses the political context within which a community is seeking to become empowered. Types of context range from 'political context is supportive' to 'an uncooperative political context' to 'political context is not supportive'. At the supported extreme of the range, collective action can be negotiated to encourage change. At the other end of the range, actions to accomplish change may include revolt and insurgency. Between these two extremes, collective action may force change onto the political hierarchy — through actions such as lobbying, protests, demonstrations or riots (Laverack 2004, pp. 127–31).

Labonte (1990, pp. 73–74) limits his discussion of political and social activism, as he is writing for professional people who are seeking empowerment within the programs they are running and, he says, are less likely to participate in political actions as part of that work. Thus his focus is on the social aspects of health policy. His suggested requirements for optimum social welfare and human health within a society include equitable access to economic benefits, access to creative, education and caring services, supportive and well-defined social relationships, decentralised decision making that supports communal values, sustainable use of natural capital and, lastly, involvement in collective decision making. These requirements cover the economic, political and social spectra of any society, and together form what Laverack describes as a supportive context (Labonte1990, pp. 73–74).

This suggests that if a community attempts to gain empowerment, having gone through the stages outlined in the continuum, in a society which is supportive, a negotiated change may be achieved with shared input, (or power-with, to use power terminology). However, if members of society who have power-over are not prepared to negotiate, then Laverack's other scenario — unsupportive political context — will require the seizing of power through increasing levels of conflict.

4.4 Processes of community empowerment: nine domains

In his work on health education and development, Laverack identifies nine key domains of empowerment which he uses during strategic program planning. They each operate over one or more of the levels within the continuum (Laverack & Wallerstein 2001, p. 181; Laverack 2004, ch. 7; Laverack 2007, ch. 5). He identifies participation, leadership, asking 'why', problem assessment, organisational structures, resource mobilisation, links to others, program management, role of outside agencies. Like other researchers, he suggests that this is not necessarily a complete list of operational domains (Laverack 2004, p. 60).

4.4.1 Participation

Laverack stresses that participation is essential to empowerment, being common to all levels of the continuum. He goes on to state that there is a considerable overlap between community participation and community empowerment; however, they are not the same concept, and the difference lies in how people participate or become empowered. (Laverack 2004, pp. 86–87). (This was previously discussed in Section 4.2.2 on health and empowerment.) The nature of the participation is therefore critical: people need to be involved in decision making, have access to community-level resources, and be given the skills to participate effectively.

Several researchers examining participation have identified failures in these and other areas. Problems relating to participation include a negative impact on physical and emotional health (Ziersch & Baum 2004, pp. 497–99), as well as financial, energy and time costs (Chau 2007). However, Attree and colleagues (2011) found that, in general, participation was beneficial to health. Bickerstaff and Walker (2005) discussed community participation, as part of community consultation processes during modification of public transport within UK local councils. In addition to the emotional problems described by participants, they also identified problems related to developing power-with between the council, the employees of the council and the various representatives of community organisations. These arose principally because of power inequity (power -over rather than power-with), lack of practical outcomes, and 'consultation fatigue' (Bickerstaff & Walker 2005, p. 2138). These examples suggest there is a cost to participation, and it needs to be matched with benefits of gaining power-with, or power-within.

4.4.2 Leadership

Leadership is the second of Laverack's (2004) domains of empowerment. The leader's role is to give direction to the group, taking responsibility for getting things done and for dealing with conflict within the group (p. 88). Leaders can be drawn from either within or from outside the community. In programs with input from outside the community, for example, a leader may be introduced because they are seen to have skills not available within the community; however, leadership in most communities is an integral part of the community structure and ignoring that structure reduces the chances of success (Laverack 2004, p. 88). Elsewhere Laverack has suggested that one role of outsiders in programs which integrate empowerment into their structure is to provide technical support.

4.4.3 Organisational structures

Organisational structures have been examined in situations where 'people come together in order to socialise and to address their concerns and problems' (Laverack 2009, p. 67); they include small groups, such as youth groups, churches and committees. However, these

groupings alone are not sufficient to enable the community to mobilise — there also needs to be a sense of community among the members, which Laverack suggests comes about when there is a sense of connection to the people (Laverack 2004, p. 90). In his ordinal scale of features of organisational structures Lavarack's scale ranges from a community having no organisational structures to organisations being actively involved both inside and outside the community and the community being committed to its own and other organisations. Features of organisational structure which are evident in this scale include the development of organisations, those organisations enabling participation, and an ability to work with other organisations.

4.4.4 Capacity to assess problems

The capacity to assess problems is an activity fundamental to empowerment. It presupposes that problem assessment and solution identification can be performed by the community, and that the community has the capacity to act in order to achieve that solution (Laverack 2009, p. 67). This may in some cases require the community to acquire new skills and competencies; however, programs in which the stakeholders (i.e. the community) display commitment and are involved in the identification of problems and solutions are more likely to succeed (Laverack 2004, p. 92). Laverack's five-point scale starts at the point where there is no problem assessment undertaken by a community, and progresses to the point where a community has the ongoing capacity to identify and own problems, solutions and actions. Further factors identified as points along this scale include the gaining of skills and rising levels of participation by the whole community (Laverack 2007, p. 73).

4.4.5 Resource mobilisation

Resource mobilisation includes the ability to mobilise resources from within the community, and from outside the community (Laverack 2009, p. 67). Internal resources can include land, food, buildings, money, people, skills and local knowledge, while external resources can include money, technical expertise, and equipment (Laverack 2004, p. 93). In his five-point scale Laverack describes the first point as 'the community mobilising no resources' and progresses to 'considerable resources raised'. The final point on the scale also requires that the community decides how resources will be distributed, and how fairly they can be distributed. Progress along the scale increases as communities gain control over the resources and manages them equitably (Laverack 2007, p. 74).

4.4.6 Asking why

Fundamental to understanding the problems of the community is the ability to ask why: to critically assess the underlying reasons for an inequitable situation (Laverack 2009, p. 67). This process includes reflecting on the assumptions underlying our own and others' ideas and

actions and considering alternatives (Laverack 2004, p. 94). On a five-point scale for this domain, Laverack starts with ‘no group discussions held to ask why about community issues’ and finishes with ‘community groups have the ability to self-analyse and improve efforts over time’. As groups progress along this scale, their ability to challenge received wisdom, to reflect on assumptions underlying their actions, and to self-test their solutions increases. Further, while initially these reflections are taking place in small groups, the skills gained can be transferred to larger groups and partnerships (Laverack 2007, p. 75).

4.4.7 Links with others

Forming links with others is an intrinsic part of Labonte’s continuum of community empowerment, being the fourth step on that continuum. How those links are forged comes under organisation which is an essential factor in the empowerment of the community (Laverack 2004, p. 95). On Laverack’s five-point scale this domain ranges from ‘no partnerships’ to ‘links which generate resources, finances and recruits’, and additionally, ‘decisions which result in improvements for the community’. The scale moves from informal and undefined partnerships to more formal and defined partnerships, progressing to greater interdependence (Laverack 2007, p. 75).

4.4.8 Role of outside agents

The role of outside agents can be an important way to gain access to resources (both physical resources and skills). However, the associated risks from top-down management, which may not be supportive of empowering the community, may limit the benefits (Laverack 2004, pp. 97–8). Laverack focuses on this question in structuring the ordinal scale for this domain: at one end of the scale the outside agents control policy, finances, resources and evaluation of programs; at the other endpoint, agents facilitate change at the request of the community and act on behalf of the community to build capacity. Between these two extremes the community takes increasing control of decision-making processes (Laverack 2007, p. 76).

4.4.8.1 The role of professional support and assistance

The potential support provided by outside professional agents needs further discussion, as this can be critical to the empowerment of a community. Many authors have discussed the role of professionals in the empowerment of communities, pointing to the supportive actions and methods of educators (Freire 1996), health promoters (Laverack & Labonte 2000, Laverack 2009), and nurses (Spence-Laschinger, Gilbert et al. 2010). Most authors seek to highlight methods which facilitate empowerment, but Freire also discusses methods which be inhibiting, either intentionally or coincidentally (Freire 1996).

4.4.8.2 Teaching techniques

There are major roles for outside agencies in the areas of capacity building and training. Freire (1996) discusses a range of teaching methods which may either block or encourage empowerment (pp. 52–67). While Freire is writing about the teaching of literacy, his methods have been adopted and applied by health educators and others interested in promoting empowerment. Teaching methods which do not enhance critical thinking are referred to by Freire as the 'banking concept of education'. He sees the student in that situation as being the 'passive recipient of narratives', without the motivation or skills to think critically about them. The teacher imparts or deposits these narratives from a position of power over the student and uses them as a means of control over the student through these narratives (pp. 52–53). The banking method of teaching is not necessarily used with the conscious intention of maintaining power over the student; having been taught himself by this method, the teacher may be unintentionally perpetuating what is in fact a power structure (p. 56). Professionals who embark on teaching to promote empowerment need to use problem-posing methods, as these encourage development of not only of knowledge and skills but also a belief in one's own skills (self-efficacy). On the other hand, the 'banking method' maintains power-over the recipients by controlling the knowledge and skills they have access to.

4.4.8.3 Seizing power vs. being given power

There is a subtle difference between helping people to gain the skills and resources needed to take power and delegating a part of one's own power to a disempowered group of people. In looking at some projects and models it is clear that this distinction has become blurred. Spence Laschinger and colleagues (Spence Laschinger, Gilbert et al. 2010) argue that an organisational structure which is empowering to nursing staff can also be more empowering for the patient. This assumption, that a person with power-over can empower the person over whom they have power, relates to definitions of empowerment that involve power being bestowed on people by those with power-over them (Labonte 1990, p. 64). In this case the professional retains control over the process, and as such it is debatable that the recipient has, in fact, been empowered. Alternatively, Laverack (2007, p. 18) maintains that the key role of the public health worker 'is to provide technical assistance and resources at the request of the community': here the power stems from and rests within the community.

Freire (1996) discusses this issue in the context of *conscientizacao* He describes several problems which may arise when those with power assist those without power. Those with power may bring with them their 'prejudices and deformities', including 'a lack of confidence in people's ability to think' (p. 42). This concept has been explored by researchers who study lay knowledge (Frankel, Davison & Smith 1991; Brown 1995). For example, Brown studied toxic waste management as handled by US communities, noting that local organisations often met with

resistance from government health agencies (professionals employed to maintain the welfare of the community) when investigating toxic waste (p. 94). Frankel and colleagues studied lay knowledge of heart disease and compared the material presented to the general public via health educators with the detailed knowledge found in epidemiological literature. They found that the general public has a quite sophisticated understanding of heart disease, so when health educators oversimplify their message they lose credibility. Thus, there is a place for the outside helper, but that person or organisation needs to adopt a non-controlling role of offering technical support and acting as a resource for the community.

4.4.9 Program management

Program management needs to focus on how activities (programs) are structured so that they are empowering to the community: importantly, who manages the programs and who makes decisions on matters such as planning, implementation, evaluation, finances, reporting, and conflict resolution. Good management takes into account feelings of ownership of the program (Laverack 2004, pp. 98–99). Within the five-point scale for program management there is a progression from ‘all management coming from an outside agent’ to ‘complete self-management’. The organisation progresses along the scale, as they move from discussion to shared responsibility, with reducing levels of support as the members gain skills in program management (Laverack 2007, p. 75).

4.4.9.1 Including empowerment-facilitating activities within programs

Laverack and Labonte (2000) discuss the dichotomy in health promotion projects between top-down and bottom-up program design. They note that the bottom-up design will best facilitate empowerment; however, disease prevention through lifestyle change projects will often feature top-down program design (p. 256). The authors link this problem in part to certain expectations of the health authorities who provide the funding. However, they suggest a strategy whereby a parallel track of bottom-up activities can be undertaken and linked to the top-down activities — a strategy which funders find more acceptable. They present an example (p. 259) of a refugee community targeted by health authorities to receive anti-smoking programs. The refugee community identified concerns related to youth activities, rather than smoking, as being their primary concern. By combining the two aims (smoking education and youth activities) a single program emerged which empowered the community and also improved health.

However, not all activities succeed in facilitating empowerment. Bickerstaff and Walker (2005) examined two community consultation processes relating to public transport. This represents aspects of community empowerment which can be described in two ways: as forming partnerships (between the local government and community-based organisations) and also as a way of participating in social and political action (by the community-based organisations). The

authors found that the people who participated in the consultative process had found it unsatisfactory. People from the community-based organisations felt frustrated because the final outcomes of the process were constrained by ‘top-down’ factors, such as statutory requirements and limitations (p. 2139) while at the same time the local government members felt threatened by the process (p. 2136). Fundamentally, this consultative process was a top-down initiative. Though the aim was to involve community-based organisations in developing transport systems, the power to effect changes remained with the governing authorities, and the participants were aware of this.

4.4.10 Methodological aspects of introducing domains of empowerment

While these domains are separate and distinct, they are closely linked, and in several situations the concepts relating to one domain overlap with concepts in another domain. For example, organisational structure refers to the general way in which organisations organise themselves, but program management considers how the organisation manages interventions — representing two overlapping but different concepts.

While the ordinal scale suggested by Laverack presents a method of quantifying the domains of empowerment, the acquisition of information needed to evaluate the level of empowerment reached would require the use of complex qualitative research techniques: specifically, field observations, participatory observations, review of documents, and discussion with people in the community, including community, organisation, and program leaders, as well as general members of the community.

This literature review was undertaken in the quest to identify a suitable methodology to evaluate the quality of community empowerment. As such, a greater depth of understanding of these domains is needed than ordinal scales. However, the domains themselves provide a basis for thematic analysis of the process of empowerment. Additionally, Laverack has stated that these domains are not necessarily a definitive list, and so, during the process of collecting and analysing data, further domains may be identified. Thus the nine domains offer a basic structure for considering the processes of empowerment in a community, but others may be identified in the ensuing analysis.

4.5 Evaluating empowerment

So far I have considered empowerment processes, but empowerment is also an outcome (Zimmerman 1995; Zimmerman 2000). The obvious outcome of empowerment processes is that the community gains greater control. However the question then becomes ‘How does one assess the outcomes of empowerment processes?’ As already discussed in Section 4.2,

Zimmerman defines outcomes as the ‘specific measurement operations (whether qualitative or quantitative in nature) that may be used to study the effects of interventions designed to empower participants’ (Zimmerman 1995, p. 585).

Measuring empowerment has previously been attempted by several researchers. Rissel and colleagues (Rissel, Perry et al. 1996, p. 212) state that it is important to quantify and measure empowerment. They looked at four previous instruments designed to evaluate psychological empowerment, finding that two were specific to professional groups (social workers and teachers) and were not appropriate for general use and a third was very long, with over 200 items. The authors selected the final one, a 46-item instrument, for their research (pp. 212–13). This list of instruments highlights two problems with trying to measure empowerment. Firstly, it is a complex construct and there are many variables which need to be assessed. Secondly, the nature of empowerment changes from situation to situation. Finally, the instruments listed above were principally developed to evaluate psychological empowerment, which is only the first stage on the continuum towards community empowerment.

Other researchers have therefore thought that empowerment needs to be judged on a case-by-case basis. Zimmerman (1995, p. 596) considers that ‘a global construct may be inappropriately conceptualised as a static personality trait instead of a more dynamic contextual construct’. In a later work (Zimmerman 2000, p. 46) he discusses the outcomes of empowerment as the ‘operationalization of empowerment so we can study the consequences of citizens’ attempts to gain greater control in their community or the effects of interventions designed to empower participants’ This latter definition highlights two methods for evaluating empowerment at the community level: the level of control that the community has over its circumstances, and also the effectiveness of the activities which have been undertaken to achieve that end. It is not enough to evaluate the processes, nor is it enough to evaluate the outcomes — both need to be addressed to fully understand, and develop empowerment theory.

Rappaport suggests linking empowerment theory and narrative theory to create an evaluation tool. He suggests that for many people their stories are created by others and may be negative or narrow (p. 796); however, the ability to tell one’s own story or contribute to the telling of one’s community story is a powerful tool (p. 802), giving a voice to the person, organisation or community which can become a resource to change the balance of power and also serve as a way to strengthen self-efficacy. Rappaport is suggesting a process by which communities and individuals within communities can take control of their narratives and lives (p. 796); he also sees the evaluation of narratives as a way in which to evaluate the outcomes of empowerment.

The narratives people tell may indeed be sufficient to evaluate the outcomes of empowerment. But only understanding the process of empowerment can enlighten us as to why, in any given situation, community empowerment has been either a success or a failure. Sound knowledge of

the theory of empowerment can guide a community which seeks greater control over its future development. Thus we need to apply the five-point continuum of community empowerment, considering the effectiveness of actions at each level, using the domains outlined by Laverack. By combining these two concepts we can properly judge the processes and outcomes of projects to promote empowerment.

4.6 Disempowerment

Zimmerman (2000, p. 57) identifies a risk of blaming the people who have not seized control or power in their lives and communities, describing this as 'hold(ing) individuals responsible for their life situations and provid(ing) a rationale for relieving institutional responsibility'. In considering the failure to be empowered (the opposite of achieving empowerment), it becomes important to consider the underlying reasons. The literature gives few examples of failure to empower, though authors who discuss the role of professionals in the empowerment process do suggest ways in which the input of an outside professional can inhibit or block empowerment.

In their analysis of 22 studies of community engagement (a process in the forming of coalitions or political activism) Attree and her colleagues (Attree, French et al. 2011) cite two studies identifying that 'physical and psychological demands of engagement '[…] were particularly onerous for people with disabilities', (p. 255). In another study, 'the majority reported negative physical and psychological effects, such as exhaustion and stress'. Attree reports that most of the respondents in these 22 projects experienced positive benefits, including 'individual empowerment (defined as the feeling that they are being useful to others, feeling in control of events, being able to express ideas and having an awareness of individual rights)' (p. 252). While this is a loose definition of empowerment, it does include several aspects of empowerment theory important to the present study. This paper (and the 22 papers on which it draws) concludes that negative health consequences are linked to failed attempts to become empowered, though there is no suggestion of causation in either direction.

An analysis of how various activities relate to the community empowerment continuum, extrapolating the factors that support community empowerment, may help us to understand the problems encountered by a particular community. Thus, empowerment can be operationalised by identifying which stages of the continuum of community empowerment have so far been attempted; then applying a thematic analysis, starting from Laverack's nine factors, but looking for any further factors which may support empowerment or limit it.

4.7 In conclusion

I have here considered community empowerment from both outcome and process perspectives. The outcomes can be considered when examining the community through the lens of the

continuum of community empowerment, while the processes can be reviewed through Laverack's domains of community empowerment. I have also considered several specific potential problems in evaluating empowerment in a community, including linguistic and cultural differences between cultures, and the risk of blaming victims if their community has not achieved empowerment.

5
METHODOLOGY

This chapter looks at the epistemology underlying the methodology, specifically considering the theoretical underpinning of qualitative and case study methods. I then go on to review the problems of carrying out research under difficult circumstances before considering both the theory and practical aspects of sampling methods, data collection and analysis. Finally, I discuss ethical considerations that apply to the chosen methodology.

The overall purpose of this research is to understand how the lived experience of being a refugee has contributed to health among elderly Palestinian refugees living in Lebanon, and the implications of these experiences when addressing health issues. This of course entails close contact with the Palestinian community living in Lebanon, which in itself presents challenges for a non-Palestinian researcher. These problems can be considered in two parts: What is the best way to answer the research questions posed? And how can a non-Palestinian researcher approach this community appropriately?

The research questions, discussed in the first four chapters, in relation to the Palestinian refugees in Lebanon, are:

1. What aspects of their lived experiences impact upon health in old age?
2. How do their life experiences interact with each other to support or detract from good health in old age?
3. Where does the power to change these life experiences to promote better health in old age lie?
4. How do these lived experiences, the interactions between experiences and the power to control the lived experiences impact on health services in this community?

These questions were addressed by asking members of the community to tell their stories in their own words, and by asking elderly refugees to take photographs to illustrate their current environment. The community members, including both service providers and refugees, were prompted to make links between their experiences and their health. The first level of analysis examined these stories to answer questions one and two. A second level of analysis considered how civil society functioned within the camp, and the implications the stories might hold for that civil society in terms of perceived health outcomes, thus relating to the latter two research questions. The first stage of analysis used the ecosocial model as a lens through which to view the data, and the second stage used Laverack's concepts of community empowerment as a framework to develop understanding.

5.1 Methodological approach

The overall aim of this study, to increase understanding of life experiences and their effect on health in old age, entails looking at multiple levels of society, from the personal to the international in considering how societal factors may be embodied. I am attempting to build on the work of researchers such as Krieger, who first suggested the 'ecosocial model' (Krieger, 1994, p. 111; Krieger 2008), and others who have used this model (Levins & Lopez 1999, Chilton 2006, Godette, Headen et al. 2006, Teti, Chilton et al. 2006).

A range of epistemological approaches has been developed to answer different types of research questions. Each approach caters for a range of specific types of research and suggests a methodology appropriate to the research questions being asked (Crotty 1998). In addition to choosing an appropriate methodology to suit my particular research questions, there are the additional challenges of working with a community that speaks a language in which I am not fluent, which has suffered extensive persecution from outsiders (as outlined in section 1.2), and which has a fragmented system of governance. I will consider these two problems separately before outlining the method chosen to answer the research questions posed.

5.1.1 Epistemological theories which support the research questions

I spent some time evaluating the most appropriate approach to answering the research questions. Crotty (1998, pp. 67–72) considered the development of two distinct areas of research: firstly, natural sciences which focus on explaining the processes involved in the natural world; and secondly, the science which studies the social interactions of groups of people. Health science can be conceived of as both natural and social science. The progress of disease can be explained biologically, determining what happens in the disease process at a cellular and biochemical level within the body — such research tends towards the positivist, experimental approach. At the same time, the body operates within a social environment, and we know that disease processes can be influenced by the social conditions of the life lived (Krieger 1994, pp .889–94). This kind of research usually follows an interpretive approach. The present study, looking as it does at lived experiences and their effects on health in old age, requires a constructionist and interpretive approach.

I have thus developed my methodology on principles of interpretive theory (Crotty 1998; Neuman 2003). This is based on the epistemological concept that although objects have a reality of their own, interpretations of what these objects mean is 'constructed' by the observer. (Crotty 1998, pp. 42–43). Interpretive social science seeks to discover how people construct meaning in their lives and what is meaningful or relevant to the people being studied (Neuman 2003, p. 76). The collected data is usually qualitative. A wide range of options is available for interpreting the data; for example, hermeneutics, ethnography, cognitive, phenomenological,

and others (Neuman 2003, p. 76). I have used concepts drawn from both hermeneutics, which stresses how prior experiences can affect the interpretation of data, and phenomenology, which allows analysis of the complex array of phenomena presented in the data (Denzin & Lincoln 2005, p. 27, n. 6). While I was aware of ideas based on my experiences as a clinician, I tried to ignore these and see the phenomena being described from the speakers' perspectives (Crotty 1998, pp. 81–85). I needed to interpret the interview data by constantly seeking to understand how the social and environmental factors, suggested by Krieger's ecosocial theory, are entwined with the overt biological factors stemming from the chronic illnesses of old age. In this endeavour I have also drawn on some of the ideas in hermeneutics (Crotty 1998, pp. 90–111), considering the lay or professional knowledge of the informants and theorising as to how it may link with the existing body of knowledge on chronic illness.

Interpretive epistemology inherently values the experience of the person or community being studied. Value is given to their understanding of their own experiences and their interpretation of these experiences. In the areas of medical practice and research there can be a tension between the lay knowledge of community members and the professional knowledge of the service providers. As discussed in section 3.3, several authors have suggested that the general public can be sceptical of scientifically generated theories, and that professionals tend to belittle lay knowledge (Popay & Williams 1996; Popay, Rogers et al. 1998; Kangas 2002; Williams & Popay 2006). In developing this methodology I have aimed to collect data from a variety of service providers, including refugees working within their own community and outside professionals, as well as from the elderly refugees whose lifetime experiences and health outcomes form the purpose of this study.

5.1.2 Case study

I decided that interpretive and qualitative methodology provided a good epistemological basis for the design of a research method to answer my questions. Within that broad concept I chose case study methodology because case study is ideally suited to explanatory research — that is, asking how and why phenomena occur (Yin 1994, p. 4). In addition to identifying 'which' life experiences have affected the health of elderly Palestinians, I am also interested in 'how' and 'why' those experiences have influenced the development of health problems over a lifetime. The research takes place within a single refugee camp in Lebanon, exploring the phenomenon of health problems and chronic illness among elderly refugees. There is, of course, a range of sources of data within a complex community such as this, because case studies take place in a real life context, exploring contemporary phenomena, with multiple sources of data. (Yin 1994, p. 18) This meant that I could consult a wide range of people in the Palestinian community in Lebanon, using the most appropriate method of data collection for each group. A major criticism of case study methodology is that it provides a limited basis for generalising from a single case

to the general situation (Yin 1994, p. 15). However, in considering my chosen theoretical frameworks, Krieger's ecosocial theoretical framework of health and Lavarack's community empowerment processes, I believe that I can use the flexibility of these systems and also understand them more fully by applying them in different populations from where they were originally developed.

Case studies can consist of a single study or may alternatively consist of the study of two or more groups looking at similarities and differences. In practice this meant I could collect data across two or more camps, or I could focus just on one camp. Based on reasons related to matters discussed in section 5.1.3, I chose to study a single camp, Bourj-el-Barajneh camp. I had useful contacts, both among the service providers and the lay population. I was also familiar with the physical environment of this camp, having previously lived in there for two years.

Subdivisions within a community are social constructions, and can be divided and defined in a variety of ways. For the purposes of this study, I have considered the community of Bourj-el-Barajneh camp in three interlinked groups, related to the type of knowledge they could potentially have. These include, firstly, Palestinian residents who live within its boundaries, and who would have a lay knowledge of health and the underlying influences on it; secondly, people who both live within the camp and who work in the area of service provision (for example teachers, nurses, sanitary workers), whose knowledge will include lay knowledge common to the community and also a level of professional knowledge based on their training and their work; and thirdly, service providers who live outside the camp, but who interact regularly with the people living in the camp (for example senior NGO staff). This group of informants may have a certain amount of lay knowledge of the community but principally will have professional knowledge based on their training and past experiences. In addition to these three groups there is a fourth group of senior international administrative staff who may have an impact on the community through project implementation and fund raising, but who visit the camps less frequently and whose knowledge is purely professional in nature. I have combined these separate groups into 'camp residents', and 'service providers'; however, as mentioned, these groups overlap.

These two main groups have been treated as two units of analysis within the single case study, making this a 'single case, embedded design', using Yin's classifications of case studies. Yin identifies case study design in terms of being single or multiple studies, Single case study design can be used when the case is a critical case used to test a theory, when it is an extreme or unique case, or if it is a particularly revealing case (Yin 1994, pp. 38-40). In this case I am testing the flexibility of Krieger's ecosocial model of health and Laverack's understanding of empowerment processes in a refugee context. In addition, Yin classifies the nature of the unit of

analysis into single units of analysis (holistic case studies) or multiple units of analysis (embedded case studies) (p. 39), the unit of analysis being the 'case' itself — for example, an individual, a community, a group of people, or the economy of a country (pp. 21–22). I have chosen to view the camp as a single case study with two embedded units of analysis: the elderly people who live in the camp and the professionals who provide services. The second group consists of both field staff and management of local and international NGOs, and the donors who fund their services. Thus data will reflect both lay knowledge and professional knowledge within the community.

Within the structure of the case study, and considering both professional knowledge and lay knowledge, it will be possible to build an understanding of the residents' lived experiences and how they influence their health, constructing a more detailed model within the ecosocial model as described by Krieger.

5.1.3 Working in difficult situations

Having considered the epistemological approaches which support the research questions, I now turn to the challenges of working in a community where I have limited facility with the language and, moreover, where the people have experienced a host of traumatic incidents over many years (see section 1.2).

While many researchers have no prior experience of the community in which they undertake research (unless it is their own community), Swedenburg (1995, p. 27) asked if the researcher with expert knowledge of the field of study may use this to enrich their study. He acknowledged that he made use of his prior experience of life in the Middle East in his later research field trips, suggesting that his experiences provided both motivation and capacity for undertaking field work successfully (p. 29). In a similar way, it is relevant to discuss the motivation and capacity that my own experience of working with Palestinian refugees has brought to the present study.

As discussed in section 1.2, the Palestinian refugees have experienced several episodes of war, although at the time of the data collection there had been no war for three years. In their discussion on research during war conditions, Barakat and Ellis (1996) considered the problems of undertaking fieldwork in a war zone. They considered it important to identify 'gatekeepers', for example, a local person, speaking the local language, who can identify and contact the correct people, talk to the right officials, and generally ease the researcher's way into the community (pp. 151–52). My prior experiences in the camp assisted in nominating and recruiting such a gatekeeper.

In practice, having worked with both a local NGO and an international NGO, I had a network of contacts with NGOs working within the camps, as well as several international organisations,

including UNRWA, international NGOs and donors. I also met and became friends with many refugees across several camps and gatherings. This prior contact with the camps and their communities is both advantageous and problematic. It gave me an initial group of people to contact as potential informants from among the service providers, and from this group establish other contacts to update my knowledge about current services. In addition, it gave me a network of non-informants who could advise and suggest solutions to problematic factors which arose in the methodology. For example, when planning my method of contacting NGO informants, I had planned to email and await a response, either by phone or email. After two weeks and getting few responses, a discussion with a friend working for an international NGO helped to identify the problem. NGOs are very busy and telephone contact can be expensive in Lebanon. The NGOs would be expecting me to make direct telephone contact with them. This proved to be the case and after that I made rapid progress in finding informants among service providers.

A second consideration was that although Lebanon was not suffering from either internal or external conflict at the time of data collection, I had experienced both during my previous work, and I was aware of the need to monitor for potential threats to my safety while in Lebanon. Three friends from the local Lebanese and Palestinian community agreed to contact me if any signs of possible civil unrest (such as the 2005 assassination of a political leader), or invasion (such as the Israeli–Lebanese war of 2006) developed. This network of contacts provided important practical support during data collection as a source of information on security concerns.

In the search for a gatekeeper (Barakat & Ellis, 1996) to assist me, I contacted a Palestinian friend living in the camp, who has previously worked as a gatekeeper, translator and interviewer with several researchers (Holt 2004; Acknowledgments; Khalili 2007, p. x) as well as facilitating access for journalists wanting to work within the camps. This woman helped me to make contact with the Popular Committee, which is considered advisable when undertaking research in a camp, and helped me to find accommodation close to, but not inside, Bourj-el-Barajneh camp. She also helped to find interviewers from among the local community and acted as an interviewer herself (see section 5.4.1).

Weighed against the advantages of having some lay knowledge of the research field before undertaking research is the risk that the researcher will enter the field with preconceived ideas and fixed points of view. However, interpretive researchers (as opposed to positivist researchers) include the specific contexts and meanings of the observed facts as they reflect on their data, and include analysis of personal points of view in their overall data analysis (Neuman 2003, pp. 79–80). There is thus a requirement to empathise with the informants, attempting to understand the emotional context as well the facts or sequence of events (p. 80). Within the context of examining health and chronic illness, where stress, depression and other

psychological factors underlie the development of these illnesses, the emotional context of the collected data is critical (McEwen 2004; Chandola, Britton et al. 2008). I have constantly reflected on my own perspective in order to relate to the data objectively, avoiding unconscious contamination of the data in the process of analysis. However, as interpretive research need not be value-free, analysis of personal points of view and feelings can and should be included in the analysis of data.

Barakat and Ellis also review appropriate methods of data collection among people who have experienced war, identifying surveys and structured interviews as being problematic, as they tend to arouse fear and suspicion (p. 154). This was my own experience in evaluating the provision of NGO services (Campbell 2008). When evaluations were made in the form of surveys, people became hostile and uncooperative, as my colleagues and I found in 2005. However, when we modified the data collection methods for our annual evaluation in 2006, using less structured interviews, group discussions, and art activities, people were much more cooperative. Roberts (2004, p. 144), when undertaking research in post-conflict reconstruction in three Lebanese refugee camps, discussed this problem, suggesting that informants have conflicting values — traditional hospitality on one hand and suspicion of outsiders' motivations for conducting research on the other. They are especially suspicion of questionnaires, and have been known to physically force interviewers collecting statistical data to leave the camp (Roberts 2004, p. 139). From an ethical perspective it was important to minimise distress to a community which has experienced traumatic events and deprivation. This consideration points to the need for a qualitative and less invasive methodology.

5.1.3.1 PEER ethnography

In considering Robert's experiences(1999, 2004) and my own (Campbell 2008) in conducting research in refugee camps in Lebanon, and taking into account the travel warning issued by the Australian Department of Foreign Affairs and Trade (DFAT), advising Australians not to go to the Palestinian camps in Lebanon (which the university required me to observe), some consideration had to be given to methods of data collection which would provide the qualitative data necessary to answer the questions posed, and would also be appropriate to the community and its quite reasonable sensitivities.

The techniques of participatory ethnographic evaluation and research (PEER) seemed to offer an appropriate method for collecting data from elderly refugees. Price and Hawkins (2002, p. 1328) found that poor and marginalised communities find it difficult to discuss beliefs and practices openly and honestly with outsiders. They suggest the problem can be addressed by using local members of the community to collect qualitative data, outlining a specific methodology which they call PEER ethnography. Several studies and NGO needs analyses have been conducted using this methodological approach, including studies among south Asian

male sex workers (Collumbein, Qureshi et al. 2009), fertility-related behaviours among Zambian women (Price & Hawkins 2002), and reproductive health among Ethiopian women (Hemmings, Wubshet et al. 2008).

The technique requires the recruitment of local community members who are trained to conduct interviews within their community and then to feedback the information from these interviews to the primary researcher. Therefore, rather than collect data from local people directly, I employed experienced local people, through my gatekeeper, to plan and implement data collection using principles of PEER ethnography to do this.

In constructing interview schedules I varied the PEER process to some extent. As described in the literature, the PEER interviewers discuss the subject in terms of the third person, avoiding discussion of the informant's personal experience.(Price & Hawkins 2002, p. 1329; Hemmings, Wubshet et al. 2008, p. 8; Collumbein, Qureshi et al. 2009, p. 85). However, one research question asks 'What aspects of their lived experiences impact upon health in old age?' Zinn (2005, p. 2) suggests that the 'biographical embeddedness of health and illness relates to how people define risks and link management to their lives', which suggests that biographical interviews can be used to examine how people link their life experiences to their health status. As the people in Bourj-el-Barajneh camp have experience of interviews about their life and experiences with both researchers (Roberts 1999; Holt 2004; Roberts 2004; Khalili 2005, Sayigh 2007) and local people (personal observations of NGO activities), the idea of recounting their life experiences to a third person was already familiar to the community.

I therefore adapted the methodological approach. I decided to have the PEER interviewers make recorded interviews, initially exploring the life experiences of the informants. I then interviewed the PEER interviewers about what they had understood from the interview on the same day, usually immediately after the interview. The PEER interviews were translated into English, but feedback interview recordings were retained but not transcribed. These were used as part of the iterative process to understand what data I had collected, as well as being used in the data analysis. This meant I was able to modify the interview schedule and suggest areas where I would like more, or less information.

5.1.3.2 PhotoVoice

As Swedenberg (1995) discussed in his paper, where the researcher works in a community they have known there are advantages and disadvantages. One disadvantage which I identified was that, having lived in Bourj-el-Barajneh camp, I knew my own conflicted reactions to its social and physical environment. The problems of getting safe drinking water, or keeping warm when there was no glass in a window, had challenged me personally when I lived in the camp. In contrast, I had enjoyed the welcoming social life where casual acquaintances made me

welcome whenever I chose to drop in unannounced. However, my personal reaction to the social and physical environment of a refugee camp is not relevant to this research, and my perceptions may not be those of the local people who have lived in camps for much of their lives. To avoid adulterating this research with my own perceptions of the camp environment, I chose to look at such perceptions specifically from the point of view of the older refugees.

To collect this kind of data I used a form of participant-employed photography known as PhotoVoice to generate qualitative data. PhotoVoice's strengths lie firstly in assisting informants in personally recording and reflecting on community issues; secondly, in encouraging group dialogue on these issues; and finally, in influencing policy makers (Castleden, Garvin et al. 2008, p. 1395). This latter strength was not directly related to the research in terms of addressing the research questions; however, it was hoped it could give insights into the third question which related to implications for civil society organisations, in addition to providing data on the more specific questions of how the physical and social environment interacted with other life experiences to affect the health of members of the community.

Wang and colleagues (1997, pp. 370–71) have suggested that the advantage of PhotoVoice is based on three theoretical principles. Firstly, it adapts Freire's problem-posing education method, initiated by Wallerstein and Bernstein, which identifies what people regard as being central to their lives and helps them to discuss it. A second principle relates to work done by feminist researchers, who have found that with a camera women can no longer be made invisible; this new-found visibility can help women to explore any socially stigmatising health condition or status. Finally, the method draws on the field of documentary photography, where visual images are used to highlight social problems. These three theoretical principles come together in the use of PhotoVoice.

Methods have to vary with the nature of the community. For example, Peirce and McKay (2008, pp. 161–62), in their work in rural South Australia, took photographs and kept diaries with associated notes. The diaries also included reminders from the researchers on the nature of the study and the themes for the photographs. Australia has a high level of literacy, which makes this use of written information and data written by the participants practical. However Castleden and colleagues (2008, pp.1396–98), working with Canadian Indigenous people, focused on oral presentations of the methodology and ethical concerns, and on interviews and discussion at 'potluck' dinners around the themes of the photographs. Thus, there is a methodological flexibility inherent in PhotoVoice, based on the fundamental principle that 'virtually anyone can learn to use a camera, workers, children, peasants, people who do not read or write' (Wang & Burris 1997, p. 370).

The data collected in PhotoVoice includes both the photographs themselves and the reflections of the informants on these photographs. Thus the data has a richness which cannot be

conveyed by words alone, and which can be useful to illustrate informants' comments and opinions about their environment.

5.1.3.3 In-depth interviewing

While there are no specific rules for conducting in-depth interviews, there are guidelines and suggestions which can guide the researcher (Minichello, Aroni et al. 1991, p. 107). The difference between a scheduled, structured interview and the in-depth interview can be seen when examining interview schedules, or protocols. In a large-scale survey the interview schedule is standardised, and includes a full list of all questions to be asked, and may also include instructions on how the questions are to be asked, and when to probe or cross-check (Minichello, Aroni et al. 1991, p. 113). The schedule for an in-depth interview, sometimes called an 'aide memoire', or guide, consists of a list of general issues This schedule is developed through preparatory work on the subject, reading the work of previous researchers, and other writings on the subject which may be relevant to the research questions (Brenner 1985, p. 152, Minichello, Aroni et al. 1991, p. 114). The schedule may be modified, based on previous interviews, as the interviewer gains an understanding of the subject from the earlier interviews. This iterative process is a part of the early analysis of the data, and permits a flexible approach to both gathering qualitative data and analysing it (Ezzy 2002).

Having established what one wants to discuss during an in-depth interview, the method of getting the information becomes important, that is, the techniques for conducting a successful in-depth interview. The interview process falls into three sections: an introductory section, the actual gathering of information, and the conclusions. Briefly, the introduction may either include information about the research or be a simple, general introduction — this depends on how much collaboration the researcher expects from the informant (Minichello, Aroni et al. 1991, p. 109). Likewise, there is a range of ways of finalising the interview, including a plain statement that the interview is over, a request for any further information that the informant may consider relevant, a brief summary of what has been discussed, an expression of thanks, and (if the interviewer has such knowledge) some personal comment not related to the interview. Any combination of these elements can be used to finalise the interview (Minichello, Aroni et al. 1991, pp. 130–33).

However one structures an in-depth interview, the rapport between interviewer and informant is all-important. Rapport, sometimes referred to as 'establishing a productive interpersonal climate' can be defined as 'understanding their model of the world and communicating your understanding symmetrically' (Minichello, Aroni et al. 1991, pp.110–11). Minichello and colleagues go on to describe how this can be done by matching perceptual language, images of the world, speech patterns, pitch, tone, speed, posture and breathing patterns. Rapport is enhanced by using the recursive model, meaning that the interview relies on the process of

conversational interaction, where one remark leads to another (Minichello, Aroni et al. 1991, p. 112) This model of interviewing permits the interviewer to treat each informant as an individual, whose information is unique. However, there is a risk of 'going off at a tangent' collecting irrelevant information and it is important to refocus the interview if this becomes apparent. These concepts together will contribute to what Brenner calls a 'social effective interaction that helps the informant to report adequately, that is within the frame of reference within which the intensive interviewing is conducted' (1985, p. 151).

A third concept, which seemed very relevant to in-depth interviewing with Palestinians, is the concept of storytelling. From reading other qualitative studies on Palestinians, I know their undoubted ability to tell a story (Sayigh 1994; Khalili 2004; Khalili 2005; Holt 2007; Sayigh 2007; Latif 2008; Latif 2008). These authors conducted in-depth interviews and have discovered a variety of narratives, told from historical, political, environmental and feminist perspectives, based on interviews given by people living in refugee camps. As discussed in section 5.1.3.1, on PEER research, Zinn (2005) suggests that biographical interviewing can draw out a narrative that reveals health-related life experiences. However, when interviewing service providers about health-related issues, their stories about their projects — how they developed and how they affected health in the community — may present a very different narrative that needs careful interpretation. As storytelling can be part of normal conversational practice and parallels social interaction, it may be a valuable support in the establishment of rapport.

Having discussed the interview structure and its style, I will now turn to the specific interview questions. As qualitative research is about 'what' rather than 'how often', the questions need to focus on finding out what has happened (Brenner 1985, p. 150). Thus the interview may cover questions about knowledge (facts), sensations (things seen, heard, smelt, touched tasted), opinions (how the informant interprets facts and sensations) (Minichello, Aroni et al. 1991, p. 122). In gathering this information, the interviewer may need to probe or question further to elicit the information more fully, to clarify a point, or to gain an understanding of what the previous answer might mean to the informant (Minichello, Aroni et al. 1991, pp. 123–24). Minichello and colleagues (1991, pp. 124–25) identify a range of probing questions, such as presenting an opposing argument, posing a hypothetical question, nudging the informant into continuing (with either body language, or verbal encouragements), and reflecting back the answer; that is, the interview should be conducted in such a way that the responses are those of the informant without encouraging the informant to answer in a particular way (Brenner 1985, pp. 151–52).

Thus, while there are no specific rules for the conducting of in-depth interviews, there are guidelines which support quality interviewing. These include preparing for the interview by acquiring background knowledge of the subject matter. A wide range of questioning techniques

can be used to elicit the information sought, but establishing rapport and adopting a conversational (recursive) approach will relax the informant and so encourage in-depth responses and the disclosure of more complex information.

5.1.3.4 Focus group

Providers of clinical services within the camp fall into a wide range of professions with a variety of training backgrounds. They range from doctors with medical degrees to people trained by the NGOs to undertake specific tasks. However, most of them have at some time lived in a camp, and many were living in the camps at the time of data collection. This group of people have both lay knowledge of what it is like to live in the camp, and varying levels of professional knowledge of health and illness.

I had considered using group interviews for this section of the population early in the development of this methodology, based on my experiences of training local nursing staff in the skills of community nursing. I had used group techniques, such as small and large group discussions; brainstorming and role play, and found that the nurses (who were principally Palestinians living in camps) were able to extrapolate from their own experiences into new situations and then were able to incorporate new ideas into their work practices. It was therefore reasonable to consider using a form of group interview technique, where data is generated in the discussion between the research participants (Kitzinger 1995, p. 299), with those service providers who personally provided health care to the camp population, so that they could explore the links between their observations of the lives of their patients and health. The integration of their various types of knowledge could emerge best in discussion, using the existing group dynamics among colleagues, rather than one-on-one interview. However, an understanding of how group work could be applied as a research tool was needed to develop this dataset systematically.

Throughout this research I have referred to these group interviews as ‘focus groups’; however, Coreil disputes this nomenclature, suggesting that a more appropriate term is ‘group interview’ (Coreil 1995, p.194). Coreil divides group interviews into four subgroups, consensus panels, focus groups, natural groups and community interviews. These ideal groups may overlap and the differences be less obvious than the categories suggest (p. 196) The first and the last of these types are not relevant to this section of the methodology, the first being primarily concerned with discussion among key informants or experts, and the last with larger segments of the community. We are left then with focus groups and natural groups. Coreil regards the principal difference between these two types of group interview to be the sampling technique used: the focus group is formed specifically for the purpose of collecting data, while the natural group is an existing group which agrees to meet with and be interviewed by the researcher (p. 195).

A main difference between a focus group and a natural group is that there is an existing group dynamic in the natural group, and Coreil (1995, pp. 198–99) discusses the differences with reference to an example where both forms of group interview were used within the same research. This may lead to self-consciousness and desire to provide socially desirable responses (Coreil 1995, p. 199). However, colleagues and friends may relate to each other's comments, or challenge them if they disagree (Kitzinger 1995, p. 300). With careful facilitation the latter response behaviour can be encouraged. Accommodating existing group dynamic may require a less structured schedule of subjects for discussion and a more flexible approach to following this schedule, permitting a wider range of discussion than may be appropriate for a group whose members do not know each other.

A second difference noted by Coreil is that natural groups may not be audiotaped or videotaped, the data coming from detailed notes kept by the facilitators (Coreil, 1995, p. 194 and p. 199). Coreil does not expand on why the natural group may not be ideally suited to recording; however, on discussing the options with my translator (a local Palestinian, not a professional translator), she felt that it would be beyond her ability to translate multiple voices which (she believed from her experience attending focus groups) would involve people speaking over each other.

While some of the service providers spoke English, many did not. UNRWA teaches English as a second language in its schools; however, many people do not speak fluently, having not used the language regularly since school. Therefore, these group interviews were co-facilitated by my gatekeeper and myself. She had had training from qualified social workers in how to conduct focus groups and had conducted and participated in many. She acted as a principal facilitator, and also translated the discussion in real time. She also recorded, on large sheets of paper, in both English and Arabic, the results of brainstorms and discussions. I took notes, and suggested questions, or comments to facilitate the discussion. Following the focus group session, we would discuss the group, consolidating our notes into a single report constituting the data from that group.

While Coreil defines four types of group interview, others continue to use the term focus group for all group interviews, and explain their sampling, structuring and recording of the group (Coreil 1995; Kitzinger 1995; Willkinson 1998). Accordingly, I have used the term 'focus group' from here on, as that is the term that was familiar to my co-facilitator and the organisations which assisted with this research.

5.1.4 Choice of research approach

Both the appropriate epistemology for the research questions and the literature on working with traumatised and marginalised communities suggested the choice of a qualitative methodology. I

therefore decided to develop a case study with two units of analysis, the elderly refugees and their service providers, using a qualitative approach with both groups. The work with the elderly refugees was undertaken using a modified form of PEER interviewing, which will be discussed further in section 5.4.1, which reviews the experience of data collection. I undertook the data collection with service providers, with an interpreter where necessary, at the request of the informant.

5.2 Target population

My choice of which population of refugees I would study was based on my previous work with Palestinians in Lebanon, I had a clinician's understanding of the community and in gaining that understanding I had already read widely on the historical and health problems within that community. In Swedenburg's (1995) discussion of his work in the Middle East he poses a question which all of us in this situation must consider. To paraphrase Swedenburg, should only the months spent in in the field, as an accredited researcher, form the database used for subsequent academic writing (Swedenberg 1995, p. 27)? I have kept this question in mind during methodological planning, collecting and analysing the data. The advantages of researching among the Palestinian refugees in Lebanon included both my knowledge of their community and their knowledge of me. By choosing to remain with a refugee group I knew as a clinician, I had already built up background knowledge of the history of the community and their health which, while not sufficient to base my research on, did give me a beginning point, just as researchers working in their own community have background knowledge of the history and geography of their own community. I had visited eight of the twelve camps in Lebanon, and knew a little of their geography and history. Even though I had this acquired knowledge, it should not (and did not) stop me conducting a systematic search of the literature, particularly that relating to the health of the Palestinians in Lebanon. In addition, both service providers and refugees knew me and my previous work.

The disadvantages were that I would have inside knowledge of what people might tell me or I might have heard stories from other sources during my stay in the camps. This meant that great care had to be taken to ensure that conclusions were based *only* on the material in the data. Furthermore, I needed to monitor my own reactions to avoid projecting my own feelings about life in the camp onto the informants. As a Westerner studying a camp community I would not necessarily respond in the same way as residents who had lived in this social and physical environment for much if not all of their lives. Another disadvantage of working where I was known was that people might assume that the results of this study would transfer directly into improved service provision. I was careful to explicitly refute this idea both in the information presented formally to informants and less formally when talking with Palestinians and service providers.

I judged that the advantages outweighed the disadvantages; therefore the next choice was which camp or camps would I study? In consideration of current official warnings which advise Australians to avoid the refugee camps in Lebanon, Flinders University considered that it would be inadvisable for me to physically enter the Palestinian camps. This suggested that the camp of which I had greatest experience would make the most appropriate case study, because of my familiarity with the geography of the camp. The advantages of this choice was demonstrated during interviews where I was able to visualise the locations of places without having to visit them; for example, in discussing the sewage and water supply with several informants, I was able to visualise where communal facilities had been situated (interview 115, pp. 14–17; interview 107, p. 29). Having considered these matters, I chose to make a case study of Bourj-el-Barajneh camp, in the southern suburbs of Beirut. In line with the DFAT travel advice I rented a room close to the camp in the home of an ex-colleague, making it possible to have easy contact with my gatekeeper and any such people in the camp who wanted to visit me. It also facilitated visits to organisations which provide services to the camp and whose offices were outside the camp.

5.3 Sampling methods

With both the elderly refugees and the service providers I collected two data sets. Each of these four data sets was collected with different sampling methods, so will be dealt with separately. However, the general principle in considering sampling size was to continue interviewing until no new information was emerging.

5.3.1 Sample of elderly refugees (life experience interviews)

The majority of interviews with elderly refugees, exploring their life experiences, were undertaken by PEER interviewers using a modified form of the PEER methodology. These interviewers used a snowball sampling technique, starting by approaching older members of their extended family and older neighbours. They then asked these older members of their social network for introductions to other older refugees. As the research continued, people in the camp became aware that it was happening and in some cases approached the PEER interviews asking to be interviewed; these people tended to be ex-patients and ex-colleagues from my work with NGOs. We continued interviewing until both the peer interviewers and I agreed that no significantly different themes were emerging from the interviews. We interviewed 26 elderly Palestinians, but one interview was stopped early in the process because the elderly male informant had found it difficult to discuss his life experiences, responding to questions with yes, no, and very short phrases. Thus, the data finally includes twenty five interviews.

This sampling technique presents a risk that the sample will focus on one demographic group in the target population, for example women rather than men, or people who are relatively more or

less poor. To avoid this problem we recorded a range of data on each person, including age, gender, mobility and socioeconomic status. While nether wanting nor achieving a statistically 'normal sample' this process did ensure a wide range of informants from different social and physical parts of the camp.

An elderly refugee, for the purpose of this study, was classified as a Palestinian over the age of 50. This age was chosen based on a needs analysis undertaken by an international NGO (the results of which are supported by published quantitative research) that suggests this is the age when most people in the camp start to consider themselves as elderly. In the aged care projects developed by local NGOs the age of inclusion was chosen as 'at least 55 years of age' as an appropriate for aged care services (Kelly & Campbell 2005, pp.14–15). However, in a survey of needs of all elderly people in the refugee camps in and around Beirut, this project found that many people under the age of 55 suffered from the chronic illnesses usually associated with old age. Forty-two of the 800 surveyed were 50 to 54 years of age and suffered from a chronic illness, while only three in the 45 to 49 age cohort mentioned having chronic illness (Campbell 2005, p. 4). While this survey suffers from incomplete responses, and only interviewed the under 55 cohort if they had a chronic illness, it suggests that health starts to fail and chronic illness becomes a problem in the early fifties among this population. This needs assessment demonstrated a similar trend to that found by Ugland (2003, pp. 69–70), who described an increasing rate of chronic illness over the age of 50. Based on these two surveys, I chose to define elderly refugees as those over the age of 50.

The age of elderly refugees was recorded and ranged from 51 years to over 80. While several people were unsure of their ages, I categorised age in three groups, which could be deduced from the data (Table 2).

Table 2: Age categories of elderly refugees

Age group	Frequency
Born in Palestine, and remembers life there	10
Born in Palestine but has no recollection of it	7
Born in Lebanon	8

In the early stages of data collection we tended to focus on the older refugees, but when this tendency became apparent we specifically looked for people in younger categories to interview.

We interviewed 10 men and 15 women.

The PEER interviewers observed the mobility of informants and drew clues on mobility from the interview. An ordinal scale was used to quantify this data (table 2).

Table 3: Mobility of elderly informants

Mobility	Frequency
Housebound	1
Limited to the immediate neighbourhood	3
Limited to the camp	3
Unlimited mobility	18

As part of the interview schedule there was a discussion on chronic illness, at which time the informants were asked if they had a chronic illness and what these illnesses were. According to the PEER interviewers the term generally used for chronic illness in the camps translates as 'illness for which there is no cure' and is generally understood to mean the same range of illnesses which chronic illness refers to in English. Only five informants reported having no chronic illnesses; 20 reported having chronic illnesses, which principally included hypertension, diabetes, heart disease, and arthritis, as well as some less common chronic illnesses, such as hernias, and stomach problems.

Socio-economic status is difficult to measure in the camps, where most people are poor compared to the Lebanese population (Ugland 2003, pp. 156–57). However, Roberts (2004, pp. 236–37 and pp. 483–84), in collaboration with camp communities, developed a scale for judging socioeconomic status within the camp, using a three-point scale. Her scale was based on income, educational level, use of private rather than NGO or UN services, political affiliations, and physical possessions. As socioeconomic status was identified to ensure a wide range of informants, I did not implement the whole of Roberts' scale. The interviewers were asked to observe the home, evaluating the indicators identified in the physical possessions section of Roberts' scale, and make a judgement about the socioeconomic status of the informant (Table 4).

Table 4: Socioeconomic status of elderly informants

Socioeconomic status	Indicators used to judge socioeconomic status	Frequency
Good	Good housing Good quality furniture New/modern electrical appliances Mobile telephone	2
Fair	Reasonable housing Older/simpler furniture Cheaper electrical appliances Mobile telephones	14
Poor	Poor housing Sparse furniture, in poor condition Second-hand or very old electrical appliances No telephone	8

Thus, although this snowball sample was not representative of the camp population, we did interview a range of people from within the camp community.

5.3.2 Sample of elderly refugees (PhotoVoice)

The PhotoVoice activity requires two group activities, as well as interviews by a PEER interviewer. I therefore elected to work through the social clubs run for older people, which provided naturally occurring groups. With the help of my gatekeeper I approached these clubs and, after discussion with the elderly refugees, one agreed to host this research activity for people who attended other clubs. Initially, I had planned to recruit ten people to take photographs and be interviewed, limiting the logistical problems of taking cameras to Lebanon from Australia, while providing a range of perspectives from different refugees. However, following the introductory workshop only four people volunteered to take photographs, and later a fifth participant approached us, and asked to take a camera. The people attending the first workshop and who chose not to take cameras had found operating the camera difficult, and one person found that his eyesight was not good enough to see through the viewfinder.

This convenience sampling technique was used because the people attending social clubs were used to activities involving discussion and would have adequate mobility (because they attended a club outside their home). Even with these skills, many found it difficult to take the photographs and several needed replacement cameras as they had accidents with the one-use cameras we gave to them.

5.3.3 Sample of NGO managers to be interviewed

The sampling method for NGOs was again carried out with a snowball technique. We started by identifying NGOs who provided social activities and health services for elderly camp residents. These included UNRWA and the PRCS hospital in Bourj-el-Barajneh camp. These starting points were expanded as informants among elderly Palestinians identified other services they used. As I interviewed NGO managers they also suggested service providers who might inform my research, both within and beyond their organisations. Informants included executive officers, project managers and technical advisors. In some organisations I interviewed only one person; in others several people, usually because that person might have special information which would give me deeper understanding of the projects being run and the philosophy of the organisation as it pertained to health.

Overall I interviewed 32 senior and middle-management staff from NGOs and donors; one interview, however, was not used because the informant had been unwilling to sign a consent form (although there was verbal agreement to be interviewed) (Table 4).

Table 5: Types of organisations and numbers of interviews conducted with NGO management

Type of organisation	Number of interviews conducted	Number of organisations involved
Local NGO	12	9
International NGO	13	8
Small donor	4	4
Large donor	3	1
Political party	2	2
Private health provider	1	1

Small donors may provide act as international NGOs — for example technical support and involvement in project management — and so have been listed under both categories.

While I tried to collect data principally from NGOs working with refugees in Bourj-el-Barajneh, if no organisation offered a specific service in Bourj-el-Barajneh camp, but that service was offered in another camp, I would include discussion of their services despite their not being available to my specific refugee informants. For example, mental health problems, such as depression and anxiety, were identified by some elderly refugees as factors linked to their ill health. Providers of health services mentioned in interview that currently there were no mental health services provided for Bourj-el-Barajneh camp. However, on further enquiry among the NGOs I found two different services provided in other camps and it was suggested that I could interview the program coordinator for that project.

Respondents often indicated they were unhappy with the camp's built environment, and so when I interviewed a local man working with NGOs and he mentioned that he had worked as a builder before working with NGOs, I took the opportunity to discuss in detail methods of building houses in the camps, in addition to discussing his NGO work.

Towards the end of data collection, it emerged that the political parties of the PLO had affected the daily lives of the elderly refugees in many areas, including provision of work, medical services and pensions, as well as various levels of involvement in the Lebanese Civil War. Initially, when planning the field trip, I had not intended to contact representatives from the political parties. However, I consulted my gatekeeper, who said she could liaise with people she knew to be leaders of political parties operating within Bourj el Barajneh camp. Two local leaders of different parties within the PLO agreed to be interviewed on conditions of anonymity, as long as the subject would revolve around their roles in social situations and would not encroach on their political or military roles. I agreed to these conditions and the interviews were recorded.

The snowball method of sampling depended partly on my knowledge of the camps and NGOs, but also depended heavily on the help of my gatekeeper and the cooperation of the NGOs. Several NGOs and individuals refused to be interviewed but always suggested someone that they believed would provide information to assist the research. In several cases these provided further contacts of which I had been unaware.

5.3.4 Sample of NGO staff (focus groups)

The NGO managers whose organisations provided direct health services to the refugees were asked if I could meet with those of their staff who were willing in a focus group designed to

discuss the nature of chronic health problems in the camps (five organisations) All the managers I asked agreed to make this request. Participation was voluntary, and not all available staff chose to attend. In organisations where there were larger numbers of staff I ran several focus groups; therefore five organisations participated, and I conducted nine group interviews with forty-one people participated.

5.3.5 Overlapping of units of analysis

As discussed in Section 5.1.2, the two units of analysis, the service providers and the elderly refugees, were not mutually exclusive. In addition to the overlapping groups discussed, for example, NGO workers living in the camp, I also found that elderly refugees were sometimes still working for NGOs or political organisations. Palestinian informants from both groups were invited to discuss their life experiences as well as their work with organisations operating in the camp. As such, the distinction between being an elderly refugee and being a worker in a service-providing organisation was not clear-cut, and though people participated in the research in one or the other of the units of analysis, the data obtained did not necessarily fall wholly into one area or the other. Therefore, during the analysis phase, data was considered according to its subject matter rather than from whom it had been acquired.

5.4 Data collection

Data was collected in a 13-week field trip to Lebanon, from August to November 2009 to collect data from local informants, including NGO employees and older refugees. This was followed by three weeks in Europe during November 2009 where I collected data from international organisations with connections to Bourj-el-Barajneh camp. On arrival I met with my gatekeeper, and discussed the nature of the research and her role. We approached the Popular Committee with Arabic versions of information sheets and a letter from my supervisor (in English), which was translated for them by my gatekeeper, and we discussed the research plans. The committee agreed that this research was acceptable to them, and gave verbal permission, as is customary.

As mentioned earlier, data was qualitative, and collected as four separate sets of data: biographical interviews recalling the life experiences of older refugees; PhotoVoice photographs and interviews focusing on the physical and social environment of the camp; interviews with managers of organisations about their programs and how these impacted on the health of the community; and focus groups with hands-on clinicians adding their perspective on health promotion and management of chronic illness. In the following sections I discuss the collection of each of these sets of data separately.

5.4.1 Data collection from elderly refugees

Two sets of data were collected from elderly refugees who were all more comfortable speaking the local dialect of Arabic. Therefore, data from this group was collected in Arabic using a modified form of peer ethnography (PEER), the technique discussed in section 5.1.3.1. However, all one-on-one interviews were recorded for detailed analysis and notes were taken during group activities.

5.4.1.1 Biographical interviews

Biographical interviews were planned and conducted by three PEER researchers, my gatekeeper and two other women trained to become PEER interviewers. My gatekeeper has acted as an interpreter for academic researchers and journalists, and has also conducted interviews for researchers independently. The other women had collected information as part of oral history activities run by local NGOs.

I conducted a one-day training session (Appendix 3), in my home. Training included reviewing the consent procedure, discussing a simple concept of health and chronic illness, going through the interview schedule (Appendix 3) and role-playing interviews, initially in English and then in Arabic. It included discussion of which specific language would be most appropriate for the elderly refugees: most of the interviews were finally conducted in Arabic, with decisions being made between the PEER researchers and myself on the appropriate Arabic for key concepts, such as chronic illness, anxiety, and environment. We discussed how to obtain information relevant to the study, and how to manage difficult situations, such as the informant becoming distressed (including information on available support services). This training session is a key component of the PEER methodology as set out by Collumbein and colleagues (2009, p. ii4), with Hemmings and colleagues (2008, p. 11) suggesting a four-day training session. The main aspects of their training included identification and discussion of the important issues in the community, with a focus on the research topic; work around the most important issues of the interviews, practising interview techniques, including the use of open-ended questions; probing and eliciting stories; practice in asking their friends to take part, and practising 'third-person interviewing' (Hemmings, Wubshet et al. 2008, p. 12). These aspects were covered in our training session, excepting the last point, where discussion and practice of biographical interviewing was undertaken, as described in Zinn's work (2005, pp. 6–7). My PEER training workshop was much shorter than those recommended, probably because we were a small group, with one trainer and three trainees, and so activities such as role-plays could be carried out by all trainees more quickly. In addition, all trainees had had prior experience of biographical interviewing as part of their experiences with NGO projects collecting oral histories. While a second training session had been planned if necessary, it was not considered necessary either by myself or the other PEER researchers.

The PEER interviewers arranged their own interviews and, after gaining informed consent for a recorded interview, they would start recording the interview. The aim of the interviews was to gain an understanding of informants' life experiences, particularly focusing on the day-to-day activities, both during the extraordinary periods of displacement, becoming a refugee and living in a civil war, and the daily routines of calmer periods. We used a biographical approach to the conduct of these interviews. As Zinn (2005, p. 6) suggests, the PEER interviewers used trigger questions to lead the elderly refugees into their life stories and then used probing questions to explore topics that had not been covered earlier. Thus the first part of the interview included compiling a life history, with exploration of the lifestyle at each period. For example, when an elderly refugee recalled life in Palestine, the interviewer would encourage discussion about the house, daily activities, diet, schooling and work. Inevitably, informants focused on the traumatic events in their lives. NGOs often run oral history activities to allow younger people to learn about the historical events their elders have experienced; in this case, the interviewers were encouraged to explore in depth how people lived during those times, as opposed to life in more 'normal' times. Having discussed the person's life experiences, the interviewers would go on to discuss a range of services, including education, health, and built environment, if these topics had not emerged during the retelling of life experiences. Finally, a few questions at the end of the interview established the elderly refugee's understanding of their own health status at the time of interview. Interview lengths varied from 40 to 90 minutes.

These interviews were all recorded on a small digital recorder and one PEER interviewer volunteered to translate all the interviews (thus giving consistency to the translations). The recording was stored as an MP3 file on a laptop computer. After the interview, I met with the PEER interviewer on the same day and I carried out a 'feedback' interview. This took 20 to 30 minutes, and provided me with a summary of the information gathered. In a pure PEER technique this would constitute the major part of the data. However, in this research feedback interviews served the double purpose of providing the interviewer's more detailed understanding of subjects discussed by the elderly refugees and providing me with summaries of the data which could be used iteratively to direct further data collection.

During the feedback interviews, PEER interviewers noticed that the informants were puzzled at the interest in day-to-day activities — previous biographical interviews had focused on the historical events experienced by the refugees. I also noticed that whereas the informants were happy to discuss the events of their lives, they were much less willing to discuss the emotions which they had felt at the time. I was interested in behaviour, mental wellbeing, and environmental factors, aspects of life which, as discussed in Chapter 3, could contribute to health in old age. In discussing this problem during feedback sessions, the PEER interviewers suggested that I might better understand the problem if I undertook some interviews myself. They arranged for me to do this in my own home, or outside, but close to, the camp. The

problem then became clear to me: the informants could comfortably recount the events of a difficult time, but when asked about how they felt during those times they appeared to relive them, becoming teary or unwilling to talk.

I asked the PEER interviewers to meet with me, and recorded our discussions. I explained that I could not rely on my own thoughts about how I would react in the traumatic situations being described, because I came from a different background; equally, we should not cause our informants distress. After considerable discussion, one PEER interviewer suggested we initiate a discussion about the happiest and the saddest experiences in the person's life. It was hoped that these two balanced questions would provide insight into emotional responses at both extremes of the emotional range. On implementing the revised schedule we found this provided more useful data on links between life experiences and emotional responses to them.

In terms of quality and quantity of data, the feedback from the PEER researchers as the data was collected, coupled with the translated and transcribed recordings of the interviews, worked well. This method assisted and deepened my understanding when I formally analysed the data. However, without oral history programs run by NGOs which had previously accustomed the community in the camps to having their stories recorded, I suspect that it would have been more difficult to have participants agree to the recorded discussions.

5.4.1.2 PhotoVoice on environmental factors

The second set of data collected from elderly refugees was designed to use PhotoVoice techniques (Castleden, Garvin et al. 2008; Pierce & McKay 2008), where informants are asked to take photographs of their environment, and are then interviewed, using the photographs as triggers to elicit the deeper meanings of the subjects chosen. I chose this technique to gain a greater understanding of the refugees' social and physical environment, and to provide data to indicate how these might affect health.

To facilitate this activity I had brought with me 20 single-use cameras. I negotiated the development of these photographs with a photography shop in the camp, including a copy of the photographs for each photographer, a copy for myself, and digital copies for each film on a compact disc. All costs of development were paid for by the researcher and the photographer agreed to maintain confidentiality (signing a consent form to this effect).

A workshop (Appendix 3) was run with an interpreter, where we discussed the voluntary nature of participating, the purpose of the research and the use of the cameras, practising with a spare camera. I had planned the session to run in this order; however, the elderly refugees were much more interested in how to operate the cameras and wanted to do that first. We eventually discussed the environment and some of the ways it could be portrayed in photographs. In this we were assisted because one older refugee had been a professional photographer and was

keen to discuss subject matter and composition. At the conclusion of this workshop we asked if anyone would be interested in taking photographs and being interviewed. They were advised that they should take 10 to 12 photographs for the project and then they could use the rest of the photographs for their own purposes.

The interviews were undertaken by the PEER interviewers (Appendix 3) and as part of their training in this they also took photographs and I interviewed them to demonstrate interview techniques. The PEER interviewers found it difficult to stimulate an in-depth discussion of the photographs, despite having training, so interviews were short, and tended to ask simply to describe what is in the photograph, As these interviews were carried out in one day, towards the end of the field trip, there was no chance to correct the technique for the individual interviews that followed.

A final group activity was conducted (Appendix 3), and I took the lead in asking people to discuss their photographs, asking which showed the most unhealthy and the most healthy aspects of their environment. The PEER interviewers acted as translators for this activity, and detailed notes were taken which, with the recorded interviews and the photographs themselves constituted the data. During this workshop I did question for greater depth of meaning, as people were encouraged to explain why they thought the photographs had demonstrated the healthy or unhealthy aspects of their environment to me as a person from outside the Palestinian community. The elderly refugees were very happy to have participated in the research, and were delighted to have a set of photographs to remind them of this summer, their families, and their visitors.

Several problems arose in collecting this data, stemming from the mechanics of photo taking and the novelty of the activity. During the introductory workshop the elderly refugees primarily focused on the new experience of using a camera, and were less focused on the discussion of their environment and its implications. When photographs were being taken, the cameras were often broken, requiring people request a replacement (16 of the cameras were used by the participants, two by the PEER interviewers and two were used to demonstrate; but we only had five participants who took photographs). Finally, the PEER interviewers were perhaps too close to the camp environment to enquire about the meaning of the photographs — the responses were obvious to them so they did not go deeply into the meaning and significance of the informants' responses. These problems could be minimised in the future by using more robust cameras — perhaps digital cameras — which may be more familiar to the Palestinians, having seen photographs taken with more modern devices such as mobile phones. Two separate and short initial group activities would be more appropriate with this community, one teaching people how to use the cameras, and letting them practise with them, followed by a second group activity where the type of photograph to be taken could be discussed. Finally, I would suggest

that in this situation the interviews would be better conducted by an outsider rather than by a member of the refugee community; the outsider who would find the photographs novel, and so would be better able to probe what the pictures meant to the photographer, and the informants may be more eager to explain the context of the photographs to the interviewer.

The data collected in this way is not of the quality normally achieved with PhotoVoice, and accordingly, when I have used this data, I refer to it as photographic data. However, it has served to highlight for me both the social and the physical environment of the camp; it enabled me to illustrate the physical environment and better understand the social environment in conjunction with the life experience interviews.

5.4.2 Data collection from service providers

The second unit of analysis entailed working with the employees of organisations that provided services in the camp. Again, I collected two data sets; one from the managers of programs, and the other from the clinicians who have daily contact with the residents of the camps. With the managers I used in-depth interviews, on a one-on-one basis, usually in English, though several were conducted in Arabic, with my gatekeeper as interpreter. The data collected from the clinicians was gathered in focus groups, with my gatekeeper acting as a leader, and myself as co-leader.

Unlike the data collected from elderly refugees, in these data sets I focused on the projects and services provided by these organisations, and the impact these services had made on the community. However, many of the Palestinian informants and some of the foreign informants provided example from their personal experiences to demonstrate points they wished to make, meaning that elements of life experience stories also occur in these data sets.

5.4.2.1 Interviews with managers

The aim of these interviews was to gain an understanding of the nature and extent of health problems among the elderly refugees in the camp, and the organisation, nature and extent of services which helped them to manage health problems of old age. I used an interview schedule (Appendix 3) which started by enquiring about the organisation's programs which might affect the health of the participants of the program, and then progressed to discuss the health problems that they had observed, and the reasons for the development of such health problems.

Each interview schedule was tailored to the person being interviewed, based on information gained from available reports, websites of the organisations and previous interviews, including interviews with elderly refugees and other service providers. In addition to tailoring the interview schedule to the organisation, I tried to customise it to the person being interviewed. These

people were not necessarily health experts; skills ranged from people with management expertise, social workers, nurses, doctors, psychologists, as well as some who had no formal training in the area of aid and development. I tried to gain as much information as possible, depending on the type of programs they were involved with and the skill set the person had. For example, one project manager had lived in Bourj-el-Barajneh through the sieges of the late 1980s and had also been a builder; his personal experiences were critical in gaining an understanding of the built environment, and the effects of war on that infrastructure. Another older Palestinian, a social worker and program manager, when discussing the role of coffee and smoking in facilitating social situations, described her own experiences with these substances when she visited clients as part of her work. Often I only became aware of these experiences during the interview. Thus the interview schedule was tailored to the informant, but if other subjects relevant to the research emerged during the interview, I would explore these.

I initially made contact by emails which including introductory letters and a request to interview appropriate staff. However, as discussed in Section 5.1.3, except for those potential informants who knew me personally, I received no responses, so following discussion with my acquaintance I made follow-up phone calls. This need to make phone contact relates to both the cost of making calls to mobile phones (I only had a mobile phone) in Lebanon, and the work practices of the people I was contacting. I found most people had indeed been awaiting a call and many were willing to be interviewed. Permission to interview UNRWA staff required a written request through their publicity officer. Palestinian Red Crescent Society (PRCS), which runs hospital services in the Bourj-el-Barajneh camp, asked me to get verbal permission from their director in Lebanon. Some of the smaller organisations are staffed by people with poor English, and in these situations I asked my gatekeeper to phone the offices of these organisations. She also accompanied me to these interviews and acted as an interpreter when necessary.

Twenty-nine interviews were undertaken in Lebanon, and a further three were conducted in Europe after the main data collection had occurred in Lebanon. One interview was with the director of an international NGO which runs programs in the camps, to gain an understanding of his role, and another was with the Lebanon desk officer of a large donor organisation; finally, I interviewed a European ex-employee of several local NGOs who had worked on several projects that were relevant to this research.

5.4.2.2 Focus groups with service-providing workers

When service providers indicated that they employed people to provide health care I asked if I could approach those staff, asking them to be involved in focus groups to discuss health and chronic illness in the camp. These staff are mainly local, living inside or close to the camp where they are employed. The aim of these focus groups was to understand how the clinicians

understood health and chronic illness in the camp — what factors contributed to or conversely gave protection from chronic illness among the camp population. As already discussed, I chose to collect this data in focus groups because I had experienced the depth of knowledge that such groups could develop given the chance to discuss and work out ideas in groups.

Initially I had planned to conduct these focus groups with my gatekeeper as a co-leader, out of working hours and away from the workplace. However, none of the organisations I approached was prepared to encourage their staff to work outside their normal working hours, and all of them were willing to provide a venue and to allow staff time to participate in the focus groups.

The groups were conducted in Arabic, and followed a similar pattern (Appendix 3). We started with a brainstorm to identify what health problems the elderly residents typically had. In one focus group, conducted with doctors, this constituted the major part of the discussion. We then went on to consider what the group considered had contributed to these health problems and what protected some people from experiencing them. Finally, we discussed their organisations' programs, and how these affected the health outcomes of the elderly in the camp.

The Arabic-speaking group leader conducted most of the discussion, and fed back points to me in English, which I noted. I would ask trigger questions through her, to either encourage the group to go deeper into a subject or get them to move on to a related but different concept. I was principally an observer, allowing me to watch the group dynamics and where necessary make suggestions; for example, when quieter members of the group appeared to be excluded, I could suggest my questions be directed to that person. My gatekeeper had had some training in running focus groups from an NGO she had worked with, and we quickly developed a functional partnership.

As already discussed, these focus groups were not recorded (section 5.1.3.4) because the difficulty of transcribing several simultaneous voices from Arabic to English was not practical for the translator. I made detailed notes during the focus groups and we used butchers' paper to record brainstorm results and discussion subjects. The latter helped the focus group to see what had been discussed and to follow the direction of their arguments. Following the group, my co-leader and I would review these notes and make a detailed written record of the group's ideas, which ultimately formed the data.

This data was particularly interesting, as most of the participants were also residents of Bourj el Barajneh camp, and so could draw both on their lay knowledge of living in the community and also their clinical experiences with residents. They were often able to empathise with their clients and highlight the underlying community, national and international rationale for health-affecting life experiences.

5.4.3 Notes on managing data collected in Arabic

Several tools were used to manage the linguistic problems of collecting data in a primarily Arabic speaking community, some of which have been discussed in the relevant sections above. These include using aspects of PEER ethnography, and using a single translator to translate interviews undertaken by the PEER ethnographers.

While many Palestinians speak English as a second language, it is not universal among the NGO managers and so, where there was doubt as to an interviewees English skills, I would take an interpreter with me (my gatekeeper is an experienced interpreter, though without formal qualifications). These interviews were recorded, and the English parts of the conversations were transcribed.

Thus the data sets included either English translations of interviews undertaken in Arabic, English transcriptions of English Interviews, or English sections of Interviews undertaken with an Arabic-to-English interpreter.

A sample of these interpretations and translations was checked for accuracy by a native speaker of Palestinian Arabic, who is fluent in English, and he certified that these samples were good translations/interpretations of the original Arabic.

5.5 Analysis

The purpose of analysis is to transform and interpret qualitative data in order to capture the complexities of the social worlds the researcher is trying to explain. To do this, researchers have developed a wide range of perspectives and practices which support the answering of the particular research questions being asked (Punch 2005, pp. 194–95). The mixture of analytical techniques are often interconnected and can be used in combination. In this study I have combined narrative with thematic analysis. Thematic analysis, with its coding and segmentation of the data, assists with conceptualising regularities in the data, but tends to break up the data 'fostering a culture of fragmentation' which may de-contextualise the data, losing the rich ethnographic content of the data (Grbich 1999, p. 230; Punch 2005, pp. 216–17).

5.5.1 Analysis in the field

Data from elderly refugees has been collected in a narrative form. I have also included some of the service provider data into these stories, either from the informants' own life stories or the discussions of a health-related project. The analysis of these stories can give a rich understanding of the life experiences which informants share with the researchers (Punch 2005, p. 217). By using the analytical strengths of thematic analysis, but linking it back to the narratives of the informants, the coherence of the community's story is maintained.

During the process of collecting data there was an opportunity to review it, principally to see if modifications to the interview schedules were needed. However, as suggested by grounded theory exponents, this iterative process is similar to that of grounded theory (Liamputtong & Ezzy 2005, p. 266), involving me in analysis from the moment that the data was collected. In this early analysis of data, collective narratives and the beginnings of a coding frame both started to emerge. This early stage of data analysis shaped the data collected and signalled the direction the analysis would need to take.

5.5.2 The narratives

In analysing narrative data, we should consider both the form and the content in order to understand it (Punch 2005, p. 218). Thus, as well as thinking about the story itself as told, we should consider the language used, the use of imagery, metaphors, irony, and other tropes or literary devices (Punch 2005, pp. 218–19). In this data set the life experiences of the refugees were expressed in Arabic and I was analysing it from translations. However, several interesting tropes emerged; for example, when discussing traumatic events informants needed very few probing questions, as seen in interview 101 (pp. 6–11). Here there is a description of the Tel az Zaatar siege and massacre of 1976 and the female informant gives an account of approximately 1,700 words, describing her experiences with only 20 words from the PEER interviewer. As this woman was widowed by this incident, at a young age and with several small children, it has left her with vivid memories which poured out with little prompting. The way that this data is imparted is as significant as the story itself and the themes raised. Emotion can often be judged from the translated content; for example, another informant appears very angry:

> *May Allah refuse to grant anything for the ones who made us leave. May Allah refuse to grant anything for all the Arab leaders. (107, p. 3)*

Though I have not heard these words spoken from the recording, the translator has made the anger clear.

The use of narrative form at this stage of analysis sits well with Krieger's ecosocial model, linking the experiences of the refugees over their lifetime to their health, or in Krieger's words, the refugees 'literally incorporate, biologically, the world around [them]' (2001, p. 668). Analysing the stories they recall about the world as they experienced it provides a starting point to answer the first two research question: 'What aspects of refugees' lived experiences impact on health in old age?', and then, 'How do these life experiences interact with each other to support or detract from good health in old age?'. There were other narratives embedded in the stories beyond the biographies. I searched the interviews for narratives related to health, commencing with behaviours which are known to contribute to chronic illness in old age, such as eating habits, smoking patterns and level of exercise. I put together narratives relating to each theme, from the time in Palestine to the present day, noting changes, and including

variations from the major story line. During this process I started to code the data, looking for emerging themes which could suggest how and why their narrative developed as it did.

5.5.3 Thematic analysis

Thematic analysis, according to Liampittong and Ezzy (2005, p. 265), differs from grounded theory principally in that grounded theory includes theoretical sampling, while thematic analysis does not. I used the coding concepts involved in grounded theory when analysing the data thematically. Open codes are drawn from the data in what Lamputtong and Ezzy (2005, p. 268) describe as 'the first run at coding'. These comprise comparisons between events, actions, and interactions, and the researcher attaches labels accordingly. In this study the data most drawn on for this part of the analysis was that provided by the refugees themselves, both the elderly refugees and those refugees who discussed their personal experiences while describing the work they did for their employing organisation.

Axial coding follows, as the initial categories and relationships develop in the open codes; again in Lamputtong and Ezzy's words (2005, p. 269) 'If open coding attempts to break down data and reconceptualise it, axial coding puts those data back together in new ways by making connections between a category and its sub categories'. In developing axial coding I adopted the principles of Krieger's ecosocial model by following the links between the societal levels (2008, pp. 223–28). For example, when people had discussed eating patterns in conjunction with poverty or war, I looked at why the refugees had been exposed to poverty or war and how these were linked. I did not assume that the underlying determinants of population distribution of health would be the same as those described by Krieger, because the lived experiences would be different in a North American context, so I looked for underlying determinants which could apply to a Middle Eastern refugee community.

Lamputtong and Ezzy (2005, p. 269) suggest a yet further level of codes — selective coding. This process involves the unification of the categories around a core concept, a theoretical point of integration for the study. Lamputtong and Ezzy (2005, pp. 269–70) liken this level of coding to that of telling the story of the narratives, where the plot and the action is more important than the actors.

For example a range of themes emerged relating to behaviours, such as food eaten, sources of food, types of employment, and income, methods of cooking, social life, and how it was conducted. These open codes were organised to gain an understanding of why diet had changed over the years, as axial codes. These were then incorporated into the narrative about dietary patterns and why they had occurred.

5.5.4 Using Krieger's ecosocial model as an analytical tool

In using qualitative data to address the research questions, the researcher collects extensive data and must sift that data to find material that will best answer the research questions; in contrast, quantitative research tailors the data collected to the questions (Roberts 2004, pp. 131–32). The answers to my research questions require exploring the complexity of influences over health outcomes. While some research focuses on the behavior of individuals (Keys, Mienotti et al. 1986; Summerbell, Waters et al. 2001; Chaaya, Mehio-Sibai et al. 2006), and other research focuses on impact of society on the individual (Rose & Marmot 1981; Jones 2000; Commission On Social Determinants Of Health 2007), I am examining the complex relationships between individuals and the society in which they live. I am not trying to limit this to the examination of a few factors, but rather examining the 'web' of factors and looking for the 'spider' that controls it (Krieger 1994, pp. 896–88). As discussed in Chapter 3, Krieger's model allows the incorporation a range of theories into a single model. The starting point of these analyses has been the refugees' life experiences (Figure 9).

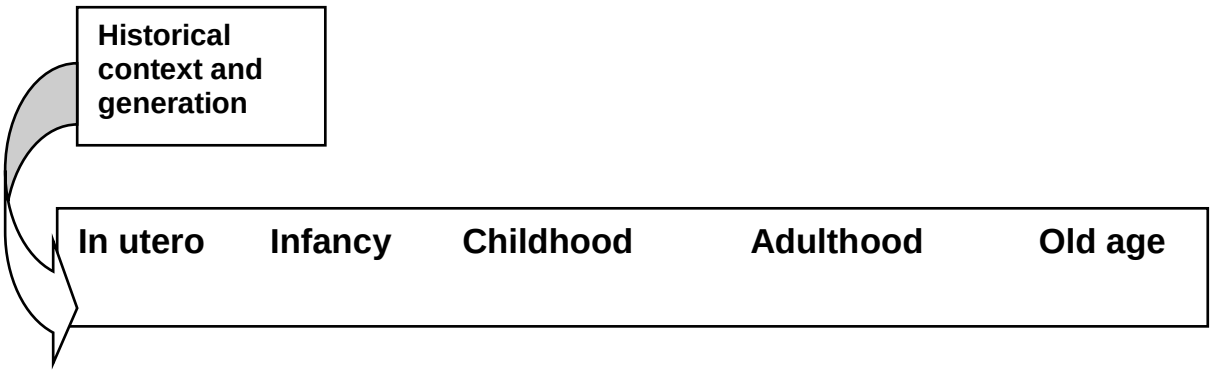

Figure 9: The influences of life experience over a lifetime (from diagram of Krieger's ecosocial model (2008, p. 224)

In order to highlight the nature of this complex phenomenon known as health, I have taken three narratives from the life experiences of the elderly Palestinians who were interviewed. These narratives illustrate firstly, what people ate; secondly, their smoking practices (with some comments on drug and other substance uses); and thirdly, the type and nature of their physical activity. These stories were chosen firstly because they were narratives close to the data, these were stories about what people actually remembered doing and why. Secondly, these are the aspects of people's behavior that are usually addressed by health educators, (Lalonde 1974; Fleming, Lee et al. 2007) and by concentrating my analysis on these three narrative strands I will develop material that may help health educators to understand why certain behaviours have developed. Thirdly, when I considered a range of other narratives, they tended to overlap the three types mentioned, so that when I looked at aspects of the physical and social environment, or at emotional wellbeing, I found that these were already reflected in the details of the three key narratives.

In addition to these simple narratives of how behaviors changed, I undertook a thematic analysis of the data pertaining to each narrative. This linked the data to another aspect of Krieger's model and allowed me to chart the societal and ecological levels affecting the behavioral options available and hence choices made from these options. I also considered emotional and psychological wellbeing thematically, although the narratives relating to this subject varied from informant to informant, making it difficult to develop a single community-wide narrative. Within Krieger's model the societal and ecological levels connect the individual to their environment and wider society. As discussed in Chapter 3, the levels are listed in a sequential order from international to the individual; however, this does not suggest that the connections follow this sequence and, as will be seen in these results, any of the levels may impact directly or indirectly on the individual. Because there are some unusual elements in the particular camp society, I have modified Krieger's ecological and societal levels, to conform to the community I studied. These modifications are illustrated in Figure 10.

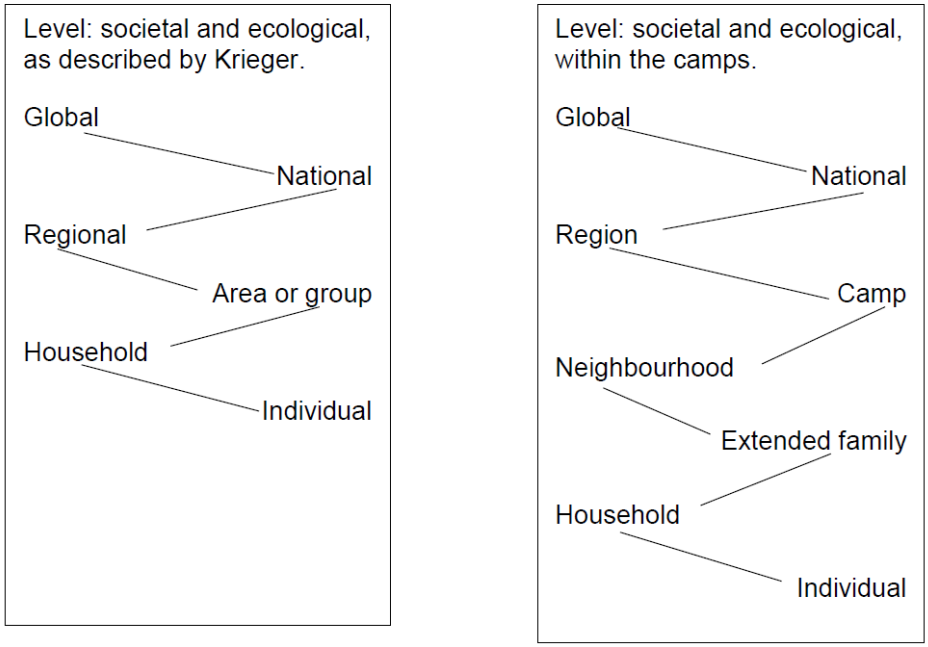

Figure 10: Modification of societal and ecological levels from Krieger, to those more descriptive for the camp community

In these modifications I have expanded the concepts of area or group and household to consider the entire camp community with its unique organizational structures, including neighborhoods, small areas within the camp where people know each other, and extended family who may live in the neighborhood, or camp, or who may live elsewhere in Lebanon or in another country, visiting and helping the camp households when needed.

Within Krieger's model, study of life experiences, and the ecological and social levels contribute to an understanding of the population's health (see Figure 11. She has identified three pivotal concepts: racial/ethnic inequality, class inequality, and gender inequality, as being the principal 'drivers' of a population's distribution of health. By examining the data from this population, I consider if these 'drivers' are applicable in this refugee camp and if not, how they could be modified.

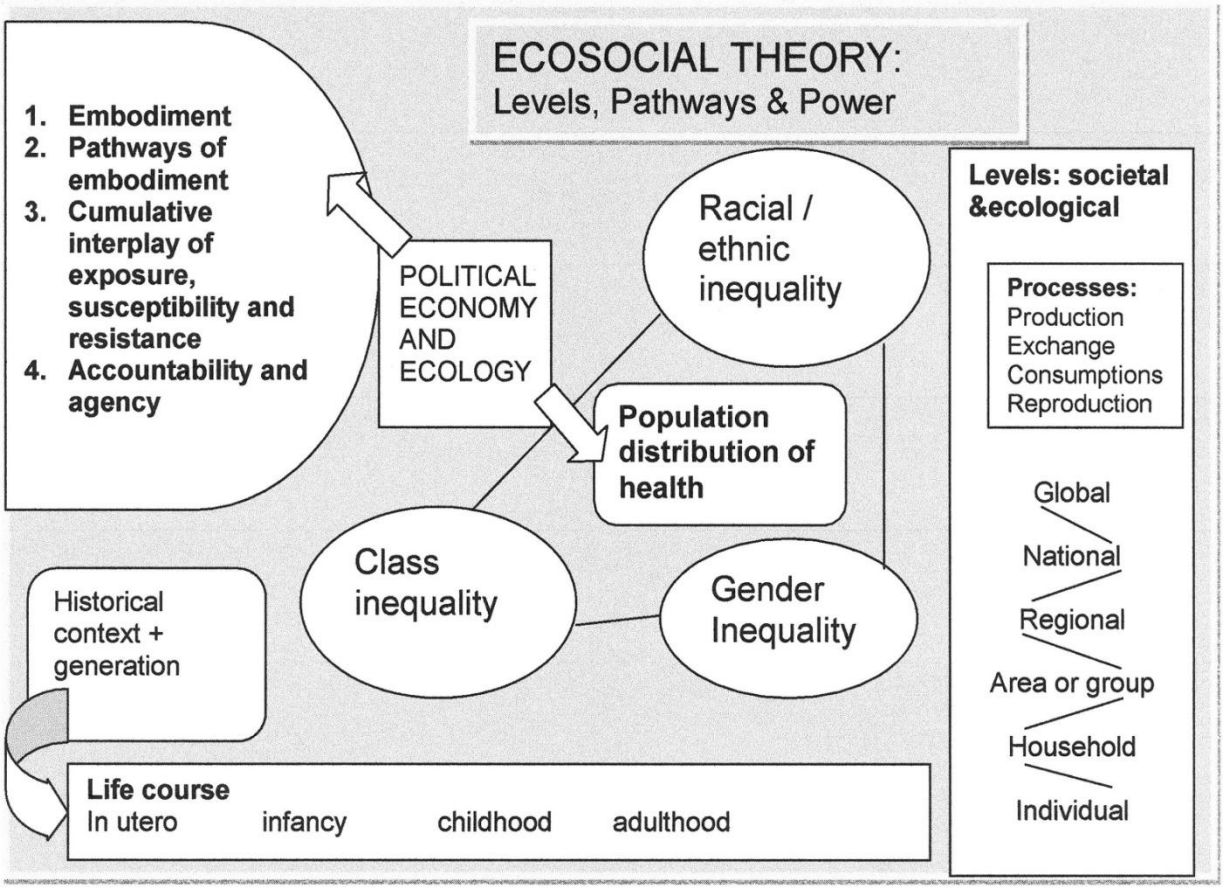

Figure 11: A diagrammatic model of Krieger's ecosocial theory (2008, p. 224)

5.5.5 Further analysis

However, this part of the analysis addresses only the first two research questions: how lived experiences affect perceptions of health, and how these lived experiences interact. In considering further analysis to develop future directions which would assist the community to improve health outcomes I considered several theoretical lenses, all of which could have been used, including human rights theory, war (and post-war reconstruction theory), and theories of poverty and inequity. However, a predominant theme in the data was that of feeling helpless, and being unable to make a difference. Therefore, a second level of analysis focused on where the power lies to make changes and how the camp community could gain more power to control of their lives.

Having examined the literature on power and empowerment, and its relationship with health the concept of community empowerment suggested ways to consider how members of a community can take control of aspects of their lives. I examined my data, looking for previous attempts at empowerment and identified two groups within the community who had made attempts towards community empowerment: the political parties of the PLO, who had dominated the civil society in the 1970s (Khalili 2007; Sayigh 2007), and the increasing numbers of NGOs that have emerged on the scene since the 1990s (Roberts 2004; Khalili 2007). While my data collection had not specifically collected information on the narratives of these organisations, many informants had referred to them. This proved inadequate to develop a coherent narrative; however, by linking the literature and the data I could detect the growth of a cohesive narrative over the time of the camp's existence. Rappaport (1995, p. 796) suggests that by understanding how people tell the stories of their communities and their organisations we can gain an understanding of their potential for empowerment. Thus the stories told about the institutions of civil society organisations, such as NGOs and political parties can, when analysed, give insights into community empowerment.

I shaped my thematic analysis from Laverack's nine domains of community empowerment (2009, chapter 5), but included other open codes which emerged from my own data. Axial codes were developed to consider why the community did not feel empowered in general and specifically in managing their health. Finally, selective codes were applied and linked back to the initial narrative as developed from both the data and the literature.

This further analysis mirrors the combination of thematic coding and narrative and I have been able to both look at the story being told by the people, and the themes which emerge from these stories. I have avoided fragmentation of the qualitative data by linking the stories told by the refugees with the story emerging from the thematic analysis. This has been done by addressing the questions on the community's health and drawing implications from the health analysis to improve service provision.

5.6 Ethics

Ethical approval was granted by the Social and Behavioural Research Ethics Committee of Flinders University (SBREC). The main concerns of the committee were that the informants would not be coerced into participating, that their participation would not harm them, and that if they felt psychologically harmed, there were resources to support them within the community. Thus a process of informing both elderly refugees and service providers about the nature of the study and gaining their informed consent was necessary. The committee was also concerned that my own safety could be ensured.

I also consulted with a Lebanese academic, at that time on the staff of the American University of Beirut, about requirements for ethical approval of research conducted in Lebanon, and was informed that this was not a requirement in Lebanon but that ethical approval from a university outside Lebanon was appropriate (personal comment from Sayigh (2009)) I also contacted a local NGO and asked what would be appropriate ethical approval within the camp of Bourj el Barajneh, and was advised that an approach to the Popular Committee could be made by my gatekeeper, with supporting information and letters from the appropriate university department (personal communication from Mahmoud (2009)).

The avoidance of coercion was ensured by preparing information sheets appropriate for each group of informants, explaining in appropriate language what the study was for, and what I was asking them to do. Information for elderly Palestinians, some of whom were illiterate, was read and discussed with them by an Arabic speaker, either a PEER interviewer or an interpreter. Their permission was then asked for verbally, by the Arabic speaker, who then signed a form that the person had agreed to participate in the interview. The NGO workers read the information sheets in either Arabic or English, as they preferred, and signed a consent form.

PEER interviewers canvassed neighbours, friends and family, asking if they would participate, and while most were happy to be interviewed, those who chose not to participate were free not to do so, and several people did choose not to participate. The approaches to NGOs were made by email, with the appropriate information sheet attached. As discussed in section 5.1.3 there had been problems with making initial contact with NGOs as these busy organisations do not respond to requests for interviews in emails, rather expect to be contacted by phone. I therefore modified my method to accommodate this practice. The NGOs are not as powerless as the older refugees, and did not feel intimidated by my direct contact; rather they saw my follow up as a courtesy and made informed decisions to participate or not, as they saw fit.

Prior to undertaking the study I asked my gatekeeper to prepare a list of services which offered psychological support within Bourj el Barajneh camp, and during data collection from NGOs others were identified. Anonymity was guaranteed, though several informants specifically said that this was not necessary (for example, interview 401).

Personal safety was addressed through preparation of a security plan based on the security plan developed and used by Caritas Austria in 2006–07 during aid and reconstruction work undertaken following the 2006 war with Israel. Key points within this plan included asking three local friends to contact me if there was anything in the Arabic media suggesting imminent civil unrest or war; carrying all documentation and adequate US currency to leave Lebanon at short notice at all times; having a place to stay outside Beirut if necessary; and finally, developing a methodology which did not require me to enter any of the camps.

Ethics approval was given and minor modifications made in the field were approved.

5.7 Summary

This research attempts to understand how the lived experiences of Palestinian refugees, living in Lebanon have contributed to their health status in old age, and the implications for addressing problems identified. This type of research is best approached from an interpretive and constructionist perspective using qualitative data. I limited the scope of the research to a single urban camp, using a case study approach. A range of data sets, including in-depth interviews, group interviews, and photographic data was collected in an ethically appropriate manner and analysed using both narrative and thematic approaches.

6
HEALTH AND BEHAVIOUR IN BOURJ-EL-BARAJNEH CAMP

This chapter examines three behaviours known to be linked to health: diet, smoking (with limited mention of other substance uses) and physical activity. These were chosen because they were subjects which people spoke freely about, and which the literature has linked to health outcomes. As discussed in chapter 5, I consider each by firstly identifying a community narrative of the behaviour, followed by a thematic analysis of why behaviours change over time. I finally combine these two analyses into pathways of embodiment — a process that will identify accountability and agency for behaviours that impact on health.

6.1 Diet and access to food

The elderly Palestinians described several changes in their diet from the time before the *Nakba* (1948) when they lived in Palestine to the present day. In Palestine the diet was basically that of a peasant farming community, where they lived on products that they grew themselves. These included fruit, vegetables, wheat, pulses, olive oil, some meat, such as poultry, and dairy products. Their means of acquiring food changed when they left Palestine in 1948. From then on they purchased food with their wages or received rations from international organizations rather than growing their own food. Minor changes to the diet included a reduction in meat consumption and a change in the type of oil used for cooking, (i.e. from olive oil to canola oil), but on the whole the diet remained traditional.

However, as civil unrest became prevalent, informants reported dietary changes when upheaval meant that people had to eat whatever was available. The first disruption to their traditional diet came in the early 1970s, when civil unrest started, culminating in the Lebanese Civil War from 1975 to 1990. During this period people ate whatever they could get, prepared in any way that was possible. In general, food supply was restricted during the war, and at certain periods other combatants tried to starve the Palestinian community by besieging their camps. During this period UNRWA tried to provide food rations but was not always able to access the camps. Both Dr. Giannou (1990, p. 178) and Dr. Cutting (1988, p.168 and p. 183), who have written about their experiences in the camp sieges, include descriptions of the first United Nations rations arriving in the camps at the end of the longest siege. Following the war UNRWA provided rations only to ‘special hardship cases’.

During the years since the war, there appears to be two different but overlapping narratives; some people tell the story of increasing use of quickly cooked foods and ready-prepared foods, with an increased use of meat and fat, and reduced use of vegetables, grains and legumes.

However, another narrative talks of depletion of the traditional diet, with much less meat and vegetables and a reliance on rice, legumes and starchy vegetables. This second group also refers to fast food, in the form of *manaqish*, a very cheap, tasty traditional pizza-like dish which can be bought from *forns* (bakery shops with large ovens) in the camp very cheaply.

There is a second narrative with relevance to nutrition. Two informants, NGO workers who lived in the camp for most of their lives, told me that in the early days most people mostly drank water, with tea served at breakfast, and coffee drunk with visitors. The tea was sweetened with a single teaspoon of sugar. However, since the civil war, there has been an increase in both tea and coffee drinking and an increase in the sugar added, with many people adding three spoonfuls per glass. This narrative indicates a shift in both the use of caffeine, possibly as a stimulant, and an increase in carbohydrate intake through heavily sweetened drinks.

6.1.1 How healthy has this diet been?

The diet of the peasant farmers in Palestine was based on what they could grow, or purchase with the surplus food they produced. It conformed closely to the Mediterranean diet suggested by Keys and colleagues (Keys, Mienotti et al. 1986) and which a Cochrane Collaboration abstract suggests may have beneficial effects in reducing cardiac risk factors (.Rees, Hartley, et al. 2013). The principal elements of this diet were a mixture of animal and vegetable proteins, carbohydrates which tend to have a low glycaemic index (Brand-Miller, Foster-Powell et al. 2011, p. 52), and use of olive oil rather than animal fats.

Following the *Nakba* the diet remained similar, though the proportion of animal protein to plant protein was reduced. This change may have affected the iron content of the diet, as iron from animal sources is more readily absorbed than that from plant sources (NHMRC, Australian Department of Health and Ageing et al. 2006, p. 186). Certainly, today there is considerable incidence of anaemia, particularly among women in the camp population, as described by a technical advisor to a women's health program (404, p. 4), and confirmed by a recent UNRWA program (UNHCR 2009, UNRWA 2013).

The description given of the UNRWA ration includes rice rather than bourghul which people recall from Palestine — rice having a medium-to-high glycaemic index while bourghul has a low glycaemic index (Brand-Miller, Foster-Powell et al. 2011, pp. 345 and 348). This may have been a little less healthy but the balance of nutrients would have remained similar. In addition, bourghul is a whole grain, while rice as distributed in the camps was polished. When considering the micronutrient value of these grains, the level of iron from plant sources may be reduced (NHMRC, Australian Department of Health and Ageing et al. 2006, p. 187). Thus, though the general dietary patterns changed little, there appears to have been a slight shift to a less healthy diet,

This shift to a less healthy diet intensified during the civil war years. The foods people recall eating tended to be largely carbohydrates, both the starchy grains and vegetables and the simple sugars. The inclusion of legumes as emergency food, during the sieges provided some plant protein, but the severe weight loss reported by Europeans living in the camps through the sieges suggests that starvation occurred for up to six months at a time (Cutting 1988, p. 170, Giannou 1990, pp. 155 and 184).

As discussed in Chapter 3, children who experience poor nutrition are at greater risk of adult chronic illnesses, including heart disease (Barker, Forsen et al. 2001, p. 1275). Studies of famine and siege suggest that there are long-term consequences to the health of survivors. It is difficult to tease apart the factors contributing to chronic illnesses in later life — traumatic events, the nature and amount of food available, the resilience to survive a siege, the nature of the siege, being some mentioned (Sparen, Vagero et al. 2004; Li, He et al. 2010, van Abeelen, Elias et al. 2012). Sparen and colleagues (2004) found that those who experienced the Leningrad siege (1941–44) developed higher blood pressure, with increased mortality from stroke and ischemic heart disease. Those researchers found that the greatest effect was on men who went through puberty during the siege rather than younger children and neonates. Diabetes has also been commonly noted among victims of famine, Van Abeelen and colleagues (2012) found that those born during or just before the Dutch famine (1944–45) were significantly more likely to develop type 2 diabetes, and Li and colleagues, looking at survivors of the Chinese famine of 1959–61 (2010), found that this was exacerbated by exposure to a nutritionally rich environment later in life. Thus, though the data depends on studies of historical situations, there is evidence that starvation, such as was experienced by the camp refugees, will have long-term health effects. It is therefore possible that the nature of the sieges has contributed to the increase in chronic illness reported by the surveys discussed in Chapter 2, and the problems with poor health described by the staff and managers of the health service providers.

The effects on health of the post-civil war dietary changes, like the narrative itself, falls into two areas: the move towards fast foods, and the move away from fresh fruit and vegetables. An NGO manager mentioned the change to more meat, but cheaper fattier cuts (401, p. 13). The predominantly saturated fats in meat are not essential nutrients as body synthesises them, and it is recommended that their consumption be minimised (NHMRC, Australian Department of Health and Ageing et al. 2006, pp. 35 and 271). Thus, though there are some benefits to having some red meat, particularly for iron, saturated fat intake is problematic and often unhealthy.

Regardless of whether Western-style fast foods are chosen or a more traditional diet, there appears to have been a reduction in the intake of fruit and vegetables in favour of either starchy vegetables and grains or meat. There is a wide range of beneficial micronutrients in fruit and

vegetables which the consumer will lack with this dietary trend. For example, vitamin C aids the absorption of iron, particularly from plant sources, so the reduction in vegetables and fruit rich in this vitamin may be contributing to anaemia among the women in the community — a problem which has already been described (NHMRC, Australian Department of Health and Ageing et al. 2006, pp. 119 and 187).

I have only touched on a few of the health-related problems that dietary changes have actually or potentially generated. A detailed study of the diet, over time would give a more accurate and detailed understanding of the health implications of dietary changes. However, this study focuses on the reasons for the changes, as well as the nature of them. Therefore the thematic analysis of the changes to diet over time offers insights into why people have changed their diet.

6.1.2 Why did the diet change?

Several themes emerged to contribute to these changes, including, inability to afford the more expensive foods, unavailability of certain types of food, distrust of modern food production techniques, eating foods which people find enjoyable, and eating to maintain social networks.

6.1.2.1 Inability to pay for food

Inability to afford the more expensive food is a thread throughout the data. Even in the pre-*Nakba* period one elderly refugee suggests that meat was beyond his family's ability to provide, because his father was sick.

> *He (father) had something like nerves, in his legs and back, so he couldn't work… you know how, I don't know but we had little daily bread in Palestine, figs, olives, they used to live on them. (118, p.5)*

However, others who recall Palestine described a varied diet with home-produced vegetables, grains, fruit, and olive oil. Red meat was bought from a butcher and several families recall keeping hens for eggs, and eating the cockerels. Animal protein was generally eaten one to three times a week.

> *They used to slaughter the roosters, it would be the best food for them and if they wanted meat for the food, they used to buy it from the butcher (117, p. 4).*

Following the Nakba people had to purchase much of their food, though UNRWA provided rations, including rice, salt, dates, oil, lentils, chickpeas, sugar, milk (powder), beans, and tea (125, p. 8). The recollections from the camps in the 1950s and 1960s are that meat consumption had become dependent on family finance, and that it was served only once a week, in small portions (35–85 g. per person).

Interviewer *….How often would you have meat in a week? Would you have it every day, or...? [Arabic, Interpreter, X]*

Interpreter *He said that, if financially they were good they would buy like half a kilo, or 200 grams, 300 grams, or 400 grams of meat.....*

Interviewer *To share between 6 or 7 of them...?*

Interpreter *Yeah, on Sunday only. And for chicken, maybe once a month, or once every two months. It depends. (116, p.7)*

Lack of money to buy food became a greater problem during the war, as men were less able to work; for example, a man described losing his job as a butcher working in Christian East Beirut (118, p.19), and a woman explained that her husband was not able to work during the war, and family food for the day could include only a kilo of potatoes (109, p. 12).

Following the civil war, after 1990, the problem of affordability became more complex, as suggested by the two narratives, one a depleted traditional diet, and the second a fast-food diet. Lack of income drives the depleted traditional diet, with people choosing the cheaper foods, such as starchy vegetables, cheap rice, and cheap cooking oils. For example, a woman who had been widowed with young children in 1976 described her distress at being unable to buy fruit for her children:

> *My mother used to go and buy fruits and my son wants fruit and I used to tell him, I will bring you tomorrow and I start crying and become depressed and it affects me. (101, p.19).*

She is aware of the dietary need for fruit, and was distressed she did not have the money to buy this necessity for her family's health.

In the early 1990s UNRWA moved from a universal ration to a ration for people with 'special hardship' (401, p. 12). Free staple foods were no longer provided for the general refugee population and the refugees could buy only what they could afford. The people who were judged to be special hardship cases continued to get rations every three months. Thus the very poor continued to get basic provisions, but the general population had to purchase their food from commercial outlets.

The depleted traditional diet was not without fast foods. One NGO manager describes families buying *manaqish* as a breakfast food; they supply their own topping (usually a mixture of cheap oil and zaatar) and spread it onto the bakers' *manaqish* bases. The cost is 1000 LL (US 66 cents) for ten *manaqish* (each about the size of an eight-inch pizza) (417, pp. 11–12). *Manaqish* was a special treat at family feasts as another NGO manager recalls:

> *Especially manaqish it's very cheap now in the camp, and tasty, I remember when we used, as a child we used to have manaqish only during the feast, when we celebrate the feast my grandmother had, would have this … like very thin bread, she will make at home and we will have manaqish. (401, p.14)*

The fast food diet also has some relation to family income, as I found from the focus groups of health workers, some of whom were working married women. One older man in a focus group of nurses suggested that modern women were lazy (302, p. 7), but a colleague, an older

woman, challenged this by describing her working day — rising at the dawn-prayer to prepare the evening meal, working a six-hour nursing shift, going home and finishing preparation for her husband's and son's meal, then spending the evening on housework and preparation for the next day's meal (302, p. 7). In a social worker focus group, one woman discussed her own diet, saying when she cooked a traditional lentil and bourghul dish, which is served with either salad or yoghurt, she usually chose yoghurt because it was easier (309, p. 5). More women now work, because it is easier to for them to find jobs (309, p. 5) and so they have enough money for their children to buy fast foods. This broaches the subject of women in the workforce, which will be further discussed in section 6.4.

So over their lifetime the elderly refugees have had financial constraints, limiting for most families the ability to provide what they consider to be a balanced diet. This not only impacted on their nutritional wellbeing, but in some cases caused psychological distress because of their inability to provide their families with foods they know to be part of a healthy diet. This is illustrated in Figure 12.

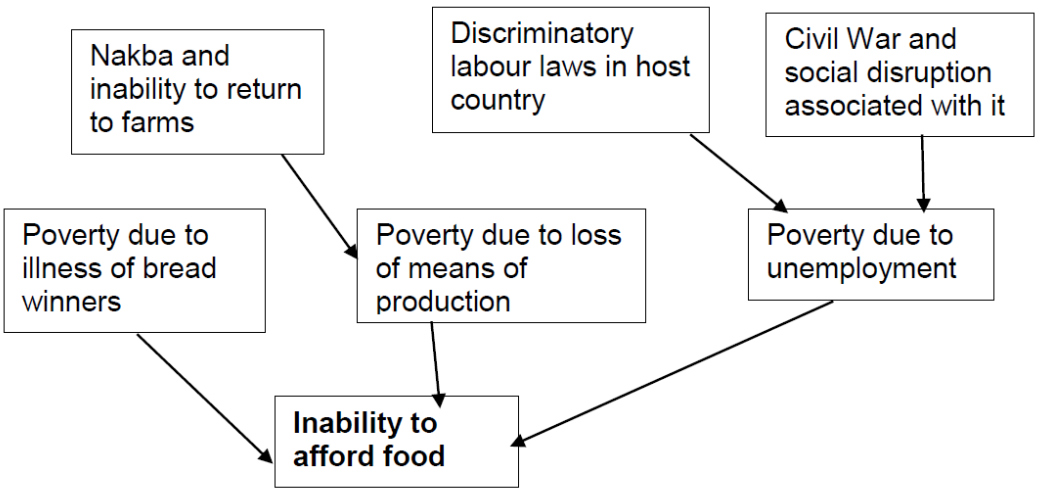

Figure 12: Some connections identified between diet and ability to pay for food

6.1.2.2 Unavailability of some or all food types

Within this thematic concept I considered situations where some or all foods, were not available, rather than unaffordable. I have also included food types which were available but which, for various reason, were considered by the refugees to be of poor quality.

Both the elderly refugees and the nutritional literature suggest that diet in pre-war Palestine was healthy. During the *Nakba*, when the refugees fled, there was a period of shortage, as people had left their farms but had not established a place of residence in their country of first refuge. Recollections vary depending on the local conditions; for example, the same woman recalls being refused food in one village and treated generously in another.

> *My mother asked them there to give her water, to give it to us, me and my brother. I was young and he was seven months old. They told her go and drink from the sewage water. (102, p.6)*

But then

> *Ein Ebil's people welcomed us — you know everyone should be honest — they cooked for us and I remember it was red Mogdara. (102, pp.6–7)*

Such difficulty accessing food was directly attributable to the war situation, which caused people to flee from their homes. Elderly refugees recall fleeing with only what they could carry, (109, p.3). Those who had money or saleable goods (such as farm animals) were able to buy food (114, p.14; 111, p.6), but others had to beg (102, p.6).

The next period when some food types became unavailable was during the civil war. There were times when people could not afford food, but there were also times when they said it was not available. The period which the refugees recall most strongly was when their camps were besieged. Many recall the period known as the War of the Camps, when a Shi'a militia specifically attacked some of the camps; however, other informants had lived in the East Beirut camp of Tel-Az-Zaatar, which was besieged and destroyed in 1976. When a camp was besieged the surrounding forces tried to prevent supplies from entering the camp and anybody from leaving it. These experiences have been written about by Western doctors who were working in the camps at the time of the sieges; they report severe weight loss for all residents in the camps (Cutting 1988, Giannou 1990).

One man, who had lived in the camps during the sieges, gave me a detailed picture of how his family stockpiled food.

Informant	*Number one canned foods, number two grains, number three flour, number four sugar, these are the number one, all of them, you can't…*
Interviewer	*Yes, without these you can't manage.*
Informant	*The priority…*
Interviewer	*Lentils?*
Informant	*Yeah, all kinds of grains, rice, lentils, chickpeas, beans. All of these grains, dry grains that can last. …And of course, onion, potato. (405, p.14)*

A glance at these food types suggests that they were high in both complex and simple carbohydrates; however, beans, lentils and wheat products also provide vegetable protein. There were very limited supplies of fresh vegetables, fruits, dairy products and meat, which suggests that many of the nutrients associated with these foods were missing from the diet for periods of up to six months.

An ongoing concern for many informants is a fear that some food types are not safe to eat, because of modern farming practices — i.e. the food that is available is not the type or quality that people wish to buy. The older refugees compare modern food production with the traditional practices they recall as children, and link modern methods with chronic illness in

older people. One older woman believes that hypertension and anemia are linked to the chemicals used in farming:

> *Because the food contains lots of chemical substances and in fruit, in the beginning, you used to eat an apple and smell it a kilometre away or a cucumber or a tomato or anything. Now it is all on chemicals. Now you see the cucumber. You planted it and it became like this, all of it is chemical substances, there is nothing natural (123, p.42)*

It is not only the fruit and vegetables which they distrust:

> *The chicken who is 45 days old becomes three kilos — three kilos! It is hormones — the fowl are, it is all injected with hormones all of these are diseases for the body that is entering the body and the people don't know. (121, pp.31–32)*

The service providers also discussed this matter; one group of social workers/health educators explained that there have been media reports about Lebanese farming practices relying heavily on poisons and chemicals, which has scared people. (309, p. 5)

Thus we know that at certain times war has reduced the availability of foods, to the point of starvation, if only for limited periods. However, currently people in the camps are becoming aware that their food may contain chemical residues and that alternatives such as certified organic produce are not available. These connections are summarised in Figure 13.

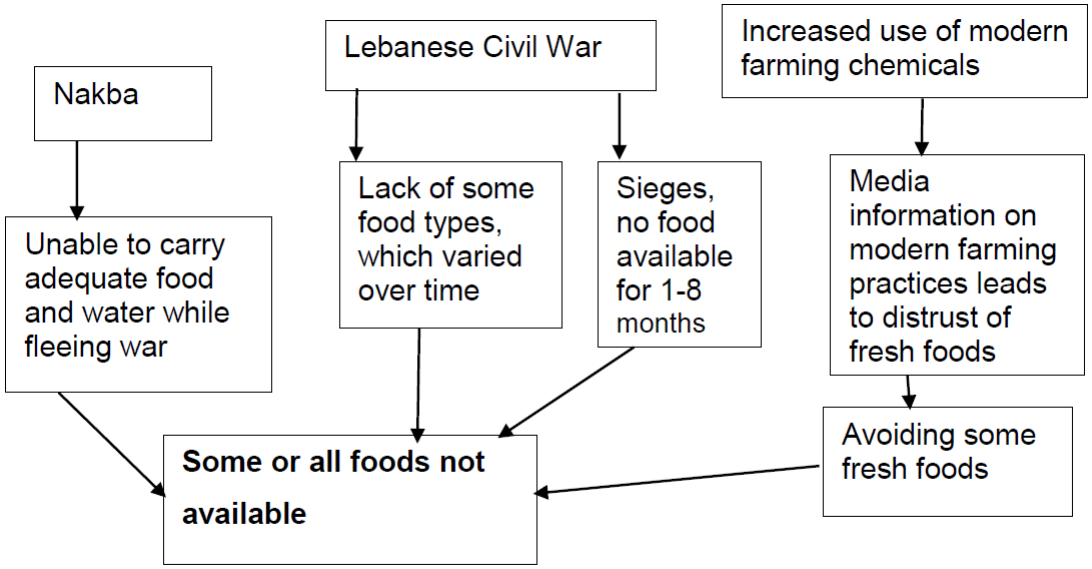

Figure 13: connections which influence food availability

6.1.2.3 Food as a pleasure, supporting social cohesion

While the elderly refugees did not specifically refer to the concept of food as a pleasure, the service providers involved in health education told me that when they discussed healthy eating their patients told them they did not want to give up one of the few pleasures they had. Another linked concept to this was that the elderly needed to eat similar food to the rest of the family, and they could not ask the other family members to give up eating pleasant food for more

healthy food. A focus group of nurses had found that foods which older people eat for pleasure tend to be sweet. When they suggested to patients with diabetes that they should not eat sweets, they would be told by some of their patients that as they had not got long to live they wanted to enjoy their sweets now (303, p.5). The manager of another health education program commented that the elderly refugees believe that one's psychological state is more important to health than diet:

> *You know, they love food and when you are.… Let me tell you something really, when I sat with them and said "you should eat this, and eat this, and eat that. You should get away from this, and this, and this", she says, "No, believe me, believe me — what matters and what keeps you away from disease is your psychological state". They believe in that. (427, p.23)*

The local NGO manager who recalled as a child people adding one spoonful of sugar to tea or coffee, but now they add three or four spoons of sugar (401, p.13) suggests that there are psychological needs met by the increased sugar:

> *Yeah, I don't know why, why people increase — why? When you feel stress you need more sugar? So [that's why] people need more sugar. (401, p.14)*

She suggests that the change in sugar consumption is a form of stress management, though probably at an unconscious level, because until this discussion she had not made the connection. The NGO manager then extends her argument, suggesting other pleasant ('tasty') high-carbohydrate snacks have become daily food rather than treats:

> *.[…].The food they are eating now is more carbohydrates — like maybe all day they have carbohydrates, all day. Especially manaqish. It's very cheap now in the camp, and tasty, I remember when we used, as a child we used to have manaqish only during the feast (401, p.14)*

As well as the suggestion that food was used as a pleasure and as a stress management strategy, NGO staff also discussed coffee drinking as a social formality. An NGO which runs women's meetings said that they always have coffee (with lots of sugar) and cigarettes (412, p.19). A social worker described always being offered coffee as she made her home visits (428, p.12). Other NGO workers described women spending 'too much time' making visits and drinking coffee (417, pp.29–30). As mentioned, this coffee is usually heavily sugared contributing a high-energy supplement in the diet, while at the same time contributing to the maintenance of extended family relations and other social networks.

Thus the consumption of food may be contributing to the emotional and psychological wellbeing of the refugees by providing personal pleasure, and social 'lubricants' within the extended family, the neighborhood, and across the camp (see Figure14).

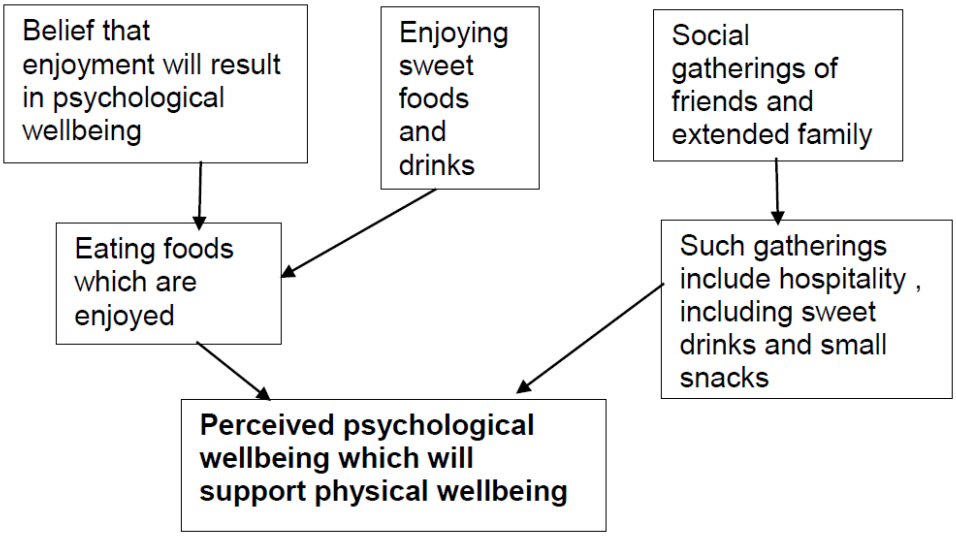

Figure 14: Links between diet, psychological and social wellbeing

6.1.3 The complexity of food choices

The life experiences which the refugees link to their diet are complex, In Figure 15. I have outlined these connections, focusing on the societal level to which each link is related. The dimension of time is limited in this representation, some factors of the web occurred for a short period, others continue over years. Even this complexity may not represent the full picture, as participants may have avoided discussing some aspects. For example, much of the data relating to using diet for enjoyment or stress relief comes from service providers, not from the refugees themselves. Possibly the refugees were prepared to discuss this with their service providers when discussing the management of their health and chronic illnesses, but not with a researcher, either a PEER interviewer or myself.

At the international and the national level, diet is affected by the impact of war conditions limiting access to food, and loss of human rights, especially access to employment, which keeps the community in continuing poverty. At the personal level, stress and anxiety dominate dietary patterns. There is a side issue of new community fears, as people appear to have learned facts about modern food production technology which they are told uses excessive agricultural chemicals. Between these extremes of the 'societal and ecological levels' (Krieger 2008, p. 224) there is a range of negative life experiences, common in the refugee community, relating to poverty and attempts to maintain emotional wellbeing.

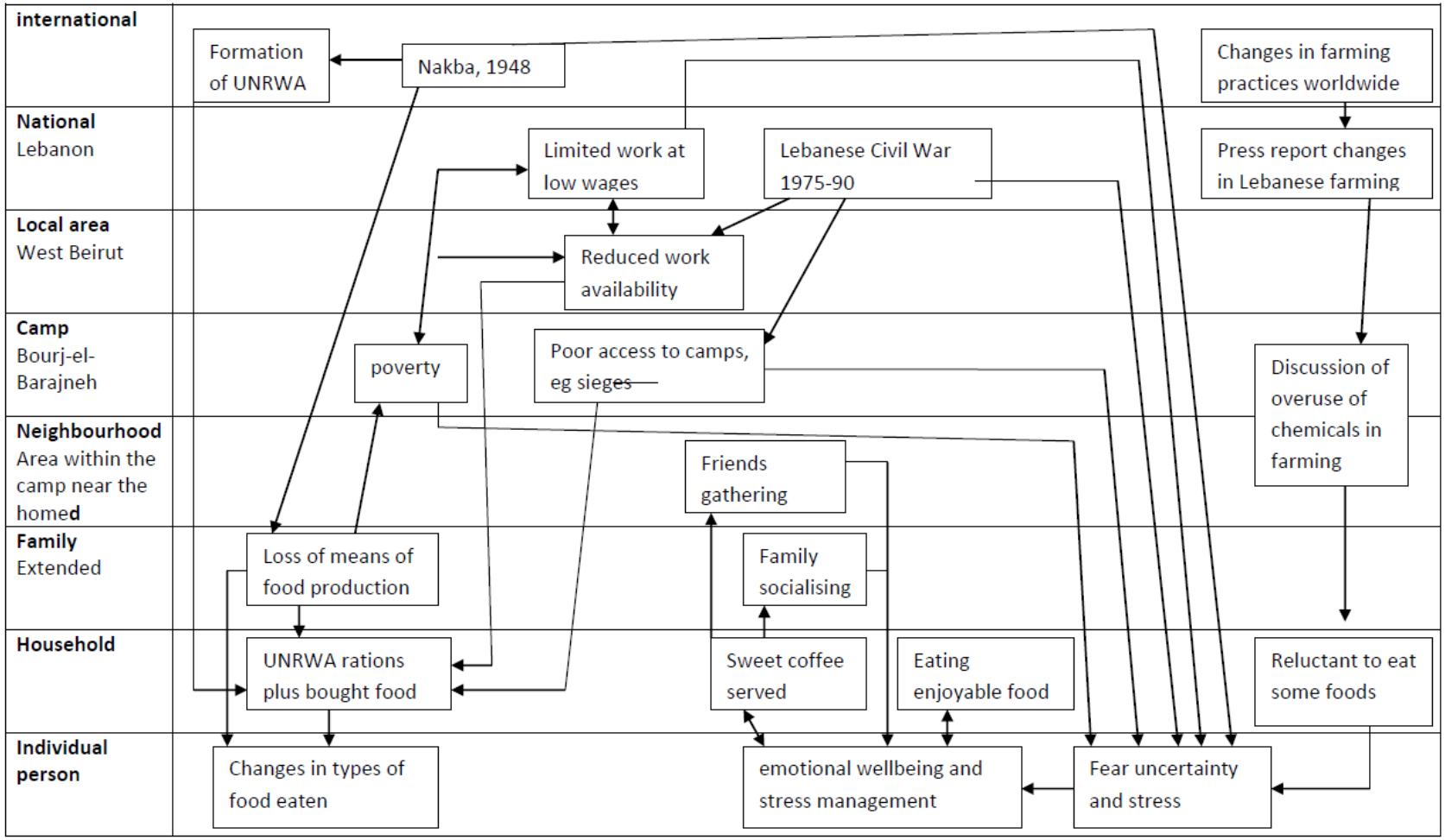

Figure 15: Linking dietary choices with the reasons for those choices

6.1.3.1 Emotional wellbeing

The life of a refugee contains many stress factors. As they try to manage the chronic stress, anxiety and depression, people seek to maintain a strong social network by means of informal and formal gatherings involving the sharing of hospitality — usually including the serving of beverages and sometimes snacks (428, p. 12; 412, p. 11; 109, p. 17; 410, p. 5). While this social networking has been noted by several of the foreign service providers (428, pp. 37–39; 431, p. 11), there are some indications that the local population believe that social networks in the camp are weakening (102, p. 11; 104, p. 7; 106, p. 27; 117, pp. 17–18; 125, pp. 18–19). However, social ties, either within the household, the extended family or the neighbourhood, continue to be fostered by the NGOs, and many projects which include social activities for young, women, elderly people and children were described by local NGOs (401, 402, 407, 412, 416,423, 427).

Several informants also mentioned that, to avoid friction within the family, older people living with younger relatives, for example sons , would eat food prepared for the whole family, even if they had been advised to avoid some of the foods served for health reasons. This information arose during the focus groups with health educators. When I suggested that a healthy diet for a person with hypertension or diabetes was also a generally healthy diet, the health educators responded that while they knew this to be true, the community as a whole did not accept this. They added that to provide two different meals, one for the elderly person with chronic illness, and the other acceptable to the rest of the family, would take extra time and money (309, p. 9). Thus the camp community links food and beverage choices with both formal and informal community activities, from family meals to organized social activities.

As already discussed in the previous paragraph, health educators have found it difficult to help people in the camp to understand a relationship between food eaten and health outcomes; indeed, people see that stress and poverty are more to blame for their increasing levels of chronic illness. For example, a woman who has managed her type 2 diabetes since the end of the civil war, believes that the condition was caused by difficult times in her life:

> *None of my family members have diabetes. I had it from sadness and gloominess. I was upset and suddenly I found I had diabetes. (104, p. 30)*

This woman misses eating foods which she enjoyed in the past, but knows she should eat as advised by the health educators or she feels ill:

> *How I deal with it? Allah knows. Sometimes I cry alone because I look at things and I am deprived from them (104, p. 30)*

As a woman who lives alone she can manage her diet as she has been advised, but it remains a struggle, as she denies herself pleasures, such as sweets and cakes.

What foods do people eat for pleasure? Several NGO workers mentioned *manaqish*. It started as a special home-made treat during the feasts (Eid al Fitr and Eid al Adha) (401, p. 12), but it has now become a common food item bought from *forns* (bakeries). However, there are also those who have slightly more money who choose to eat foods that are cooked more quickly than traditional dishes, or which can be bought ready-made. These tend to be Western-style dishes, European or American, with more meat and less vegetable than the traditional menu. People mentioned sandwiches (meaning either rolled flatbread, with a variety of fillings, falafel, meat, cheeses, or hamburgers, or similar Western fast foods), but they also describe home-cooked meals with chicken as the basic ingredient (chicken being the cheapest meat available).

In addition, service providers have mentioned the predominance of sweet foods, cakes or *baqlawa* (a sweet of filo pastry, nuts and syrup). This was described by an NGO manager:

> *Informant* *We eat lots of vegetables, you know…. And we don't eat so much meat every day, like in the… in the…. outside in the American… America or in Australia. You know, maybe we eat meat once per week, or once per two weeks, you know… just grilled —, but every day we eat vegetables and rice.*
>
> *Interviewer* *Right…..*
>
> *Informant* *So it's not very difficult to give them a healthy diet. But we eat sweets a lot. The sweets, they can do without it. (415, pp. 20–21)*

These sweets may have been mentioned since they form a part of the traditional meals at Ramadan and Eid al Fitr, which occurred early in my data collection; or they may have become a common treat obtained throughout the whole year.

The increase in consumption of meat, sweets and savory snacks has generated concern among health educators, and they suggest that these foods are being eaten mainly because they are pleasurable.

6.1.3.2 Poverty

Poverty has generated mental states such as depression and stress in the community and it has also radically changed eating patterns. On becoming refugees the Palestinians lost the means of food production when people grew most of what they ate on their land or farms. Sayigh also identifies high levels of debt, related to taxation, drawing on data sources from the British Mandate era (Sayigh 2007, pp. 24–26). This did not affect diet greatly because the peasants produced their own food. However, once separated from their land, the refugees became highly dependent on the wages they could earn and the generosity of the international community.

6.2 Smoking tobacco products and other substance abuses

Smoking has been considered unhealthy since at least the middle of the last century, causing the development of some lung cancers (Berridge & Loughlin 2005; Berlivet 2008), chronic lung

diseases (Burney, Jithoo et al. 2014; Dijkstra, de Jong et al. 2014) and vascular diseases, including coronary artery disease and myocardial infarcts (Al Mutairi, Shihab-Eldeen et al. 2006). In addition to cigarette smoking, many refugees also smoke tobacco via the *nargileh*, or water pipe. This carries similar risks to cigarette smoking as well as the additional risks of infectious disease, such as tuberculosis and *helicobacter pylori* from shared use of the mouthpiece (Knishkowy & Amitai 2005, pp.15–16).

Currently, studies based on quantitative data suggest that smoking in the refugee camps is quite prevalent. Ugland and colleagues found 44% of men and 16% of women smoked daily, with the greatest numbers being in the 30 to 50 year cohort (2003, pp. 99–101); Chaaya and colleagues found that 38.6% of elderly people living in Bourj-el-Barajneh camp smoked regularly or occasionally, and only 38.6% had never smoked. This former figure was significantly higher than among poorer Lebanese suburbs of Beirut (2006, p. 920); and finally Afifa and colleagues found 10.3% of youth (13 to 20 years old) in Bourj-el-Barajneh camp smoked (2009, p. 458). However, smoking patterns among Palestinians have changed dramatically over the 61 years between the *Nakba* and the time that interviews were conducted. The data from elderly Palestinians provides some suggestions as to why smokers among the informants started to smoke or in one case stopped smoking. When combined with the information from NGO managers and workers, further reasons for the changes emerged. In addition to smoking, several informants voiced concerns that there is an increase in use of other drugs, including both misuse of prescription drugs and use of illegal or socially unacceptable drugs, including alcohol and amphetamines. These narratives, with thematic analysis of the stories, will be explored in this section.

6.2.1 Narratives about smoking and other substance abuse

The practices relating to smoking have changed over time, with numbers of smokers apparently increasing, and the habit extending from home-made cigarettes to commercial cigarettes and *nargileh*. People were quite happy to discuss their personal experiences of smoking, suggesting that it is still socially acceptable. However, a second strand of information from the NGO workers suggests that there are other substances which have recently started to be used in the camps, including misuse of medical drugs and use of ‘recreational drugs’ including alcohol and illegal drugs. While information on this latter usage was not sought, people did volunteer hearsay data which I deemed sufficiently significant to mention briefly.

6.2.1.1 Smoking practices in the camp community

Smoking among the villagers in Mandate Palestine was limited to the elderly men:

In the past the elders who were smoking Arab tobacco, and they were rolling themselves, and they were buying, like, 10 kilos of this tobacco and keep it, and save it. (114, p. 19).

The women at this time did not smoke. This pattern appears to have continued in the early days in Lebanon; however, by the late 1960s both young men and young women were smoking, as this man explained:

I've been smoking since I was 13 years old. I was 13 years old, and the one should be honest (121, p. 30)

And a woman of similar age started to smoke in her late teens.

Let me tell you, I have been smoking for 40 years; for 20 years my parents didn't know. (123, p. 12)

During the years of the civil war (1975–90) smoking became much more common, in all ages, though the men seem to have smoked more than women, according to this man:

Interviewer *Were the men smoking in the (bomb) shelter in that time?*

Informant *Yes, they used to smoke. Who used to smoke, he smoked but the women used to tell them, go up to the camp, the doors, it had two doors from here, go and smoke outside, you are suffocating us, there are babies, and you find them sleeping.*

Interviewer *Didn't the women smoke?*

Interviewer *There are but not all of them, but there are…*

Interviewer *Low percent?*

Interviewer *It was low percent back in those days. (118, pp. 30–31)*

In the 1990s and 2000s smoking had become very common, with both men and women smoking openly. In the past women would not smoke in the street, but that has changed in recent years, as suggested by a young woman. An NGO manager, who has lived in the camp all her life.

Interviewer *Is it still considered not good for a woman to smoke in the street?*

Informant *No, it's khalas (Arabic word meaning 'no more').... We are an open society.*

Interviewer *You smoke in the streets?*

Informant *Yeah, we are with the... with men, with every.... Before it was very conservative even in this issue. (417, p.34)*

She went on to discuss the use of *nargileh*:

Interviewer *Now you see people smoking in the street?*

Informant *Yeah, and even nargileh, they can [smoke]..... Before it was... It's forbidden to smoke nargileh with the presence of men. (417, p.34)*

A further concern of some of the health workers has been evidence of very young children smoking. For example, a nurse working in a clinic recalls seeing a child, probably less than school age, picking up a discarded, but burning cigarette and smoking it (303, p. 9). Another NGO has conducted group activities around child smoking and has been told by children that they steal cigarettes from their parents or they get them from friends. Another worker in this focus group said that she was aware that cigarettes could be bought in ones and twos outside the UNRWA schools (308, p.4).

In the latter part of the civil war a new form of smoking started to emerge, the *nargileh* (Figure, 16).

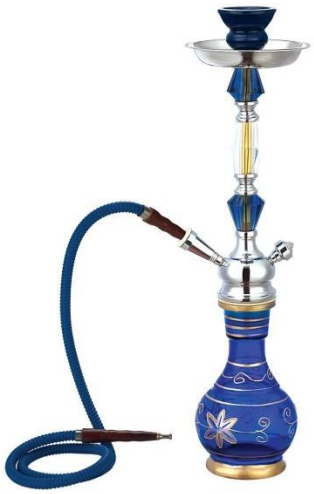

Figure 16: nargileh (pronounced argileh)

Only one older refugee recalls smoking *nargileh* during the civil war, (118, pp. 30–31), but gradually it has become more common. In the 1990s and early 2000s people who used *nargileh* owned their own equipment, which they cleaned after each use. An NGO manager told me of a new phenomenon: the home delivered *nargileh*.

Interviewer	*Yes I remember when I first came to camp (2001) nargileh was not very common, but (a PEER interviewer's name) tells me there's shops all over the camp where you can go and get ready made nargileh....*
Informant	*It's 1000 (Lebanese pounds, about US$0.60).....*
Interviewer	*1000?*
Informant	*Yeah, and even....*
Interviewer	*For a pipe with tobacco and everything?*
Informant	*With the tobacco and charcoal.*
Interviewer	*My God! That's ridiculous, because in the cafes (in Beirut) it's 15,000.(US$10) (417, pp. 25–26)*

She went on to discuss the hygiene of these shops.

Informant	*For sure, it's not an.... and it's not clean, if you look at the water it's.....*
Interviewer	*Are they using the same water over again?*
Informant	*Yeah, and also the.... you know, the....*
Interviewer	*The pipe... yeah, the actual pipe?*
Informant	*Yeah, all the camp are using the same pipe.*
Interviewer	*That's not good for acute illnesses.....*
Informant	*Yeah!!!... (417, p. 26)*

This discussion gives insight into the economic aspects of *nargileh* smoking. It also suggests that infectious diseases may be transmitted through this form of shared smoking (Knishkowy & Amitai 2005, p. 116).

Thus during the 63 years since the *Nakba*, smoking has changed from being an activity of the older men to a common practice, extending even to small children. Smokers have moved from home-made cigarettes to commercially manufactured cigarettes and even home-delivered *nargileh*.

6.2.1.2 Misuse of drugs

Another new phenomenon, discussed by the NGO workers, and which caused them concern is use of drugs primarily, but not exclusively, by younger people. These include alcohol, usually cheap spirits (412, p. 7), misuse of prescription medications including cough mixtures, Valium, and other drugs which affect mental state (412, p. 7), addition of substances to the *nargileh*, (paracetamol was specifically mentioned) (412, p. 7), amphetamines (419) and solvent sniffing (415, p. 45). These reports are made by senior NGO workers (often but not always foreigners), who are reporting second-hand information from their field colleagues. However, an interview with a local Palestinian pharmacist did confirm the misuse of prescription drugs:

> *Look, there was a case here that a pharmacy was selling drugs, the kind of drugs, err …. not legally or ….to whoever wants them. But this pharmacy was closed (he was selling) neurological medicines. (429. pp .9–10)*

One of the focus groups also discussed the increase in drug use which they had observed in the camp, both in their work and their own lives (303). It appears that a wide variety of cheap drugs are available in the camp, but that the local people are not happy to discuss this with outsiders unless they have a close relationship with that person. I present this hearsay data briefly because it suggests a line of further research, which would need careful planning with community members but which some NGOs consider is needed.

6.2.2 Why have smoking patterns changed?

The major themes to emerge from the interviews and focus groups related to the low cost of cigarettes and the belief that smoking helped to maintain, or regain emotional wellbeing. Balanced against these is an understanding that smoking is unhealthy and social pressure from elders that smoking is not acceptable socially. In fact, there are social pressures both encouraging smoking and discouraging it.

6.2.2.1 Cost of smoking

The price of cigarettes is relatively low in Lebanon. One informant told me that a cheap brand costs LL500 (about US 35c) for a packet of 20 (417, p. 31), though my observations during the data collection visit suggest that most brands of cigarettes cost LL1000 to LL2000 (US 65c to $1.35). One of the reasons for the low cost is the small amount of tax levied in Lebanon on tobacco products, compared with similar countries (Salti, Chaaban et al. 2013, p. 1). When compared with food costs, such as LL500 to LL1000 per kilogram for seasonal fruit or

vegetables (tomatoes, cucumber, and apples), or meat from LL10,000 to LL18,000 (307, p. 7) these very cheap cigarettes are relatively affordable on the low incomes most Palestinian refugees are able to earn.

As already mentioned, one NGO manager identified the very cheap 'home delivered' *nargileh* as a reason for an increase in smoking this form of tobacco (417, pp. 25–26). While many people own a water pipe, putting their own tobacco in it and cleaning it themselves, this takes time, so home delivery is cheap and convenient. The tobacco for *nargileh* attracts even less tax than cigarettes, being taxed at a rate of 30% according to Salti and colleagues (2013, p. 1.). Thus it appears that tobacco products are very cheap (Fig 17).

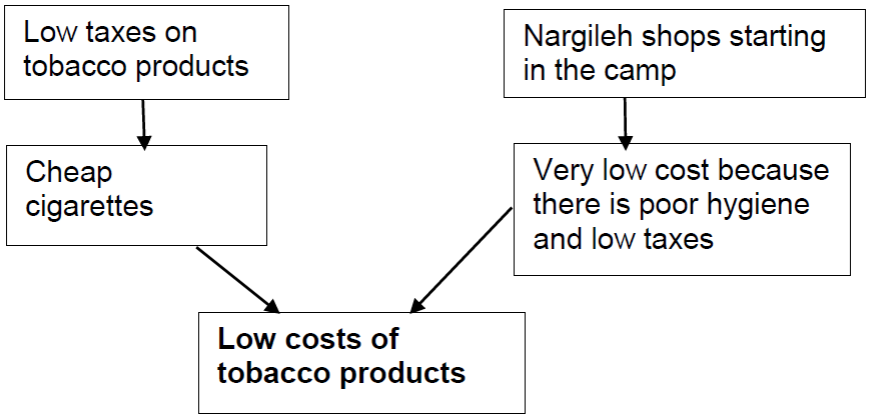

Figure 17: Factors which reduce the cost of tobacco products

6.2.2.2 Smoking to remedy emotional and psychological problems

As already discussed, the refugees use food to manage stress. This theme emerged even more strongly when refugees discussed smoking. A social worker with an NGO, who is also elderly, explained (through the interpreter) how she started smoking following the death of her husband.

> *You know, her husband died when she was pregnant with her last daughter and she was only 24, and as usual, you know the people come to give condolence to her and sit with her so each one was... Each one of the woman were saying 'take this cigarette, you will forget your problems, you will take out the pressure'… She said that she was smoking three packets a day. (428, p. 10)*

A man who was young during the shelling of the camp recalls starting to smoke at this time, with his friends, as they played cards throughout the shelling.

> *W)e used to go to his (a relative's) house, it was 2, 3 floors and his house is almost like a shelter, we used to say it is good; the missiles won't fall on us. We used to sit and play cards and smoke nargileh. (118, p. 31)*

These extreme episodes, involving widowhood and war, illustrate traumatic life events that have been linked to smoking. Greenberg and his colleagues suggest that smoking is linked with post-traumatic stress disorder, 'both above and below the diagnostic threshold' (2011, p. 94). The

interviews for this study were not designed to identify psychological illnesses such as PTSD and, according to a doctor working in the hospital, there are few diagnostic or treatment services for psychological illness in the camp (408, p. 6). However, both the quoted informants discuss starting to smoke at during traumatic events in their lives. Considering Greenberg's list of traumatic events (2011, p. 93), which she used to identify people likely to have PTSD, all the elderly refugees interviewed and many of the Palestinians working as service providers have experienced potentially traumatic life events.

Not only do some people see smoking as a way to manage the emotional turmoil of traumatic events; they also see it as a way of managing the day-to-day tensions which life as a refugee brings. For example, a man in his 50s who has had surgery for coronary artery disease explained why he found it difficult to stop smoking.

Interpreter	*(H)e was forbidden from smoking but he put all his anger, and all his stress in this cigarette.*
Interviewer	*So he puts his anger into the cigarettes? [Arabic Interpreter, Informant]*
Interpreter	*Well, it's better than beating his children. [Arabic Informant] He said that when he works he doesn't smoke.*
Interviewer	*So it's when he sits around the house unemployed, then he smokes a lot?*
Interpreter	*Yeah.*
Interviewer	*Can I be very personal and ask how many packets a day you smoke at the moment? [Arabic Informant] Tellateh? (three in Arabic) And how many... when you're working, how much would you smoke? [Arabic Interpreter, Informant)*
Interpreter	*One (124, pp. 27–28)*

He explained that home is small — two rooms plus the kitchen — with two teenagers studying, which may explain why he might become angry with 'his kids'. Though he is well aware that his health is damaged by his smoking he finds that it helps to manage the stresses of daily life, particularly unemployment, and it is a better trade-off than being constantly angry, especially with family members. His stress is made worse by the difficulty of getting work, he works in the building industry, and since his surgery he finds it difficult to obtain work.

The management of emotional and probably psychological problems encourages smoking, because there is an understanding that smoking reduces stress — something that has been observed in other poor communities (Popay, Bennett et al. 2003). When advised by medical practitioners and health educators to stop smoking, the refugees balance the health benefits of stopping smoking with the emotional benefits of continuing to smoke (see Figure 18).

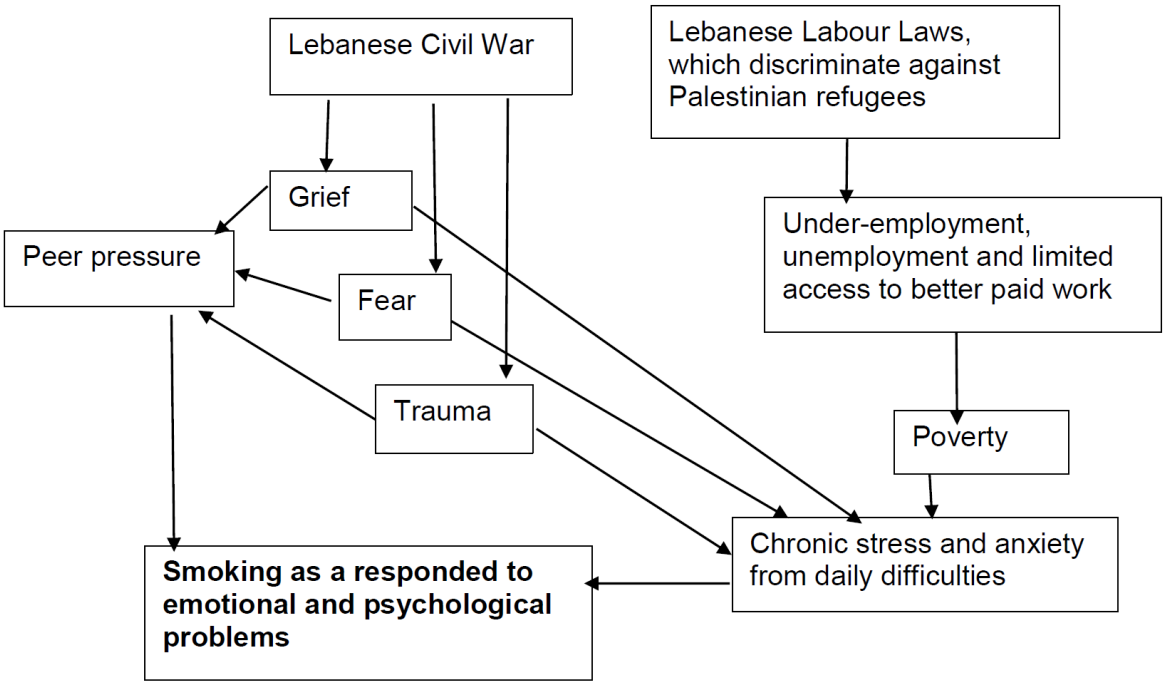

Figure 18: The emotional and psychological links to smoking

These problems can also be managed by medications, including a range of prescription psychoactive medications. However, as there was (at the time of data collection) minimal access to medical specialists to manage these illnesses, the drugs are prescribed by general doctors, who are concerned for their patients mental health but who may have little formal, or informal training in the area. (408, p. 6)

In addition, many people who need these prescription medications cannot afford to purchase them on a regular basis when, importantly, these are not medications that should be taken intermittently. (429, p. 7)

6.2.2.3 Community pressure, elders and peers

As suggested when discussing diet (section 6.2.3.1) and also in discussing smoking (section 6.3.2), in relation to emotional health the refugees make choices based not only on their own wellbeing but also in relation to the wellbeing of others in their community. When discussing smoking, the refugees (both the elderly participants and the those who work as service providers) describe these influences as two opposing pressures: one coming from more traditionally-minded people, who tend to be older and the health workers and educators — all of whom encourage people not to smoke — and the other coming from younger people who encourage their contemporaries to smoke.

The refugees linked smoking to poor health outcomes and also poor moral outcomes. A grandmother described her daughter telling her not to smoke in the same room as the baby:

> *And if she was carrying the cigarette and went to the baby's room, her daughter was telling her please smoke outside the room… and because she wanted to be with her granddaughter, so she told her son-in-law, 'That's it, I'm not going to smoke anymore'. (428, p. 12)*

However, this grandmother, who works as a social worker for an NGO, is aware that such health messages are not universally heeded in the camp, despite NGOs running health education programs which recommend cessation of smoking. She said:

> *Despite all the lectures that they are giving the people about smoking and how harmful it is for them, and what they are doing with their chest, no one is listening. (428, p. 9)*

Those who have developed smoking-related chronic illnesses are personally advised to stop smoking, but they find it difficult:

> *Since I was 13 years, I've been smoking; I stopped it for six months when I did an operation for my heart. They tell you, once you smoke the cigarettes, you won't forget it. (121, p. 30)*

Even those providing health education may be smokers. I observed, following a focus group with nurses providing advice on chronic illnesses, that several started smoking as we left the room, joking that they know it causes heart disease and asthma. However, one ex-smoker commented on how well she felt since giving up (303, p. 10).

As well as one-on-one health education for those with chronic smoking-related illnesses, several NGOs have run health education programs to reduce smoking. The field officer of one small donor described a program his organization has funded across the Palestinian and poor Lebanese communities:

> *You're getting kids going out to their… parents and saying you shouldn't smoke, it's not good for you. ….. and we've produced a lot of material, anti (smoking), not smoking campaign, and games and things, but kids can do, all with the message of anti-smoking (421, p. 5)*

He also shared a poster used in their campaign (Fig. 19)

Figure 19. An anti-smoking poster illustrating both cigarettes and nargileh (from a children's program, funded by a small donor and run by several local NGOs)

Thus smoking cessation information is reaching the refugee community, but other factors are making it difficult to heed the message.

There are several overlapping concepts here which I have collectively categorized as moral pressures to not smoke: these include respect for elders in the family, need to undertake one's responsibilities, religious beliefs, and sexual morality. These themes emerged principally from the elderly refugees, and focused on the trend towards smoking and its harmful effects on the community. While these beliefs may be less common than in the past, one older woman, a smoker, described her own and her children's (aged in their 20s and 30s) smoking patterns:

Interpreter	*She's saying that her (late) son, despite, ….., despite he was married and he had two kids, he wasn't daring to smoke in front of his dad.*
Interviewer	*When did you start smoking? [Arabic Interpreter, Informant]*
Interpreter	*When she got married.*
Interviewer	*When you got married. So your husband let you smoke? [Arabic Interpreter, Informant] But you're saying your kids don't smoke?*
Interpreter	*Only the one that died.*
Interviewer	*Only the one that died, yes... [Arabic Interviewer]*
Interpreter	*All of them, they don't smoke.*
Interviewer	*Neven? Abadan? (Arabic for never). [Arabic Informant] None of them? [Arabic Informant, Interpreter] Why do your kids not smoke if you smoke? [Arabic Interpreter, Informant]*
Interpreter	*She told them that it's not allowed and its shame, and they ask her 'Why you are smoking and you're forbidding us? She said 'I got used to it'.(125, p. 35)*

Thus these young refugees have a strong respect for their parents, even though one parent smoked, only one son (out of five children) smoked, and even then not in the presence of his father. Several of the younger cohort of elderly refugees (those born in the camps) reported

smoking without their parents' knowledge, as already mentioned in section 6.3.1. (123, p. 30; 126, p. 2.)

Only one informant discussed religion in relation to smoking, when he explained why his father had not smoked:

> *My father didn't smoke or smoked nargileh, nothing. He was a believer. (109, p. 4)*

However, several people considered that smoking was linked to sexual morality, boys flirting with girls:

> *Smoking nargileh. It is a big problem and it is not right. And you find them here and there in the streets and if a girl passes by them, they flirt with her, it is not the view we ask for. If a stranger came and saw this view, he would say these are street boys. (106, p. 26)*

Some women have started smoking in public and the young woman who told me this suggested that this was a very new behaviour (I had asked this question because in 2002 I was told that women did not smoke in the street.)

> *Interviewer* *Is it still considered not good for a woman to smoke in the street?*
>
> *Interviewee* *No, it's halas (finished).... We are open society.*
>
> *Interviewer* *You smoke in the streets?*
>
> *Interviewee* *Yeah, we are [equal] with the... with men, with every.... Before it was very conservative even in this issue. (417, p. 34)*

Thus the moral pressure for women not to smoke in public is relaxing amongst younger people.

A final aspect of the moral pressure to not smoke also tends to involve women. Several people suggested that women and children are neglecting their work to smoke *nargileh*.

> *And now the woman go and visit her friends and have nargileh for two hours, and her son comes from school, throws his school bag and goes to play. (109, p. 19)*

not forgetting the children:

> *… the most important things are the nargileh and cigarettes. … This nargileh that the 10-year-old boy smokes. And only Allah knows what they put in it that makes the children like it and stop liking the education. (110, pp. 26–27)*

Thus there are social mores against smoking (Fig. 20), originally based around moral constraints, but these are countered by unrelenting social pressures to smoke (Fig. 21).

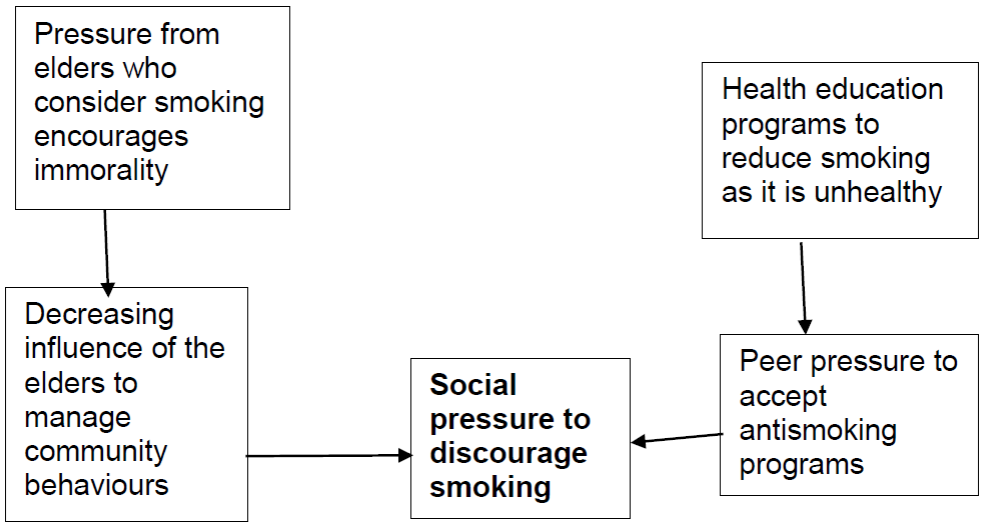

Figure 20: Social pressures that discourage smoking

There is, however, a second strand of community pressure — that exerted by peers. While the elderly informants discussed the health problems of smoking and its links with perceived immorality, the NGO staff discussed the links between social activities, smoking and coffee drinking. As already discussed (section 6.3.2.2), two refugees started to smoke among friends — a young widow, now a grandmother, whose friends advised her to smoke while making formal condolence visits (428, p. 10), and a young man (in the 1980s, now in his sixties) who recalls smoking while playing cards with friends to take his mind off bombing (118, p. 31).

The links between visiting, drinking coffee and smoking have become embedded in the social structure of the camp so that the local people rarely mentioned it; however, the European service providers usually commented on this aspect of the camp social life. One NGO field manager, whose programs include many community meetings, commented:

> *but I think cigarettes is a huge (problem), cigarettes and coffee, [we] can't have a meeting without cigarettes and coffee — I mean, you can still smoke in PRCS hospitals., (412, p. 18)*

Another NGO worker who had also lived in camps when volunteering said:

> *…extreme consumption of cigarettes. Never ever in my life, in whatever situation I was in, country, or context, have people smoked so much. Non-stop. Coffee and cigarettes. There is definitely something which leads to chronic illness. Yeah and an indicator of the mental-health situation of lots of Palestinians like drinking coffee and smoking two packets of cigarettes a day. (431, p. 10)*

Both these people sounded shocked at the amount of smoking observed during their work and socializing among the Palestinians. The second informant sees it as an indicator of the emotional and psychological situation where people are smoking to preserve their mental health.

One Palestinian program manager (a non-smoker) also commented on coffee and cigarettes as part of the social pattern:

Even if they (her parents) took coffee, like they are taking one cup of it, but now ... Like, women in the home, they are spending three hours drinking coffee and smoking cigarettes. (417, pp. 29–30)

As a non-smoker this young woman finds it socially difficult when she is with her contemporaries:

I sat with my friends and they are, like 'How comes you are not smoking? You don't smoke nargileh?' and 'You are very strange, oh!' (417, p. 25)

Thus there is peer pressure among the younger refugees to smoke when they are together socializing.

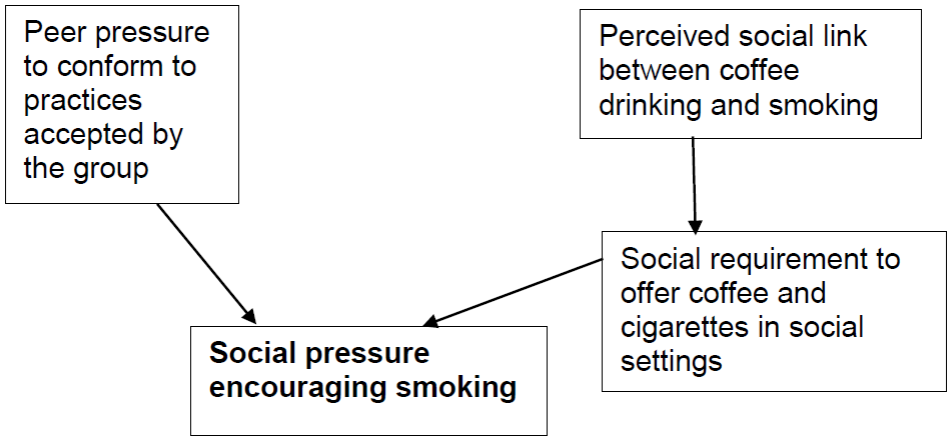

Figure 21: Social pressures that encourage smoking

The tension between peer pressure and the traditional role of elders in determining appropriate behaviour in general was discussed by a Palestinian academic who has conducted program evaluations as well as health research in Lebanon. She drew my attention to the changing position of the elderly in the camps, which may partly explain the social pressures around smoking. She suggested that the elderly refugees are marginalised within the community, which is itself marginalised within Lebanese society (413, p .2). Traditionally, she told me, the elderly were community leaders:

The traditional role of the elderly in Palestine — as I know from the accounts — elderly were the leaders, the family leaders, and their opinions were respected and sort [after]. Most probably this is related to the social hierarchy of the fellaheen, the peasants. Now the elderly had control over the land, as long as they live, the male elderly, the male elder, and the woman elder, of course, she is the head of the patriarchal household, so she has influence over the …. (413 p. 3)

Thus with the diminishing power held by parents over their adult children, the adult children are taking up smoking, a practice which their elders still see as wrong because they consider that it leads to immoral behaviour. While some families continue to observe parental direction in the matter of smoking, there has been a gradual change and now peer pressure dominates, along with new social customs.

6.2.3 The complexity of smoking choices

The narrative of changing smoking patterns, linked to the thematic analysis suggests a complex series of life events and changing social structures which contribute to the reported changes in smoking patterns. These have been illustrated in Figure 22, which depicts the pathways which have either discouraged or encouraged smoking.

The belief that stress can be managed by smoking is a strong belief among the refugees, both the elderly people and the NGO staff who are also refugees. This includes both the stress linked with major traumatic events, such as widowhood (428), or being under bombardment in a war (118); and the day-to-day frustrations of life as a refugee, such as the man who smoked to help control his temper with his teenage children or to manage boredom when he could not get work (124). Peers encouraged this practice to help their friends deal with difficult times in their lives. Smokers reported that they found it difficult to stop smoking as they found that smoking helped to manage the stresses of life, including unemployment and raising children in small overcrowded homes.

There is pressure to smoke as part of normal social activities, both formal meetings and informal family or neighborhood gatherings, because socialising invariably includes serving coffee and offering cigarettes. *Nargileh* is smoked in small groups, with the pipe being handed from person to person and the ability to get ready-prepared equipment has facilitated this social activity. This social pressure among peers is supported by the low cost of tobacco, which is directly linked to the low tobacco taxes in Lebanon, making tobacco products available to even the poorer people in the camp.

There are two principal factors which work to discourage smoking: the first is the health education programs, run by several NGOs. Some target the refugees who have already developed smoking-related illnesses; these are generally provided by service providers, including nurses and doctors within clinics and hospitals. NGOs also run health education programs (421, p. 5; 308, p. 3). These programs are funded through a range of donors (421, p. 5, 420, p .21). Those implementing these programs had varied opinions as to their effectiveness in discouraging smoking; however, as one donor of a children's anti-smoking campaign said:

> *(It's) difficult to ascribe ..., causality, because it's such a — there's so many factors involved. (421, p. 5)*

Thus the effectiveness of health education programs is difficult to evaluate over the short term.

In the past the elderly Palestinians have discouraged smoking, based on perceptions that it is irreligious or immoral. This was discussed both in terms of stopping young people from taking up smoking and in hiding their smoking from their parents. However, in the opinion of one

informant who has evaluated several healthcare programs in the camps of Lebanon (413), the authority of the elderly Palestinians has been eroded gradually over time, because the power to manage the community was rooted in ownership of property or land that was lost at the time of the *Nakba* (1948). Thus, though some of the younger generation show their respect for their parents by not smoking, gradually over the years this has become less common.

One of the major encouragements to smoke can be traced back to the stresses of the civil war. Low taxation levied by the national government, makes smoking a cheap way of managing the stresses of both war and life as a refugee. In addition smoking has become an integral part of social activities, supporting social cohesion, despite its being frowned on by elders and discouraged by health workers.

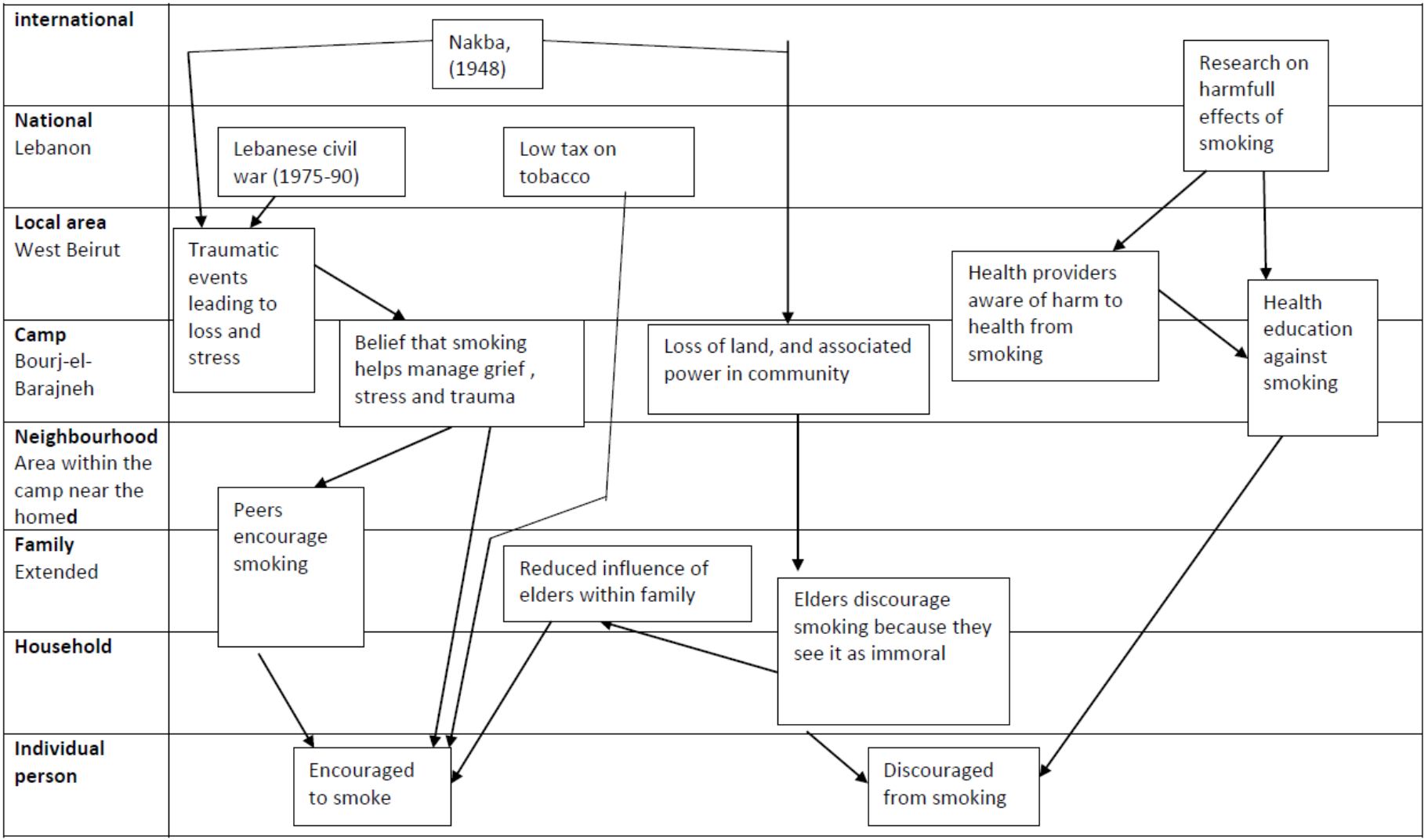

Figure 22: Connections between societal levels which affect smoking

6.3 Physical activity

The elderly Palestinians tended to discuss physical activity as part of their activities of daily life, i.e. employment and home duties. If they discussed play and sport specifically it was in the context of childhood. In the words of a physiotherapist who conducts exercise and walking groups for the elderly in several camps, 'there is no culture of sport' among the camp residents (304, p. 6). The narratives varied depending on gender and age; thus, I will consider the descriptions of physical activity in Palestine, and then describe physical activity over time among children, women and men separately.

6.3.1 Narratives about physical exercise

The life of the peasant farmers has been described by Sayigh (2007, chap. 1), based on data collected in Bourj–el-Barajneh camp in the late 1960s. The perspective has changed, as my informants were generally children at this time, but both my data and Sayigh's describes peasant farming life, with the whole family actively involved in production of food.

> *[My family] had a land, olives and we had cows and goats. My father — May he rest in peace — used to graze the goats, my brothers used to take the cows out and my mother used to go to the land and my aunt (mother's side) raised me; she doesn't have children. (102, p. 2)*

The children were involved in this work as well.

> *[We would]….help our mother in raising the children that are younger than us; of course I have younger sister and brother, and I used to help my mother with them. We had a daily bread, and my father used to tell us to go and collect the olives that have fallen on the ground, you see? Or go and wait next to the figs before someone comes and collect them, and sit in the farm among the figs, guard the figs, collect it, we used to go with them climb the tree and collect the figs with them and put it on the floor and spread it in order to expose it to the sun, to dry, this is what we used to do, my siblings and I. (110, pp. 2-3)*

Those who were not involved in farming were also physically active, such as the man whose father was a trader — he remembers his father's work going to the villages with a donkey loaded with goods to trade:

> *He was a trader, and the Kabri people used to buy from him and Ghabseye ,Sheikh Dawood, Kwaikat, A'ama'a people used to buy from him and my father was…. Em el Faraj people used to buy and Naher, all of them… Every day he went to a village, he used to go and sell, put them on a donkey, he put load here….(117, p. 2)*

The family's village of Ghabseye, is walking distance from the other villages named, being within two to five kilometres. This suggests this trader was walking five to ten kilometres most days, to conduct business.

Thus peasant farmers did not need to deliberately seek to exercise for their health — they gained it from their daily activities. However, once they had become refugees this situation changed.

6.3.1.1 Narratives of the men

When the refugees left Palestine, they left their farms and land behind them, but many continued to work in agriculture. Several of the refugees recall the men going from the camps to work on farms remote from Beirut, staying there for two weeks at a time. One woman grew up in Tel-az-Zaatar camp, and recalls:

> *The men used to go to Al Barouk (a farming area about 40 km from Beirut) once in two weeks, this was in 1953 or 1954. They used to come once every two weeks, they can't come every day because the owners of the work can't bring them every day. There were about 15 or 16 men; they used to come every 15 days (101, p. 4)*

The building industry also employed Palestinian men, and the younger cohort of elderly refugees, now in their 50s, describe entering the workforce in the building trade, as painters, (116, 124), plumbers (121), tilers (111), marble workers (110) and plasterers (107), as well as general labourers. Other work was available, including dock work:

> *I started to go with about 20 men from the camp here (Bourj-el-Barajneh) and work in Beirut's port. We were working in the cargo deck, arrange the products that used to come from outside (imported). We did this for about five years, we used to leave the camp, more than 25 of us. (117, p. 16)*

And some found more sedentary work, such as being a building concierge:

> *He worked here… he also worked in the orchards. Excuse me, then Abu Essam -my cousin- came and told him that there is a building needed a janitor and so he worked as a janitor at this building (109, p. 6)*

The areas of employment undertaken by the men involved some physical activity; even concierges would have been required to clean corridors and stairs and carry goods for residents, though this appears to have been one of the more sedentary jobs for men.

There was also unemployment in the 1960s, as this woman explains that her husband had a skill in the building trade but was not able to find work:

> *Interviewer* *What did your husband work?*
>
> *Informant* *He was hanging [out] in the streets. He didn't have any profession. Unemployment was a problem at this time.*
>
> *Interviewer* *How did you live then?*
>
> *Informant* *From the food. He was hanging in the streets. We used to get food from my mother and my father; she used to bring us this and that. (We) lived from the charity of her family. He was hanging in the streets here and there.*
>
> *Interviewer* *Didn't he have a profession?*
>
> *Informant* *Nothing. No, he used to smooth the walls [plasterer] (107, pp. 19–20)*

However, work in the building industry increased in the pre-civil war period. Following the Cairo Accords the PLO took over the management of the camps, and there was a building boom within the camp, as the restriction on building above the ground floor was removed. This old lady recalls:

> *They (the PLO) had a negative and a positive side; we started to have our freedom, so the people replaced the zinco roof with a cement one. Why? Because the intelligence and detectives stopped coming. (109, p. 10)*

When only corrugated iron (zinco) roofs were allowed it was not possible to build beyond the ground level, but with a concrete roof, it was not only more weatherproof, but allowed a second storey to be added.

The PLO itself became an employer. One man describes leaving school at grade 7, and joining a political party, where he worked as a printer for over 30 years (119, p .6). The PLO also set up factories in Bourj-el- Barajneh camp, including furniture making, food processing, textile work, among others, through the Palestinian Martyrs Works Society (SAMED), (424, pp. 6-7,112, p. 12), (Rubenberg 1983, p. 66). Older refugees recall that the PLO was seen as an employer of last resort:

> *Men who had work will stay in their work, they won't leave their work to join the strugglers but the unemployed ones would join the strugglers. … My husband was a butcher but he used to go and help them in (X) party but he wasn't with [employed by] them (101, p. 7)*

As this woman explained, her husband 'helped' a political party but was not an employee. Another woman however recalls moving to Bourj-el- Barajneh from the south of Lebanon, so that her husband could work:

> *I swear… you can live everywhere, but the person goes where there is work. He worked here, he worked in SAMED here and we stayed … we lived here and we took a house and lived in it. … It was for the revolution, it was an organisation works… it had blacksmith, sweets factory, it had sewing, it had carpentry (112, p. 12)*

Thus with the arrival of the PLO the range of work available increased, though much of it was still manual labour.

When the civil war started, the availability of work beyond the Palestinian community became more difficult to access, though not impossible. One informant had been working as a butcher in Christian East Beirut and his employer told him he could not employ him anymore.

> *They told me, we can't protect you here anymore and that's today is the last day and stop coming here. … I ran out of money and I want to live (118, p. 19)*

This man had a wife and seven children to support, so like several others among the elderly refugees interviewed, he travelled abroad to earn money, first to Libya, and later to Syria, then Abu Dhabi, leaving his family with their relatives in Bourj-el-Barajneh. This was a difficult situation, as for another man, who worked for 17 years in Kuwait, while his family lived in war-torn Lebanon. He said:

> *I was confused* … when there was a situation, [such as] fighting near th*e camps… the work owners said you are upset, …, take anything but take them [the family] outside the country, don't leave them there. (121, p. 11)*

Following the war, the PLO was no longer a major employer, though some activity continued. Unemployment and irregular employment again became a problem. Several of the elderly

refugees explicitly said that they were unable to continue work because illness limited their physical activity:

> *I got tired from it; my body couldn't handle it [building work] anymore. I stopped [doing] it. (121, p. 18)*

This man has heart disease, and had been advised to limit heavy work, but to walk regularly, which he does. Another man found he was unable to continue his work as a painter following a serious accident, but was able to get an administrative job (116, pp. 12–13), thus reducing his physical activity.

However it is not only the older men with chronic illnesses who find it difficult to work. A younger man who works for an NGO as a program manager explained that he went into this work because he was unable to find work in the building industry.

> *Part of it was the competition, the Syrian workers, possibly the general market in the country. I don't know, I don't remember, but the construction market is like slowing down unlike now. And the prices with cheap, competition, and in the camp same situation, not much building and lots of competition. I used to find work but not much. One, stop for two months, one, stop for five months one, then stop for one month. But this is okay this is how I always worked, even when there's lots of construction. Even when there's lots of construction you can't do more than that. I'm not a company. Even if you have 1000 houses I can do one you have one house I can do one. It's the same. …. I went to the vocational training. I went in 1998. I decided to do something different so ... That was … I wasn't thinking of doing that I couldn't imagine that I would do studying. After 18 years out of school. I studied fabrication training at Sukaina's [a local NGO specialising in vocational training]. Architectural drawing, something linked to my work. I was thinking this would add to my skills, instead of skilled worker when I work with my hands I can do foreman. (405, pp. 44-45)*

So this man left the building industry, due to cheap Syrian labour coming into the country, and a reduction in the demand for building. He did this despite liking the work, and gaining extra building skills. He was able to move into NGO employment, which is considerably more sedentary than building.

So overall the work undertaken by men has gradually involved less physical activity, particularly among the older men. In addition, employment is not regular, but can be intermittent, and is becoming harder to find. Some men will maintain some physical activity walking, but sport or exercise for its own sake was not mentioned.

6.3.1.2 Narratives of the women

The women in Palestine participated in farm work, as well as housekeeping, as described. They were physically fit, their children describe them walking long distances carrying heavy loads as they fled during the *Nakba*. Once settled in Lebanon, the younger women, and girls recall a range of paid employment opportunities. For example a woman who lived in Tel-az-Zaatar camp recalls:

I worked in a wool factory when I was single but when I got married I didn't work. Also the women worked in flowers shops; there was a shop called Al- Shami Bashir and another one called Al-Arabi. They worked there and others worked in farms, I didn't work in farms. (101, p. 4)

Another woman who has spent most of her life in or near Bourj-el-Barajneh camp recalls:

Informant *I worked in Ghandour and also Gaber Factory and also worked in Tin Factory.*

Interviewer *What was Gaber factory?*

Informant *It was biscuits.*

Interviewer *Ghandour was biscuits too?*

Informant *Biscuits, macaroni [pasta], vermicelli and suchlike. Then there was a company that made tins, boxes, big tins and all kinds of tins. (104, p. 6)*

Jobs such as factory work and shop work require physical activity. However, as the first quote suggests, in the early days it was uncommon for married women to work for wages. Several commented that it was not considered appropriate for the wife to be a bread winner, as it would undermine her husband's role; several women discussed this, but it was best expressed here:

She said that she was working when she was single and her mother's will was not to work if she got married, because if she got married and she was working her husband will depend on her and there will be money problems, so when she got married she left the work. She did the work at home. [Arabic Informant] Even her mother-in-law agreed with her mother and when she got engaged to her son, like she's talking about her mother-in-law, her mother-in-law told her 'Don't think of working because your husband also will depend on you and money problems will happen'. (108, p. 16)

However, women who did not enter the paid workforce, were involved in the physical activity of housework. This was discussed during a focus group with older health educators:

It is important for the women to work by hand, making the bread, and washing clothes, this was good exercise, but now it is all bought bread and washing machines. (302, p.6)

Several women discussed the way in which they had done housework in the earlier days of the camp; for example, boiling clothes over a wood fire:

Interpreter *And they were boiling the water for washing the laundry and they were on wood.... Like they were set the wood and the washing the laundry on fire, because you know they were putting the white clothes and boiling.*

Interviewer *Yes, they boil them.....*

Interpreter *And then they wash it.*

Interviewer *And then they wash them out and that makes them really white?*

Interpreter *Yeah, why we don't do this?*

Interviewer *It's hard work?*

Interpreter *I used to do this. (Interpreter in her early 40s)*

Interviewer *It's very hard work, this…. [Arabic Interpreter, Informant]*

Interpreter *They used to do it twice, not only once.*

Interviewer *Boiling it twice?*

Interpreter *Washing it twice. Boil it once and wash it, then rinse it, then wash it again. (125, pp. 5–6)*

This activity involves someone collecting the wood, collecting the water, moving heavy wet laundry from the hot water to cooler water to be rinsed — all strenuous physical exercise. The interpreter's comment that she did laundry in this way suggests that this method of washing

clothes continued until the early 1990s. The kitchen also involved physical work, as this lady explains:

> *Interviewer ….there are stoves now. How was it in the past?*
>
> *Informant We used… it was baking stoves, we made baking stoves… they used to make dough and bake it; we didn't buy the bread like now. Now the baking shops… the bread now comes to your house.*
>
> *Interviewer Did you know how to make dough?*
>
> *Informant Yes, I know how to make dough and to bake.*
>
> *Interviewer Do you make the thick or thin bread?*
>
> *Informant No, the thick one, the house bread.*
>
> *Interviewer This one is more delicious, I want to ask you about the rest of the kitchen equipment, like the spoons, knives, were they the same?*
>
> *Informant Yes, the same.*
>
> *Interviewer The same thing. So the stove was only different.*
>
> *Informant It was on the small stove in the beginning. It was rarely to find… or find the stove with two eyes and cook on it or the small stove sometimes. Some people used to cook on a wood fire. (122, pp. 30–31)*

This same lady discusses collecting water in the past, and how now she does not have to do this so she goes out less often:

> *I was stronger in the past more than now. Now, sometimes… no, sometimes I don't leave the house unless I want to go and get the food. Only. In the past, we used to go and fill the water; we used to go to the army barracks to fill the water. (122, p. 29)*

The need to carry water at least daily meant that people in the family had to carry heavy loads over significant distances. The reports of these activities are mainly from women, suggesting it is their job, and they report carrying water distances from 100 metres (125, p. 4) to 500 metres (115, p. 14). It is difficult to estimate the size of the water containers, but based on some comments in interview 125, (p. 3), they were probably carrying 10–20 litres of water in steel containers on their heads. Over time there has been a reduction in the heavy work required to maintain the home, as facilities like non-potable running water, washing machines, and ready-prepared foods (specifically bread) have become available.

During the civil war many women were widowed and needed to support their families, but they found going out to work shameful, as this woman, widowed in the Tel-az-Zaatar massacre discussed:

> *Informant I suffered a lot to find a job in order to build this house.*
>
> *Interviewer What did you work?*
>
> *Informant I worked as a maid in houses, washing dishes.*
>
> *Interviewer It is not wrong.*
>
> *Informant Yes, it is not wrong, excuse me, but I clean the floors and washed the dishes but I can feed my children, So thanks God. (101, p. 17)*

She shows both pride in supporting her children, and shame in having to work, suggesting a conflict of two important social mores of the time.

However data from both the service providers and the older Palestinians suggest that the constraint to work only in the home has reduced over time. Women may find work easier to get than their husbands, in factories for example, (307, p. 4). However, like the widows, the social norms are being disrupted. This was discussed during a focus group among working social workers; one recalled that her father, although a good cook, only cooked the family meals if their mother was away from home; another commented that cooking made men more like women (apparently something they disapproved of). The two married social workers had both negotiated with their husbands to help with housework, but they acknowledged this was not common. (309, p. 6). Holt refers to this tension in her study of Palestinian women and violence, when she suggests that Palestinian women 'must strike a careful balance' between the need to support their families and traditional family relationships (2014, pp. 54–55).

Thus women have always maintained a level of physical activity, either from paid work in a range of situations, including factory work, shop work, farming and domestic service or in heavy unpaid work, maintaining the home. This latter has become less physically demanding with labour-saving innovations such as washing machines, shop-bought bread etc.; however, that has been balanced by the tendency for some women to enter the paid workforce in addition to continuing to keep house as before.

6.3.1.3 Narratives from childhood

The children's narrative on physical activity varies from the adult narratives principally in the role that outdoor play has had in their lives when young. Following the *Nakba* many children worked from quite young ages, and others were in school; however, informal games were common:

Informant	*We used to go up to the sand hill to play. it was…*
Interviewer	*Was it near your house?*
Informant	*Up near your house almost. We used to go and play all day long and we used to come home dirty and then we were hit and [told to] sit.*
Interviewer	*How old were you when you used to go and play?*
Informant	*We were around 7, 8 years. In our days…*
Interviewer	*And in the neighbourhood?*
Informant	*In the neighbourhood… here in our neighbourhood, the lands were sand and things. The houses were different than these. The roads were wider; our days [then] were more beautiful than these days.(123, pp. 2–3)*

The 'sand-hill' is mentioned by many people who were children in the camp, it has now been built over by houses and the hospital. However, there is a photograph from this area in the UNRWA photograph archive (Figure 23).

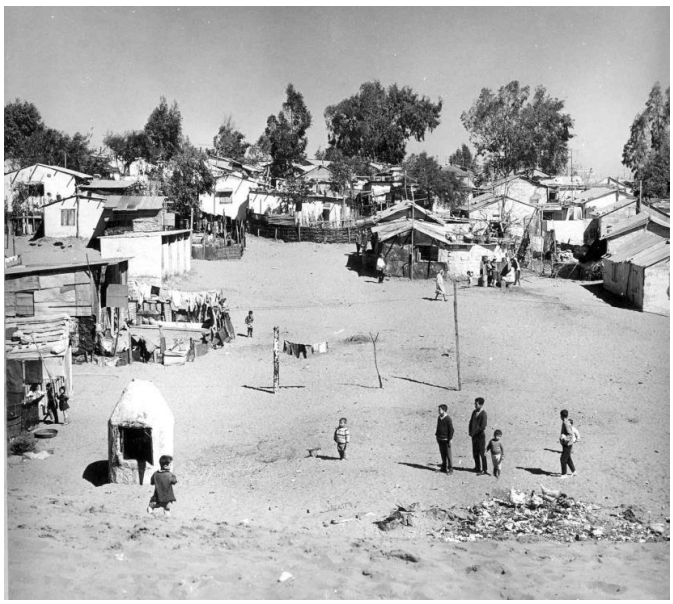

Figure 23: Bourj-el-Barajneh in 1967 showing a large sandy area, probably close to the area described by the informants as 'the sand hill'. (Courtesy of UNRWA photo archives)

Games played include very active games, such as football, two-sticks, and hide and seek (mentioned by 121, p. 2, a man), hoola-hoop games, skipping rope and something called the X game, which I understood was the local name for hopscotch, (mentioned by 123, on p. 5, a woman). Though some of these games may still be played in the modern alleys of the camp, the elderly people are concerned that the children now have no room to play, as this lady explains:

> *The people… the children play in the narrow streets (alleys) and if a child fell on the other, he would fight because there is no space for them to play. These children need gardens…. Our children are deprived a lot; they are deprived of many things. (112, p. 24)*

NGO workers told me that the children spend their leisure time on the computer, in the internet shops rather than playing active games, for example, a focus group with staff who provided exercise classes in the camp discussed this problem, saying that children would nag their parents for money for the internet shop, which is sedentary, rather than play actively. (304, p. 7)

The school system is trying to encourage healthy lifestyles, including the encouragement of physical activity. UNRWA schools include two periods a week of sport till the final two years of secondary school, when it is reduced to one period (411, p. 2). The activities include 'football, volleyball, running, and jumping' during these periods; however, in Beirut the space is limited for some activities. UNRWA school system also has links with organisations which send volunteers from Europe and America to staff the summer programs, and these programs include sporting activities. Some are offered at the vocational training centre outside Beirut, which has football fields. (411, pp. 2–4)

There have been some concerns that children focus on computer activities rather than playing; this was raised particularly among the health workers in the camps, (304, p. 4; 302, p. 3).

However, their concerns were more focused on the problems of finding places to play, since the camp has become heavily built up.

Thus the children have enjoyed physical activity, through play among friends and more recently through organized sporting activities, both at school and as part of the summer activities. However, the facilities for these activities have reduced since the 1960s as the camp has become more crowded.

6.3.2 Why have physical exercise practices changed in the camp?

In the thematic analyses of the physical activity narratives, two major themes emerge: firstly the problems of exercising in the modern camp environment, and secondly, changing work practices, both for paid and unpaid areas of work. Both of these can be traced back to the Lebanese host community which does not give the refugees the same rights as its own citizens. The Palestinians have generally been physically very active through their usual daily activities and have not needed to add any other form of exercise to their lives to maintain good health. However, this pattern is now changing. At the same time, the physical environment of the camp has not been conducive to 'encouraging a culture of sport' to use the phrase of physiotherapists who work in the Lebanese community and also in the Palestinian camps (304, p. 6).

6.3.2.1 Work patterns

The diminishing availability of work has had significant impact on the physical activity of the refugees, because work has previously been the principal reason for their physical activity. Likewise, changes in the unpaid work of home management have affected the level of physical activity among women. These themes are illustrated in Figure 24.

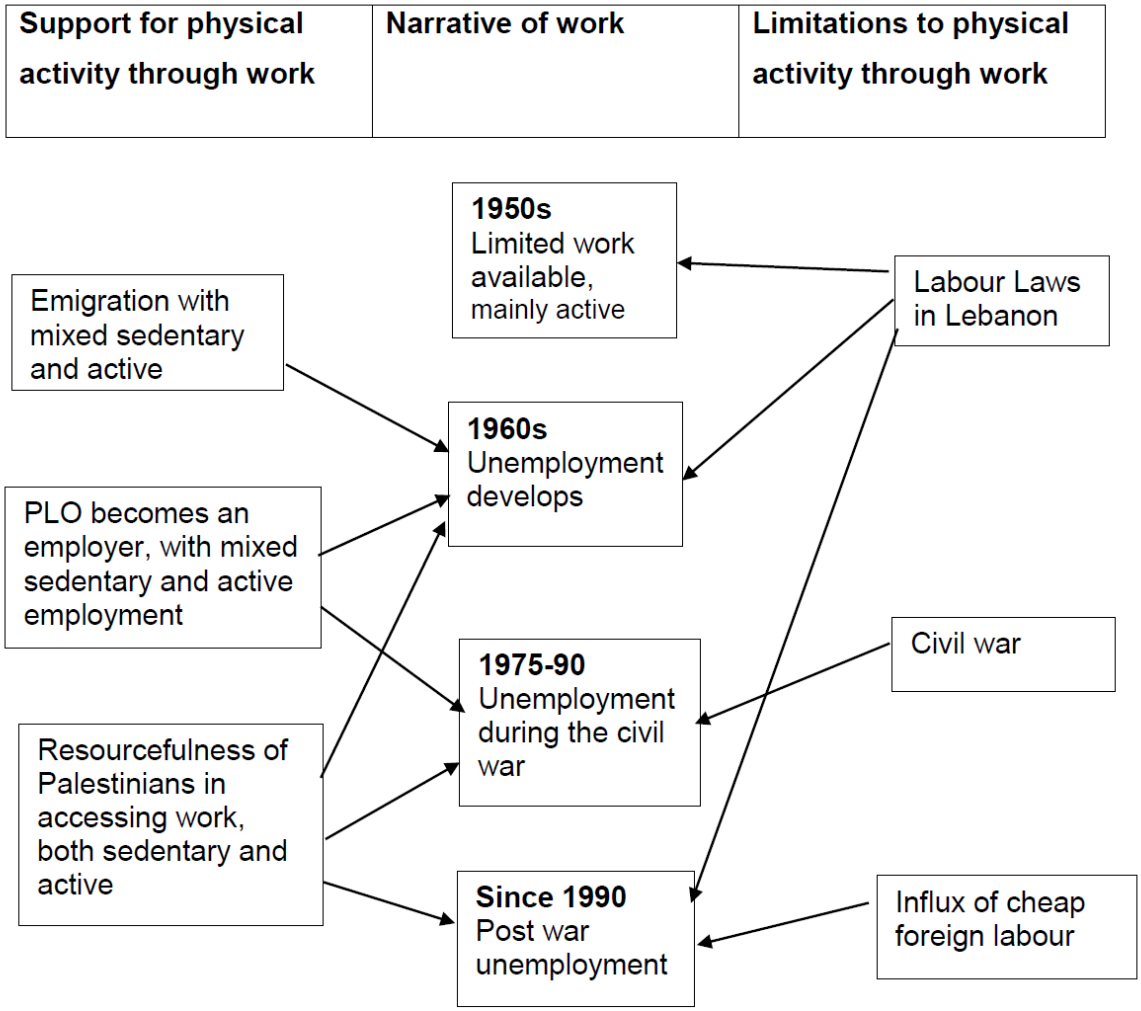

Figure 24: Diagrammatic summary of men's labour narrative and the influences which have shaped it

The Palestinians seem to have been able to find paid employment with relative ease in the first decade following the *Nakba*. Most work was in the less regulated areas, such as farming, building, domestic service, factory work and shop work — all requiring physical activity (but offering limited opportunities to them as stateless refugees). However, by the 1960s the older refugees start to mention chronic unemployment, as mentioned by the respondent whose husband 'hung [around] in the street' (107, p. 19). The narratives suggest that the post-civil war period was also characterized by unemployment, as suggested by the NGO worker who, unable to find work in the building industry, had moved into NGO work (405, p. 45). He considers that part of the problem in the post-war period was the influx of Syrian workers who came to work in the Lebanese building industry (405, p. 44). When physical activity has hitherto revolved around work, chronic unemployment means one becomes quite sedentary, failing the availability of suitable recreational activities.

The refugees reported using a range of strategies to maintain their incomes during times of unemployment, all of which have had contributed to a gradual decline of physical activity

connected with employment. A common strategy in the 1960s was to emigrate: those informants who migrated to other Arab countries tended to go temporarily and then return to the camp for a range of reasons. However, some have gained permanent settlement in Western countries and several informants mentioned family members living overseas. Those who migrated describe working in trades, similar to those in Lebanon: a butcher (118), a painter (116), a marble worker (111), and a plasterer (106).

> *I learnt how to become a wall smoother [plasterer] in that time. I had a chance to go to Qatar in 1956 in that time; I went and stayed one year and 16 days in Qatar. (106, p. 9)*

Some worked in more sedentary jobs, such as government employees (120). However, opportunities to travel abroad for work seem to have diminished since the 1990s, with some informants returning to Lebanon since the Iraq wars. One man recalls that he lost his job in the Emirates because he was a Palestinian in 1990, when Iraq invaded Kuwait (120, p. 17).

Several informants showed resourcefulness in obtaining work within Lebanon. For example, a man who had left school with no formal qualifications used certificates from a building engineering course when applying for an office manager's job (405, p. 45), while a woman described getting work in a home nursing program based on her training in first aid during the civil war and her care for a frail elderly mother (104, pp. 20–21). While the community nurse would have maintained a high level of physical activity, the office manager would have become more sedentary.

Although many respondents describe work involving physical activity, there is a general trend towards less physical activity, both from unemployment and from changing employment patterns. The challenges of getting any work at all are centred on Lebanese labour laws, mentioned by several NGO managers, which limit the type of work that the refugees can do 'And also, of course, the right to work… they are not able to work' (415, p. 2). In addition, there have been changes in the international political situation which has restricted their possibility of emigrating to obtain work.

Women's physical activity has also diminished, with the introduction of affordable labour-saving devices and products, including commercially-made bread, washing machines and piped water for all purposes except drinking. While some women have entered the workforce in a wide range of positions, including varying levels of physical activity, others at home have more time to socialise in what has been described as basically a sedentary lifestyle.

6.3.2.2 Physical environment

To repeat the words of a Lebanese physiotherapist who works in Bourj-el-Barajneh 'There is no culture of sport' (304, p. 6), and the data suggests she is correct in that in all the discussion of health, healthy behaviours, and chronic illnesses there is no mention of adult sport. Children

play, and adults work, and some old people take therapeutic exercise, but the only mention of sport is related to the school curriculum. Moreover, a problem identified by many informants, both from service providers and elderly refugees, is lack of space for children to play, and for elderly people to take therapeutic walks. This may be contributing to the lack of a 'culture of sport' developing at all age levels. There is no space. In considering this theme, I identified two problems: there is no open ground, and what space there is has known dangers. These factors are illustrated in Figure 25.

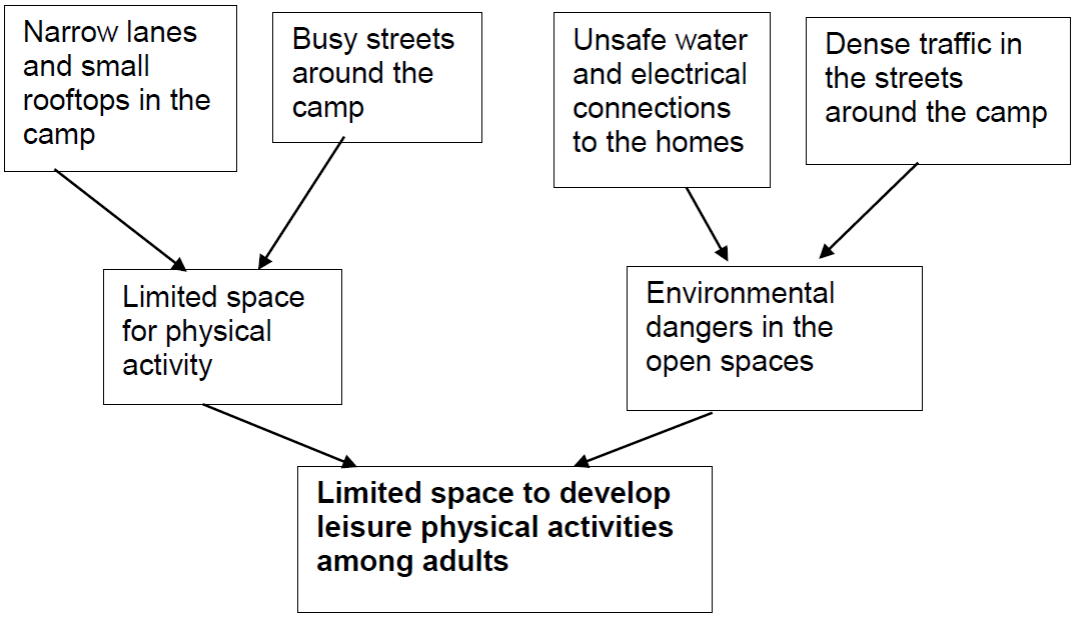

Figure 25: Summary of the environmental limitations to physical activity

In considering lack of space for physical activity, poverty has limited the ability of the refugees to move out of the camp into the Lebanese community and more recently there have been legal barriers preventing those with enough money from buying homes in Lebanon. This was explained to me by an NGO manager:

> *Informant* *But the right to own a property, they used to have it, but then it was taken away.*
>
> *Interviewer* *That was in 2001, or 2002 I think?*
>
> *Informant* *Yes. … When Prime Minister Hariri issued presidential decree… that Palestinians cannot own a property in Lebanon and they would be treated, you know …. That if you are carrying a nationality, or a passport of a very well-known country …. recognized country … you can own a property in Lebanon. But because of the Palestinians, they don't have a passport …. [issued by] a recognised government, or a recognised country, they cannot own a property.*
>
> *Interviewer* *Right, so …. the law doesn't specify that Palestinians can't own property?*
>
> *Informant* *Directly not, but indirectly they were implying. The only people who are not carrying [approved nationality] are the Israelis and the Palestinians. (415, pp. 2–4)*

We went on to discuss the implications of this to the camp community and environment.

Informant *Now the camps are more crowded, you know, it's so dark… the houses are so dark, overpopulated, no proper electricity, no proper sewerage, no proper water, you know all this… you know, it's… it's..*

Interviewer *Yes, do you think the crowding increased since….?*

Informant *Yes, of course… some of the young people they go to the Emirates and they work there so… So before, they used to come and invest and buy paying instalments — they used to buy small houses, you know in the vicinity of the camp, or outside Beirut and…. and improve the situation of his family, but now people are hesitant because you know, they cannot register it.*

Interviewer *What happened to the people that did own property? Do they still own it?*

Informant *They have some problems because some of them they paid a down payment and then they are paying monthly instalments and by the time they finish the… the… the cost of the apartment the loan was assured so they couldn't register. Now their apartments are in the name of the owners.*

Interviewer *Of the previous owner?*

Informant *The initial owner. So, we have lots of lender problems concerning [this]… and those who… who register their houses before they have a legal problem — if they die their heirs will not inherit. (415, pp. 4–6)*

With these concerns very few Palestinians can risk moving out of the camps, even if they can afford to live elsewhere, making the camps more overcrowded. Bourj-el-Barajneh was originally developed to house a few thousand people, as one of the NGO manager explained:

> *This camp when it was established in 1950 it was the basic of the houses were built for about 2 or 3000 population. Why now, it's about 18 or 19,000 and they still have the same [amount of]…. spaces (416, p.12)*

This population increase of the camp is multi-factorial. Firstly, there is a high birth rate, as mentioned by McCue who found that her informants saw children as a support in their old age, as well as contributing to the Palestinian causes (1994, p. 19). Secondly, there are fewer camps, as indicated by the elderly refugees who have moved to Bourj-el-Barajneh following the Tel-az-Zaatar massacre (101, 103, 123,). Initially, UNRWA established 15 camps and there are now only 12. Finally, some refugees have moved to the Beirut camps in search of work, including several informants (108, 112, 114, 117, 124). Thus more people are living in fewer camps. As the population has gradually increased, the amount of open space has diminished and numbers of houses has increased. An NGO manager described how houses had encroached on the pathways to increase available space:

> *This house was very small so they took part from outside [the pathway], the other 2 houses, again, like this house took from one side and this from that side so there is no path, you hardly walk in. ….. So they can give their children more rooms, (401, p. 16)*

The sand hill where it was reported that children played had disappeared by the 1970s, as illustrated by this archival photograph from the 1970s (Fig. 26).

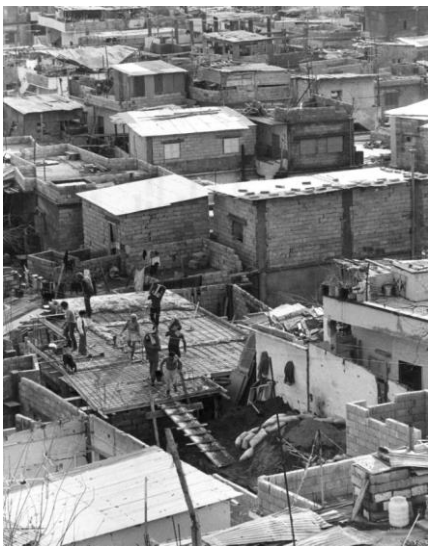

Figure 26: Building work in Bourj-el-Barajneh camp in the 1970s. (Courtesy of UNRWA photo archives)

The narrow alleys are all that is left for children to play in and of course there is no place for adults to exercise either, or to develop a 'culture of sport'.

In focus groups with people who provide health education we discussed therapeutic exercise for the elderly refugees. One group told me that some older people walked on the Airport Road, a major six-lane highway, with wide footpaths, but this became less popular following the injury of one person and the death of another in traffic accidents.

This raises another problem with exercising in the limited spaces available: there are significant environmental risks in and around the camp. I discussed the problems of electrocution from inadequate wiring with an NGO manager.

Informant	*Today a child killed by, was electrocuted.*
Interviewer	*Electrocuted! A child!*
Informant	*Yes.*
Interviewer	*What happened?*
Informant	*[I] didn't know the details. I heard it as I left to come here. They were taking him to the hospital, he died on the way. Around 1 pm.*
Interviewer	*Just touched something that was live? Or…?*
Informant	*Yes, of course, and a few months ago a woman died….. Recently we have had many of these incidents.*
Interviewer	*Yeah so it's becoming more [common]?*
Informant	*And it's not the electric items — it's the lines. (405, p. 38)*

In the photographic data elderly refugees identified the wiring as a concern. The photo below (Figure 27) was taken on the roof of the family home; it shows electrical wiring situated close to water pipes.

Figure 27: Taken by an elderly refugee on her family's roof, showing the dense network of electrical wiring and water piping (thicker black strands) (201, photograph 8)

The perceptions of the community are that nowhere is safe to exercise or play, which is predominantly responsible for the lack of sporting activity among adults.

6.3.3 Current trends in physical activity

While the narratives seen in the data suggest that there has been a general trend towards a more sedentary lifestyle, many people have remained physically active. There is less than half a kilometer of roads wide enough to drive a car within the one square mile of the camp, so people walk around the camp. Although water for household use is piped to homes, drinking water must be carried to the house, and also many people continue to work in physically demanding jobs. However, there is a general trend to less physically active work, and the opportunities to replace this with sport, or recreational activities is limited. The social experiences which result in slowly declining physical activity are charted in Figure 28.

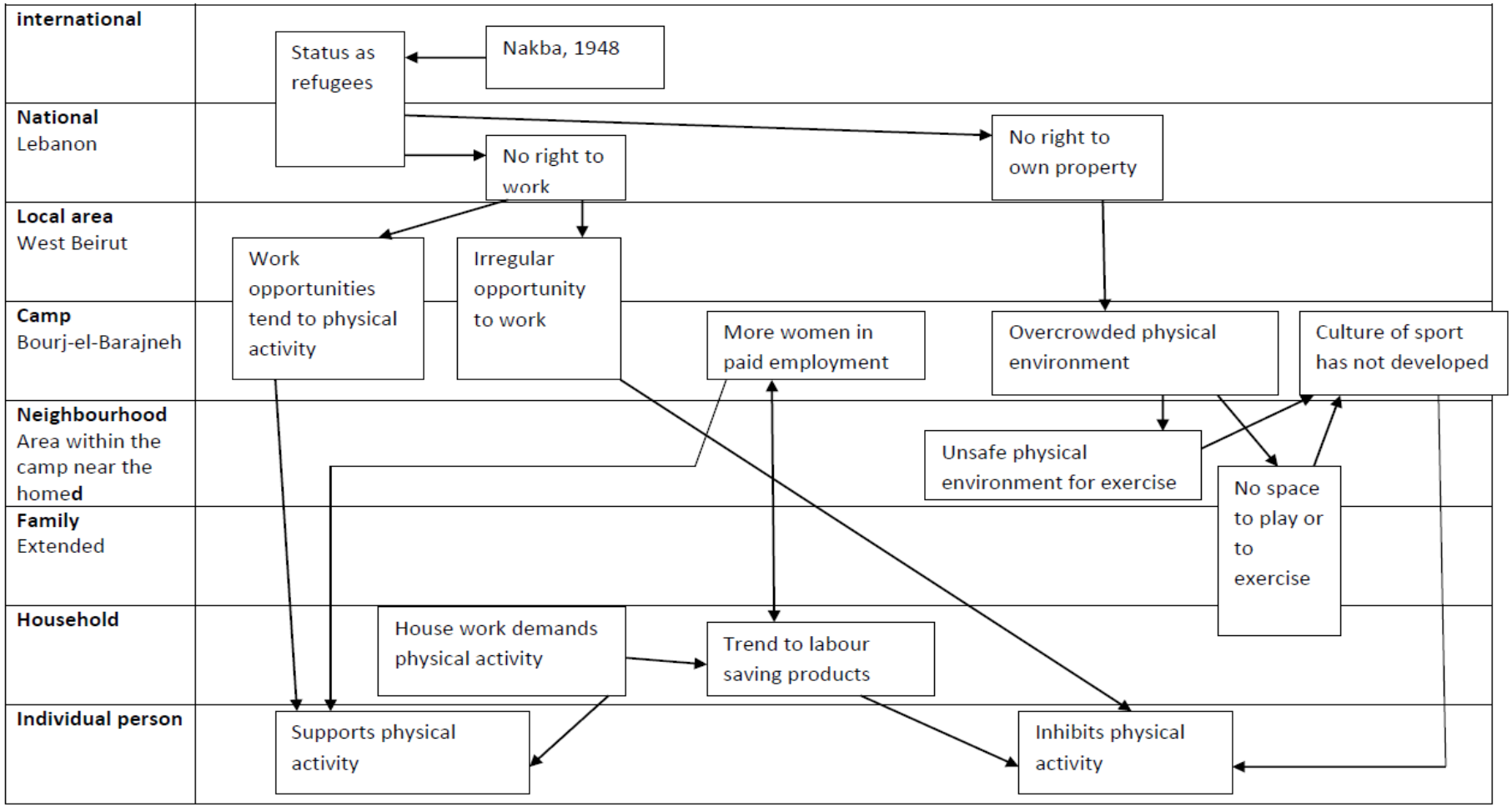

Figure 28: Connections between societal levels which affect physical activity

These factors have their roots in the ongoing refugee status of the community and in the Lebanese government's structural discrimination against Palestinian refugees. This is reflected in the employment policy which limits the availability and type of work. Secondly, property laws have affected the refugees' ability to leave the camp, leading to overcrowding.

6.4 Control over healthy behaviours

If we consider these three important health-related behavioural patterns — diet, smoking and physical activity — the impact of becoming a refugee, coupled with the host country's historical management of the refugees, has made healthy behaviour difficult, if not impossible. The impact of periods of war within the host country has also had severe impacts on the refugees, and probably also the local population, undermining their ability to make healthy lifestyle choices. These national and international factors are mediated through endemic poverty and related emotional and psychological factors, which will directly affect health as the refugee individual ages. This picture differs from analyses undertaken using Krieger's ecosocial model in the US; therefore in the next chapter I will consider how this ecosocial model may be adapted to the data analysis of the present study.

7
HEALTH IN BOURJ-EL-BARAJNEH CAMP AND THE ECOSOCIAL MODEL

This chapter analyses how the behavioural narratives and the pathways of diet, smoking and physical activity which link life experiences with these behaviours relate to Krieger's ecosocial model. I have considered the pathways of embodiment outlined in Chapter 6, including emotional and psychological links, poverty and equity links, and social and physical environmental links. I now turn to the identification of Krieger's 'spiders' — agents that have contributed to creating this web of connections which predict the lifetime health outcomes of the refugees in Bourj-el-Barajneh. While Krieger identifies the inequities of class, race and gender as societal divisons and historical realities which define the community, these did not entirely fit this case study, and so I will discuss how these could be modified and added to. I conclude by proposing a modified form of Krieger's ecosocial model, one that describes the community I have studied, and that could be modified to fit other communities using as needed.

7.1 The common threads which link life experiences to individual behaviours

As discussed in Chapter 2, behaviours account for only about 50% of chronic health problems (Syme 1994, p. 81), and many social determinants appear to account for the balance of causation, along with biological determinants (Krieger 1994, p. 896). The narratives I have presented in the previous chapter identify several common threads, some of which are specific to a single narrative while others cover more than one. Stress, poverty and the environment, both social and physical, were identified as common pathways in many narratives.

7.1.1 Chronic stress, depression and anxiety: emotional and psychological threads that link the narratives

There is a body of literature which considers the impact of stress on health in general and on the chronic illnesses of old age. There is also a developing body of knowledge which looks at the psychological sequelae of traumatic experiences, including war. These have been discussed in Chapter 3. This study methodology is not designed to add to the knowledge of how emotional and psychological factors effect health, but rather looks at which life experiences affect emotional and psychological wellbeing.

The narratives presented in Chapter 6 consider emotional and psychological health in various contexts; for example, people discussed using smoking as a method of managing stress and trauma. Also, in the dietary narratives, we saw that social gatherings were usually conducted with coffee, sweets, and tobacco as social lubricants —another way of managing stress.

Many elderly refugees discussed their emotional and psychological health, and service providers also discussed these problems and the paucity of services to support them. The literature outlined in Chapter 2 suggests that the Palestinians have a higher incidence of mental health problems than other local communities, although these studies did not reveal details of the types of illnesses (Ugland 2003; Lemire, Dubois-Rondon et al. 2004; Saab, Salem et al. 2005; Chaaya, Mehio-Sibai et al. 2007). However, since data collection in 2009, a health service has been established by Médecins Sans Frontières (MSF). The local manager shared their first three trimester reports for 2010 with me. In terms of mental health, the most common diagnosis was depression, seen in between 24% and 60% of new patients seen in each trimester. The report for the second trimester identified, in descending order, depression, anxiety, psychosis, substance abuse, adjustment disorders, bipolar disorders and somatoform conditions as the conditions treated. These reports suggest that there is a wide range of mental health problems, with depression and anxiety being the most common (MSF Switzerland 2010).

The literature identifies psychological and emotional problems as affecting health outcomes causally, both directly through stress hormones and neuro-transmitters and indirectly, through behaviour changes (McEwen 2004; Chandola, Britton et al. 2008; Abraham, Brunner et al. 2007). Several studies of refugees have identified links between chronic illness in elderly people, mental health, and experience of war situations; however, the findings from studies so far undertaken are not conclusive in identifying causation or pathways. For example, Muhtz and colleagues (2011) studied the association between traumatic stress and physical disease in elderly ex-refugees and found that PTSD was not a mediating mechanism. In a longitudinal study Mollica and colleagues (2001) considered both PTSD and depression as well as mortality, disability and emigration. They found a weak link between mortality and depression, but none between PTSD and mortality. However, the relatively low numbers of deaths in the sample suggests that further research is needed to fully understand the phenomenon.

In considering the information from the MSF reports together with my own qualitative data, it is clear that high levels of depression and anxiety, are common in Bourj-el-Barajneh camp. Both the clinicians and the older refugees link this phenomenon to chronic physical illness, and the literature concurs. For example, as already mentioned (section 6.2.3.1) one informant's lay knowledge of her own experience refers to this phenomenon by specifically linking her development of diabetes to the sadness and grief following the sieges during which several relatives were killed, rather than to the traumatic events themselves (some of which she also described) (104, p. 30). Another woman commented that her blood pressure rose whenever there were political problems in the camp community, as she was fearful of how they could develop and whether she would need to flee once again (109, p. 27).

While problems relating to poor physical environment will be discussed in section 7.1.1.3, it is clear that some aspects of the physical environment affect anxiety. Both NGO staff and local people discussed their fear that the buildings may not be safely constructed. One elderly refugee described being unable to work following the collapse of the roof of his home, in which he received a head injury. I had carried out this interview with the help of an interpreter, who lived about a quarter of a kilometre from the informant. She explained:

> *He said that it's true because, for both... because it was difficult to find a job, and also because he has pain in his back, and also the ceiling of his house fell on his head and he lost the sight of his eyes. Because I remember his story. (116, p. 12)*

Not only was this man seriously injured by the collapse of his home, but the story was remembered in the neighbourhood several years after the event. Likewise, the discussions about electrocutions from poor wiring appear to be generally known and recalled, with some anxiety (405, p. 38).

Another cause of anxiety which arose from the data was the possibility of a new outbreak of war, with its attendant destruction of property and loss of the necessities of life. I interviewed a woman whose home and all her possessions had been destroyed in the early 70s, when she lived in a camp near Tyre. The family moved to Chatilla camp, where she was injured while running away during the massacre of 1982. Her home in Chatilla was burned during the siege of that camp in the late 1980s. At that time her husband retired, and they bought a small apartment close to Bourj-el-Barajneh camp with his retirement money. However, in 2006 this area was heavily bombed in the Summer War, and she again had to leave everything and run, though luckily her building sustained only slight damage. When I asked her how this had felt, she replied (through the interpreter):

> *It's difficult but we can't do anything. What can we do? [Arabic Informant] …nothing is better. We have to live this life. (108, p. 19)*

While this woman's story recounts involvement in multiple episodes of war, losing her property several times, most people interviewed had first-hand experience of at least one war situation; only those who had spent time working outside Lebanon had avoided experiences such as these.

One informant, who has lived much of her life in the camp, and now manages an NGO described her personal concept of stress, as seen through her own professional and personal experiences. She talks about two related groups of stressors: one is related to the international political situation for Palestinians — fear of future wars, fear about what will happen to the camps, fear that they will be further displaced, fear for the fate of Palestinians around the world. The second group of stressors relates to the immediate life situation: will they have enough money if they get sick? Will their home flood or leak when it rains? Will they be able to find work? (401, pp. 9–12).

This model has similarities to Miller and Rasmussen's model which identifies contributions to mental health problems during an armed conflict (Figure 29):

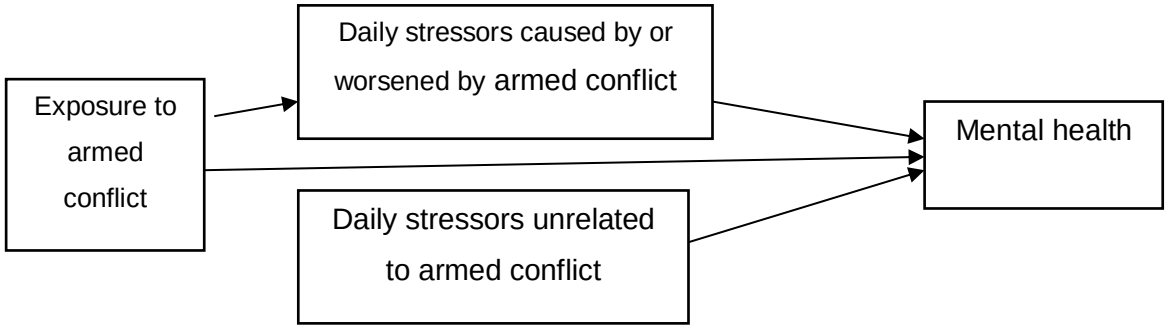

Figure 29: Daily stressors, partially mediating the relationship of armed conflict to mental health and psychosocial status (Miller and Rasmussen, 2010, p. 9)

My informant appears to have combined the first and third arm of Miller and Rasmussen's model, where daily life stresses are exacerbated by exposure to war. This may be because her whole experience of life has been shaped by war, added to the unusual stresses caused by spending her everyday life as a refugee. Life in increasingly overcrowded camps, limited employment opportunities are all experienced in the context of war: for the refugees in Bourj-el-Barajneh camp, all their experiences seem to be related to their and their ancestors' exposure to war.

Others, who were involved in actual warfare, discussed the acute stress of being under attack as a transient feeling, and they do not relate it to stress or ongoing anxiety:

> *… there was a lot of frighten and horrify, but there was contentment, and by the way, we didn't think about the money; we ate normally, we didn't care for money or anything — believe me we didn't because we had contentment that we are working for real. I swear, once I wanted to bring food for my mother and the missiles were falling in front of me and behind me, and the people in the office were screaming at me to come back. I told them [that] my mother is alone in the house and who knows what happened to her. (104, p.19)*

Although frightening and distressing events happened, there was action and community support to help resolve the stress of such events; this is not McEwen's chronic stress, but acute stress which occurs and is then resolved.

Thus emotional and psychological wellbeing is constituted by a wide range of factors, including those discussed in the narratives, where smoking and socialising are used to manage extreme and daily stressors, which include the poor quality of the built environment, fear of violence, both externally imposed war and internal disputes which may be resolved with violence, fear of financial problems and many others.

7.1.2 Poverty

Poverty was identified as one of the factors which limited the ability of the refugees to buy food for a healthy diet, and the limitations to the right to work have been discussed as a contributing factor, as has the loss of property at the time that the people became refugees. However, the narratives around poverty are more complex than others discussed in these thematic analyses. As the UNRWA officer for social services in the Lebanon field, Mrs. Leila Kaissi, explained, poverty relates to both income and expenditure. She told me about their new method of identifying refugee families needing assistance:

> *Interviewer* *What sort of socioeconomic variables will you use to identify people who need to be involved in the safety net?*
>
> *Informant* *We ask questions first, about the, the home, the house, the dwelling — the condition of the house, lighting, all the specifics, then we ask questions about the, specifically about the family members, and part of them it will be, it would be like, it would be education level; then we have the health, health status also. Of course we already have all of these items in our records, but these [questions] are more detailed. We asked about the employment, if they are working, currently or they are not working, these are specific questions about the individual, all of the individuals. And then we have a question about expenditure; so now we introduce, which we didn't have before, we have introduced a whole set of expenditure, what does this family spend its money on, do they spend, do they spend the money, how much you're spending per month, on, on, food, on health. (410, p. 1)*

Refugees identified reduction of service provision by UNRWA as a cause of increasing poverty. As discussed in the dietary narrative, in the early days rations were provided to all refugees by UNRWA; this practice has been cut back, so that now rations are provided only to those considered to be special hardship cases (410, pp. 2–3, 125, p. 8). As Mrs. Kaissi explained (410, pp. 1–3), UNRWA was in the process of changing at the time of data collection from an assessment of special needs (based on whether a family included a wage earner) to an assessment of poverty based on both income and expenditure, thus including the working poor (UNRWA 2009). However, as this system was in the process of introduction, informants could only discuss the old system. The earlier move from universal rations to limited rations added to the burden of household expenditure, as provision of the basic staple foods ceased for most families.

A more serious reduction in services has been the reduction in the provision of universal free-at-the-the-point-of-delivery healthcare services. UNRWA continues to provide free primary health clinics in the camps and at several gatherings. However, there has been reduced support for tertiary services (hospital and specialist services), which may cost refugee families several thousand dollars.

Medical fees used to be covered by UNRWA, but in recent years the budget is not available. This reduction of services was illustrated by an elderly refugee woman's story. She recalls her first total hip replacement was covered by UNRWA (102, p. 21), but it now needs revision and she cannot afford it:

I broke my hip badly when I was a child. …. When I got older, the bones were damaged... and they change it with an artificial hip. I have been suffering for 19 years now. I am suffering from it and I had to change it 9 years ago but I don't have the money to change it. (102 pp .2-3)

She later goes on to discuss the expenses of this surgery:

I did two operations on UNRWA'S expense; each operation's cost was seven million L.L; no-one ever told me pay a penny. (102, p. 21)

In the past UNRWA paid for treatments such as total hip replacement, but now they do not, leaving the cost payable by the patients. Thus there is a fear of getting sick and needing treatment which is beyond the family budget:

I discussed the services provided by UNRWA with the director of health services in the Lebanon field, Dr Yusif:

Dr Yusif *And if the patient needs, for example, have surgery, he is referred to the governmental hospital…. the Ministry of health rate for heart surgery, open-heart surgery, is $6000. We have agreed with the hospitals to have a discount, and we have this operation done at this hospital, for $5400.*

Interviewer *So that is 10% discount?*

Dr. Yusif *10% discount. And other hospitals we have less than that even. But we couldn't get more than this with the hospital. We will try this, this year.*

Interviewer *Right, now who, who actually pays that?*

Dr. Yusif. *Then it is $5000 for open-heart, and we discriminate on age lines; that's because of, err, limited funds. Because those below 60 are earners, and then our contribution is $3000 out of the $5000, which means 60% of the total. For those over 60 our contribution is half of that amount. It's a problem of funding.*

With this example, the refugees have to find either US$2,000, if they are under 60 years old, or US$3,500 if they are older than 60. De Yusif appears to be saying that the donors to UNRWA do not contribute sufficient funds to cover the more expensive treatments. The question then arises, how do the refugees raise this money? Several NGOs and political parties provide small contributions in the order of 10% of the costs (414, 423, and 424); however, some, such as the lady needing a total hip replacement, go without treatment because the family cannot afford the balance.

How these extra expenses are covered was discussed by some elderly refugees. For example, an older man, living with a daughter, but unable to work himself, described how they manage:

Interviewer *Who secures the house expenses?*

Informant *Expenses? Thank God your aunt works and helps us and your uncles send me money from Germany. (103, p. 9)*

Another older couple live in their own home, but rely on family for day-to-day expenses.

My son who secures the house expenses because my husband doesn't work. He is in his 60s; no one hires him now. If it wasn't for my son… he has two houses to support, yes; I don't have anyone but him. (112, p. 19)

An NGO manager who lived in Bourj-ell-Barajneh for most of her life went into more detail about how people managed expenses in the past:

> *[It was the] early 90s when everything in the Palestinian community started to collapse; what I mean like the UNRWA — they had very limited services before [but then] Palestinians were provided, all Palestinians, not just hardship cases, with monthly packages of food. …. Also when PLO was in Lebanon …it's a military and political body, but actually they have other departments — they have social department where many people they have pensions, a type of pension. We had education department, we had ….. So at least there were job opportunities more for people within the Palestinian workforce and there was like some sort of social support like pensions and medical support with PRCS. So all of this collapsed after 82, and after the camps, [the War of the Camps] … and COMPLETELY after the Oslo Accords. …. So after 82, it's true that PLO [pulled out], … but at least people still had something from the past, you know, maybe some of them saved some money …. but for how long you will be able to …… But everything has gone and people economically they were…they are gone. (401, p. 12)*

Thus now people rely on family networks, including expatriate family members, whereas in the past they had savings from better times, which have now gone.

This burden of expenses also has its effect on community cohesion and emotional wellbeing of family members. The person unable to pay for services has to ask several organisations for help, and they have to know which organisations have funds to help, and in some cases may need contacts within those organisations. They may also need to rely on family, friends or acquaintances to meet the shortfall. Allen addresses these problems in her work in Chatilla camp, highlighting the stresses and strains on family relationships because of the need to beg from so many sources (Allan 2014, pp. 69–71).

Thus poverty for the families of the camp has increased because there is under-employment and unemployment, and because expenses are increasing at the same time as UNRWA services are being reduced. This causes anxiety among families trying to cover unexpected costs, contributing to the mental health problems of the community.

7.1.3 Physical environment

The disadvantages of the physical environment were discussed in relationship to their impact on exercise (section 6.3) and mental health (section 7.1.1); however, informants also identified environmental conditions as a primary contributor to poor physical health. As already discussed in section 6.4.2.2, the camp has become overcrowded, with narrow alleys, leaving little space for exercise. Buildings are multi-storied, rising from two to five stories above the alleys, giving poor access to light for the lower floors. The crowded nature of the camp can be seen from the Google Earth aerial photographs of the camp below (Fig 30):

Figure 30: Aerial photograph of Bourj-al-Barajneh camp, taken from Google Earth. The camp can be differentiated from the surrounding suburbs by the small crammed houses, with few streets visible.

The darkness and dampness of these streets can be seen in some of the photographs taken by the elderly refugees (Fig. 31):

Figure 31: A pathway in the camp photographed by an elderly refugee (204, photo 15)

This means that homes on the lower floors will have little natural light or ventilation. A European who had worked and lived in several camps as a health volunteer recalled living in such homes:

> *The bad air circulation, within the camp, definitely. I mean when you walk through the small alley as you feel that is not much air coming through, and circulating around. For this I believe could lead to chronic illness, and the bad quality of the water is part of the pollution as well. In general the pollution in Lebanon, but that's Lebanon, but [pollution is] even worse with the lack of air circulation ….I remember I was sick nonstop. As well what I thought was that I was living in Bourj myself, it seems like, the bad, the quality of the houses. I remember the walls were … they were wet, not* ***wet*** *wet, but it was all a bit like, do you say clammy, and the clothes as well. (431, p. 9)*

An elderly refugee talked about the disadvantages of living in the camp:

Informant. *Its disadvantages are the rats and the smell of the sewers. Nothing is perfect, what can we do?*

Interviewer *It has many disadvantages; the electricity goes off a lot, salty water.*

Informant *Yes, the electricity goes off and the water is salty, the people's hair is falling down but we heard that the salty water is good, why it is doing this? I noticed this here, in my hair, yesterday (113, pp. 48-49)*

The sewerage system was discussed by several elderly refugees who recall the early days before piped sewerage was installed, and they believe that the underground sewers encourage vermin:

> *Sewers are full of dirt and cockroaches come out and rats. … In the beginning, we dig in the ground, everyone has his own sewer in front of his house and put his water inside it but now it smells very bad in the camp and it floats down in Tarshiha [area in the camp] area and enters the houses (110, pp. 28-29)*

Thus both vermin and smells have been attributed to the closely packed buildings and overcrowding of the camps, and while the nineteenth-century miasma theory of disease is no longer considered valid (Baum 2008, p. 20), bad odours are an indicator of environmental problems which may affect health and which indicate significant overcrowding, poorly ventilated homes and other risk factors for poor health outcomes (Zabaneh, Watt et al. 2008).

7.1.4 Social environment

The social environment of Bourj-el-Barajneh camp was discussed in the smoking and dietary analyses, suggesting that people placed value on maintaining both family and neighborhood social networks, and that they saw these as being important to health and wellbeing. Those who come to the camp to work in their adult years, both foreign and Palestinian, commented on the strong social networks, into which they are often invited.

The nature of the family includes both the nuclear family, living in a single home, and the extended family, which may live close by in the same neighbourhood, or may have emigrated to other countries. One informant, who has evaluated several projects, suggested that the family unit was pivotal to the camp's social structure:

> *Look at the family and the social unit. The social unit in our society is not the individual; the social unit is the family, is the household, those [who] are living together. So, so even the individual behaviour is linked to [wider behaviours] … , to a great extent, by this social network that the individual is embedded in (413, p. 12)*

This is seen in the data; for example, when elderly people avoid family disruption by eating the food prepared for the family rather than suggesting the whole family eat their 'special diet' for diabetes or hypertension (309, p. 5). It is also observed in the man who continued to use smoking as a method of stress management rather than be so stressed that he would be violent to his children, despite understanding that smoking would harm his health. (124, pp. 27–28).

However, though there are negative aspects of these close nuclear family responsibilities, the wider extended family supports people both practically and emotionally. One elderly refugee

took several photographs of his recently widowed son-in-law and his family, who had come to visit from Europe; the family had spent time together discussing old times and grieving for their dead daughter/wife (focus group of photographic activity, p. 3). The informant specifically mentioned both his pleasure that his son-in-law still wanted to visit, and the pleasure of having a memento of that visit. Financial support is common from extended family who live overseas (103, p. 9), and may be expected by the family, as explained by this older woman, through an interpreter:

> *She (the informant's mother-in-law) kicked them out (of her home) because they didn't have money. I said 'Listen, for how long you stayed in Libya?' She said 30 years', I said 'For 30 years you didn't save any money?' She said 'No. What they were earning they were spending it in Libya.' (125, p. 25)*

The mother-in-law had expected the family to have saved enough money to support her as well as themselves, and she was so angry that they had not that she would not give them any accommodation. However, this story seems to have been the exception; most extended families who are able to assist financially do so, and relatives expressed gratitude rather than seeing it as an expectation.

Family connections outweigh other loyalties. A man involved in the fighting between Palestinian factions in 1988 describes how he surrendered, with the help of a cousin.

> *My cousin, he was in the PFLP [a pro-Syrian faction of the PLO] and he convinced us that he can manage, like a safe leave for us, without being detained by Fatah-pro-Syria. And he managed; he took us from the graveyard [at the edge of the camp] … and he took us [to their headquarters]. They had a short talk with us. (405, p. 27)*

When the interrogators wanted to send the man on to Syrian authorities, the cousin refused, saying he would return his relatives to the camp:

> *….. He said, he told me, if you want to go further out, like interrogation I will take them back, to the camp. He warned them (405, p. 27)*

Thus family connections in this case outweighed both political loyalty and military discipline.

Social networks go beyond the extended family and include neighbours and friends, as well as the extended family. The NGO workers working in the camp, but not born into the camp community commented on this. For example, this lady has developed aged care centers in several camps and recalls:

> *I was walking to the centre; just one of the last turns you take there is this little grocer on the right. I walked in the other day and wanted to buy a pack of biscuits; he didn't allow me to pay because he recognised... I mean, can you imagine what that means? … That's not going to happen anywhere else.(426, p. 38)*

Another informant believed the community has developed social skills which have enabled them to live and support each other in difficult situations:

> We were always wondering … [why] nothing was, was breaking out actually, I mean how can you keep people like that in a cage for years and generations, and [expect them] … they still stay like that? So there's always something. When I say I think it was passive and people like feel helpless, that's definitely a point, but as well as, like, this is kind of like social skills — they stick together, and that's very close family, social network which is a great resource as well when it comes to mental health. Or like health issues [long pause] yes definitely. *(431, p. 11)*

Many informants who have lived in the camp for much of their lives, however, feel that these social networks are breaking down. They recall in the past a greater sense of community cohesion. For example, an NGO manager remembers her home in the 1960s and 1970s:

> *I*n my house, my dad used to make coffee and the men from the camp used to come, sit and talk, they were many about 60 or 70 men and some used to sit on the stairs because they were many — this is of course after finishing their work — and stay till midnight or 1 am (401, p. 5)

She also recalls:

> *If someone had a funeral, they would all go, and the same for the wedding, but of course who knew about it, but all the camp respected each other, no difference among people. (401, p.5)*

An older informant told us, through an interpreter, that she went on trips:

> *We had time for everything, for picnics, for outdoor trips, if someone is … [Informant interrupts], Sunday was for going out. If someone is sick they were seeing him, if there is funeral they go; if there is a wedding, they [would] go. So the Sunday was for them, not for work. (114, p.15)*

However, people said that this closeness and social interaction was less prevalent now than in the past:

> *Our house was from zinco boards and we had a tree, but the life was very innocent and beautiful; it's true that [the house] it was zinco, rain, it was raining on us and we were hearing the sound of the rain, but our life was very innocent; the people were liking each other, at that time, that's how I recognized people were visiting each other, but now the situation is different (119, p. 3)*

Having heard similar stories from several informants, I asked the PEER interviewers to explore this perceived change further. A wide range of reasons for the reduction in social cohesion were identified, including overcrowding and lack of privacy.

> *The houses were … far away from each other so each house [had] its own* privacy …. while here the neighbours *are very close to each other, so they hear each other. … So that's why the life here is not that good. (124, p.15)*

Another woman suggests that the growing incidence of those with power and those without in the camp community has led to problems, and described a confrontation she saw her son have.

> *So her son told him 'It's not allowed for you to go [in], it's my house', so he hit him. Because he's got a high position in the camp he said, 'I can go where ever I want; it's none of your business.' So [the son told] him, 'No, it's my house and it's not allowed for you [to enter].' (125, p. 28)*

This confrontation resulted in the death of the woman's son. Though the man with the 'high position' and his family were ultimately 'kicked out of the camp' (125, p. 29) this story suggests the development of a hierarchy which some of the more powerful may attempt to use to their advantage. Another, but related, concept is that some have more money than others, while in

the past that was less obvious. With the risks of large bills for hospitalisation or education of children, it becomes more difficult to share.

Interviewer *What do you think changed the people, because many people are saying that there was love before?*

Informant *There was poverty; there wasn't money like today.*

Interviewer *What changed the people's personalities?*

Informant *Some people were poor and Allah gave them [provided for them].*

Interviewer *Allah is the one who gives.*

Informant *And some people, when Allah gives them [money], they become snooty, you can't talk to them.*

Interviewer *The problem is that the whole people are saying the same thing that in the past they were something, love and help. Now you see [how the people are]. … What do you think the reason is?*

Informant *The reason is the increase in money; only, the increase of money, the people will become snooty.*

Interviewer *Can we say that there are rich people in the camp?*

Informant *How?*

Interviewer *Are there rich people in the camp?*

Informant *Yes, they are some people whose situation is better than the other, How? Some people has better situation than the others.*

Interviewer *So do you think money is the reason that people have changed?*

Informant *Yes, [that's] right. (117, pp.28–29)*

A final idea, suggested by several people, was that people's emotional and psychological feelings were making them less able to be supportive to their neighbours.

Informant *No one responds to the other. The people used to visit each other but not anymore.*

Interviewer *Why do you think so?*

Informant *I don't know. The people are apart from each other. Despair, the people are depressed. This one is sick, [this one] poor or someone has died. This is how the people are. (107, p.33)*

The problems of depression and despair have already been discussed in section 7.1.1, and their effects on health have been discussed in Chapter 6; however, their effect on the social cohesion of the camp community can also be seen.

While many informants discussed increasing lack of social cohesion, some did discuss social activities which supported their neighbours and friends. A man who spends time in the mosque also provides social support, such as visiting sick people or visiting the hospital:

I thought I was the only one who helped the others and I found that there are other people help in many things, like, if someone is sick or he has something wrong, they will help him. (106, p. 27)

A woman who had moved to the camp following a divorce found the social structure supportive:

I have been divorced for seven years from my man. I came here and found the society; there are religious lessons that a person can go and have fun. I can visit a sick person; I participate in a funeral; I go and visit my relatives (109, p.14)

Despite the reduced social cohesion in recent years, such cohesion remains stronger than in many communities, as indicated by the comments of non-residents of the camp who see it with

outsiders' eyes. As discussed in the narratives on diet (6.2.) and smoking (6.3.), this sense of communal cohesion has provided emotional support to people, but has also shaped their behaviours in ways which may be less healthy.

The sense of community extends beyond the camp, both to the extended family and to Palestinians generally. At times this has added to their emotional distress when other Palestinians are at risk. For example, there had been fighting in Gaza before I started collecting data, and one of the managers of a local NGO, as well as a focus group of health educators both raised this subject; they believed the conflict caused the people they served increased anxiety (401, supplementary interview, pp. 4–5 and 308, p. 4). In addition, both expressed a belief that the communal feeling of helplessness and political abandonment as Palestinians was unhealthy.

7.1.5 Societal and ecological levels

As Krieger suggests, there is not a sequential series of factors which trigger the embodiment of poor mental and physical wellbeing from one societal or ecological level to the next, through each of the intervening societal or ecological levels (Krieger 2008, p. 223). For the refugees, the decisions made by the United Nations (global level) regarding the Palestinian Mandate in 1948 (national level) had direct effects on each individual's wellbeing. The subsequent first Arab–Israeli war, also called the *Nakba* (national level), saw them exposed to the loss of property, poverty, the deaths of family members (family level), and the associated anxiety and depression (108, p. 6) which some recalled either in themselves or in close relatives. Similarly, the Lebanese Civil War (national level) saw loss of property, increased poverty, the experience of traumatic events (104, p. 15; 405, pp. 24–26; and 405, pp. 29–30), and the destabilization of the PLO and its civil society structures, including provision of pensions and jobs. This latter change will be examined further in Chapter 8. In addition, the problems of providing the essentials of life when, as stateless people (national level), they are not permitted to work other than in low-paid jobs, adds to chronic stress and depression (415, pp. 49–50), and contributes to poorer physical health. The lack of resolution to their refugee status, combined with the Lebanese government's discriminatory laws (national level) have contributed directly to their psychological and emotional health, and to their health in old age. The right to work is considered one of the basic human rights as outlined in the Universal Declaration of Human Rights (Article 23), as is the right to citizenship (Article 15, United Nations 1948) Here both international and national policies are impacting directly on individuals and through the individual on their families. The camp community as a whole represents a very poor community of individuals who are disadvantaged by their own poverty and by constantly seeing the same situation all around them.

Thus Krieger's argument, that the societal and ecological levels which are removed from the individual (referred to by many as 'upstream' or 'distal') can directly impact on the individual (Krieger 2008), is well illustrated in this case study.

7.2 The spiders in the web

In section 7.1 I considered in greater depth some of the community characteristics which have been further expounded in the narratives and thematic analyses, shaping the pathways which link the societal and ecological levels with the health outcomes of the individuals in the camp community. However, Krieger's ecosocial model (Fig.32) looks specifically for both accountability and agency. Within this model Krieger identifies three prime inequities; namely, racial or ethnic, gender and class. As discussed in Chapter 3, these inequities especially fit the situation in the US where the model was developed. The model has often been used as a research tool (Zierler & Krieger 1997; Levins & Lopez 1999; Krieger & Higgins 2002; Krieger 2005; Rodrigo & Rajapakse 2009; Schensul & Trickett 2009). However, in terms of my own data analysis the model's parameters do not fit so well with an Arab refugee population, such as Bourj-el-Barajneh camp. So, having considered my suite of narratives that cover the lifetimes of the refugees and having also considered the interconnected themes which emerged from their stories, it is time to look for 'the spider in this web of causation', to use Krieger's metaphor (Krieger 1994).

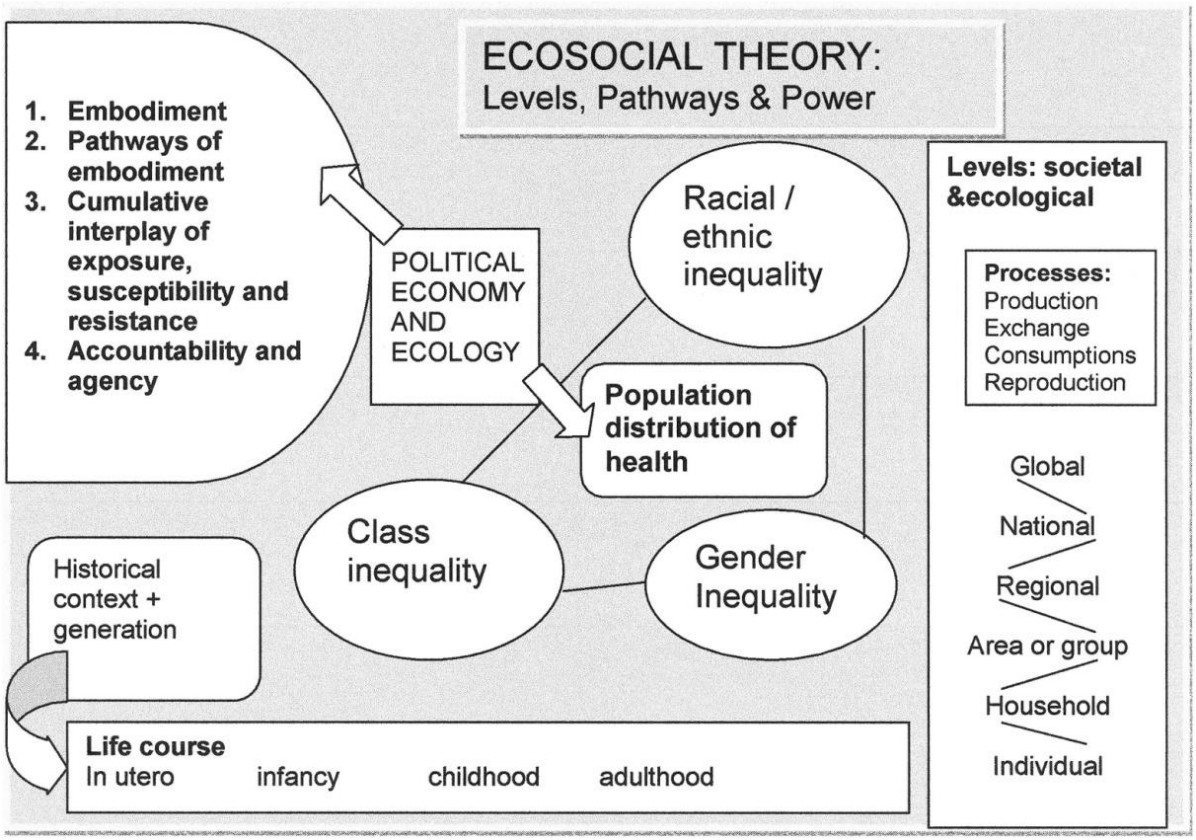

Figure 32: Diagrammatic representation of Krieger's ecosocial model (Krieger 2008, p. 224)

In the following section I will consider how well the model applies, and specifically how applicable these societal divisions and historical experiences are in this case study and also extrapolate any other core experiences which emerged from the data analysis or from the literature on Palestinians.

7.2.1 Class Inequality

The Palestinian society traditionally had a class structure, described by Fleischmann (2003, pp. 25–27) in her history of political activism of women during the Mandate, and Davis (2011) in her work on Palestinian village histories. Both authors describe a small, land-owning upper class, with a much larger poor and ill-educated peasant or urban community. Fleischmann also describes a middle class which consists of professional people and merchants and small manufacturers.

Treatment of refugees varies from class to class among Palestinians who fled to Lebanon once they arrived. For example, Edward Said (Said 1999, p. 269) describes his father's position in old age. Displaced from both Palestine (the country of his birth) and Egypt (the country of his working life), he settled in a mountain community near Beirut. According to both Said's biography (Said 1999) and his sister's family history (Makdasi 2005) the family connections to

Lebanon were extensive. Not only was Mrs Said (senior) matrilineally descended from a Lebanese family, but both Edward Said and Jean Makdasi married Lebanese citizens; yet the father remained an outsider in the wider Lebanese community. Similarly, among my informants from the NGO community, I interviewed several people who considered themselves Palestinians, although they held Lebanese nationality. These people described acquiring citizenship through their business skills and money (426), being born into prestigious upper-class families (413) or through marriage to a Lebanese (415 and 420). However, they continued to identify with Palestine and to work with the poor of the Palestinian community. This solidarity, along with comments such as Said's, suggests that social discrimination against the refugees is not limited to the poor living in camps and gatherings, but extends to all Palestinians, even after they have been granted Lebanese citizenship. This complex amalgamation of people identifying as Palestinian was described by Rubenberg as 'poverty-stricken refugees living in camps, middle class bureaucrats, intellectuals and dedicated military personnel' when she described the people represented by the PLO in 1982 (1983, p. 60).

The pathway followed by refugees as they left Lebanon was shaped by their original social class in Palestine. Those who were able to remove real wealth when they left have been able to establish themselves in Lebanon, although they continue to consider themselves as Palestinians, as does the Lebanese community. Thus Said's family, who had a prosperous business in Egypt and Palestine, as well as a second citizenship (US citizenship based on the Mr Said's US Army service) were able to move into Lebanon and live within the community on their assets. This contrasts with the life stories of the village Palestinians, who fled with what they could carry; even the wealthier villagers, who left with livestock, possessions and cash, had spent these assets in the first years (111, p. 6; 114, p. 4). So within the camp community class distinctions are less important, but throughout the Palestinian diaspora class has had an effect on the life experiences of the refugees which is likely to have had an effect on their health outcomes.

Roberts (2004, pp. 236–37) also identified a class structure within the camp, as discussed in Chapter 5. Section 7.1.4 describes how older refugees and service providers who live in the camp identified the beginnings of social inequities within the camp, dating it to the 1990s; some have identified this as a factor in reducing social cohesion. Roberts developed her methods of classifying socioeconomic status with the assistance of the community, using focus groups to identify how people in the community judge social status. She uses seven indicators: physical conditions of the home and furnishings, social situation of the family, how the family socialises with the rest of the community, educational levels in the family, how health services are accessed, income levels and regularity, and finally, attitudes to self-sufficiency (Roberts 2004, Appendix 12).

However, there appears to be a second strand to class in the camp, related to position within the power structures, which may or may not be related to family finances. This was illustrated by examples of violence and threats of violence which was attributed to the perpetrators' position in the camp. For example, in a focus group of nurses working in the hospital there was a discussion of episodes where young men brought in fellow members of political parties who had been injured in fighting demanding (and receiving) treatment at gun-point because of their privileged position in the camp (302, pp. 5–6). This suggests a hierarchy of those politically aligned over those not so aligned. Such privilege gives access to resources before others, and may contributes to a developing class system.

Thus class certainly has a bearing on where a person displaced by war goes and what level of discrimination they attract. Within the camp for many years there were few evident class distinctions; however, since the 1990s there appears to be a class system developing which has affected the social cohesion of the community. As has been suggested in the first Whitehall study (Rose & Marmot 1981), and subsequently in the Whitehall 2 study (Marmot, Shipley et al. 2001; Griffin, Fuhrer et al. 2002, Chandola, Britton et al. 2008) social gradients and class structure can influence health through several causal pathways.

7.2.2 Gender Inequality, or family structure?

Gender inequality was not referred to as a major concern by the elderly refugees, although a possible indicator of gender inequality— domestic violence — was introduced by NGO managers, as a growing problem. Makdasi, (2005, pp. 9–24) in her introduction to her matrilineal family history, discusses the role of the Arab woman. She considers the Arab woman's role as more complex and requiring more strength than she, as a modern Arab feminist, would have expected. Another researcher studied the feminist movement in Mandate Palestine as far back as the 1920s and found that that there was full participation by women in political, social, cultural and economic spheres. However, that study was based principally within the upper and middle classes (Fleischmann 2003, pp. 202–05). A trained researcher, discussing her evaluations of camp programs, mentioned the traditional role of the older woman in Palestinian society in these terms:

> *Now the elderly had control over the land, as long as they live, the male elderly, the male elders, and the woman elder, of course, she is the head of the patriarchal household, so she has influence over the … errr . the elderly woman has the role of perpetuator of the culture. (413, p. 12)*

This identifies a significant role within the family for the women to fill or aspire to as they age, though it also of course concedes that the family structure is basically patriarchal. Thus the literature emphasises that Palestinian society is patriarchal across all classes, but also has a feminist movement dating back at least to the 1920s; it also provides important roles for women,

again for all classes. As such, a more nuanced critique of the societal position of women is called for, one that values their traditional place in the family, and their role in wider society.

An early observation was the number of women who were involved in the local NGOs. Only one program manager and one executive officer of the local NGOs was male, while six women were executive officers and five project managers were women. This fits with the traditional roles of women in caring for and supporting the family and community. Fleischmann suggests that the roots of the Palestinian feminist movement lay in female-dominated charitable institutions, and this then led them to positions of national and political power (Fleischmann 2003, p. 209). Thus the employment patterns of local NGOs within the camps may be following in the footsteps of earlier middle- and upper-class women.

Support for women can be seen in the accounts of NGOs who are working to reduce domestic against women and children:

> *There is lots of incidents of personal violence, one-on-one, where it is used as the first point of conflict resolution, rather than the last. (412, p. 5)*

> *You know, because of the situation inside the… you know, because of the situation that the father is not able to work and the son is not able to work, and secure [the family's] future, then there's domestic violence inside the family. (415, p. 8)*

and in accounts of programs developed to mitigate the problem.

> *No, before it was not talked about it, but now we have a project, we have very good partners who have listening centres, who have lawyers also, they give legal advice and they work with the… with the women and with the men also.(415, p.10)*

Thus Palestinian women working for local NGOs are seeing problems in the area of gender inequity, which affect several pathways of health embodiment, including their ability to support themselves and their families and the stress of living in a community where domestic violence occurs regularly.

I have already noted the problems faced by women who are widowed, in both the dietary and smoking narratives (sections 6.1 and 6.2), where women found it difficult to provide a balanced diet when they became the principal breadwinner for the family, and when dealing with the stress caused by recent loss of a husband. Some single women (widowed or divorced) described similar problems, but others were well supported by adult children and extended family. For example, another widow described having support from her children, both financially and emotionally:

> *Thanks Allah. My relationship with my children is good and they don't let me need anything. I already don't need anything. Thanks Allah. I am not like the others who say 'My children don't send me anything'. When they tell me they are coming, I tell them, 'Don't bring anything with you. The closet is full of things. I always put [those sorts of] conditions because for them, today she told me, 'My mother in-law, I wish you came and had Ramadan with us, because you said it is hot there'… I don't know what happened, they were going to take us but I refused to [let them] take us there. We went once there and stayed two months. (113, p. 29)*

Divorce and polygamy featured in another woman's life story, giving her limited financial stability (114). She married at about 20, and at this time had her own business as a tailor (114, pp. 6, 8, and 10). However, her husband took a second wife (114, p. 10). Although he could well maintain two households, she wanted to educate her children, so she worked from home in her business of tailoring, converting one room into a shop (p. 15). Eventually, they divorced (p. 14), and so she has had to support herself ever since, first with her tailoring and later with a food shop. Her family and one surviving son have helped her in this.

Thus both education and family networks support women when the traditional patriarchal family breaks down, through war and widowhood, polygamy, or divorce. However, I observed that when the family network is poorly established or breaks down, it is not only the women who suffer. For example, one elderly man in his eighties, who had never married, lived in severe poverty, with no furniture, sleeping on a foam mattress on the floor, in a single room, with only basic kitchen and bathroom facilities. He is working as a cobbler in this single room, despite his advanced age. He described having money as a young man, which he had used to help family members to travel to the Gulf States, but he was reduced to shoe repairing now and living in his very basic home (feedback interview 111, 8.59–10.06 mins). Thus assessing the nature of the family unit may be more useful than taking a simple view of gender inequality. However, any analysis of the family unit sees that it is deeply entwined with issues of gender roles. From among my elderly informants I observed that divorced and widowed women seem less likely to remarry than widowed men (117, 118). However, the nature of the family structure is more relevant to health than to gender ineqality.

The study data suggests that the links between gender, health, and poverty are complex, and nuanced. Educational level and employability have a bearing on health status, as does support from children, parents and extended family. I would suggest that the quality of the family support network is a more reliable indicator than gender inequity for poorer or better health outcomes. Single people, including those widowed or divorced, those who have not facilitated their employability through education and training, and those who are childless have greater problems in maintaining good health in old age. However, another, closer ethnographic study would be needed to confirm these suggestions.

7.2.3 Race or refugee status?

The Palestinian and the Lebanese people are not ethnically or racially different from each other, and have been regarded as the same country during various historical periods — for example, during the period of the Ottoman Empire. Current national boundaries were established by the Treaty of Sevres at the end of World War I (Hourani 2002, pp. 316–17). Both the literature and the data collected during this study refer to the existence of cross-border marriages (Makdasi 2005, pp. 214–19; interview 125). However, the Palestinians have been treated differently, not because they are ethnically or racially different, but because they are refugees. This distinction between Lebanese and Palestinian also crosses all social classes. In examining the thematic analysis, it is clear that refugee status has contributed to loss of human rights and poverty (both directly and indirectly).

In the case of the Palestinian refugees, their refugee status originated in the period of the *Nakba* (Israeli War of Independence). The process of their becoming refugees has had long-term implications for health over their lifetimes, as can be seen from the elderly refugees' narratives and associated thematic analyses. The Palestinians living in the camps have suffered multiple losses of human rights since becoming refugees, as described in the literature (Roberts 2010, p. 1, p. 5; Allan 2014, p. 3) and the data (e.g. 415, pp. 26–27). The first and most fundamental is that they have become stateless. Article 15 of the Universal Declaration of Human Rights specifies: 'Everyone has the right to a nationality' (United Nations 1948). Statelessness infringes on several other rights under the Universal Declaration; for example, it means that people have no guarantee that they can obtain employment (Article 23), go to school (Article 26), have access to public services (Article 23), participate in the political process (Article 21), have access to judicial services (Articles 6,7&8) or obtain a passport (Article 13(2), United Nations 1948; UNHCR 1999, p. 111). The loss of some of these guarantees may have minimal effect on the refugees in the camps, but others have had an enormous effect. For example, one elderly refugee described his problems: he left school before completing high school, because the Civil War had started, and went to work in the United Arab Emirates (UAE) as a government employee (120, p. 14). Following the Iraqi invasion of Kuwait in 1990, and having worked for 15 years for the UAE government, he and other Palestinians were sacked. He explains:

> *We were all punished because we are Palestinian and we were the ones who instigated Saddam to occupy the Kuwait (120, p. 17)*

He remained in the UAE, working for private companies, and he further recalls:

> *I was a foreman in building aspect, in many companies, and we lost some money or a lot of money because some companies swindle and took our money. (120, p. 17)*

Another man working in Kuwait at this time was unable to bring any money home when he was sacked during the same war, and for similar reasons (121, p. 18).

Thus, as stateless people they were sacked when the PLO gave support to the Iraqi government in 1990 and they had no recourse to law. They perceive that they were collectively punished for the actions of the PLO, a body which they had no control over, either through elections or membership. They had no protection through governments, courts, or international bodies. The effect of this experience was that these men returned to Lebanon without the financial security they had experienced in the Gulf from having permanent work, and without any savings to support themselves and their families. One mentions that he does not have the money to pay for education for his children, one of whom wants to go to university. He now lives in a refugee camp; he runs a small shop with a brother, and the family barely make enough money to keep themselves (120, p. 20).

Within Lebanon the government has passed laws which institutionalize discrimination against the Palestinians, specifically in regard to employment, property ownership and formation of associations. The first two points were mentioned by several NGO managers, and were discussed in section 6.4. The final point was mentioned by an NGO manager when she said that the Palestinians do not have the right of association. She explained her organisation's status and its relationship with the Lebanese government:

Informant	*We don't have the right to associate. We cannot form our NGOs, or our associations, or anything….*
Interviewer	*But there are some unions, though?*
Informant	*Yeah, but they are registered in the name of Lebanese people.*
Interviewer	*Ah! So [NGO name] itself is registered with?*
Informant	*No, we are different; we are a branch of the foreign NGO.*
Interviewer	*Ah, right. So you count as an international…?*
Informant	*We are not a Lebanese NGO, but anyway, we are supposed to employ — maybe the majority of our employees should be Lebanese, but we are not accepting this law and we should register our Palestinian employees in the National and Social Security file. We are not, because we pay for them and they don't benefit. That's why we using the money for private insurance. ... Yeah, but [if they try to stop us] we will tell them 'We are foreigners and if you are not happy we will withdraw [from other specifically Lebanese programs]', (415, pp.27–28)*

Several other local NGOs were eager to explain their status as Lebanese NGOs, and how they need links to the Lebanese community in order to register their association. As international donors are usually only able to make donations to official organizations, the status of NGO is critical to attract funds and to provide expensive services.

Thus, though racially and ethnically they are Levant Arabs, as are the Lebanese, the Palestinians are artificially segregated because of their refugee status. This continues over generations because refugee status is inherited. Many of my informants, whether young or old, as well as the NGO workers, have been born in Lebanon, but they continue to be stateless and classified as refugees.

7.2.4 War

A final historical aspect for the Palestinians has been their experiences of war. It has been a life-long experience for these refugees. Many of my informants have early memories of either the *Nakba* or the Arab revolt of 1936–39. Others, from the next generation, had their first memories of war in the 1970s, when they were in their teens or twenties. The long Civil War of 1975–90 impacted on the lives of all of them, and the war of 2006 affected all the inhabitants of Bourj-el- Barajneh camp, through destruction of the suburbs surrounding the camp, though the camp itself was not bombed.

The impacts of war on this population have been examined in the thematic and narrative analyses, and can be summarized briefly as increasing poverty by minimizing chances of employment and loss or destruction of their property. War also affected their emotional and psychological wellbeing, through the incidence of chronic stress and depression. These harm health via several pathways, including diet and substance abuse (nicotine, as well as other substances which were mentioned but not fully explored), and directly contribute to the development of chronic illnesses.

Injuries during periods of war, both among combatants and civilians, are common, and the books written by doctors who worked in Lebanon during the Civil War highlight this (Cutting 1988; Swee 1989; Giannou 1990). Medical services were limited during the fighting, especially during the sieges, as this lady describes:

> *Interviewer* *Did anyone of you get injured during this war in the camp?*
>
> *Informant* *Yes, my oldest sister was injured.*
>
> *Interviewer* *She was injured?*
>
> *Informant* *Her kidney, her spleen was injured.*
>
> *Interviewer* *Were there any medical sources that helped?*
>
> *Informant* *There was some from outside and the hospital reached a period where there wasn't medicine. They used to do the operation without aesthetic and with water and salt, and serum.*
>
> *Interviewer* *Were they from UNRWA or from the Red Cross or…?*
>
> *Informant* *The Red Cross wasn't entering. It was from… it wasn't from the UNRWA; UNRWA didn't have anyone, it was the PRCS and there were two foreigners from outside [working for PRCS]. (123, pp.32–33)*

One of Dr Cutting's patients was also one of my elderly informants, and recalls having her kidney removed:

> *Yes, Dr Paulina [Cutting] who operated me; I wasn't sick but the snipper snipped me in my kidney and liver. So they took out my right kidney, (101, p. 21)*

However, it was not the short-term effects of injury which worries her most now, but fatigue, as she goes on to discuss her visits to a doctor (possibly a psychiatrist, from her description below of treatment).

> *So I started to get tired. I couldn't sleep, I was worried and scared. Once we went to UNRWA; they told us there is a Palestinian doctor for these cases ... I was snipped, this is what is happening with me, there is nothing wrong with me, they used to bring Doctor for these cases but he used to sit and ask like 'How you are doing now?' He used to ask: ' What [problem] do you have? What's wrong? I told him that I have nothing [wrong] but after I was injured I really got tired, from the trauma. (101, p. 21)*

It is unclear whether her problems of fatigue relate to the liver and kidney damage she suffered or to psychiatric problems related to the trauma, but she now has worse health because of her injuries. This woman had already been widowed in 1976 at the Tel-az-Zaatar sieges, and had struggled to raise her children alone.

Another woman recalls running away from Chatilla camp following the 1982 Israeli invasion. She had avoided the massacre at this camp, but being fearful of further problems, she ran away from her home one night.

> *And [she was] frightened of the Israelis, at that time the Israelis came back and they want to massacre you again, so the people were.... Everyone is scared then. So one day she was pregnant and she was carrying her daughter... Her son in her hand and grabbing her daughter … so they were escaping to the Beirut area when she fell and an iron bar entered under her knee, which caused her a bad injury and she was* bleeding (108, p. 15)

Thus injuries occurred both directly from enemy attack and from trying to avoid it.

In addition there is ever-present fear that further wars could occur. I experienced this directly when collecting data, when holding a meeting with the PEER interviewers on the 11th of September 2009. One of the PEER interviewers received a message on her telephone that there was bombing in the south of Lebanon. Everyone was anxious and the younger interviewers looked particularly worried. I was sufficiently concerned to activate my security plan, ringing friends who had agreed to help in the event of possible security problem (field notes 11-09-2009; Agence France Presse 2009). While this event did not develop, the incident showed me the fears which people live with and which are easily brought to the surface. Informants found it difficult to discuss their anxiety; however, the experience of seeing my PEER interviewers distressed during this episode suggests that anxiety is prevalent for at least some of the community, and may have an impact on their emotional and psychological wellbeing

Thus war is a major historical aspect of this society, shaping behaviours and emotions, as well as causing physical injuries to both combatants and civilians.

7.3 How does this affect the ecosocial model?

In considering my findings in the light of Krieger's ecosocial model, there are concepts which do not match exactly her published model. Her ecosocial model considers societal levels, embodiment over the lifetime and a group of inequities which are a feature of populations and which influence health. She uses a combination of these to identify:

1. Embodiment
2. Pathways of embodiment
3. Cumulative interplay of exposure, susceptibility and resistance
4. Accountability and agency (Krieger 2008, p. 224)

In Chapter 3 I discussed the ecosocial model in the light of other theories, which together provided me with a more comprehensive understanding of health. I concluded that theories of embodying health over a lifetime are well supported, as is the concept that there are multiple levels of societal and ecological factors that can impact on the health of a population. The inequities identified by Krieger have been used to assess population health in the US context (Levins and Lopez 1999; Teti, Chilton et al. 2006; Buffardi, Thomas et al. 2008), However, Krieger, in a personal communication (2009) expresses a view that these three criteria of inequity may not be the same in all communities.

> *Ecosocial theory encourages addressing whatever are the relevant societal divisions and histories germane to the health problem under analysis. Examples of these types of societal divisions include but are not limited to class, gender inequality, and racial/ethnic inequality.*

It is in these inequities that the data suggests changes should be made to accommodate the different experiences of the community being studied.

During my review of the narratives and thematic analysis of the data, I found that the principal discrepancies within my analysis lay in these societal divisions and historical episodes. Thus the diagrammatic representation of Krieger's ecosocial model as it applies to the refugee community of Bourg el Barajneh refugee camp is better represented in Figure 33.

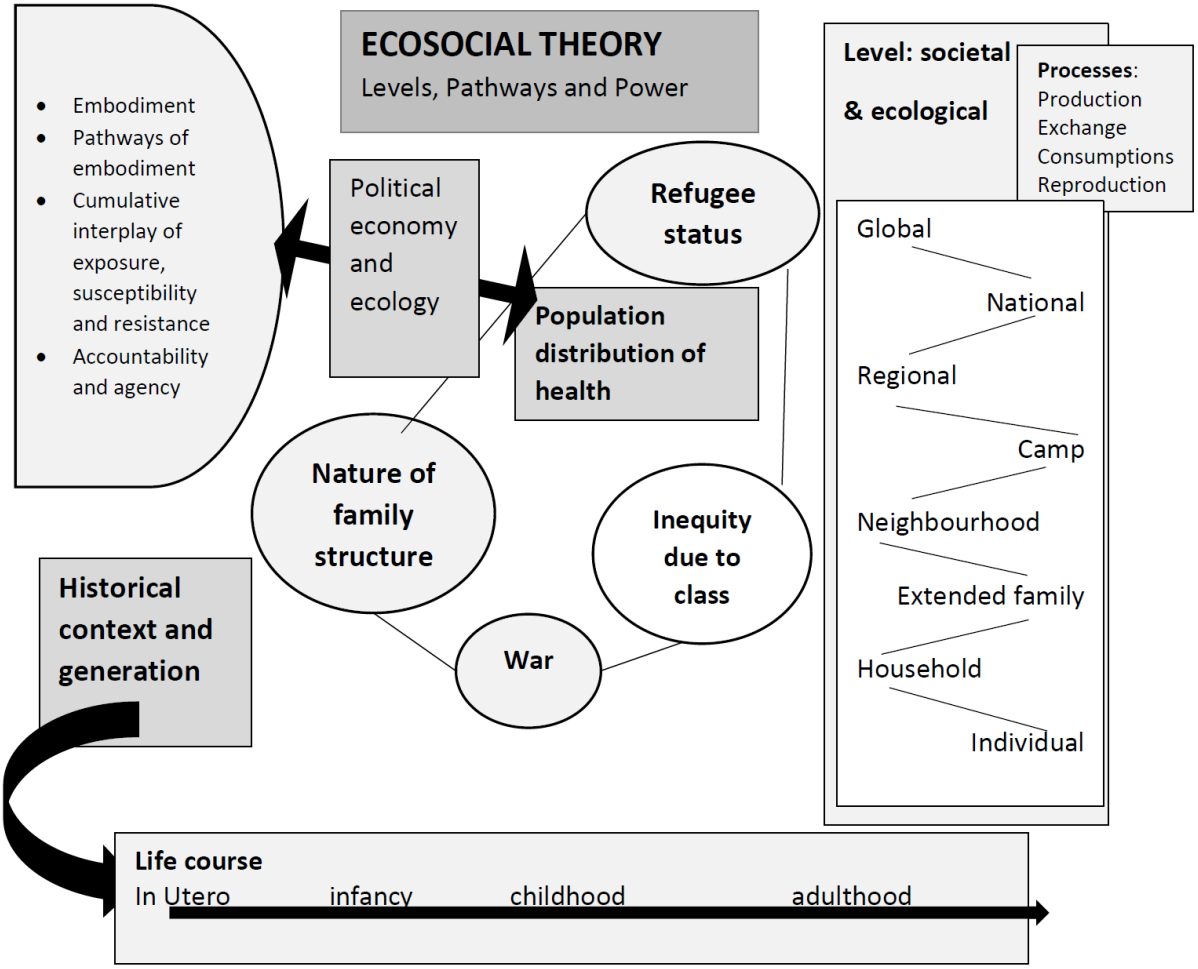

Figure 33: Ecosocial model as modified to suit the Palestinian community at Bourj-el-Barajneh camp, Lebanon (based on Krieger)

I would suggest, however, that the principal criteria of population distribution for this community are war and refugee status. While gender inequality does have impacts on health outcomes, I have aligned gender inequity with the nature of the overall family support structure. In some families the support structure is poor due to gender inequality in that family, but there may be other reasons, as I have outlined (section 7.2.2). Ultimately, it is social, class that defines the displaced person's acceptability to the host country and therefore the likelihood that they can be accepted as Lebanese citizens within the wider Lebanese community rather than remaining as stateless people living in camps.

7.4 The power to change

Having identified some of the life experiences embodied and the pathways of embodiment which cumulatively interplay, resulting in either susceptibility or resistance to illness towards the end of life, we now need to consider the agency and accountability for these pathways to embodiment. The Palestinians consistently use words about their health suggesting that they

feel powerless to make changes. For example, this elderly man discussing his feelings during war:

> *Informant* *What was our feeling? We were dying slowly. The life was very, very difficult.*
>
> *Interviewer* *Were you able to do anything?*
>
> *Informant* *What can we do? We used to hide and sit in the corners of the walls like cats and dogs. We used to hide here and there, right or not (109, p.13)*

Another elderly refugee used much more blunt language; having described a particularly distressing episode from the Civil War she said:

> *This is our life and fuck life. (104, p. 18)*

This woman's narrative suggested she was capable of using all the resources available to her to control her life. She had been actively involved in one of the PLO parties and also with NGOs. As she had left school before she could read and write Arabic to the standard she wanted to, she later studied classical Arabic with a religious leader to improve her skills. She managed her diabetes for eighteen years with few side effects, using exercise, diet and medication. However, she attributed the development of diabetes to her sad life experiences over which she feels she has had no control.

Therefore we can now consider the final two research questions:

3. Where does the power to change these life experiences to promote better health in old age lie
4. How do these lived experiences, the interactions between experiences and the power to control the lived experiences impact on health services in this community

To answer these questions we need to understand the accountability and agency of the processes identified, and to consider if or how the community can gain more control over these. To do this I reviewed the theory of empowerment, focusing on community empowerment (Chapter 4). Having understood the concepts involved, and having reviewed the literature on the Palestinian refugee community in Lebanon, the data was analysed to discover what has so far been attempted to empower the community and why, despite such effort, the refugees still say they feel powerless

.

8
POWER AND EMPOWERMENT IN BOURJ EL-BARAJNEH CAMP

In this chapter I re-examin the data to consider power in the camp and the processes of community empowerment, because as discussed in section 4.2 communities with greater levels of empowerment are more able to manage health problems, and thus often have better health outcomes. I have drawn from the literature where my own data was insufficient. The iterative nature of the PEER interview methodology encouraged preliminary analysis during data collection and hence some informants were chosen based on the need to explore social and power structures within the camp community which has facilitated this part of the analysis. For example, the role of the PLO as a provider of services and as a factor in health outcomes was emerging towards the end of data collection, so my gatekeeper arranged interviews with two PLO officials from different political parties who live in the camp. I also discussed with an NGO employee his role in a militarised political party during his youth.

I will begin this chapter by reviewing the history of the camp as it relates to power — that is, power to control social and physical environmental conditions. I will then consider when or if individuals or organisations in the camp have felt empowered, in the light of the continuum of empowerment as described in section 4.3. I will examine the processes of empowerment using Laverack's domains as described in section 4.4 and other domains which emerged from the study data during coding. Finally, I will draw from both the interviews and empowerment theory to consider which elements contributed towards and which alleviated the feelings of powerlessness described by informants.

8.1 Power in the camps: Who was responsible for management and services in the camps?

The study data suggested to me that many informants living in the camps felt powerless. For example, one man suggested that the Palestinians in the camps exist in a state of 'living survival', and also that people were aware that these losses have been imposed on them by powerful outsiders:

> *So the living survival started because the people faced a real situation, no return for Palestine, no money, no land, no future; your future is only is just how to live. The people… our people in spite of their simplicity, they realized somehow, after a period of time, they realized the size of the conspiracy on the nation, the Palestinians, the Palestinians nation, so they started to think, how will they live? (120, p. 10)*

However, others seemed more fatalistic, seeing that they live with hardships, but accepting that this is their fate from God.

> *The electricity goes off for two or three days also and people suffer and the water is salty. This is the life and the person should be patient and who is bad financially, he goes out and watches the people who have comfort more than the usual. They say that Allah created us like this and we have to face the lack of comfort and we say thank Allah. This is the person, and this is what Allah wrote for his destiny. (109, p. 16)*

Whichever attitude people adopt, few now seem to believe that they could overcome this level of disadvantage. However, at various times in the past some, or possibly most, have exercised a degree of power over their destiny within their community. For example, people have accessed education to improve their situation.

> *We started to learn how to cutting out clothes... though we weren't educated… we even learnt the numbers and the letters. I can read anything now, I can read you the signs now, I can read from the book, I can read. (110, p. 7)*

> *My children are all fine. Thank God, all of them got education and now they are in Germany and their children have graduated as doctors. (103, p. 8)*

At times they discussed the process of coming together as a community to improve their lot; for example, at the time that the Cairo Accords were negotiated between the Lebanese government and the PLO:

> *Frankly, when the revolution came, we demonstrated. … [a long description of the demonstrations] … and then the policemen ran away. So we occupied the police stations here we occupied the police station and the policemen ran away, (102, p. 7)*

So though informants have described feeling powerless now, there have been periods when they have exercised both collective and individual power.

Thus it is critical to understand who exercises power in the camp, who has authority, and in what areas. The governance of the camps has changed over time, with control of its various aspects held by different groups and organisations. Following Hanafi (2010, p. 5), I have considered governance to include 'the exercise of economic, political and administrative authority to manage a country's affairs at all levels'. Hanafi drew this definition from the United Nations Development Program. Obviously, this study focuses on a single camp and the administrative levels which affect it, though those administrative organisations may be national or international.

8.1.1 The early days, 1948–1969

Initially the camps were set up by international NGOs (Latif 2008) who aimed to support the refugees in what was expected to be a short-term exile. According to refugee informants, many initially lived in South Lebanon, supporting themselves:

> *We stayed in the south with the Lebanese, we stayed [there for] two years. They came and said they opened a camp in Beirut, so come. We came here and it was sand … they brought us tents and we pitched it. Our life is compulsion. (107, p. 6)*

Others needed help from early on in their refugee experience:

> *Then they said there is a place in Dbayeh, let's take you there. We went to Dbayeh and we stayed there for 15 days they said we want to take you to Syria… then some people brought buses and put people in it and took them to Syria. (106, p. 7)*

Many from both groups describe being moved with no consent or discussion. Perhaps such moves were unavoidable when providing support and services, such as accommodation, medical support, food supplementation and education, for a large number of refugees, but it left them feeling powerless (Rutta, Williams et al. 2005, p. 291).

In 1951 UNRWA was established and began providing some services (UNRWA 2011, History and establishment). Many informants were children at this time, so they recall the schools; however, medical clinics and food supplies were also developed (Sayigh 2007, p. 112). Importantly, UNRWA did not have any authority to protect the refugees (UNRWA 2011). Meanwhile, the 1951 Refugee Convention (2010, article 1, section D) did not include the Palestinian refugees because it was believed that they had the support of another UN body, namely UNRWA.

During the 1950s and 1960s the camps were managed by the Lebanese government, through the *'Gendarme*', a term used by the refugees when referring to the officers of the Deuxieme Bureau, a branch of the military. Their regime was recalled by several informants as characterised by the enforcement of many rules, with harsh punishments. For example, one man recalls:

> *… throwing water outside, you would get a ticket, a ticket for this thing and we were hit many times for such thing. (121, p. 8)*

Another man who ran a vegetable shop recalls:

> *One day … [the gendarmes] passed from here; I used to bring vegetables, what was there on that ledge? Two pieces of cabbage, I think a woman took them off and threw them. He said, 'What is this? What is this?' I said … 'Two pieces of cabbage. A woman bought a cabbage and she took [some leaves] and threw them off [and left them]'. They said 'Give me your Identity card', He wrote me a ticket of 21 LL. The lire was back then better than 2000 L.L now. (117, p. 21)*

This illustrates how management of the camps was not within the control of Palestinians but lay with the police of the host country. The manner in which they governed the camps appeared to community members who recall that time, to have been arbitrary and harsh.

With the formation of the PLO as a political entity to represent the Palestinian people, independently of other Arab countries, there was a framework for a government in exile (Rubenberg 1983, p. 55; Sayigh 1997, p. 19). The PLO provided the range of services and institutions which would normally be provided by governments of nation states, as Rubenberg describes in her article. However, political action at an international level and also local action in the form of demonstrations were needed before the PLO was established as the quasi-government of Palestinians in Lebanon. The refugees remember this eventuality with pride; they perceive that with it they could seize control of many aspects of their lives.

Frankly, when the revolution came, we demonstrated. I'll tell you [about it] from the beginning. We demonstrated near the Ghorabey restaurant [outside the camp] , there was a coffee shop and a police station. The people went to demonstrate down, it consisted of young men, women — we were all there. Then the police started to fire at us in the middle of the street, then a guy from [xxxxx] family, … so the policeman caught him and wanted to shoot him, and that guy had a water pipe in his hand; so he hit the policeman with it so the policeman wanted to shoot him. So I came from behind and hugged him, I was a strong woman – I didn't get scared. I hugged him and they started to shoot. Everyone was running and there was a woman running with her breast out because she was feeding her son. All women hid and I hid in the shops. I was looking and saw them shooting that same guy from [xxxxx] family – he was a child – they shot him and wanted to throw him in the water tank near Dr. Lama — they were constructing the building — they wanted to throw him So I jumped over a wall higher than this wall and entered an alley. I screamed for our guys and told him they shot the child and they want to throw him in the water tank, so the camp's people attacked them and then the policemen ran away. We occupied the police stations here – is it okay if I say this? We occupied the police station; the policemen ran away. (102, p. 7)

8.1.2 The PLO years1969–1982

Following these demonstrations the gendarmes ceased to govern the camps and the PLO set up structures to manage the camps themselves.

> *Of course, once the gendarmerie left the camp and they didn't have the control over us, we took our freedom. The one who wanted to build, he built and the one… what's important the government was almost slaughtering the people. This injustice was stopped when the PLO came. (117, p. 21)*

Informants did not discuss management of the camps at this time in detail; however, they mentioned that they were allowed to build weatherproof houses, and that work was available through PLO-managed organisations such as SAMID whenever they could not find work independently. On the other hand, some people criticised the PLO for attracting boys to join their military organisations. One woman (through the interpreter), commented thus:

> *she [saw] the youth … quit from their school instead of educate them and how to join them. [Arabic X] She said her son was in Brevet and because he refused to go with them to camp they put him in jail. (114, p. 21)*

While informants seemed reluctant to discuss management of the camps, other researchers were willing to do so. The demonstrations recalled by my informants were underpinned by the Cairo Accords, an international agreement between the PLO and the Lebanese government; this officially ended Lebanese management of the camps. Sayigh (2007, p. 179) found that 'almost as soon as the camps were liberated, popular committees were formed in a similar manner to the village leadership in pre-1948 Palestine'. In her later work, based on research in Chatilla camp, Sayigh goes into more detail. The Cairo Accords called for each camp to have a management committee. These started to form immediately from among the political parties under the PLO umbrella. While Sayigh describes some friction between the PLO and camp residents, she notes that these were managed with consultation and consensus (Sayigh 1994, pp. 94–96). In 1973 the PLO executive committee called for the formation of popular committees in all camps and laid down guidelines for their composition, tasks and procedures (Sayigh 1994, p. 95).

Having heard about the establishment of these committees, I set about searching the literature for information on what management the popular committees performed in the periods before

and during the Civil War. I refer to Sayigh (1994, 2007), who carried out research into the Lebanese camps during these times, and Rubenberg's (1983) description of the pseudo-state which the PLO had established in Lebanon prior to 1982, when they were expelled.

The first management actions undertaken were improvements to infrastructure and utilities. In Chatilla, the focus of Sayigh's 1994 book, *Too Many Enemies*, she describes mending and asphalting roads, digging wells, and organising water and electrical supplies (Sayigh 1994, p. 96). As these activities were funded by the central PLO body, I suggest it is reasonable to assume that similar activities occurred in all camps. Sayigh lists a wider range of activities undertaken by the popular committees in her 1979 book, *The Palestinians* (Sayigh 2007); these include defence, public hygiene, sport and cultural activities, as well as addressing other day-to-day local problems. However, in the background UNRWA continued to provide education, medical services, both curative and preventative, and social supports, such as supplementary rations.

Rubenberg describes the PLO as the institutional expression of Palestinian nationalism; following the Cairo Accords. From 1970 to 1982 it was based in Lebanon, along with much of its organisational infrastructure (Rubenberg 1983, p. 54). She goes on to describe a range of institutions which served Palestinians everywhere, but focusing on Lebanon.

Firstly, she describes the structure and management of the PLO, identifying members of this coalition of organisations, and describing how it was managed. This will be looked at in detail in section 8.3.4 when considering how relevant organisations participated in community empowerment.

She then reviews the services provided specifically by the PLO. These include PRCS, SAMED, Department of Information and Culture, Department of Mass Organisation, Institution for Social Affairs and Families of Martyrs and Prisoners, as well as departments of education, information and politics. Several of these departments overlap with the work of UNRWA, suggesting that UNRWA was either not meeting the needs of the camp community or that the PLO expanded the types of services they were providing.

The PRCS was founded in 1965 and in 1969 was included in the PLO. In 1982, when Rubenberg undertook her field work, it had 11 hospitals (with 700 beds) in Lebanon; one was in Bourj el Barajneh (Haifa Hospital). There were 60 clinics practising both curative and preventative medicine. These clinics provided services for 50 to 70 patients daily, with small charges for services, though some received treatment free, including PLO employees and their families. As PRCS operated side-by-side with the UNRWA clinics, there may have been unmet needs which PRCS attempted to meet, both within the camps and among the general Lebanese population, who were also allowed to access these services. PRCS ran a training school for

nurses and paramedical staff, and employed mostly Palestinians. Preventative health programs included campaigns on water safety (boiling drinking water), managing hard rubbish, anti-rodent campaigns, and mother-and-child centres. PRCS took a broad view of health promotion, running adult literacy courses, and vocational training for unemployed women (Rubenberg 1983, pp. 61–66).

As discussed in section 6.4, the principal PLO organisation providing vocational training and employment opportunities was SAMID. This organisation manufactured various products and trained men and women in factory skills in their own factories inside the Bourj-el-Barajneh camp

One of the departments which appears to have impacted directly on the camp residents was the Institute of Social Affairs and Welfare for Families of Martyrs and Prisoners. This body officially provided assistance, as well as health and educational benefits for the families of deceased PLO employees. The term 'martyr' is translated from the Arabic *shaheed* 'one who is killed for his/her faith, homeland or ideals' (Laidi 2003, p. 209). In practice the institute paid pensions to families of those killed in the Civil War and in ongoing conflicts with Israel. For example, a widow from Tel-az-Zaatar, who said her late husband had not been employed by the PLO (101, p. 7), recounts an episode when her daughter was given a scholarship for her schooling from the PLO.

> *Abu Ammar (Yasser Arafat) came and she started to cry, she was in Baccalaureate I; she told him 'I am crying for my dad', so he ordered someone to make a monthly allowance for her and she stayed and passed her Baccalaureate 2, thank God, and she didn't go with them. I used to work and buy bread, cook and manage my children. I used to save some, spend my husband's salary (martyr's family pension) and save from my salary. What can you do? This is the only way (101, p. .19)*

This quotation suggests that while the PLO pension was not enough to support her family, it helped to supplement the wages she could earn as a maid, making it possible to educate her daughter.

The various unions formed among the Palestinian diaspora, for example, the General Union of Palestinian Workers, and the General Union of Women, were subsumed by the Department of Mass Organisation (Rubenberg 1983, p. 71). While many of these functioned as trades unions, no informants would discuss membership. The reasons for this are not clear, either from the literature or my data. The education department offered preschool education for camp children to attend the UNRWA schools, tertiary scholarships and adult literacy classes (Rubenberg 1983, p. 77). These were not mentioned either in the interviews with elderly Palestinians; the reason may be that those with tertiary education may have found it easier to leave the camps, or that these activities did not feature strongly in their memories, but this is supposition. Other departments related to work on the international stage, and are less relevant to this research.

8.1.3 The Civil War following the departure of the PLO in 1982 (1982–1990)

The invasion of Lebanon by the Israelis in 1982 culminated in the siege of West Beirut. Rubenberg saw this as a 'systematic attempt to destroy the entire civilian infrastructure of the PLO' (1983, p. 54) and Jansen suggests that senior Israeli politicians aimed to 'destroy the PLO structures and disperse its fighters (Jansen 1982, p. 62). The PLO hierarchy and a substantial proportion of its fighting men were forced to leave Beirut (Jansen 1982, p. 91), but Palestinians whose families had come to Lebanon in 1948 remained. Fiske discusses the PLO's belief that the presence of the PLO leadership was not needed to maintain the concept of an Arab Middle East; that by withdrawing the PLO organisational structure and re-establishing it in a more distant Arab country, the revolution could be maintained (Fisk 2001, pp. 333-35). Fisk also discusses the subsequent events, including the election of a president with known anti-Palestinian policies, his assassination, and the Sabra-Chatilla Massacre, conducted by his party's militia with the cooperation of the Israeli army (Fisk 2001, pp. 333–99). On the evacuation of the PLO, the safety of the refugees had been guaranteed by the US Secretary of State; however, he demonstrably did not have the power to keep this pledge and the refugees in the camps were well aware of this (Fisk 2001, pp. 324,334 and 372).

In the following years the popular committees continued to function as managers of the camps and organisers of services; likewise UNRWA continued to provide health education and social support services. However, the PLO, which had instituted and organised membership of the popular committees, was in disarray. There was conflict between the armed political parties in what was called the War of the Camps. Some parties had formed in opposition to the PLO leadership, and were based in Damascus with the support of the Syrian government (an active participant in the Lebanese Civil War). This conflict ultimately led to the sieges of three camps (including Bourj-el-Barajneh) by a Syrian-backed Lebanese militia, Amal (Sayigh 1997, p. 30), The final siege of Bourj-el-Barajneh was followed by a war between the factions within Bourj-el-Barajneh with the pro-Syrian factions being supported by the Syrian army (Sayigh 1997, pp. 30 and 406, pp.18–24).

While the political details of these conflicts within the Lebanese Civil War are not directly relevant to the health of the Palestinian refugees in the camp, their effect on the power structures in the camps is very relevant to the welfare of the refugees: it compromised their ability to control their environment, society, and indirectly their health. In collecting data I first became aware that these conflicts were significant when a PEER interviewer fed back her distress on hearing, during an interview, an episode where the elderly refugee had observed one young Palestinian shooting at another during this conflict (Feedback interview 117, 28.10 minutes). When the interview was translated, I found the section which had distressed her:

> *(pro-Syrian supporters) started to fight Fatah supporters inside the camp; they started to fight them and they tell you, guys from this part and guys from the other part, they started saying get out you pimp [a serious insult in this culture], Abu Rayad, you… pimp!… they humiliated him and swore at him and shot from there and here. (117, p. 24)*

The informant's trust in the PLO was damaged by this episode. Several other informants also felt that the PLO had failed the Palestinian people because of factionalism (103, p. 5; 104, p. 8; 111, pp. 25–27; 115, p.28–29; 119, p. 4; 121, pp. 41–43).

Thus there was a falling away of support for the PLO during this period, but it and UNRWA retained responsibility for services they had provided, and tried to maintain those services during difficult times.

8.1.4 The further diversification of service provision, 1990–2009

Service provision organisations, UNRWA, the PLO and its members, and the Popular Committee continued to provide some of their previous services; for example the PRCS continue to operate Haifa Hospital, in the camp, the UNRWA clinic continues, and the Popular Committee continue to provide water services. In addition, a rapidly expanding number of local NGOs provided services in coordination with international NGOs and donors following the Civil War. The rise of the NGOs appears to compensate for reduced services from other service providers, particularly UNRWA and the PLO. I draw this conclusion both from my reading of the literature and from my interviews with service providers and refugees.

Khalili identifies functions undertaken by local NGOs as including childcare for working mothers, after school tutoring for children, supplementary health services, vocational training, and legal rights training (Khalili 2007, pp.58-9). From my own data, I would add that NGOs provide health services not provided by either PRCS or UNRWA (401, 402, 404, 412, 414, 415, 417 and 420), and provide empowerment and human rights activities across all age groups for both men and women (401, 407, 412, 415, 417, 420, 426, 427 and 431). The nature of these services, their problems and their successes will be further discussed in section 8.3.

The winding back of UNRWA services has been discussed in section 7.1.2 when analysing the problems of poverty (especially the impact of increasing health expenses), as well as the stress that occurs when illness affects the family. Local NGOs provide parallel services to UNRWA and PRCS; for example, one provides home visits by nurses and rehabilitation workers (401, 417, 303, 304); another operates a clinic with specialist doctors (420), and yet another operates a rehabilitation centre (415). These services rely on donations from multiple sources; some charge affordable fees, others are free to users. Local Palestinian and Lebanese NGOs do not have access to the large donors, such as Ausaid, USAid, or ECHO, but by forming collaborations with international NGOs they gain access to such funding for larger projects. An international NGO desk officer explained his perception of this relationship.

> *It's really three players; it is the organisations in Lebanon doing the day-to-day work, and who all do to it because they see it as part of their mandate, and that needs to be stressed I think as well. Another part is, definitely the [a large donor] and, as a funder, who is a very active funder, in the sense that they question what is being done, and that they want to see development, and in improvement, and changes in qualities, standards, and things like that. So that they are really at counterparts, a true counterparts — not always easy to tackle with, but —, but they, I would give it to them they are involved and that is to be, in general, a very positive approach I would say. And ours, as international NGO), is rather to interact between these two, it's to, it's a kind of mediating role. (430, p. 2)*

Thus the field work is undertaken by the local NGO, the donor provides the money, and being what this desk officer refers to as a 'very active funder' the donor can exercise enormous control over the direction the program takes. As a local NGO manager said when asked why she had not implemented a project she felt was needed:

> *This is the problem, you receive, like there is a fund[ing] opportunity but they [the donor] give you the priorities, and none, none in ..., you don't find elderly. (401, p. 7)*

I have used health programs as an example of the relationships between NGOs and government-backed donors, to demonstrate the links between these three groups. However there are other sources of funding, including small donor organisations, often channelling the donations of individual donors (406, 421), and individual people who fund projects (416, 426). I will examine this relationship further when discussing coalitions between organisations, in section 8.3.4.

While the narratives of the elderly refugees focused on reductions in services from UNRWA, there has also been a reduction in services from the PLO-supported PRCS clinics and hospitals. The refugee informants only touched on this, but interviews with service providers identified a deterioration in the quality of the PRCS services since the War of the Camps. A small donor manager provided her perceptions of this lowering of standards.

> *I have always had the opinion that health services run for people …. to whom they are targeted, and not as a symbol for some of the struggle, so the quality of services that people experience is I think extremely important.(406, p. 2)*

She is claiming that the PRCS operates as a symbol of a Palestinian state rather than as a true service provider. She goes on to suggest that the PLO in recent years has not been either willing or perhaps able, to hold the PRCS accountable for service quality.

> *And I think that's what has happened, for the Palestinian refugees here in Lebanon is that the quality of service, because there has been no authority to which that service is accountable, has got so bad that it's actually doing more harm to Palestinian population than the government of Israel ever will. (406, p. 2)*

These comments seem controversial, but they may be part of the explanation for the reduction in quality of PRCS services since they were described by authors in the early and mid-1980s. Haifa Hospital, the PRCS hospital in Bourj-el-Barajneh camp, offers outpatient clinics which see seven to ten patients per doctor per day, (compared to 60 to 80 patients at the UNRWA clinic) (408, p. 4). However, UNRWA now funds refugees inpatient services at Haifa hospital (which is

cheaper for the patient than the Lebanese Government Hospitals) only for the simpler procedures (409, p. 1).

While I have focused on the medical services and their costs, the NGOs have increased services in a wide range of areas. The dependence on women's wages to support the family has fed the need for early childhood education centres and programs to provide supervised activities for children during the long summer holidays. With the destruction of the SAMID factories during the War of the Camps, NGOs have undertaken vocational training programs. Human rights education, program management and governance practices are also emerging NGO programs.

To summarise this period, services from UNRWA and the PLO services were gradually in decline, and NGOs have tried to support the community with compensatory programs. .All these service providers are dependent on donors, either from national governments contributing directly to UNRWA, or via their international aid organisations to local NGOs, or else on smaller donors who raise funds from community participation.

8.1.5 The complex network of service providers: Who has the power to manage the camps?

This narrative shows a gradual increase in the number of service providers and a decrease in sources of funds. Thus, though the power to manage the camp communities started with UNRWA and the Lebanese government that has fragmented, with services now provided by a plethora of NGOs, UNRWA, and the popular committees. All of these bodies are financially dependent on outside organisations — the camp population is able to finance only the most basic of services.

Table 6 illustrates that with the gradual decrease in services from UNRWA, and that services have developed from other organisations, a trend which has increased the complexity of service provision in the camps.

Table 6: Increasing diversity of service providers

	UNRWA	PLO	Popular committee	NGOs
1948–69	• Provision of tents • Primary health clinics • Payment for hospital services • Environmental health, including water and public bathrooms			

	• Ration of staple foods and other needs • School education			
1969–90	• Primary health clinics • Payment for hospital services • Ration of staple foods • School education •	• Provision of pensions for widows and orphans • PRCS clinics and hospital services • Vocational training and employment • Protection (until 1982)	• Electricity • Water • Sealed roads and paths •	
1990–2009	• Primary health clinics • Limited payment for hospital services • Environmental health, underground sewage and hard rubbish management • Ration of staple foods for special hardship cases • School education	• Provision of pensions for widows and orphans • PRCS clinics and hospital services • Limited payments for hospital services	• Electricity • Water • Sealed roads and paths	• Early childhood education • Rehabilitation, primary health clinics and home nursing • Childcare • Limited payments for hospital care • Social and empowerment programs • Vocational training

There has been a gradual fragmentation of service providers, from the original principal provider, UNRWA, to the various organisations which combined to form the PLO, and then to the multiplicity of local NGOs and their supporting international NGOs.

8.2 The continuum of empowerment

The powerlessness expressed by the refugees when addressing major concerns in their lives, such as their health status, suggests that whatever measures have been implemented have failed to significantly empower the community. Any analysis of attempts to empower the community should cast light on some reasons for this failure. One way of examining this is through the lens of the continuum of empowerment, discussed in section 4.3. Community empowerment can be seen as occurring on a scale of increasingly complex civil society organisations; it can originate from one or several of these levels, according to Labonte (1990, p. 67).

In considering empowerment processes within the camp, I have equated the structures of camp society to the continuum levels proposed by other researchers, as illustrated in Figure 34.

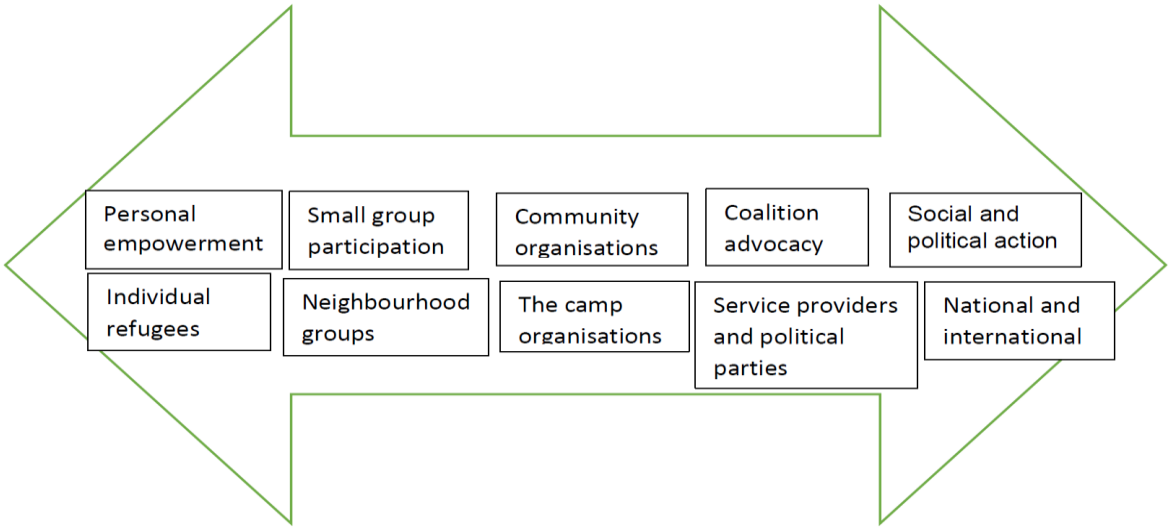

Figure 34: Continuum of community empowerment within the Palestinian community (modified fromLabonte 1990, Rissel 1994, Laverack 2004)

This model can accommodate the wide range of service providers and organisations which have power-over or exercise power-with the population of the camp, and can also take into account the nature of the Palestinian community, both in the camps and in the diaspora generally.

Individual informants from the elderly Palestinian refugees have described episodes in their lives when they have set meaningful goals towards increasing their power and taken action to achieve them; a significant factor of individual empowerment as described by Cattaneo and Chapman (2010, p. 53). Examples of this in the study data include a girl who, having left school in grade 4, wished to improve her reading and writing skills in standard Arabic. She considered returning to school, but rejected the suggestion of returning to a lower grade than her friends, and instead approached a Koranic scholar and learned classical Arabic from him (104, pp. 5–6). An elderly man whose chronic illnesses prevented him from working as a plumber found work with the Popular Committee delivering the water supply to homes; his skills as a plumber helped maintain the system, but the work was less physically demanding than full-time plumbing (121, pp. 18–19). These examples demonstrate that some, if not all, refugees can take effective action in daily aspects of their lives — that at times they can be psychologically empowered.

The concept of small group participation covers a wide range of activities, including helping neighbours and extended family or participating in small structured activities. Ramadan occurred early in data collection; it is an important time for social gatherings. I was invited to several Ramadan social events, and made field notes following them. These included an invitation to break the fast with an old colleague, who had invited her extended family, most of whom lived in Bourj-el-Barajneh camp. Conversations covered topics such as ways of

accessing treatment for a relative with thalassemia (a common genetic disease found in the community) and how to organise the care of a lady suffering from dementia (Field notes, 16 September 2009). I was also invited to a coffee evening at a beach café held for the employees of a local NGO. Most of the staff of this NGO attended, several bringing family members, children and grandchildren — we required two buses, both filled to capacity. People sat at a long table, smoking *nargeleh*, drinking coffee and chatting. Younger party guests performed traditional dances, but most people chatted about a variety of social and political subjects (Field notes 11 September 2009).

More structured activities include NGO activities based on neighbourhood small groups. For example, a health promotion activity run by an NGO trains volunteers who then pass on the information they have gained throughout their own social networks in a more or less structured way (420, 308).

As discussed in sections 8.1.2 and 8.1.3, organisations supporting the Palestinian refugees arose in the 1960s, including PRCS providing curative and preventative medical services, some unions, the armed political parties aiming to return to Palestine by force, and some NGOs. The number of NGOs involved in camp services increased following the Civil War; by the time of data collection there were many, some dating back to the Civil War and others newly established. I conducted interviews with people from ten local NGOs, nine of which focused principally on the Palestinian communities, although as registered Lebanese NGOs they cannot discriminate. My sampling was not exhaustive of all NGOs, but focused on those with programs impacting on health or activities operating in Bourj-el-Barajneh. Thus there have been organisations working within the community, including political parties (usually with armed militias) and NGOs. A few informants also discussed participation in other organisations or venues, such as the mosque (106, pp. 24–25).

The formation of coalitions is seen early, in the narrative of the Palestinian diaspora, for example the formation of the PLO, itself a coalition of organisations. The NGOs themselves have formed coalitions, though not on the scale of the long-term, organised structures formed by the PLO. These develop projects which are too big or resource-hungry for one organisation to manage, and operate on the basis that when the project ends the coalition will be dissolved.

The final level of the continuum sees the development of social and political action. Television news reports from the 1970s onwards have regularly included the political activities of the PLO, including actions taken at an international level, such as Arafat's speech to the general assembly in 1988, which included phrases such as 'peace with justice' (Morris 2001, pp. 607–08), and the Oslo Agreement, (Ashrawi 1995, pp. 259–69). However, international negotiations have not included representation from the refugee population, who remain stateless people in their camps. The NGOs work on a more local level, but some of them are developing political

actions, as described by some of the NGO managers. For example, a protection project which encouraged the participation of local people in the management of their local community, developed from a program to assist refugees without the right to reside in Lebanon to gain official recognition (412, p. 1 and p. 11). In such projects we start to see refugee participation in the political process.

Thus there are existing community structures from which empowerment of the community may arise; however, that does not necessarily mean that the community is using these structures for that purpose — to gain control of their community. For this we need to examine the goals of these structures and how they operate.

8.3 Processes of management in the camp: are they empowering?

I undertook a thematic analysis to better understand the processes of empowerment within the community of Bourj-el-Barajneh. The basis of the analysis was Lavarack's nine domains of empowering processes; however, two further areas emerged as major drivers of empowerment within this community: conflict resolution and lay knowledge. Additionally I found that two of Laverack's domains, related to outside agencies and coalitions between agencies, were very closely linked, and so combined them as a single theme. While Lavarack covers these concepts briefly within his model, my data suggests they are pivotal to understanding empowerment processes within this community.

8.3.1 'Participation'

As discussed in section 8.2, the camp community participates in both formal and informal social activities. One foreign worker who had worked and lived in several camps, including Bourj-el-Barajneh, described her experiences of informal gatherings:

> *I was never made more welcome by people than in that situation … people were very open, with the situation, like discussing a lot, talking openly about the situation, not very often in detail about the frustrations, about the specific violations, but open, and I think that that is a strength as well … Talking openly with people, foreigners, about the situation, can release kind of stress. So I think that is also a strength. And this, and the exchange, of course, of different opinions, of what people think of the situation when they come from abroad and experience such different things. (431, p. 11)*

The respondent here identifies among the refugees both social competence, and willingness to discuss the situation in which they find themselves. She sees this as a strength in helping them to manage the stresses of daily life.

However, as discussed in section 7.1.4, people fear that the social cohesion which supports this informal participation is weaker than in the past. One lady referred to this:

> *Yes, we used to (be close) but now not. The family used to sit all together and have fun and neighbours loved each other but now, no. Not even a brother wishes the good for his brother. You see, now he would say, 'Let my brother die and I live'.I don't have these thoughts. I used to go bake bread and spread them on my way back. Once I was baking near a shelter near Dayab, then a young man came and told me aunty – I was still young in that time – 'would you sell bread for 1 lire?' I told him, 'I don't sell bread'. Then he said, '[Just give me] dough, I asked him why, he said 'I'll take them, fry them and then eat them. I said 'OK'. I put them and gave it to him and said 'My son is living abroad and as I am feeding you, someone will do the same for my son. (102, p. 12)*

Among some families there is less participation in community activities, and the reasons people gave for this are discussed in section 7.1.4; they include development of a social gradient within the camp based on wealth and power (which may not correlate), and a decline into poor emotional and psychological wellbeing.

Informal social gathering appears to have been a strategy used by the PLO factions in the War of the Camps, following the final siege, and before the factional fighting:

> *Fatah Syria [anti-Arafat faction of Fatah] started the campaign first. They started visiting people, talking to them about the next period of time that is coming. [That is] exactly how they described [it]. They are trying to convince them that … it is necessary to ease down [undermine] Arafat, to support them (Fatah Syria), you know all this, like warning them that the coming period is harsh. (405, p. 19)*

And following this, the other principal faction used the same tactics:

> *Fatah [faction supporting Arafat] started a counter attack. Going to the same houses that Fatah pro Syria visits, and tell people more. No, on the contrary these people are saying that because they are finished, and they need support. That they are trying to hold to anything, just to stay, to keep on going. (405, p. 20)*

As discussed in section 8.1.3, following the War of the Camps people became disenchanted with the PLO. Despite that, some participation was maintained, for reasons that include the possibility of paid work:

> *After that, from the camps war, there was no work, he couldn't go and work and you know they are five children and they want to eat, drink and there isn't, so he joined a political party. He joined to a party. (122, p. 20)*

And of course there remained a belief in the overall ideology of the PLO, as observed during interviews with cadres from two PLO parties (424, 425).

The NGOs tend to organise meetings in offices rather than homes, as many have more space there to accommodate meetings. They offer a range of group activities: some offer social activities for elderly people, others run health education groups, and some offer summer activities for children and teenagers. However, social activities can have a focus of empowerment as well as entertainment, and I will discuss those which appear to be empowering or which have stated aims of empowerment.

The former group includes a centre for elderly people, where the participants are closely involved in planning activities:

> *Some of them said 'We'd like to learn how to read and write', so we started the literacy program. We ask them 'Where would you like to go?' You know... It's not like we tell them 'We're going to — I don't-know where to have a picnic'... No, we ask their opinion, which is their... We do not force them to do things they don't want to do and the... Even the literacy program, I mean, we're doing it very casually, because, you know, they cannot concentrate for too long. You cannot push them. (426, p. 4)*

The active members of this program volunteer to visit the housebound members; for example, taking meals which have been prepared at the centre to people who could not attend. (407, p. 2)

More formal empowering activities were described by a country director of an international NGO that has worked with several local NGOs to develop programs on protection, taking a broad view of who needs protection and from what (412), (Abu Sharar 2009). This program includes protection against violence, in schools, and the community, considering dignity and discrimination, governance and responsibility (Abu Sharar 2009, p. 3). For example, the international NGO funds small programs run by local NGOs including skill sharing (older women teaching younger women traditional food production), drug awareness programs, positive play activities, and non-violent behaviour (412, p. 2). Within these activities the subjects of discrimination and protection can be raised. The organisations found that trying to develop groups about esoteric subjects was less acceptable to the community than practical activities, so participation is greater when groups have a practical basis (412, p. 3).

The local community participates in activities informally among extended family and neighbours, though this form of participation may be waning, and in activities run by NGOs. They also participated in political action organised by the PLO in the late 1960s and early 1970s, but most informants had become less involved in these political activities since the War of the Camps.

I looked for a reason for this pattern of declining participation in the PLO. Originally, the PLO was seen to be progressing towards a common aim, the return to their native country, and the removal of onerous regulations imposed from outside the camps. At that stage the refugees participated in its activities. This changed as the parties split into factions, though some refugees continue to participate for financial or ideological reasons. Participation in NGO activities, on the other hand, is about sharing skills and knowledge in pleasant social interactions. Several NGOs appear to have an underlying aim of empowering disadvantaged groups in the community, but their overt focus is on pleasant activities that encourage participation.

This relates to Ziersch and Baum's (2004) work where they found that some informants associated participation in civil society groups with negative outcomes for both mental and physical health. Attree and colleagues (2011) also identified some negative effects of participation, such as exhaustion and stress because participation in activities takes effort. Thus the NGOs tend to promote participatory activities that people enjoy, and which resemble the

informal social gatherings that people are used to. On the other hand, the PLO offers work opportunities, financial support, and shared ideological beliefs as incentives to attract people to participate.

8.3.2 'Leadership'

Leaders are the people who take responsibility for getting things done, dealing with conflict and giving general direction (Laverack 2004, p. 88). Leadership within the camp as a whole is difficult to determine; there is the Popular Committee, made up of nominees from various political parties — those nominees are always male (412, p. 11); the political parties have local leaders within the camp; the NGOs have their own leaders, or executive officers, and often appoint middle managers who have a high degree of leadership within their programs. These men and women are drawn from camp residents and from the wider Palestinian community. Finally, one Palestinian (not a camp resident) remarked that the elderly resume their traditional leadership role if there is a power vacuum:

> *I was in Chatilla camp, in '82, during the massacre, when the political groups, there was not a political structure in the camp. Who assumed the responsibility? The elders, they clustered and formed a delegation that went to the Israelis. They ended up killed but at least …… They resumed, re-assumed the traditional role. So I believe the elderly are latent leaders, so whenever that is in need, they pop out. (413, p. 3)*

Thus I found a range of leaders within the camp community. In addition there is published research on general Palestinian power structures as well as the leadership styles typical of the peak bodies of the PLO.

Local NGOs run a variety of programs; even those focusing on one area, such as health services may have programs covering topics such as health education, curative services, and environmental health (420). Some NGOs focus on one program but offer it in several different camps or gatherings (426). Usually each program and/or location will have a coordinator or manager; this suggests that potentially there is a range of people able to step into more senior leadership roles when the need arises. In situations where I was able to interview both the organisation's leader and the program leader I found high levels of delegation; for example, when interviewing the NGO leader of one organisation she was able to give me an overview of all programs and the underlying philosophy of her organisation, (401). When interviewing the program coordinator for their complex health program, she was able to describe the nature of the program, its evaluation, and the numbers and types of beneficiaries (417). By working with external evaluators and her CEO she was learning about program management and development (417, p. 17)

The people in the camp are ambivalent about the leadership of the PLO. A Palestinian NGO manager explained her point of view:

> *Because from that time… you know, since that date [War of the Camps, 1986], you know, the social-economic situation of the Palestinian is going down …..People are not seeing any political… any prospects for a political solution. (415, p. 2)*

She suggests that the PLO political parties are providing neither general nor political leadership. However when interviewing a local leader of a political party in Bourj-el-Barajneh he described to me his involvement in a local environmental health problem.

The autumn rains in 2009 had flooded lower lying parts of the camp, with overflows from the drains. As these drains carry both stormwater and sewage (Davey & Maziliauskas 2003) people were distressed by this, raising the problem in the photographic data. (Fig. 35)

Figure 35: Flooding of the low-lying areas with sewage and storm water, 2009 (201, picture 2)

A group of people from this neighbourhood approached this local leader and asked his advice. He had coordinated a campaign, including a media campaign, approaches to the local (Lebanese) councils, Lebanese politicians, and internationally to the UN and UNRWA.

> *And because of the people's movements against this problem and because they published it in the media, so the European Union decided to agree to construct a new sewerage system for the whole camp. (425, p .7)*

The result was that plans were developed to replace the narrow sewers with wider ones which would alleviate the problem of flooding.

This example shows that while the PLO in general provides little leadership, some of its cadres are trusted and provide meaningful leadership when the opportunity arises.

Overall, there is a range of people who have demonstrated leadership skills, including the elderly refugees, the people working in NGOs and the cadres of the PLO. Leaders can put together large and complex programs and manage them or delegate to trusted subordinates. However, the key to management of the camp community over its long and difficult history has proven elusive. The traditional elders were supplanted by the PLO, who failed as leaders during the War of the Camps; the NGOs make no attempt to manage the whole camp community, but

rather lead within their own organisations. Whenever there is a power vacuum, one or other of these groups may step in to provide leadership.

8.3.3 'Organisational structure'

Laverack defines organisational structure as the way that people come together to solve problems. He looks both at the extent and the level (within the continuum) at which each organisation is operating functionally (Laverack 2004, p. 90).

We can identify various organisational structures within the camp. While my focus has been on local NGOs and political parties as service providers, other organisations exist which are used by some residents to provide social supports. One such is the mosque, though only one informant discussed his activities within the mosque. He explained that people go to the mosque for help, and that he and his colleagues provide support and advice there (106, pp. 25–26).

NGO representatives tended to discuss activities rather than the structure which supports them. They focused on programs which service the refugees' needs at the levels of the camp, the neighbourhood and the individual. I gained the impression that the organisational structure of the NGOs is usually bottom-up, rather than top-down, for reasons principally based on their expressed leadership styles, as discussed in the previous section. NGOs generally employ middle managers, who implement programs, or parts of programs, with input from participants and field staff. An international NGO manager described the young workers in a typical program:

> *We worked with a group of young people who [have]... an active role in our project and at the beginning of our interaction they had serious problems, in terms of relationships, in terms of personality and during these years of working together with no therapeutic approach whatsoever, because that was not our aim; we're just building a team and working together; we saw these people changing completely. Changing the way they related to themselves, changing the way they related to others, changing the way they felt about their lives and their opportunities. So, people that I would've said they need psychologist and, maybe a psychiatrist at the beginning developed into people who are, at the moment, managing their services, managing activities, being creative. (419, p. 23)*

Comments such as this suggest that ideally programs should be managed by the people who live in the community rather than by outsiders from international NGOs, or even the senior staff of other local NGOs.

Another indicator that the best organisational structures support bottom-up management can be seen by comparing data from senior managers, middle managers, and the field workers. Senior managers were able to give me sweeping overviews of their programs, goals and aims, while the middle managers talked about the mechanics of managing a program and the focus groups were able to draw ideas from their daily contact with their patients/clients. For example, one CEO explained the purpose behind the health education program and the mixed use of

volunteers and professionally trained employees (420), while the health educators talked about the subject matter they covered, and the methods used in training volunteers (308).

On the other hand, the PLO organisations appear to be authoritarian, rather than participatory/inclusive in their organisational structures. This may be at least in part because the armed political parties have dominated the PLO since the 1970s (Rubenberg 1983, p. 55), and hence these organisations are permeated by military discipline. For example, one elderly refugee recalled:

> *[My brother] felt that there will be an invasion, so he went to Saida; he was an officer, he went to Russia and took training there and he was the first one above 35 persons, he was smart you see how? … He came from Syria to here and the [political militia] caught him. Why? Because he didn't take permission, so they caught him and put him in prison (111, p. 26)*

While military discipline is a normal part of military service, many offshoot organisations within the PLO were not at all military.

The data naturally focuses on PLO activities within the camp; however, the influence of PLO organisations extends beyond the camps. In his study of the PLO, Yezid Sayigh described top-down management extending to the top of the PLO, giving the example of Arafat as relentlessly waging a feud with Syria between 1983 and 1987, leaving senior colleagues and rank and file with little choice but to back him (Y. Sayigh 1997, p. 30). Such top-down management also characterised the War of the Camps and the sieges of Bourj-el-Barajneh. However, at times the PLO has operated at all levels of the continuum, from the individual to large-scale political and social action.

Organisational structure is more complex than suggested by 'top-down' of the PLO's or the 'bottom-up' of the NGOs' management styles; however, we can regard this as an indicator that the NGOs are more likely to engender empowerment than the PLO. On the other hand, because the PLO operates at all levels of the continuum it can potentially support empowerment at all levels too.

8.3.4 'Role of outside agencies', and 'Links to other organisations'

I have combined these two domains which Laverack identifies, because in the context of the camps they overlap. It can be difficult to determine which is a Palestinian agency, and which is an outside agency, and the roles of the linked partnerships can be complex. Laverack considers the links between organisations, including partnerships, coalitions and alliances separately from the roles of these links; however, I found that in this community they are entwined.

The nature of supporting organisations in the context of the camp is difficult to define; the international NGOs are outsiders, but they work closely with local NGOs and some employ Palestinian managers (415). Donors appear to be more clear-cut outsiders. They fall into two

groups: large donors, usually funded by governments and working through international NGOs, and smaller donors, who are often individual supporters. These smaller donors function as international NGOs, collaborating with local NGOs to develop projects, providing technical support where needed. They also provide money for projects, both from their donation base and from large donors (404, p. 1; 421, pp.1–2). UNRWA relies on funding from the United Nations, taking a small budget for administration from the UN directly, and then receiving donations from countries and aid organisations (UNRWA 2014).

The relationship between the financial sources and local NGOs is often mediated by an international organisation that provides expertise in acquiring and managing the funds as well as carrying out the program. Organisations providing expertise often function in ways Lavarack suggests is appropriate; they listen to the local people and advise on ways to achieve the goals that they want to achieve in what is a bottom-up relationship (Laverack 2004, p. 97). For example, the needs analysis undertaken by an international NGO worker in 1993 for an NGO used qualitative research techniques to identify the needs of widows in Bourj-el-Barajneh camp; however, the development of programs to meet these needs came from the local NGO in collaboration with the international NGO (McCue 1994 interview 401, pp. 1–2, and interview 106).

Problems often arise in the relationship between donors and the local NGOs in terms of meeting aims and needs. For example, many NGOs with an interest in health are concerned about chronic illnesses, the management of which continues over many years, while the funding cycle usually covers only one to three years. I discussed this with the country manager of a small donor.

Interviewer	*With the projects you run, do any of them focus on long-term health of the refugees or are you focusing very much on the short-term immediate illness?*
Informant	*What do you mean by focusing on long-term health of the refugees?*
Interviewer	*Well, as you know this research is focusing on the development of chronic illness in the long-term for the refugees. And I'm wondering if you keep a partial eye even, on the long-term consequences of the health of the people in the camps, of immediate illnesses?*
Informant	*Do you think it's appropriate for NGOs to keep that kind of focus?*
Interviewer	*I'm keeping an open mind on that at the moment, it's not…….*
Informant	*You think that NGOs with short-term funding are capable of doing that? (406, pp.4-5)*

From the local NGOs' perspective, they may see potential programs which they would like to develop, but because of short funding cycles there is little chance of running such programs. A local NGO manager gave an example: she sees a need for a hospice for those too sick to be cared for at home but who need no hospital treatment. When I asked if she had tried to establish such a program she replied:

> *No actually, because we have no opportunity to do this, [and] we have not applied. … This is the problem, you receive, like, there is a fund opportunity but they give you the priorities, and [in those you typically] … don't find [the] elderly. Even like the current project, [the donor] is exceptional — like usually they fund projects for nine months, and this is really kind of them to continue funding it since 2002. But always, always they say, you know we have to think of exit, you know, [what would happen were they to exit], and they know the program is very important. But at the same time we never know when it [the end] will be, or what they will say to us. (401, pp. 7-8)*

These responses illustrate the ultimate control the donor has over the services provided in the camps. NGO service providers in the camps are funded by donors via an international NGO which operates in a top-down manner: it decides what services will be provided.

The degree of liaison between donors and both local and international NGOs will vary, but the role of the donor as a source of funding and as a determiner of the needs of the community make its role powerful.

The nature of these NGO links are loose and temporary. An example of this was cited by all the participants. Two NGO CEOs, one from Bourj el Barajneh camp, and another from a Lebanese NGO running a small program in a Palestinian Christian camp, met at an international conference on refugees. Having returned to Lebanon, they met with the local manager of an international NGO with which one NGO had previously worked. Several meetings later they had put together a plan to provide home nursing and rehabilitation services in the camps in which they worked, and the plan was submitted to a large international donor. The project expanded gradually. With funding from the same donor, it grew to incorporate most camps, and many of the smaller gatherings. A third local NGO joined the partnership, operating the program in camps unfamiliar to the initial NGOs, and the international partner changed once. Importantly, the partners continued to run other programs, independently of each other, but they worked closely on this specific project (this narrative is drawn from several interviews, 401, 402, 403, 417, 427, and 430, including respondents from the local and international partners and the donor). The advantages to this partnership included access to funding, a larger workforce to develop ideas, and local knowledge of specific camps, which the small local NGOs may not have. One partner funding a home nursing program in Bourj-el-Barajneh camp had recently lost a donor, and so was looking for another donor to fund this program. By forming a loose liaison with another NGO with connections to an international NGO, they were able to expand a home nursing program, both in extent and in size of population covered.

This partnership appears to have been initiated by the local partners; however, others have been initiated by the international partner. One such program focused on women's health, and family planning. The small donor had identified a need and employed a technical advisor. They then approached two larger local NGOs. This created a wide skill base and a wider set of communities to benefit from services (404, 419 and 423).

In another example, UNRWA and an NGO formed a temporary partnership, in developing an aged care social centre in the camp. The need had been identified by both the NGO and UNRWA, and UNRWA funded the initial costs for a venue and equipment (408, 410, & 426).

The NGOs form liaisons to maximise access to resources and penetration of their services; their multi-level focus may be on the camp as a whole, or on neighbourhoods or individuals. They include donors, international NGOs and local NGOs, as seen in Fig. 36.

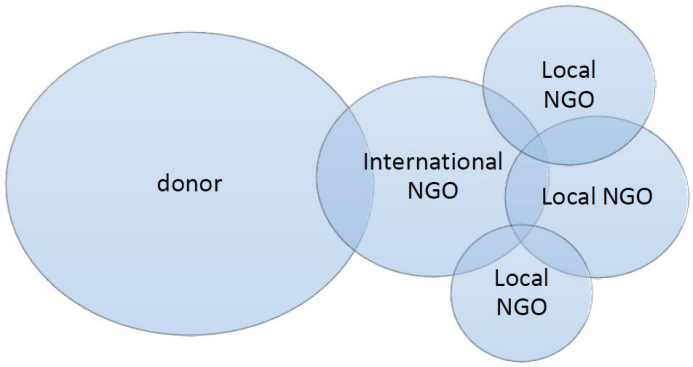

Figure 36: The liaisons formed by service providers

The PLO is both a service provider and a powerful political agency within the Palestinian community. As Rubenberg described the PLO organisational structure in her 1983 article; the National Council was then the official body, functioning as a proto-parliament. However, with Palestinians spread over much of the world, voting by individual Palestinians were not realistically possible. Membership of the National Council was chosen by the member organisations from within their memberships. To manage day-to-day-affairs an Executive Council of 15 people was elected from the National Council (Rubenberg 1983, pp. 57–60). Rubenberg believed that this system of management was working well at the time of writing; however, as described in section 8.1.3, the period following Rubenberg's study saw conflict between the armed political parties, with fighting and formation of outside alliances to support their militias. My data strongly suggests that this seriously damaged the credibility of the PLO as a political force in the eyes of the refugees. Yezid Sayigh (1997, p. 31) debates the reasons for this internal conflict between the armed political parties, relating it to problems with style of leadership which involved a 'jealous grip on power (which) prevented rational planning, minimized learning from experience and impeded coordination of resources'. Thus, though the PLO was a coalition in one sense, in another sense it had developed into a monolithic structure under the control of the armed militias.

While the PLO acts as a peak body, within the camp community it has gone from being the body which removed the gendarmes to the body which 'came and ruined everything' (103, p. 6). Rubenberg identifies a reason for this failure of the PLO, when she says the Israeli invasion 'was a systematic attempt to destroy the entire civilian infrastructure of the PLO'. This belief was supported during an interview I conducted with a PLO representative from Bourj-el-Barajneh camp. I had explored his ideas on why social services were now weaker than in the period 1969 to 1982:

> *Interpreter* *Some Arab countries [provide] aid, but right now no Arab country will give any kind of aid, or donate it for the PLO. They set some terms or conditions which the PLO don't agree with.*
>
> *Interviewer* *… Is it possible to tell me what sort of conditions that are limiting them? [Arabic Interpreter, Informant]*
>
> *Interpreter* *Some of the Arab countries are trying to put some pressure on the Palestinian decision to negotiate with the Israelis, so they [Arab governments] use money that they [Palestinians] have to depend on for many of their basic rights, so that's why they're not responding to this request from the Arab countries, and that's why the Arabs aren't giving them the money, like before because they didn't... [Arabic Informant] Also the Europeans and the Americans are … putting the same [kind of] pressure and same terms, and that's why they [PLO] are not getting the funding, like before……. And from this issue it leads us [to conclude] that these donors, the European, and the American, and the Arab countries, they don't see the humanitarian side of the Palestinian question [that exists] outside their own countries. All that they care about is their politics and the [Arab–Israeli conflict]. (424, pp. 3-4)*

Thus the international community uses aid money as a weapon to force certain political actions on the PLO, rather than attacking it directly as they did in 1982; however, the long-term effect of both types of coercion is to reduce the power of the PLO to provide services to the refugees.

However, that is not the only reason for the declining influence of the PLO. The people living in the camps felt excluded from the management of its organisations, as was explained by this woman living in the camps:

> *At the beginning, we held our heads high and we wanted to join badly, when we saw it became something else, we sat aside. We are the ones who established it but when we saw it working on things that [cause] harm. It harmed us more than helping us ... we didn't know how to manage our revolution in a right way, to be [effective]. (104, p. 8)*

Her comments suggest that initially she felt a sense of belonging, and that the PLO was supporting her views, but that ultimately the refugees did not know how to manage such an organisation and so outsiders stepped in to manage it.

Both the factionalisation and the disenchantment of the camp refugees suggests top-down management within the PLO. The organisations within the PLO fell to fighting among themselves, and the camp refugees rebelled by disengaging from the organisation.

Thus the tightly-organised partnership of the PLO eventually failed, from a combination of outside pressures and internal organisational problems. The looser NGO partnerships are temporary and project-oriented, and appear to function at that organisational level. Importantly,

the NGOs rarely try to apply political or social pressure to empower the community as the last stage of the continuum of empowerment suggests is needed.

8.3.5 'Problem identification and assessment'

Laverack uses the term 'problem assessment' to focus on the problems identified and assessed by the community, rather than needs as identified by outside agencies (Laverack 2004, p. 91). Problems in the camps have been identified by both outside agencies and the community itself. I have already referred to assessments undertaken for donors (Ugland 2003, Lemire, Dubois-Rondon et al. 2004), and by international NGOs (McCue 1994; Abu Sharar 2009). These reports include qualitative and quantitative research to identify socio-economic problems and assess their nature and extent in order to assist the NGOs and the donors to prioritise aid programs.

These assessments are linked to deep knowledge of the community. For example, the report produced by McCue concluded that women found caring for elderly relatives difficult (401, p. 1). The local NGO CEO for whom McCue's needs analysis was undertaken commented:

> *[We rely on] observation and our own experience; like … my own parents' became very sick also, noticing their needs and how it's incredible what the family will do for them, … Also watching others, like neighbours and friends, watching all the time with the older people (401, p. 1)*

Thus the organisation identified a problem informally and the international NGO provided a formal 'needs analysis' such as a donor would find acceptable. In a second example, a social program for elderly refugees (run by another NGO) identified the problems which elderly beneficiaries have in affording medicines not provided by UNRWA clinics:

> *… After eight months of running this program, they suggested to the donors to start helping the elders, by giving them [free] medicine because UNRWA started to decrease their services; by helping these elders, and by giving them medicine, and because of the difficult economic status for the Palestinian. (416, p. 2)*

The refugees themselves are able to identify the problems which affect their lives, as discussed in Chapter 6, where several refugees expressed a belief that their emotional and psychological health was linked to their chronic illnesses in older age.

The NGO partnerships collaborate to identify problems. For example, an international NGO technical advisor had noted within their women's health program the incidence of high levels of anaemia:

> *The anaemia, UNRWA says is about 25%. In actual fact they count anaemia as …. 9 grams/decilitre, but World Health Organisation's definition of anaemia in pregnancy is 11. So if you take into account World Health organisation definition, 60% of our mothers are anaemic and about 11% are chronically anaemic; and [that level falls] below 9% as they go into childbirth. (404, p. 4)*

This technical advisor identified a specific problem and within her program was able to act on it, including giving advice on supplements (404, pp. 4–5). However, this technical advisor also stated that UNRWA are under-assessing the prevalence of anaemia. In the year following data

collection (2010) UNRWA started a program specifically to address the problem of anaemia. In addition to iron supplementation the program included methods to improve dietary intake of iron. The program was implemented by a coalition of UNRWA and local NGOs (UNRWA 2013). In considering these two programs, the initial NGO focused on medical intervention and there then appears to have been further problem assessment ahead of the UNRWA program because, in addition to supplements, that program offers advice on dietary changes. The press release by UNRWA (2013) does not discuss the development of the program, but it is reasonable to suppose that there was some progression from the earlier NGO program, suggesting that re-assessment took place.

The community is thus able to identify its problems, and with the assistance of the NGOs is able to express these in formal 'needs assessments'. The partnerships of international and local NGOs have then developed programs to address these problems. However, though community members can both identify problems and assess them, they remain dependent on donors to achieve solutions.

8.3.6 'Resource mobilisation'

Lavarack (2004, p. 93) considers that the ability to mobilise resources within the community and negotiate them from external sources requires high levels of skill and organisation. Within the community few people are able to contribute financially to community services; however, they do offer considerable human resources. The Palestinians have had access to schools since UNRWA schools started in 1950. Employment outside the camps is restricted, meaning few people can work in skilled employment. Many have benefited from vocational training through UNRWA's schools or higher education but despite this they can only work inside the camps. This means that the NGOs have a valuable source of skilled labour to draw upon. In addition, they can provide a body of local knowledge about the camps and how they operate not available to outsiders. Thus human resources are mobilised by linking educational achievement and local knowledge. For example, the doctors and nurses from the UNRWA clinic were all Palestinian and fully qualified in their fields (305 and 306). I also interviewed the physiotherapists of a home rehabilitation program (304), who were both Lebanese (very few physiotherapists are Palestinian). However, they work with a locally trained registered nurse skilled in basic therapy techniques, and so they have been able to combine professional and technical skill with local knowledge.

The ability to negotiate outside resources has been discussed in relation to donors (section 8.3.4). However, there is another group of donors who come from the wealthier members of Lebanon's Palestinian community. These people have often acquired Lebanese citizenship, but still identify with the Palestinian community. They contribute time (human resources) and money (material resources) towards the welfare of the camp populations. For example, one woman

worked with one NGO and then started another; she comes from a wealthy family and described the donation of a small farm to her NGO.

> *It's like a summer house [retreat]. … Nobody's using it now and it's 24,000 square meters of land with fruit trees, and there's a house with a pool, a couple of sole buildings. I have literally confiscated it from my husband's family. I'm starting a centre….. for children and elders. So there they'll be able to do things that they would never be able to do in the in the cage of the camp ….. To be like a complimentary parallel program, we go swimming, arts, music, some farming, kids will have their own little vegetable patch — they take some parsley home. We will have something like little cuttings which will have the chickens...., rabbits and some goats. ……. Yeah.... So, we've been going with elderly to this place and that's where they meet. The ones at Bourj el Barajneh and Nahr al Barad, and they love it, for example, making jams and, you know. (426, pp. 25–26).*

Another NGO has received funding from a private individual, for one of its programs:

> *The centre has many departments, but the main department is the library which was funded by Mr (xxxxxx); this library includes many kinds of books, and includes many topics useful, also that our computers which have Internet that helped the students. (416, p. 1)*

This level of generosity appears rarely; however, several of the NGO managers I spoke with either never lived in a camp or no longer live in a camp, but still work for the community, contributing their time and expertise (401, 413,414, 415, 420, 423, 427, 428).

Human resources extend beyond the contributions of the NGOs; they include the unique characteristics of the community. Distrust of the PLO has been discussed but there were also suggestions of distrust of the NGOs in the collected data. During one social worker focus group there was a suggestion that people receiving NGO services are expecting more from service providers than can be provided, and are both angry and depressed because services do not meet their needs (309, p. 4). These social-workers found that elderly people believed that the Popular Committee, political parties and NGOs tried to help people in the camp, but were unable to meet their needs, 'People are saying that these organisations are liars' (quoted from notes taken during focus group 309). On further discussion the social workers said that people expected the organisations to provide services in the way a government would, which was unrealistic, and any shortcomings in services were blamed on the providers. For example, these social workers told me that within their program they had negotiated half-price for a few diagnostic tests, and some people then became angry that all diagnostic tests were not available at half-price.

As discussed in section 8.1.3, the PLO lost the trust of some of the refugees when factional fighting occurred in the 1980s, and there is a suggestion that some NGOs were now losing trust in the refugee population. Overall, the Palestinian organisations have managed to negotiate outside resources, and human resources within the community, but not sufficiently to provide the services which the community see as being necessary for long-term survival.

8.3.7 'Program management'

Laverack outlines the factors which indicate that program management is likely to encourage empowerment, it needs to be sustainable and it needs to use community empowerment approaches (at least in part) so that community members will continue to manage the program over the long term (Laverack 2004, pp. 98–99).

A variety of programs in the camp are currently being managed by NGOs, and though the PLO have fewer programs running at present, in the past they have managed large and complex programs. The Popular Committee and PRCS focus on service provision, as outlined in section 8.1, as does UNRWA:

An NGO which has a program of vocational training has started to focus on divorced women:

Informant	*… And lately we are having lots of divorced women.*
Interviewer	*Coming into the program?*
Informant	*Divorced women and, either divorced or battered women, or… Yeah, people … Women who have problems.*
Interviewer	*Right….*
Informant	*Sometimes they are old. Now I have somebody who's, maybe about 50.*
Interviewer	*Right…*
Informant	*She came to me. I said 'OK, come'. She has… she was divorced, now she has two daughters, one of them became married… [and there is] another daughter … she needs to sustain.*
Interviewer	*Right….*
Informant	*So we have a number of women that came to our schools in Beirut and signed up and they started studying after getting divorced, or married and after also she becomes [widowed] ….(415, p. 25).*

The program focuses on vocational training but there is an element of helping women to manage their own lives when widowed or divorced — to take on the role of bread-winner and support their family. In addition to the vocational training for women, this NGO has programs to help women to participate in political and societal activities, including training in public speaking, debating and negotiating. This program has trained trainers who then work within their own communities (both Palestinian and Lebanese). Within the camps they are negotiating with groups such as the political parties and the popular committees to include women in roles of leadership (415, pp. 29–30). In line with Laverack's indicators, this program has been funded long term by an international donor, with a decades-long commitment to Lebanon. However, the local managers are Palestinian and Lebanese, and the programs are managed from the local office. It is clear that they are empowering women by encouraging them to take roles not traditionally theirs.

A second example, within UNRWA's health program, is less likely to empower. According to the senior medical officer in Lebanon

Informant *We have a technical instruction, technical guidelines, on how to manage diabetes. And hypertension and these chronic [conditions].*

Interviewer *What are they based on?*

Informant *These are prepared at headquarters, and they look at the WHO guidelines, what is the best practices in the United States, best practices in other countries of the world, and they adapt them to the UNRWA situation. (409, p. 2)*

Thus the UNRWA doctors follow directions for treatment generated outside Lebanon. I have already discussed the problems UNRWA has in sustaining its programs (Section 8.1.4 and section 7.1.2), as they have reduced funding for hospital services. While they employ Palestinian staff, UNRWA does not encourage community or employee participation in program management.

The diversity of services operating, including UNRWA, PRCS and NGO clinics, suggests that UNRWA's approach has not met people's needs. An NGO manager whose organisation runs clinics at low cost (US$ 3 to 4 per visit) described how people reach her clinics:

> *Someone ... has an ailment, where does he go to? He goes, first of all to UNRWA. Why? Because it's free of charge. So he goes to the UNRWA clinic and there he doesn't get proper treatment, unfortunately, because ... the UNRWA doctor is overworked and he sees, according to their annual reports between 90 to 110 patients per day, and we're talking here about half a day and it means he cannot give more than 5 minutes time for each patient, which in my opinion is not enough for a good check-up and for good treatment. .... This is what mainly happens, and so although the service is free but it's not good quality service. … So that's why they go the next step, then maybe might go to PRCS clinics. PRCS clinics we have sometimes doctors, but don't have the medications to go together with the treatment.... They [patients] have to pay for the fees of the doctor, then they go and pay in the pharmacies for the medications prescribed. This is another problem. Or they might come to a clinic like (our clinics). In part they get good medical treatment, quality treatment, Medications they have to pay for but at the cost price. (420, pp. 25–26)*

This NGO clinics are run by Palestinians, employing Lebanese doctors who work for small fees with Palestinian ancillary staff. The program is sustainable while the doctors are willing to work for small fees and the Palestinian community goes on managing the program.

The PLO has run complex programs in the past, including SAMID. According to Rosenberg (1983) this program had two functions: training Palestinians and providing material necessities at affordable prices. SAMID operated as a community-owned cooperative, and workers participated directly at all management levels. The products were sold both locally and internationally. However, if capital was needed it could access loans either commercially or from the PLO (pp. 66–69). Thus it met Laverack's indicators as an empowering program — it was both sustainable and managed by the community. The factories in Bourj-el-Barajneh were destroyed in the 1980s and have not been rebuilt. When I asked a PLO cadre about the possibility of reopening these factories he said:

> *They have this idea, but the problem to prepare SAMID again, they are going to need about 10 million dollars for re ... not rehabilitation, like modification, and equipment and everything, so it's going to need about 10 million dollars, and who would give them 10 million dollars to bring this back, or to make this place work again, like in the past? In the past they used to have money. (424, p. 7)*

This program also met Laverack's indicators for empowering program management, but the destruction of war ended the program.

There are still programs running within the camp community which encourage empowerment. However, internally the poverty of the community makes it difficult to fund projects sustainably without calling on outsiders to donate time or money. While some programs encourage self-management from within the community, others do not.

8.3.8 'Asking why?'

The domain which Lavarack summarises as the ability to critically assess the reasons for their disempowerment (Laverack 2004, p. 94) is vital to the success of the preceding domains. My informants from the camp, both older refugees and local people working with NGOs, feel unable to significantly change their situation (disempowerment). They do not blame themselves. Self-blame is considered an indicator for disempowered communities by some (Labonte 1990, p. 68). Almost universally, the refugees and their organisations` blamed international politics.

Elderly refugees expressed themselves in several ways on this topic. One man was angry at being called a 'refugee':

> *We are living [by means of] our work and our children's work. This is all from Allah. The word refugee is an insult. I have been here for 65 years and you are still calling me a refugee. (103, p. 12)*

A second informant blamed the world community, saying it should support him, being responsible for his losses:

> *If you want to talk about UNRWA [why should] we be grateful for them, because no matter what they serve, or no matter they offer services for the Palestinian people they have already taken the price, because they were the ones who. , kick[ed] us from our land and brought us here and all these... The donors who donate money for the Palestinians, they were behind encouraging the Israeli, and supporting the Israeli, and that's why the Israeli are existent in our country and we are here. So they have to pay. (116, p. 20)*

A third respondent focuses on the Arab countries who have made promises which are not being fulfilled:

> *I was born in Bourj El Barajneh camp, I lived my childhood in the camp … after a very harsh [time of] suffering in both summer and winter, with a hope to return to Palestine. And our people didn't realize the international and Arab conspiracy [against] Palestine. The people were simple. The Arab countries used to promise them that they will return to Palestine after a while, and this short period [kept being] extended till this short period is now more than 60 years. (120, p. 2)*

Thus, though the refugees are aware that they have no power to change their situation, they do not internalise this powerlessness and blame themselves but rather they look at the factors which made them refugees and have condemned them to remain stateless.

One of the PLO cadres talked about the reasons for health problems among Palestinian refugees:

> *When they [can] go back to their villages, to their fields and they have their normal life that they used to have. Then this normal life, it prevents their sicknesses because they didn't have it in the past when they were in Palestine. (425, p. 17).*

Thus the blame for poor health outcomes experienced by the refugees is placed on their status as refugees rather than on their own behaviours or fecklessness.

NGO workers rarely indulged in self-blame or victim-blaming (local NGO staff are principally Palestinians). For example, a woman working with an NGO expresses her awareness of her rights in international law:

> *People kept talking about going back. Because they were promised to go back and it's guaranteed under UN (resolution) 194 (401, supplementary interview, p. 9)*

An international NGO worker observes this from her outside perspective:

> *There was this idea that's the exile was temporary and they could go back. And they held on to that. (404, p. 6)*

Even those who were not born in Palestine have a strong identity which links them to Palestine and which gives them the belief that they are the victims of an injustice. A Lebanese woman working with a local Palestinian NGO recounts what children have told her:

> *'I was born In Lebanon and so I don't know Palestine, but I want to return. (418, p. 18)*

Thus the Palestinian people of the camp do not blame themselves for their disempowerment, but world powers — Arab countries, Israel, USA, the UN — all of whom watched the newly formed Israel make them refugees, and who have maintained that status-quo since 1948. This was expressed by Olfat Mahmoud, interviewed in 2014 on a left-wing Australian radio program, *Late Night Live*, on which she was interviewed by the presenter Phillip Adams. Ms Mahmoud was born in a camp and runs a local NGO in the camps. She said:

> *But I tell you, in 1947 when the decision was made to divide Palestine into two states and the international community signed and approved this decision, they should take responsibility, they should work hard to solve this problem….*

She continues:

> *….. I felt the international community should be ashamed and embarrassed not me. Because they haven't solved the problem yet, and the problem is a man-made problem, it's not a natural catastrophe. We have [been] forced to leave our homeland and of course women and children when they left in 1948, they left in terror, and they were so scared, and they never expected to be refugees for ever (Mahmoud and Adams 2014).*

The refugees were also aware of internal problems which disempower them, including poverty, but they link these to their refugee status.

8.3.9 Beyond Laverack's domains

Lavarack identifies the nine domains of empowered communities. The camp of Bourj-el-Barajneh demonstrated some elements of empowerment processes in these nine domains.

However, there are some gaps in empowering processes. These emerged principally in two themes, and though Laverack includes them as aspects of his domains, I have chosen to treat them separately when analysing this community. These themes are, ‘knowledge within the community’ (an aspect of resource management), and ‘conflict resolution’ (an aspect of leadership).

8.3.9.1 Knowledge and its relationship to empowerment

Knowledge and the ability to use it is a fundamental power. Freire understood this when he developed his understanding of learning; he encouraged teachers to use problem solving rather than ‘banking’ concepts of education (1996, pp.52–67).Laverack considers local knowledge as a human resource (2004, p. 93). Researchers into the validity of lay knowledge have also focused on what people know and how they use that knowledge.

The refugee camp residents are aware of many reasons for their chronic illnesses. For example, this woman developed type 2 diabetes in her early forties and knows it is linked to her mental health:

> *None of my family members have diabetes. I had it from sadness and gloominess. I was upset, and suddenly I found I had diabetes (104, p. 30)*

She knows she has no family history of the disease and the PEER interviewer recalls she is not obese, but she had experienced the War of the Camps and the death of her mother (for whom she was the carer) just prior to diagnosis.

As discussed in Section 6.3, there is a common belief that smoking calms a person and helps them to manage severe stress. As someone who never smoked I find this difficult to understand; however, the literature supports the idea that nicotine (a psycho-active chemical in tobacco) links to central receptors, including cholinergic, adrenergic, dopaminergic and serotonergic receptors, which would have the effect of calming stress and elevating mood (Theraputics-initiative 1997). It also increases the sensitivity of brain reward systems (Kenny & Athina 2006, p. 1207). Thus the refugees who claimed smoking was a stress management technique were correct. However, their knowledge was incomplete; they were not aware of the long-term health damage caused by smoking, perhaps because their smoking had traditionally started in old age (114, p. 9), when the harmful effects had had less time to develop.

The incomplete knowledge of a health-damaging factor was also demonstrated in another part of the data. A western technical advisor, working and living in Beirut, told me that much of the paint sold in Lebanon has a high lead content (404, p. 3). During a discussion with a local NGO worker I asked about lead-based paints and he was not aware that they could be harmful to health.

Interviewer	*The paint that people use on the walls…..*
X	*It varies, it depends, it has no…… nothing specific, anything*
Interviewer	*Anything? Some of it is leaded paint?*
X	*Yeah.*
Interviewer	*The paint comes off because of the damp walls of course?*
X	*Yes. Previously it was better. Previously we used to do it ourselves. Used to buy calcium oxides, the white stuff, calcium it's called. You mix it in water, and we used to drop a piece of err, this blue thing we used with the laundry (405, p. 41)*

Lead pollution and chronic kidney disease are linked, and in conjunction with hypertension or diabetes may affect kidney function at quite low concentrations (Ekong, Jaar et al. 2006, p. 2074 and p. 2081). The houses are damp, with no means to prevent raising damp and limited means to seal the roofs, and so paint peels and flakes, as was seen in some of the photographic data (e.g. Figure 37).

Figure 37: Wall of a shop, showing flaking paint on a damp wall (201, photo 16)

Farfel and colleagues also pointed out that the demolition of houses finished with lead paint can present a danger to health as there can be high concentrations of lead in the dust (Farfel, Orlova et al. 2003, p. 1233). In addition, over time there has been extensive bombing of the camps and the surrounding neighbourhood. Several informants mentioned the unpleasant smells that arise whenever there had been a bombing, linking this phenomenon to illness. An NGO manager who lived in Bourj-el-Barajneh in 2006 recalls:

> *She said it's true that was around, but all the camps around were bombed, and the whole camp was shaking from the huge explosions and the smells were really horrible. (407, p. 9)*

I enquired further, and the interpreter explained:

> *Yeah. I went to Darheh especially after the war stopped and you can't imagine the smell ….. Ask [name of researcher] …. because she got sick. We went to Darheh and she really got sick when we went and took photos.*

Thus there is some lay knowledge of health problems linked to bombings, but not necessarily an understanding of which illnesses may develop.

There is extensive lay knowledge in the community, based on their experiences and the work of health educators. People have integrated this into their practices as far as they have been able to. When there is incomplete knowledge, such as harmful effects of smoking, or no knowledge, as lead poisoning from paint, they are not able to act effectively.

8.3.9.2 Conflict resolution

The second notable theme was that of conflict resolution within the camp community. We don't always agree with those around us and how these differences or conflicts are resolved strongly influences empowerment. Laverack suggests that it is the role of leaders to select and use empowering methods of conflict resolution. Conflicts in the camps are too often resolved with violence; this applies at all levels of camp life.

An NGO manager who runs empowerment programs for women explained:

> *The father is not able to carry out his traditional role. They take care of the family and bringing money and all money and take care of his children, and even the younger… son also is not able to get his education and, you know, maybe battered in the future ... That's why there is domestic violence inside the family. (415, p. 9)*

The NGO programs target both women and men, and from listening to the participants the manager has found violence is linked to emotional tension:

> *Because all this kind of situation, you know, and… sometimes they don't mean to hurt the women, but because they have to get out their tension. (415, p. 10*

I interviewed one elderly Palestinian who worked with the Popular Committee; he described some of his duties as involving mediation in family disputes, a role which he sees as very important:

> *Like if two people have problems and they want to divorce, they have like disagreements between each other they go to the Popular Committee and they work to try hard to sort out this problem and solve it. So sometimes, they [the committee] are able to solve these problems between the husband and wife, and sometimes they can't do anything so they tell them to go to the court. And sometimes, because they become cases, or sue case against each other, like the husband and wife, so the court sends the papers and the orders to the Popular Committee, and the committee takes these papers to the families or couples who are fighting. So this is their job … So their work is to solve these problems amongst the people in the camp. (116, p. 14)*

However, this role of the Popular Committee was not mentioned by other informants, when discussing conflict.

Even beyond the family unit there are episodes of violence; for example, on the night of September 26th 2009 I was awoken by the sound of gunfire. My landlady and her neighbours explained that there was fighting in the camp, about 200 metres away. When I discussed this

with my gatekeeper, she told me that there had been an inter-family argument which 'got silly' (Field notes, 27-09-2009).

These inter-family fights can lead to serious consequences. One informant was willing to share such an experience with me, through the interpreter:

> *So when this guy, he want to go up the stairs her son told him [Arabic Informant]... So her son told him 'It's not allowed for you to go, it's my house', so he [the son] hit him. Because he's got a high position in the camp, he [the guy] said 'I can go where ever I want, it's none of your business'. So he [the son] tell him 'no, it's my house and it's not allowed for you', so they start the fight together then her second son came. … She called him and told him your brother is fighting with the soldier's son. So her second son went down and the fight started and then the father came and asked 'what's happening?' So instead of solving the problem, he [the guy] said, like 'when we talk, like we use our weapons, we don't use our hands to fight, or we don't use our tongues to fight', so he went back and they almost solved the problem. So each one of them went to his place. By that time [the guy] starts to fill his gun ... [the guy] said he filled his gun and he came [Arabic Informant] .... So, he came and he shoot her son and when she saw him she think she screamed at him, so he shoot at her again, too. But he missed her. (125, pp. 28-30)*

The relevant aspects of this abbreviated story are the relative power differences; the 'guy' thought that he had the power to go into another man's house without invitation (my gatekeeper explained this is ill-mannered because the women may not be modestly dressed). Secondly, he asserted that Palestinians resolve conflict by fighting with guns, not fist-fighting or talking. So, tragically, a young man is shot leaving a widow and a fatherless son, and the 'guy' and his family lose their home.

Interfamily violence may not be common, but it can be a source of stress for others in the community. During a focus group with nurses working at Haifa Hospital in the camp, we discussed the problem of young men with guns coming to the hospital, showing disrespect towards the nurses. They even came into the operating theatre without protective clothes. The group agreed that they found this behaviour threatening (302, p. 5).

The tendency to resort to violence to resolve conflict is not a new phenomenon. One older refugee describes an incident shortly after his family arrived in Lebanon, when they were living in Qana, a village in Southern Lebanon:

> *I had a fight with someone from Qana and we hit each other. … I gave him a nice hit. ……I couldn't walk, so he hit me here in my chest with his leg. I waited him in the night and did what I had to do and ran away from Qana… I went to Syria. (111, p. 11)*

Such stories suggest that fighting between young men who have a dispute may have a long tradition in the community, though the current use of guns, rather than fists makes the potential consequences more serious.

The nurses in the hospital, as well as other informants (both elderly refugees and NGO workers) discussed problems of inter-factional fighting, over which nobody has any control. The nurses said that there was no authority to judge problems between the factions: nobody had authority over them (302, p. 5). The problem was also discussed by a PLO cadre:

> *There is no law in this society here. No one is judging and stopping these people from going too far in this violent actions. [Arabic informant] And he said the reason for these problems is that the political parties in the camp ….don't punish the person who's doing this violent action and also it's the family who protect their kids who are doing these violent actions. So that's why, in his opinion, the political parties should, like punish them, not necessarily take them out of the camp, but at least punish them inside the camp so no-one , again would dare to do anything. (425, p. 3)*

Although the Popular Committee offers voluntary mediation services, there is no organisational structure set up to resolve conflict in the camp community. The popular belief is that Popular Committee is run by the factions and that they will not rule against their own members. The family whose son was killed believe the killer had powerful friends who would protect him; the nurses in the hospital are faced with armed young men who demand treatment for their injured friends, and nobody has the authority to challenge them. The extreme level of fighting between factions was seen in the late 1980s when factions fought and destroyed large sections of the camp, as described in section 8.1.3 in the War of the Camps.

Thus conflict resolution relies on violence at all levels of camp life. People describe both acute fear when violence erupts (as I felt, waking up to gunfire), and a background level of anxiety generally. The situation was expressed by one NGO worker:

> *From talking to people mostly, and some observation within our work in the different camps and the gatherings, we see a very high level of tolerance towards violence. And this is violence in the home, which is as simple as using beating as a form of discipline, on all family members; violence in the streets exposure to small arms and light weapons. kids have to walk through checkpoints, internal checkpoints in the camp, armed people, the prevalence of guns, 412, p. 4)*

Informants told me there needs to be better conflict resolution, and less violence, but none suggested how this could be achieved. However, several programs described in the data have a focus on the empowerment of individuals or governance of the community. From the narrative in section 8.1 we see that there is no single authority in the camp; the Popular Committee assumed authority from the PLO during their time in Lebanon, but both the literature and the data suggest that since the War of the Camps their role in conflict resolution is limited.

8.4 Summary of community empowerment processes

This thematic analysis of empowerment processes illustrates the complex reasons why members of this community do not feel in control of their lives. It is summarised in Table 7.

Table 7: Summary of processes of empowerment attempted by civil society in the camp

Processes of empowerment	Successes	Failures	Implications for health
Participation	• Close family connections • Close neighbourhood connections • Participation in formal NGO activities	• From early participation in PLO activities there is less political participation	• Participation which is pleasant helps mental health • If participation is physically or emotionally demanding it can

			be harmful to health
Leadership	• NGOs have leaders who train others, and have a hierarchy of leadership • Elders (traditional leaders) will step in when needed	• PLO has a strong leadership, but with little change over the years.	
Organisational structure	• NGOs have empowering structures, but function principally within the community	• PLO has less empowering structures, but operates at the international political level as well as community	•
Role of outside agencies Links to other organisations	• International NGOs include technical advice and links to donors. • NGOs form temporary loose coalitions for specific projects The PLO is a long-term coalition of a many organisations	• Donors dictate the programs they will fund, and hence the services available • PLO donors dictate political policy of PLO • Disagreement between PLO members, with disagreement leading to war	• Health services limited to those donors consider appropriate • PLO supports its the PRCS, a provider of clinics and hospitals, • War between factions has consequences to both physical and mental health
Problem identification	• Good background in using formal needs analysis • Use of local knowledge of the community to fully understand the problems which need addressing		
Resource mobilisation	• NGOs (locals in coalition with international) have accessed donor funding • Wealthy Palestinians have donated material and human resources •	• Despite resource mobilisation the community has not managed to achieve the range of services that the community see as being needed, and so there is dissatisfaction	• There have developed a wide range of both health education and curative services • However fragmented services can be difficult to navigate
Program management	• The NGOs have attempted bottom up management, from both junior staff and	• PLO has tended to top down management structures, both at the local levels	

	participants in the programs	• UNRWA has top down management structures	
Asking 'why?'	• Blame for the health and general situation of the refugees placed on external entities, including Israel, USA, UN and Arab leaders	• Tendency therefore to not look at internal causes of problems	• Placement of blame for disempowerment on outside power structures avoids health harm from self-blame
Knowledge	• People have used information available to them to identify reasons for health problems	• There are gaps in knowledge, particularly of long term effects.	• Some long-term effects can be contributing to the chronic illnesses people suffer
Conflict resolution	• Some NGOs are exploring new ways to manage domestic, neighbourhood and community violence	• Tendency to resolve opposing positions by violence, within the family and the community	• Stress and physical injury from violent conflict resolution habits

This table illustrates some processes that facilitate empowerment within the community emanating from both the PLO and the NGOs; however, as the table shows, there are actions of organisations which have inhibited empowerment.

8.4.1 Why does the community feel it is powerless?

In considering why my informants from Bourj-el-Barajneh camp felt powerless to manage their social problems, and specifically their health problems, I have examined the issue of empowerment contextually using two methods: firstly, I asked whether the elements of an empowered community were present, using the continuum of an empowered community as my yardstick. Secondly, I considered the processes of empowerment, using and extending Lavarack's domains as relevant to this community. Using these two methods I identified some reasons why people felt powerless by looking for the pathways and agency for disempowerment and then documenting any progress towards greater empowerment.

8.4.2 Attempts at community empowerment

I found that processes are already in place to support community empowerment. These processes involve people who are personally empowered. People also communicate with each other, both formally and informally, in small groups to discuss matters of concern. There are locally based activist organisations and these form coalitions to extend their effectiveness. Finally, the PLO have effectively managed political action in the past, and the NGOs are

attempting social action currently. Thus community empowerment could arise in the future from one or more of these social structures,

However, in terms of empowerment-friendly processes within various organisations and coalitions, while some did focus positively on community empowerment, this was not consistent throughout, nor was this approach consistently adopted within organisations over time. I have focused on the PLO and the NGOs, because that was where the greatest detail lay in my data and in the literature. However, I observed from the data that UNRWA was a strongly top-down service provider, with a focus on providing services rather than encouraging self-management. I was also aware from the data that some men use the mosque as a base for social activism; however, I did not collect sufficient information to critique this in relation to empowerment processes.

The PLO appears to have originally aimed to empower the Palestinian community as a whole, including the entire diaspora. It is a coalition of the organisations which formed Palestinian civil society in the early 1960s, including political parties, service-providing organisations (NGOs) and unions. Based on Rubenberg's analysis in 1983, the PLO had attempted a form of representative democracy, drawing on representatives of the various organisations to form a body analogous to a parliament, with an executive committee analogous to the cabinet in a parliamentary democracy. However, by the later 1980s, according to Yezid Sayigh (1997) the armed political parties had come to dominate the executive committee and had also fallen to armed conflict among themselves: in Lebanon this was known as the War of the Camps. My elderly informants suggest that this whole period was one which they found disempowering, with Palestinians fighting against each other, and people no longer trusting the PLO's organisations. Yezid Sayigh also highlights the top-down management of the PLO by the 1980s, with minimal changes happening in the PLO executive committee from the 1960s to the 1990s (when he wrote). Thus the PLO fails in critical domains of empowerment; its organisational structures tended to be top-down, the coalition became factionalised, and there were poor mechanisms for conflict resolution within the organisation, leading to poor participation by the camp residents. However, the PLO had its strengths — it had links across numerous member organisations and through these good access to significant resources. The focus of political education in the 1970s appears to have established an understanding that the Palestinian diaspora was not responsible for its exile, and the subsequent social problems, thus encouraging people to look outside themselves for reasons for their dispossession, rather than falling into a pattern of self-blame, which is a common phenomenon among the disempowered.

The NGOs, both the older ones which were originally part of the PLO, and the newer ones which have arisen since the end of the Lebanese Civil War offer a wide range of services and programs, including programs linked to education, health and social support. Each program

appears to have some degree of empowerment involved in its design, some being top-down programs, such as the PRCS hospital service, while others are structured to encourage empowerment of the community members, such as the Danish Refugee Council's program on protection (Abu Sharar 2009), undertaken in collaboration with several local NGOs and funded through ECHO (the European Union emergency aid donor). Most of these programs include overt or implied elements of empowerment. However, as the funding for these programs is limited by time, geographical area or scope, and remains under the control of the donors, this often translates to a scarcity of resources for programs.

Structurally, many of the NGOs tend to have more participatory management structures, and develop leadership skills among both program participants and their workforce. Because the local NGOs draw both workers and management principally from the Palestinian community, they can demonstrate and model the strengths of a community which comes together to manage its own needs. However, the fact remains that these local NGOs cannot raise resources locally; they remain dependent on donors and the international NGOs who have access to the donors. Thus the funding structure demonstrates the subservience these organisations have to the donors, few of whom come from the Palestinian community.

Thus it appears that internally there are limits to the ability of the community to empower itself through the political actions of the PLO or the social actions of the NGOs, both having met with partial success at different times, but neither being able to sustain that success due to problems both internal and external to the community. This should not limit the ability of the civil society organisations to foster empowerment through some of their programs. As Lavarack and Labonte (2000) suggest, it is possible to combine both a top-down program design to meet the needs of a donor and a bottom-up program design to encourage empowerment of the community. Thus, while working within the guidelines of donors it may at times be possible to empower the community by addressing their needs as well as criteria imposed by the donors.

8.4.3 External influences

As discussed, donors, whether contributing to the NGOs or the PLO (section 8.3.7), inevitably have influence over the programs that are implemented with their funds. As there is no tax base within the Palestinian community, donations are the operational basis of both groups of organisations. This is seen from comments made by the local NGO managers, the local PLO cadres, and from the literature (Jansen 1982; Rubenberg 1983). Though there are some donors from the community itself, this is not sufficient to maintain the level of services the community believes it needs, nor can it match services which are available to poorer sections of the Lebanese community (402, p. 6).

A reason for the inability to provide services comes back to the refugee status of those living in the camps. As long as their status remains that of stateless refugees, they are not included in broader Lebanese society, which provides important social safety nets, such as free government hospital services (402, p. 6). The refugees are dependent on their personal earnings (limited by Lebanese law to the lower-paid jobs, as discussed in section 6.3) and their social services depend on donations, either channelled through UNRWA or the civil society organisations, including the PLO and the NGOs. Donations flow from both governments and individuals around the world. Individuals may contribute to civil society organisations or directly to families living in the camps (for example remittances from family members who have emigrated). However, it appears from discussions with both organisations in the camps and elderly refugees, that these are regarded as inadequate.

To change their status from refugees to either citizens of a new country (Lebanon or a third country) or return to their country of origin requires political action. The PLO has been attempting that political action since it formed in the 1960s, using both war and diplomacy at different times, to try to achieve this end, but has failed for a range of reasons that lie beyond the scope of a study into health. However, it is relevant to identify the strong resistance which the PLO has encountered to its political actions, and which the refugees identify as coming from Israel and the US. Several refugees made comments such as this:

> *We did the revolution to fight the Jewish [people] and go back to our country; the whole countries, USA, this and that put their hands in this [issue] but here we are, refugees in the camps for 63 years and there is no result, not inside Palestine or anywhere. (107, pp. 20-21)*

The NGOs in general avoid political activity, focusing rather on the social needs of the community. The principal exception to this, I found, was the work of the Danish Refugee Council, which was running a program on protection (Abu Sharar 2009, p. 5). This program operates at three levels: individuals, the camp communities, and regional/national levels, with advocacy, coordination, and information dissemination. Abu Sharar's study, on a part of the program, found that their unmet basic needs concerned her informants more than their lack of rights (p. 29). However, I would argue that the problem is cyclic: without political action rights will be neglected, and without rights basic needs will remain unmet. Understandably, the refugees focus on their day-to-day needs. By encouraging participation in civil society organisations, and by facilitating empowering policies and processes within them, the community may be finally be able to identify effective ways of overcoming the outside pressures which limit their effective agency.

8.4.4 Who has the power?

The overarching problems that limit the ability of camp residents to manage their health, I concluded in Chapter 7, were poverty, war, and refugee status. My informants felt powerless to manage these problems. Though I have identified both internal and external processes which

limit the development of an empowered community, I conclude that the bulk of the power to make changes rests with the international community. The Palestinian refugees have combined forces in many ways to tackle their problems, but have been frustrated by greater powers than they can overcome. The frustrations of these failures have only exacerbated social problems within the community, leading to the proliferation of small power bases with fragmented leadership and poor conflict resolution mechanisms.

Despite these setbacks, I suggest that civil society makes a conscious attempt to empower the camp community in all its social programs. As well as helping the community to manage its problems, including health problems, it may be possible to see the birth of effective political and social action that will awaken the international community and bring all parties to the negotiating table to assist in resolving the present impasse.

9
CONCLUSIONS

In this chapter I summarise the study findings in relationship to the research questions and in relationship to the body of knowledge relating to chronic illness and health in older age. I will also consider the strengths and limitations of the research. Finally, I will briefly consider further potential research among these refugees or in other communities which could draw on this research and extend its findings.

9.1 Research questions

My overarching purpose in undertaking this research has been to understand how their lived experiences have contributed to the health status in old age of Palestinian refugees living in Lebanon, and to examine the implications for addressing these health issues. In the process of identifying the contributory lived experiences, using Krieger's ecosocial model of health, I soon became aware that a feeling of powerlessness limited the community's ability to address health issues as well as other problems in their lives. The issue of powerlessness was used as a lens through which I have examined the implications for health service provision to this community.

To meet this aim I posed four research questions.

In relation to the Palestinian refugees in Lebanon:

1. What aspects of their lived experiences impact upon health in old age?
2. How do their life experiences interact with each other to support or detract from good health in old age?
3. Where does the power to change these life experiences to promote better health in old age lie?
4. How do these lived experiences, the interactions between experiences and the power to control the lived experiences impact on health services in this community?,

9.1.1 Lived experience and health in old age

The first two questions were explored and analysed through the lens of Krieger's ecosocial model (see Figure 38). This model considers how the life experiences are embodied in the individuals of a community. She also considers which societal structures contribute to health outcomes, and at which social level they operate. Krieger groups these two concepts into three overarching historical episodes and societal divisions. However, these groupings are based on the US context, and as this analysis demonstrates, can vary when applied to other communities (Krieger 2009). Thus I have re-drawn Krieger's model to make it applicable to the Palestinians living in Bourj-e-Barajneh camp.

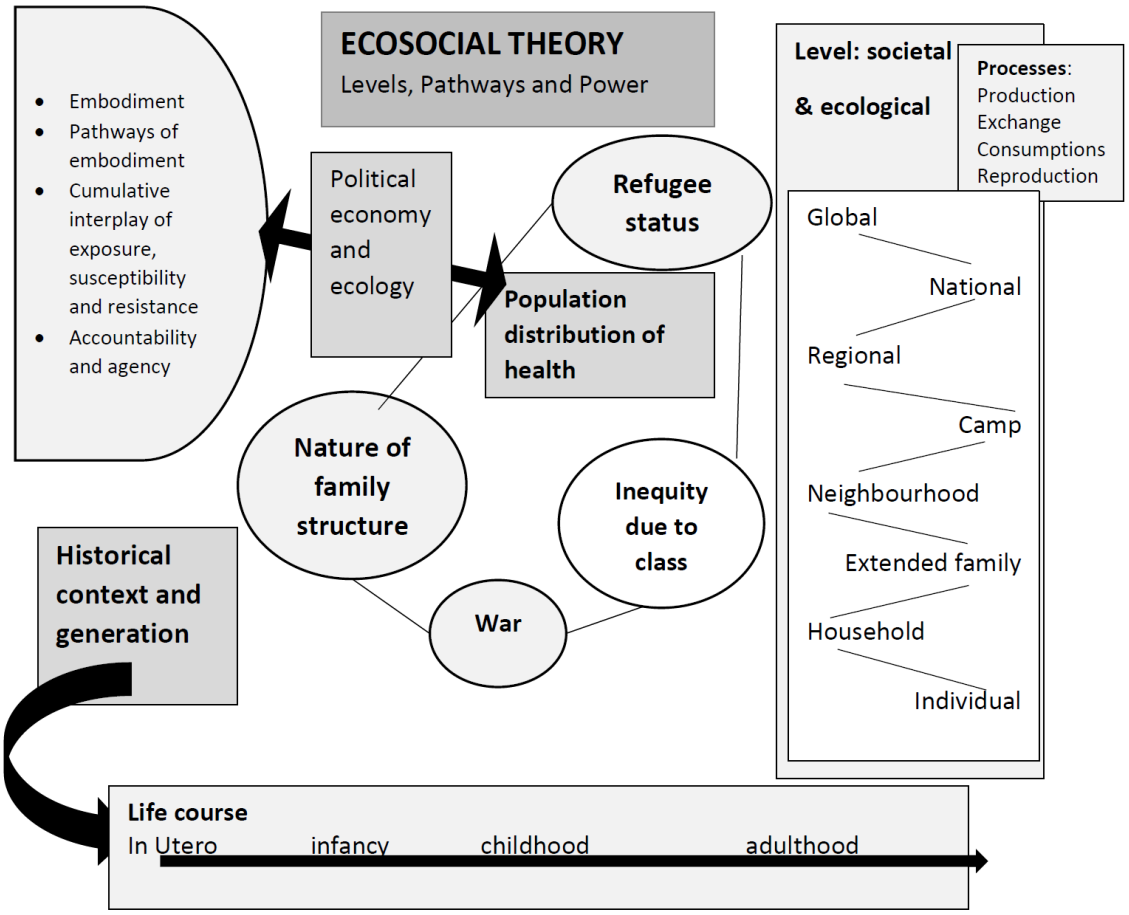

Figure 38: Ecosocial model as modified for the Palestinian community at Bourj –el-Barajneh camp, Lebanon (based on Krieger)

So in response to the question 'What aspects of their lived experiences impact upon health in old age?', the informants' experiences of war, their prolonged refugee status, their original position in the Palestinian class structure, and finally the form of family to which they belong are all factors that have contributed to their health. These aspects form a complex network of interlinked experiences that have shaped their behaviours within social and physical environments, with implications for mental, physical and emotional health.

9.1.2 Life experiences and their interrelationships with health

The second and more complex question addresses the pathways which link these various life experiences to the biological entity which is the person living the life. I have presented these pathways diagrammatically in Figures 15, 22 and 28. These diagrams each focus on a single behaviour known to be linked to health — that being the starting point for the subsequent analysis of health. When examining the pathways which led to these behaviours, including mental and emotional health, physical and social environment and poverty, it became obvious that while these aspects of life experiences have shaped behaviour they are also determinants

of health which may directly shape the health outcomes of a community and the individuals who make up that community.

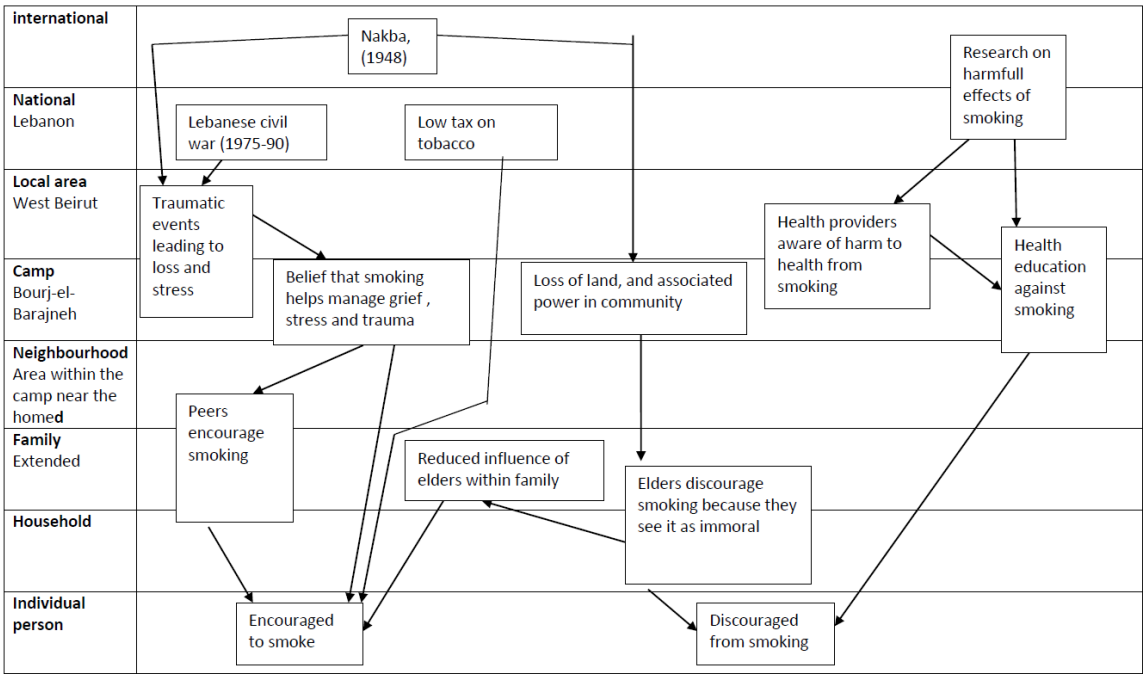

Figure 39: Connections between smoking behaviour and pathways which encourage or discourage smoking (from section 6.3.3)

As can be seen from the example of smoking (Fig. 39), many influences have either encouraged or discouraged smoking. They form an interconnecting network of factors, or web, over multiple societal levels. When this diagram is viewed in relation with the narratives about smoking, it is evident that the emphasis changes over time. Some pathways become stronger and others weaker as the community changes.

For example, there is a part of the web which presents smoking as a way of managing emotional and mental problems. As tobacco contains a range of neuroactive chemicals (Theraputics-initiative 1997) some individuals found it helped them in periods of stress. This has been observed in other communities (Popay, Bennett et al. 2003; Tsourtos, Ward et al. 2008). When people observed their peers under with stress, or other emotional problems, they encouraged them to smoke. The experiences of stress described included episodes in the war, or the loss of close family members. They also included stresses of daily life, exacerbated by poverty, overcrowding and insecurity. As cigarettes can be bought very cheaply in Lebanon, because of low levels of taxation (Salti, Chaaban et al. 2013), they are a cost-effective way of managing stress, compared to the use of medications.

Another part of the web highlights the social pressures to smoke or not to smoke. In Palestine smoking was traditionally taken up by the elderly men; these men were heads of patriarchal families, who would discourage women or younger men from smoking. However, once the

refugees were displaced these men had less control over their families because they no longer controlled the sources of wealth, i.e. the land from which they had been displaced by war. Gradually, younger men and women started secretly smoking, and then to smoke more openly, against the wishes of the elders of the community. As the influence of the elders faded, the influence of contemporaries increased, so that smoking became part of normal social interaction, with coffee and cigarettes being commonly served to visitors.

Another part of the web shows the increase in health promotion activities in recent years, when NGOs have been funded to publicise the harmful effects of tobacco on health. While these groups appear to be waging a losing battle, some older people did refer to the health consequences of smoking.

Similar visual summaries have been provided for diet and physical exercise. As can be seen from the visual analysis of smoking, it is possible to identify the pathways of embodiment, and also to consider where the power lies to make changes in behaviour patterns. For example, considering community interventions to reduce smoking, efforts have been made to inform people about the harmful health effects of smoking, both in general community campaigns, and in one-to-one counselling; however, these strategies are proving to be ineffective: young people continue to smoke, as do those who have developed smoking-related diseases. Other interventions might include the government increasing tobacco taxes, thus making it more difficult for the poor to access cigarettes, as has been suggested by Salti and colleagues (2013). However, while that has proven to be effective in reducing tobacco use in some communities, it may not be as successful as expected, because many in the community understand that smoking assists in stress management and as a social lubricant. Therefore, health education, at the camp community level, could focus on different ways of managing stress, or considering alternative social lubricants to coffee and cigarettes. Stress reduction would be helpful, but may require intervention at a different level of society, for example at the national and international levels. I suggest this because many stressors are linked to war, refugee status, and poverty life experiences beyond the control of the camp community. While Chaaya and colleagues (2006) suggest that antismoking education in the camps is needed, organising information about the camp community within Krieger's ecosocial model provides suggestions for interventions at multiple societal levels, targeted to this particular community.

The detailed discussion of behaviours relating to diet and physical exercise could also identify more nuanced and directed health promotion, based on better understanding of the fundamental problems of the community and the pathways linking behaviours to better or worse health outcomes.

9.1.3 Power to make change

The final two questions consider where the power lies to make changes, and then how that distribution of power affects service provision in the health sector. From question two, which considers the relationships between various interactions of health experiences, I was able to identify the societal forces that exert power over the Palestinian communities. These include the national and international events which have led to wars and displacement. Health has also been influenced by poverty, environmental challenges and even the social inequity that existed within the original Palestinian community of Palestine (pre-1948). In addition, the powerful social traditions of the Palestinian community often control health outcomes through the influence of class and family structure. By analysing both my own data and the political and anthropological literature of Palestinian society I have been able to identify many agents within these societal layers.

Governance structures, both within the camps and within the Palestinian diaspora generally, are complex and interconnected. They have grown more complex over time, as the community has attempted to provide services which have been unavailable under earlier management structures. Initially the primary support services for the Palestinian refugees in Lebanon and other Middle-Eastern countries was a United Nations agency, UNRWA. This agency was specifically created to provide services, not to provide an enduring resolution to the refugee problem. It is funded from direct contributions made by member states of the United Nations. Thus when, by the 1960s, the international community had failed to provide an enduring solution to the refugee problem in the Middle East, a range of organisations, including political parties, armed political militias, NGOs and trade unions came together to form a coalition, the PLO. This organisation was to provide a voice for the Palestinians and a government-in-exile, as well as to complement services provided by UNRWA. Initially based in Jordan, by the 1970s the PLO was based in Beirut. They provided work, health services, vocational training and rudimentary pension services among other activities appropriate to governments (Rubenberg 1983). However, the PLO saw its principal role as political, that of facilitating the return of all Palestinians to their home country. Laverack discusses the situation of coercive and oppressive ‘power-over’ and describes a range of responses by a group trying to empower itself in this situation, using direct action. These actions can range from peaceful protest to riot or revolt (Laverack 2009, pp. 16–19): in this case it meant attacks on the Israeli state. When the Israeli army invaded Lebanon in 1982, the army set out to destroy the infrastructure of the PLO in response to the PLO’s campaign of violent direct action (Rubenberg 1983). Since then, my informants maintain that Israel and its Western allies have used their political influence with some donors to impose stringent conditions on the donation of funds to the PLO (424). The vacuum left when the PLO was unable to provide services was filled by a range of local small NGOs which, along with the longer-established NGOs, formed coalitions with international

NGOs to provide services, using funding from a mixture of small and large donors, as well as from a few wealthy individuals. Larger donors generally have responsibilities to their financial sources (e.g. governments are responsible to tax payers) and there is global competition to attract these funds. However, there are some small donors who focus on the Palestinian diaspora.

Thus the power to influence the health outcomes of the refugees in Bourj-el-Barajneh camp is divided among a wide range of organisations. Curative and health promotional services are run by organisations who are funded by donors, some of whom make their donations conditional on political actions and policies; others look to where they see the greatest need world-wide, and some donate specifically to the Palestinian refugees. Social determinants of health, such as poverty and the physical environment, are also largely in the gift of the donors to service-providing organisations. The host government, which has maintained the Palestinians' refugee status across several generations, and legislated to limit their civil rights also exercises power in this situation.

The overarching societal and historical problems of war and displacement underlying many health problems of the refugees are linked to national and international societal levels. These can be considered separately. The Lebanese state is the host government and was the first place of refuge for the refugees. It has not offered citizenship, over several generations, to the refugees living in the camps (415). The Lebanese government has legislated to make life more difficult for the refugees in relation to the right to work, the right to access government services and the right to own property. The international community, including both Arab states and Western countries, has failed to negotiate an enduring political solution, either by providing an alternative final destination, where Palestinians could establish themselves as citizens of a new country, or else negotiating a safe return to their original villages and homes in Palestine/Israel. Thus much of the power to make changes is controlled by external organisations which wield great 'power-over' this community. While some, such as donors, are benign and often supportive, others, including nation-states, are coercive and aggressive.

9.1.4 Power, lived experiences and services which affect health

Having considered both how the lived experiences have affected health, and who, or which organisations, have power to alter these lived experiences in the future, the next step is to consider whether civil society within the camp or the wider Palestinian community can effect changes to improve the health outcomes for the camp population. I have already touched on this area, when discussing interactions of the various lived experiences, and the societal levels at which they interact (section 9.1.2). Thus, when designing a health promotion activity it helps to refer to the communal experiences that have formed the health-related behaviours; this

allows the program to target potential pathways of embodiment. However, an understanding of where in the power lies to make changes is also important.

In analysing the data regarding the power to make change I considered why the people felt they themselves had no power to effect change, using the lens of Laverack's theories on empowerment processes (2004, chaps 4 and 7; 2007, chap. 5; 2009, chaps 5 and 7). The organisations which form the PLO, the local NGOs and their international partners have all, at times and in some programs, focused on empowerment using some of Laverack's processes; however, they have not applied these concepts consistently. This may be because theories of community empowerment are still in development, and so were not available to health practitioners in past years. In addition, the process of conflict resolution throughout the community tends towards violence rather than discussion and peaceful solutions. Finally, I found at least one significant area, lead pollution, where the community lacks knowledge of environmental health problems, and there may be other gaps in knowledge, as I was not evaluating lay or professional knowledge of currently known health issues.

Thus a useful strategy flowing from the consideration of power and its relationship to health services could be to review processes of service delivery using the lens of Laverack's principles in order to involve the whole camp community in program development. Programs which focus on knowledge could include elements of Freire's problem solving techniques (1996, chap. 2), encouraging input from the wider community, as well as the developing the power of reason to solve problems.

However, as seen when discussing who has power to make changes in the camp and in the services provided to the camp community, the process of empowering the Palestinian residents of the camp to take control of their health outcomes will not happen through small projects, nor within a single camp of the diaspora of Palestinians. The highest level of Laverack and Labonte's continuum of empowerment identifies the need for social and political action. In this case I would suggest that political action at the national and international level is needed to resolve the continuing refugee status of the Palestinians in the Middle East and its associated wars and conflict. As long as both the Arab governments of the countries in which the Palestinians reside (in this case study the Lebanese government) and the Israeli government, controlling territory that was formerly Palestine, do not find a permanent resolution to the Palestinian refugee problem the embodiment of their lived experiences which relate to war and refugee status will continue to affect their health negatively through the pathways I have identified. While my data was collected in 2009, well before the civil war in Syria, and the current (2016) expanding problems of the Middle East in general, my gatekeeper now tells me about the worrying situation for the camps in Lebanon, with a flood of Palestinian refugees from Syria now seeking to access accommodation and services. As discussed in section 9.1.1, war

has always been an underlying societal factor in shaping the health of the refugees in Bourj-el-Barajneh. Thus the empowerment process at the camp level needs to be extended to the entire community of diaspora Palestinians, so that high-level diplomacy on the international and national stage may have some hope of success. However this level of political and social action is beyond the scope of this research.

9.1.5 What has this study meant?

Overall, this case-study has illustrated the complex interconnections between national and international politics, with the life experiences of individuals who are caught up in such politics, and the health of those individuals, in the long term. It also considers how these individuals have minimal power to affect national and international politics that dictate their fate and even when they unite in attempts to empower themselves, they may have little chance of making significant differences. However the larger societal structures, political and social organisations (such as NGOs and quasi-national organisations (such as the PLO, in this case study) national governments, their service providing agencies, international organisations and their service providing organisations should consider the consequences of actions including the impact that their actions have on the populations they speak and act for.

9.2 Implications for refugee health

While this is a case study for a single camp from one community of long-term refugees with an unresolved status, there are implications which should be considered when analysing the health problems of other refugee communities. These will differ with a community which has not had to flee. They may differ again if the refugee community has been absorbed into a host community without discrimination based on their refugee status. Therefore, a full analysis would be needed to identify the nature of the pathways of accountability and agency in different refugee communities. However, without generalising from one case study to all refugees, I would draw attention to some of the pathways identified in this case study that relate to the refugee experiences of this community.

The pathway to poverty starts with the loss of non-portable wealth, such as land and belongings, and is added to by restrictions on work set by the host country. From poverty the pathway extends to inability to buy healthy food, stress over ability to pay for necessities, such as advanced health services, safe housing and higher education for the children (as discussed in chapters 6 and 7). However the spiders in this web of causation include the unwillingness, for reasons not discussed in this work, of the Jewish leaders in the Palestinian Mandate to co-habit with the existing Arab population (as described in Chapter 1), and the unwillingness of the Lebanese government to integrate the poorer Palestinian refugees into the Lebanese population (as discussed in chapters 6 and 8), Since 1948 this situation has been maintained,

by both the Israeli government and the Lebanese government, with the support of the international community, to the detriment of the health of the refugees. While each refugee situation differs, the attitude and behaviour of the country of origin and the host country has an impact, for better or worse, on the refugees.

The experiences of war, both the original Israeli War of Independence / Nakba and the Lebanese Civil war have also generated webs of causation for health. The refugee status itself is caused by war; however, damage to the physical environment of the camp can be linked with bombardments during the Civil War, as can poverty, as refugees lost their jobs or were unable to find new ones. Unavailability of food, during the war changed patterns of eating, and injuries from the fighting have led to long-term health problems. Again war is beyond the control of the refugees in the camps. The political parties of Lebanon, and of the PLO have some control over the development of the situation which led to the Civil War, but the health impacts are felt by everyone, both Lebanese and refugee.

While there are some areas in which the refugee community can modify the overall effects of their refugee status and war, these are events which are beyond the control of the camp community. The areas considered in the empowerment analysis, if carried out, will have some impact on the health of the community, but are unlikely to mitigate the national and international factors that are affecting the community's health. Such actions as improved conflict resolution, increasing the knowledge base of the community, and improving program development and management, may result in empowerment to manage health problems at the local level, but it cannot manage the wider problems discussed, such as poverty and poor physical environment.

This greater understanding of the limitations of a community to manage its health can be used by health promotion workers to shape their programs, and may also be considered by policy makers when developing programs which will shape management of refugee crises.

9.3 Methodological challenges

I have used two methodological concepts: firstly, a modification of PEER research to facilitate the gathering of data; secondly I have applied narrative with Krieger's ecosocial theory, specifically to understand the life experiences embodied by the community members, and the societal sources of those experiences Finally, I have combined a model of health which helps to develop an understanding of agency and accountability, with an analysis of power and community empowerment within the community, to facilitate changes in service delivery of both curative and preventative health programs

9.3.1 PEER Research techniques

One challenge of this research was to gain an understanding of the life experiences of people with whom I shared minimal language, and who also had some distrust of outsiders. I chose to use a modified form of the PEER interview technique (Hemmings, Wubshet et al. 2008; Collumbein, Qureshi et al. 2009) for both the interviews and the PhotoVoice activity with elderly refugees. PEER interviewing relies on the recollections of the PEER interviewers when they discuss the interviews with the principal researcher at some time following the informant–PEER interview. However, the refugees have become accustomed to recording their lived experiences for various NGOs, collecting oral histories as part of other programs.

In addition, I am not entirely unknown to the community, having both lived there and worked there for several years. Thus although my Arabic is limited I am known and have friends among both professional and lay people of the community, so many people were less cautious about being recorded in interview, when asked. The PEER interviewers undertook the bulk of the interviews (largely in Arabic), and then shared that information with me verbally. Sometime later I received complete translations of the interviews (the final interviews were sent by email in January 2010). A sample of these translations has been checked by an Arabic speaker familiar with the Palestinian dialect, and they were judged to be accurate.

I have considered the quality of the data obtained from both the transcripts and the feedback interviews. The picture presented by the feedback interviews included enough facts to understand what has happened within the community, based on the congruity of data from different sources which supported the facts. However, the emotional content of the stories was sometimes more closely aligned to the response of the interviewer to the stories, than to the response of the interviewee at the time of the events. This was demonstrated by a man who described an incident which crystallised his loss of trust in the PLO during the factional fighting in 1988 (117, p. 24). The informant's focus was on the division between the political factions; however, my PEER interviewer was so shocked by the situation he described of a man being insulted and shot at by an opposing faction member that this emotion coloured her feedback for that section of the interview (Feedback interview 117 at 28.10 mins). A further example of the power of the transcripts, rather than the feedback interviews was also observed when several informants discussed traumatic events. Even in translation the emotions they recalled in telling these life experiences was obvious; people expanding a response would generally become much more fluent in describing their experiences, with no need for the interviewer to prompt or encourage (101, pp. 8–9; 405, pp. 23–24).

I had two advantages which the people who developed PEER interviewing did not have. Firstly, I was known in the community as a service provider, and secondly the people in the community had already experienced the recording of their life experiences. The PEER process was

developed to support rapid development of understanding of social situations, to provide a needs analysis for service providers (Price & Hawkins 2002, pp. 1328–30). This technique has often been used to explore subjects which could be difficult to discuss with outsiders, and where the informant may not want their accounts recorded for strangers to hear, such as sexual behaviours (Hemmings, Wubshet et al. 2008; Collumbein, Qureshi et al. 2009). Neither of these purposes applied during this research; however, using the modified PEER research process made it possible to evaluate the quality of the data during the process of data collection, despite my inability to follow Arabic, and it meant that interviews could be carried out in people's homes, where they were more likely to feel comfortable, and at the same time I could comply with the DFAT warning not to enter Palestinian camps.

However, the PEER interview process did not work well in combination with the PhotoVoice method of data collection. Though the data collected has been useful, it was not of a depth and richness I knew PhotoVoice could provide (Castleden, Garvin et al. 2008; Pierce & McKay 2008), and which I had hoped for while planning the research. On reflection this was due to a combination of inadequate training of the interviewers and the interviewers' familiarity with the physical environment. I did not focus sufficiently, in the training, on the depth of information I was hoping to achieve in these particular interviews, and the interviewers asked superficial questions about why the subject had been chosen, and what it was, rather than leading the interviewee to associate thoughts and feelings with the images. Informants found it difficult to go into depth when discussing a photographed subject with which both the interviewer and the interviewee were intimately familiar, having lived with it for most of their lives. With greater training and practice the PEER interviewers may have been able to overcome the problem; however, future researchers will have to determine this.

9.3.2 Using an ecosocial model to identify pathways of agency and accountability

A second challenge I found in working with Krieger's ecosocial model of health was to take my data and organise it so that pathways of accountability could be readily seen. In analysing the interview data I used two different tools to organise it. Firstly, I combined the many narratives and other information into a single narrative, including variations and criss-crossing pathways. These narratives each considered a single field of information with smoking, diet, and physical exercise being considered separately. These narratives were chosen because they underpin many pathways to health; previous quantitative researchers had considered them and they seemed dominant in the data. However, other topics could be considered, including family violence, alcohol use, sexual behaviour, or any other emerging from either the literature or the data.

Having constructed the narratives that related to a behaviour, I then analysed them to identify the pathways which led to specific behaviours. By identifying the life experiences which had encouraged or discouraged behaviours, I was then able to organise them diagrammatically showing connections and the pathways of embodiment. I was able to show the societal levels which shaped the life experiences, though I was not able to include the times at which such experiences were experienced.

These two stages of analysis together provide a picture of how life experiences shape the health of a person. These two analytical methods work well within the Krieger ecosocial model, exploring the life experiences of a community (the life experiences which are embodied), and the societal levels at which they occur (societal and ecological levels) It then becomes possible to identify the historical and societal factors that shape health outcomes.

This combination of methods would work well with several other complex theoretical models which view social phenomena as webs of causation. For example, when examining social determinants of health (Baum 2008, part 4), or the factors which determine behaviours, without necessarily wanting to consider the pathways of embodiment (as is central to Krieger's model) this method of analysis would be appropriate. In considering marginalised people, people who have been excluded from social, economic, cultural and political life, Block (2016, pp. 225–26) suggests that the theory of intersectionality should be used to understand where the power lies to make life changes. This theory asserts that multiple and often simultaneous categories of oppression contribute to marginalisation, taking into account the roles of power and privilege. Thus the method of analysis used in this study would also facilitate understanding of intersectionality, when considering health, and other social inequities.

Finally the combination of Krieger's ecosocial theory which opened deep insights into the power structures which influence health outcomes for a society, with community empowerment theories which highlight ways to manage health outcomes within the community has provided a link between theoretical modelling of health and service delivery. Thus I have had to adapt both data collection techniques and data analysis methods to acquire a full understanding of how life experiences have shaped health in this community, and then developed possible modifications to service delivery to the community.

9.4 Limitations and strengths of this research

In developing a research methodology there are limits to what can be achieved, and the researcher often sets limits to the study in order to achieve greater depth of understanding over that narrower area. In this research I have set such limits, by choosing to study a single camp in depth. Another limit to the methodology lies in my reliance on lay knowledge. I have focused on the life experiences of the camp residents, drawing on their intimate, first-hand knowledge of

lived experiences and acknowledging the validity of their own conclusions regarding how these experiences have affected their health.

This study therefore offers a case study of a single camp (one of twelve in Lebanon), in one of four countries that have hosted Palestinian refugees as countries of first refuge. There are many millions of Palestinians with unresolved citizenship status. The single case study approach limits the generalisability of the study, but on the other hand reduces the number of variables that have to be incorporated into the model of health being developed. This study considers one unban camp, from one refugee community. As each camp has its own history and geography, so there will be disparate factors shaping the lived experiences of residents. For example, Dbayeh camp in the northern suburbs of Beirut houses Christian Palestinians — with a different religion comes variation in many social norms. For example, use of alcohol may be more common in a non-Muslim society. Chatilla camp, one kilometre north of Bourj-el-Barajneh, experienced both the 1982 Sabra Chatilla massacre and the sieges of the late 1980s — how these historical events have changed residents' life experiences would need to be considered. Furthermore, Chatilla is situated next to the Sabra markets, where foods can be purchased more cheaply than in other areas of Beirut. Beyond this there are camps and gatherings in rural areas where work opportunities in agriculture exist, but with more limited access to some services. These economic factors were discussed by Roberts (2004, section 6.2) as a preliminary to her research into refugee capacities.

By limiting myself to a single camp I have been able to delve deeper into the experiences of a single community, at the expense of being able to generalise over the entire Palestinian community. However, service providers could consider how applicable this study model is to any local community in which they are working. For example, the *Nakba* impacted on all Palestinians; the Lebanese Civil War impacted on all Palestinian communities in Lebanon, though people's experiences and level of involvement in these events will vary. The effects of the Lebanese government's restrictions to the civil rights of Palestinians impacts all camp and gathering dwellers, though again there will be some differences between camps since they are surrounded by different kinds of Lebanese communities.

However, while this study applies principally to a single camp, within a single diaspora, the method used to evaluate both the impact of life experiences and the power to make changes could be applied to other refugee communities, and to other communities. There are many similarities between refugee communities: many have experienced war, some have unresolved status and remain displaced, while others have acquired new citizenships or have been absorbed into new communities. Some studies suggest that refugee status itself can have long-term deleterious effects on both mental and physical health even when that status is resolved and the refugees have been absorbed into a host community (Muhtz, Godemann et al. 2011).

This study has drawn its data from the lay knowledge of the refugees and the professional knowledge of the service providers. As noted during the analysis of empowerment, there were gaps in the knowledge of the refugees, and the knowledge of the some professionals. For example, there was little knowledge of the harmful effects on health of leaded paint, a product readily available in Lebanon. Both professionals and refugees are aware that renal failure is common, especially among refugees with diabetes, but none of the informants mentioned the link between renal failure in diabetics and lead exposure (Ekong, Jaar et al. 2006). Only one professional informant raised the issue — a foreign worker from a country which has a general awareness of the impact of leaded paint on neurological development in children. Neither group of informants, lay or professional, appeared to be aware of other health problems associated with lead exposure.

This raises the question of what other slow-acting environmental hazards may be present in the sub-standard camp infrastructure. In considering the one environmental toxin identified by informants — lead — I would suggest that the health hazard may lie in the universal presence of the toxin: all houses in the camp have had cheap leaded paint applied for many years, and the associated health problems are likely to be slowly developing. As discussed in Chapter 8, this emphasises the value of wide-ranging discussions using Freire's question-posing methods of education, to address this and other potential health hazards. There is a need to firstly identify those environmental health hazards in the international scientific knowledge base and then to identify solutions that would work within the camp environment and community.

I have limited the usefulness of this study in terms of generalisability of its results, but I have developed a practical method of identifying the pathways of power which in turn determine aspects of health. When applying this methodology it would behove the future researcher to also review the health literature more widely, because while lay knowledge, analysis and interpretation has validity and integrity, there may be gaps in coverage that other studies can supply. However, while the knowledge of harmful influences on health may not be apparent to the lay person the methods of managing the influence will be best addressed by involving the community at all levels.

9.5 Further directions

There are two useful directions for health research leading from this study. Firstly, the results can illuminate and inform existing or future programs in Bourj-el-Barajneh that seek to improve the health of residents. Secondly, the methodology used could be applied in other communities; for example, other refugee communities, other marginalised communities such as indigenous or migrant communities, or communities based in specific geographical locations, again with the aim of using greater understanding to improve service provision

Further research within the camp community would be most effective if generated by the camp community, based on the organisations of civil society which exist, and using techniques which empower the community. This would combine several of Laverack's processes of empowerment, including participation, 'asking why', problem assessment, program management and resource mobilisation. With careful evaluation, as suggested by action research principles, such programs would both benefit the camp community and also add to the knowledge base about health in the camps (Grbich 1999, chap. 8). The advantage of developing and conducting such programs from within the community is that the programs would be designed to meet the community's needs rather than being shaped by perceptions of external donors.

The NGOs operating in the camp are already familiar with the concepts of modifying and improving programs based on program evaluation — this is the process that underpins action research. The political parties with whom I spoke appeared less familiar with these ideas, but that may be because my research included only a limited number of these organisations. Such informants were, however, committed to improving the lot of the refugees, and may be interested in developing such action research projects.

An example of a future action research project might be an antismoking program. Informants strongly agreed that smoking is used to manage stress: therefore, by planning a program around the management of stress, discussing known ways of managing stress and considering if and how such a program could be applied in the camp community may be more effective than the current programs which simply assert that smoking is unhealthy, and so people should stop smoking. Such a tailored program could meet the priorities of the donors, as it is health promotion, but would lead the community to consider a deeper underlying health problem, the need to recognise and manage stress. Other projects could target the topic of nutrition — how working women can provide nutritionally sound meals for their families on limited budgets — using a model similar to the program UNRWA created to increase the dietary level of iron through menu choices (UNRWA 2013).

Once the community has acquired skills in self-managing programs, they may want to address the promotion of wellbeing for those living in a non-traditional family structure, a societal pattern that I found to shape health. However, it should be remembered that action research along the lines discussed above does not address the fundamental issues of recurrent exposure to war and prolonged refugee status of Palestinians from the lower classes.

The second potential research direction is to use this methodology to explore societal and historical inequities among other populations. Using this technique across a range of communities would help to identify patterns of endemic health problems. For example, by studying refugees who have been able to return to their original country, or a group that has

been absorbed into their country of refuge, we could increase our general understanding of how the refugee experience affects health. If a compatible methodology were used, it would be possible to see a range of patterns occurring among different communities, enabling us to identify differences and similarities in health patterns.

9.6 In conclusion

This study has provided a picture that illustrates the relationships between life experiences and health and chronic illness in a single community of refugees. It has identified a web of interconnecting pathways representing the societal forces which have shaped these life experiences and health outcomes. It has also examined the question of where the power lies that could empower the community to make changes. The answer suggests that while some work on community empowerment may bring about some change, in both power to manage their own community and to improve health outcomes, these advances will inevitably be limited by the national and international political forces which currently exercise power over this community's destiny.

APPENDICES

Appendix 1
Glossary of Abbreviations, Arabic Terms and Local Usage of English terms

Abbreviations

AUB	**American University of Beirut**
Bacc	Commonly used verbal abbreviation of Baccalaureate, the exam taken in Lebanon at the end of high school, needed to advance to university education
COPD	Chronic Obstructive Pulmonary Disease
ECHO	European Union Humanitarian Aid and Civil Protection, a relief and aid organisation for the European Union
Fafo	Fafo research foundation, or *Forskningsstiftelsen Fafo* in the original Norwegian,
MSF	Médecins Sans Frontières
NGO	Non Government Organisation
PLO	Palestinian Liberation organisation (a coalition of several Palestinian political parties)
PRCS	Palestinian Red Crescent Society (provider of medical services in many camps
PTSD	Post-traumatic stress disorder
SAMID	Palestine Martyrs Works Society, initially set up in Jordan to train children and a commercial and manufacturing company set up by the PLO in Lebanon. Sometimes transliterated as SAMED.
UAE	United Arab Emirates
UNHCR	United Nations High Commission for Refugees

UNRWA United Nations Relief and Works Agency for Palestinian Refugees in the Near East

Arabic terms, which lack a simple English equivalent

Bourghul Wheat which has been cooked, dried, and broken up to a coarse or fine texture. It provides a method of storing wheat so it can be easily and quickly prepared for eating

Qahwey Coffee. Palestinians make coffee in an open topped, tall “coffee pot”, boiling water with finely ground coffee beans, about 1-3heaped teaspoons of coffee is used per person. A small quantity of cardamom (heil, in Arabic) is mixed with the coffee to increase the bitter taste. The coffee is brought to the boil, then allowed to cool for a few seconds, several times, to maximise the flavour. The result is served in “demitasse’ sized cups. Sugar can be added before boiling, but if someone to be served does not use sugar, it can be added to the cup.

Eid al Adha The 3 day festival in the last calendar month of the Muslim year, linked to the Pilgrimage to Mecca.

Eid al Fitr The three day festival which comes after the month of Ramadan. The time is spent in visiting family and friends, children are given treats, and may go to fun fairs. People eat special meals, such as barbequed meat, and give sweets to their friends and neighbours. This festival occurred during the data collection

Forn Literally this word means oven, but in the camps it usually refers a commercially operated communal bakery, where people can take their own food to be cooked, buy ready prepared food or use the owner’s pastry to make their own manaqish or small pies providing a filling they have made themselves.

Halas An Arabic word, sometimes used when speaking English. When used as an imperative verb it means ‘enough’ or ‘stop’, but can also mean that something has stopped being a practice or custom

Haram This Arabic word, sometimes used when speaking English, indicates that something is incorrect behaviour, because it is forbidden by God, for example drinking alcoholic drinks is ‘haram’ according to my peer interviewers, but smoking nargeleh is not, though it may not be a good thing to do.,

Labni A milk product made by draining the whey from yoghurt, similar in texture, but not taste, to cream cheese.

Manaqish A flat bread topped with a single flavouring, usually a mixture of herbs and oil (the cheapest), but can be cheese, or a tomato mixture. They are similar in style to Italian pizza, but with different fillings.

Mugharabieh flour mixed with oil and water, till it forms small pellets, which are then boiled

Nakba literally means disaster, but when used in relation to Palestinians refers to the Arab-Israeli war of 1948, when they, or their families fled or were forced to leave

Nargileh (pronounced Argileh) The word used in the Levant for the water pipe, where tobacco is burned with charcoal, the smoke is then bubbled through water and inhaled. It is generally a sociable form of smoking tobacco, as several people will usually sit together, and pass the mouthpiece around the group, each inhaling in turn.

Ramadan The ninth month of the Islamic year, during which many people (those who practice the Islamic religion fully) fast, during daylight hours (abstain from food, liquids, and tobacco) and will recite the Koran during this month. At sunset the family will gather for a meal, and will visit or entertain visitors after this meal. They will be particularly observant of religions matters. Ramadan commenced about a week into the data collection period,

Sumud Steadfastness, not being defeated

Zaatar Thyme, it can refer either to the fresh herb, used as a salad vegetable or to a dried mixture of dried herbs, predominantly thyme, but with sesame seed and somac (another herb),

Explanations of English jargon which is commonly used in this community

Chatilla The name of a camp in the southern suburbs of Beirut, about a kilometre from Bourj-el-Barajneh camp, which has been transliterated in the French style (which I have used) and the English style, Shatila. Both forms are correct.

Gathering when used in relationship to places where people live, for example ‘camps and gatherings’ it refers to a primarily (though not necessarily exclusively) Palestinian community which is not an official UNRWA camp. The areas surrounding camps often have gatherings, but there are many which are remote from camps.

Peasants I have used the term peasant as do other authors to describe the subsistence famers of Palestine. The Arabic term fellaheen, also used by some, has gained

political connotations as it has been used as a term for the lower levels of the PLO militias, but originally meant subsistence farmer. The term does not carry the derogatory connotations sometimes found in some English dialects.

Pyjamas This English word comes from the Arabic word for clothes worn in the house. When used by bilingual speakers who are speaking in English they often use it in the Arabic sense of the word, rather than the English sense of nightclothes worn to go to bed and sleep.

The Revolution This word is often used to describe the PLO, and specifically the time when the PLO managed the camps in Lebanon, following the Cairo Accords (1969)

Appendix 2
Referencing to the data

When referring to data I have used the reference number given to the data, with a page number from the coded file of the translation or transcript. The interviews were numbered in order of the date of first interview with that person.

- Interviews from older refugees have the first number 1, and go from 101-126
- Interviews from the photographic data have the first number 2, and go from 201-208. The photographs are numbered with the interview number plus the number of the photograph in the order taken from the CD copy of the data (eg 201 photo 1)-
- The focus groups with staff of NGOs have a first number 3, and go from 301-309
- The interviews from NGO managers start with the number 4 and go from 401-432.
- When I have referred to field notes I have given the date of the activity, described in the note
- When I have referred to the feedback interviews with the PEER interviewers I have used the number of the interview being discussed followed by the time mark (minutes and seconds) in the interview, as these feedback interviews were not transcribed.

Appendix 3
Schedules and Guidelines

Schedule for training session for group leaders and interpreters

Introduction

1. Greetings,
2. Why we are meeting
3. Methodology and each person's place in it

Confidentiality

1. Explain the importance of confidentiality
2. Get each person to discuss their past experience of maintaining confidences, and discuss any differences in this methodology.
3. Get signed forms form each person
4. Stress professionalism

Discussion on chronic illness

1. Discuss what they think chronic illness is
2. Then discuss the concept that different people have different ides on what is chronic illness, and that we want to know what the local people in each group think it is
3. Review the concepts of the ecosocial model,
    a. lifetime experience,
    b. multiple societal levels (individual, community, international, etc) impacting and interconnecting
    c. Multiple societal factors which such as gender, poverty, race
4. Discussion that this is a model, and that we are looking for other factors beyond

Look at the interview schedule, and practice interviews in English

Language

1. Discuss importance of accepting common words for basic concepts, and come to a conclusion for an acceptable term for major terms used
    a. Chronic illness
    b. Factors affecting
    c. Stress
    d. Anxiety
    e. Post traumatic stress disorder
    f. Environment
    g. Social environment
    h. Physical environment
    i. Behaviour
    j. Others which will emerge during the discussion

Practice interviews in Arabic

Managing our own stress, listening to information which might distress us

1. Explain that this may arise
2. Discuss if it has been a problem in previous work
3. Plan a time following each interview/workshop to discuss the material, and vent any problems with it

Conclusions

1. Thank people for meeting
2. Coffee and chat

Schedule for interviews with elderly Palestinians

I am interested in the things that affect development of chronic illness in older people. We understand that chronic illness is related to both behaviour and experiences over your lifetime. I am interested in what there is about being a refugee which affects your chronic illness.

What is chronic illness *(early questions which are about less emotionally related subject)s*

1. What do you understand by chronic illness of old age?
2. Do you have any chronic illnesses?

Life Experiences (Be aware of emotional problems)

1. Brief life history related to the periods of Palestinian history. For example
    a. Where you born in Palestine, (pre 1948)
    b. Recollections of Nakba(1948)
    c. Recollections of establishing the camp (1948-67)
    d. Time of the PLO (1967-82)
    e. War of the Camps etc(1982-90)
    f. Since the end of the civil war (post 1990)

2. Identify aspects which might to impact on health and explore them further: for example
    a. Factors which the person seems to find emotional (anger, stress, unhappiness, but also happiness calmness joy)
    b. Explore these aspects of life form the view of
        i. International
        ii. Lebanese community
        iii. Palestinian community
        iv. Camp community
        v. Neighbourhood community
        vi. Family
        vii. individual

Behaviour (in general raise this later in the interview, as it may invoke defensive attitudes, if people are aware that a behaviour harms health but continue to practise it)

1. What behaviours do you think are healthy or unhealthy, or affect chronic illnesses?
2. Do you do any of these behaviours?
3. Why?
    1) Smoking
    2) Diet
    3) Body weight
    4) Exercise
    5) Any others

General questions to capture other information

- Are there any other aspects of life which you think would affect chronic illness, either help protect you from chronic illness., or tend to make you more likely to get chronic illnesses?

Conclusions

1. Thanks
2. Reminder that they can discuss this with the researcher further if they wish to, and how to make contact

Activity to introduce people to PhotoVoice

Introduction

1. Brief explanation of the research (repeat of the consent schedule information)
2. Discussion on confidentiality
    a. How I keep their names confidential
    b. How they should get permission for photos of people which identify a person
    c. How I will blur the identifying features of people in photos (or not publish photos which cannot be so altered
3. Answer further questions

Discussion of health and the environment (I should not put any ideas into these activities, but take notes of the ideas)

1. Physical environment
    a. Brainstorm what thinks might be included here
    b. Discuss in pairs some ways of showing these
2. Social environment
    a. Brainstorm what these might be
    b. Discuss in pairs ways of showing these

How to use a camera

1. Demonstrate how to use a camera
2. Each person to have their photo taken by the person next to them (to identify who took the photos)
3. Explain the process of taking 5 photos of something about the environment that is healthy and 5 photos which are unhealthy. The rest of the photos, they can take of anything they want.
4. Discuss how to get the film developed (take to the photo shop in the camp, and then collect the photos when he tells them to). Remind them that they will keep ALL the photos, but I will have a CD with the photos on, so I can view them on my computer.
5. Discuss my agreement with photography shop owner that he will keep the content of these photos confidential

Conclusion

1. Timeline for getting photos done (discuss this and let them decide how long it will take.
2. Then explain the interview.
3. Make a date for the next session
4. How to contact me if you have a problem
5. Thank them for participating
6. Coffee and chat

Schedule for interviews for PhotoVoice

Introduction

1. General greetings
2. How did you find using the camera?
3. Any problems taking the photos?

Photos

1. Tell me about the photos which show unhealthy aspects of the environment
    a. What is it?
    b. Why chosen?
    c. How did you feel taking these photos?

2. Tell me about the photos which show healthy aspects of the environment
    a. What is it?
    b. Why chosen?
    c. How did you feel taking these photos?
3. Is there anything else you want to tell me about the experience of taking the photos?

Conclusions

1. Remind the person of the date for the group activity
2. Ask them to bring one photo from the healthy and one from the unhealthy category which they feel comfortable discussing with the group
3. Thanks and goodbye

Group activity to debrief from the PhotoVoice activity

Introduction

Thanks for coming, and some general comments about the value of the data

Discussion on the photos

1. General discussion about the experience of taking photos

(consider borrowing a computer projector, and show the photos from the CD, however this will depend on power and availability of a projector)

2. Go round the room asking people to show one of their 'unhealthy' photos, and explain why they chose the subject.
3. Go round the room asking people to show their one of their 'healthy' photos, and explain why they chose the subject.

Discussion of the activity

1. Did you enjoy the process?
2. How else could the process be used, *(some possible uses which might come up)*
    a. Needs analysis
    b. Awareness campaigns
    c. Lobbying donors
    d. Other
3. Share information on costs of the activity
4. Who could you contact to try and use this activity to do any of the above?

Conclusion

Thank people
Coffee and chat

Interview schedule for Managers of service providing organisations

Introduction

1. Thanks for speaking to me, and run through the information sheet briefly
2. Sign consent form

Programs for chronic illness or the elderly (start with the factual)

1. What programs does your organisation run related to elderly people or chronic illnesses? *(if I know of any through officially published reports, acknowledge these and ask if there are others)* Try to get some discussion of problems across a wide range of programs, to see the whole of life experience.
2. Discuss all programs including
    a. Evidence of need
    b. Activities involved
    c. Evaluation of effectiveness
3. Do you have plans or ideas for programs you would like to run, but have not yet got running?
    a. Evidence of need,
    b. Activities involved
    c. Problems in getting the programs running

Chronic illness

1. What are the chronic illnesses which are causing problems for the elderly in the camps? How are they causing problems? (in-depth discussion here)
2. What factors influence the development of chronic illnesses, and what factors will protect against chronic illness in the camp communities? (in-depth discussion here).

Conclusions

1. Do you have any other thoughts on chronic illnesses in the camps?
2. Thanks

Schedule for focus groups with service providing staff

Introduction

1. Welcome and thanks
2. Review information sheet, informed consent and ask people to sign consent form

What are chronic illnesses of old age

1. Brainstorm what are chronic illnesses of old age
2. Review results of brainstorm, separate out actual examples of the illnesses from causes or factors which affect illnesses on separate sheets of flipchart paper
3. Discuss the actual illnesses people have raised,
    a. ask them if they want to add to the list or remove any from the list,
    b. encourage discussion on why they are on the list.

What factors affect the incidents of these chronic illnesses?

1. Start with the results of the brainstorm. Ask if people want to add to or remove any factors which affect development of chronic illness
2. Make links (how can we organise this information?)
    a. Link any that are opposite sides of the same thing (e.g. exercise helps prevent chronic illness and lack of exercise increases risk)
    b. Link any that are similar (e.g. all the things related to stress)
3. Break into pairs and discuss the linked topics, one topic per group.
4. Feed back the conclusions to the general group
5. Encourage discussion.

Programs which address these factors

1. Summarise what they think are the chronic illnesses of old age
2. Summarise the factors they think are affecting the development of chronic illnesses
3. Brainstorm “What programs do you know of in the camps which address these factors”
4. Group discussion about how these are working.
5. Revise the summary lists

Conclusion

1. Any further points you want to make
2. Any further changes to summary sheets
3. Thanks
4. Coffee and chat

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