Understanding Global Policy for Informal Caregivers of People Living with Dementia: Implications for Nepal

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Abstract

Informal caregivers of people living with dementia play a crucial role through caregiving. Their contributions reduce care costs, improve health outcomes, delay entry to institutional care, and help people living with dementia stay connected with their socio-cultural contexts. However, caregiving to people living with dementia can have significant consequences including increased stress, anxiety, depression, and job loss. Informal caregivers need support to maintain their wellbeing and ongoing ability to care. Despite there being an estimated 100,000 people living with dementia in Nepal, there are no policies to promote the wellbeing of informal caregivers in this country. The purpose of this study was to explore and analyse shared and unique features of dementia policies and supports available or recommended for informal caregivers and draw from these implications of the findings for Nepal. One hundred and five policy documents from six countries (Australia, Canada, India, the UK, the USA, and South Korea) were analysed using *content analysis*. Policy priorities, visions, objectives, and recommendations shared common themes, including research, awareness, early assessment and diagnosis, flexible care and supports, policies and programs, strengthening capacity and system, monitoring and evaluation, and a human rights-based and person-centred approach. Most policies envision a dementia-friendly society, recognise caregivers as a key component in the dementia care journey, and acknowledge the involvement of multiple stakeholders to support caregivers and families of people living with dementia. The key supports recommended for positive outcomes of informal caregivers were informational, procedural, direct, system level, and spiritual. Given there are no formal support provisions for informal caregivers of people living with dementia in low to

middle income countries like Nepal, most of such practices of other countries can be adapted in their contexts.

Dedication

This thesis is dedicated to the God who *inspired* me to put efforts in researching around dementia despite my zero-level academic knowledge on dementia until I started *Master of Disability Policy and Practice* 2 years ago. May the God be glorified from this work:

> *Speak for those who cannot speak for themselves, for rights of all who are destitute; speak up and judge fairly, defend the rights of the poor and the needy (Proverbs 31:8-9 NIV Holy Bible)*

This is also dedicated to my father-in-law who lived with the Alzheimer disease for three years, and also to people with dementia and their families. I would also dedicate this to my parents who worked hard for my education and career.

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Abbreviations

ADI	Alzheimer's disease international
ADCSI	Alzheimer's disease caregiver support initiative
ARDSN	Alzheimer and related dementia society of Nepal
CA	Content analysis
GPs	General practitioners
LMICs	Low- and middle-income countries
MMOD	Medical model of disability
MOHP	Ministry of health and population
MOWCSC	Ministry of women, children, and senior citizen
NMT	Nightingale Medical Trust
NASCIF	National senior citizens federation
SCRGSP	Steering committee for the review of government service provision
SMOD	Social model of disability
UD	Universal design
UK	United Kingdom
URLs	Uniform resource locators
USA	United States of America
UNFPA	United Nations Population Fund
WHO	World Health Organisation

Glossary

The following terms have been used as defined below in this research context which in other contexts may mean something else:

- ***Caregiver***- refers to a person who looks after a person living with dementia. The term used throughout the project refers to both carer and caregiver. The term *carer* is found used in the UK and Australian contexts, whereas *caregiver* in the USA and Canada.
- ***Informal caregivers***- refers to children, spouses, other family members, neighbours and friends who provide care to people living with dementia without any formal payment arrangements
- ***Node***- refers to a coding category on the NVivo under which coded information (also known as reference) is assembled for interpretation. Coding sub-categories or sub-nodes are also called child-nodes.
- ***NVivo*** – refers to a software programme used for qualitative and mixed methods research. It supports researchers to organise, analyse and find insights through a vast array of documents in a quick fashion.
- ***Policy***- refers to a guideline broadly used to encompass any document on dementia or dementia caregivers, such as regulations or acts, frameworks, guidelines, plans, reports, strategies, government statements from the countries under consideration.

  Provisions- refers to services, supports or interventions and is used interchangeably with them.
- ***Report***- refers to any progress or review report documents on dementia from the governments and peak bodies of the respective countries. It also includes reports of international peak bodies -ADI and WHO for the information concerning to the respective countries.

Understanding Global Policy for Informal Caregivers of People with Dementia: Implications for Nepal

Chapter 1: Introduction

Brief Overview

Nepal is a low income South Asian country with a population of 33 million, of which around 2.2 million are over 65 years old (Pathak & Montgomery, 2015)[1]. There are an estimated 100,000 people living with dementia in Nepal (Jha & Sapkota, 2013; Pathak & Montgomery, 2015). Despite the empirical findings that dementia is a most challenging life deficit, Nepal has not yet introduced any policies, frameworks or programs to address the challenges arising from dementia including timely diagnosis and post-diagnosis care (Jha & Sapkota, 2013). Some health professionals including general practitioners (GPs) have poor knowledge of dementia, leading to its misdiagnosis as depression, memory loss, vitamin deficiency or a brain tumour (Pathak & Montgomery, 2015). Additionally, there are no formal support programs for professional or informal caregivers of people living with dementia in Nepal (Jha & Sapkota, 2013; Pathak & Montgomery, 2015).

International policies for responding to dementia focus on creating a dementia-friendly world (Jolley, 2014). There is a strong consensus among the nations that the nature and characteristics of dementia need to be understood by both professionals and the general public for the respectful treatment of people living with dementia, their families and caregivers (Jolley, 2014). The burdens experienced by informal caregivers are well evidenced and policies and programs

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[1] These statistics are based on the most accessible data from Nepal. Similarly, this thesis has tried to inform the reader of the most accessible data in the rest of the chapters and content.

have been devised for the psychosocial benefits of both caregivers and care recipients in many countries such as Australia and the UK (Alzheimer's Disease International, 2011). By analysing the dementia care policy interventions existing across the world, this research endeavours to identify best policy practices applicable and adaptable in the context of Nepal.

Purpose

The purpose of this research was to identify and synthesise global policy provisions for informal caregivers of people living with dementia and draw out some practical implications for Nepal.

Structure

This study is structured into five chapters. The first chapter is the introduction which includes the study overview, purpose and structure. The second chapter is the literature review of available and accessible sources on dementia. This chapter covers the results of the review of various sources on dementia and impacts, social policy and implications for dementia care, dementia policy, informal caregiving, policy recognition of informal caregivers and programs for them, and dementia care and policy in Nepal. This also contains the conceptual framework developed in light of the literature review. The third chapter is the methodology which outlines the methodological design applied and how it was applied in the study. The fourth chapter includes the analysis, interpretation and summary of the results and thematic findings. The fifth chapter undertakes the discussion of the main findings in the result analysis and draws the implications of the findings for policy development in Nepal. The discussion chapter also contains the strengths and limitations of the study and makes some recommendations for future research for overcoming the limitations.

Chapter 2: Literature Review

More than 47 million people worldwide are living with dementia (Bosco et al., 2019). This number is estimated to triple by 2050 (Stall et al., 2019). Approximately, 58% of people living with dementia live in low- and middle-income countries [LMICs] (Gulland, 2012; Pathak & Montgomery, 2015). While high income countries recognise that dementia is partly preventable via risk reduction, dementia symptoms are perceived as a normal part of ageing in many LMICs. Intrinsically, no special preventive measures are adopted there (Ferri & Jacob, 2017). This contributes to increasing prevalence of dementia in those countries. The number of people living with dementia is rising rapidly in LMICs with a new dementia case detected every three seconds in the world (Alzheimer's Disease International, 2018). Dementia poses socio-economic challenges for governments across the world and in 2010, dementia cost US$604 billion worldwide (Pathak & Montgomery, 2015; Wimo et al., 2013).

Dementia

Dementia is a syndrome characterized by progressive deterioration of cognitive function, independence, and ability to manage daily life (World Health Organization, 2012; Chen et al., 2017). Dementia is most common after the age of 65, though a younger onset dementia (with onset before 65 years) accounts for up to 9 per cent of cases globally (Zhu et al., 2015). Dementia symptoms are irreversible and progressive in nature, gradually disabling the person and increasing dependency on others with profound impacts on people living with dementia themselves, their caregivers and society (Chen at el., 2017).

Dementia is one of the world's leading causes of death, disability, and dependency in older populations (Akarsu, Prince et al., 2019; Dua et al., 2017;

World Health Organization, 2017; World Health Organization, 2018). Dementia can be present with other health issues such as delirium, falls, fractures, urinary incontinence, and infections (Chen et al., 2017). As reported by the Alzheimer's Society (2008) people living with dementia can be stigmatized by society and self, which can reduce their willingness to seek diagnosis and subsequent support, or to participate in dementia related research (Burgerner & Berger, 2008; Milne, 2010; Swaffer, 2014). As the condition progresses, people living with dementia can be deprived of their identities and roles in society (Bosco et al., 2019). Their diminished autonomy resulting from cognitive impairment changes their formal identity (Van Gennip et al., 2016).

Research indicates that dementia caregiving is associated with negative emotional and physical health consequences, such as caregiver distress and burden, and potential apathy toward the care recipient (Dowling et al., 2014; Pinquart & Sorensen, 2007; Wong et al., 2012). Caregivers commonly report stress, isolation, sleep problems, anxiety, depression, chronic fatigue, and increased consumption of psychotropic drugs (Boustani et al., 2007; Chen et al., 2017). Dementia also creates great social and other pressure on the health care system and economic development of a country (Alzheimer's Disease International, 2010; Chen, 2017). Globally, the estimated costs of dementia care were $604 billion in 2010 attributed to three categories of care: informal unpaid care, direct costs of social care by professionals in community and residential home settings, and direct medical care costs (Alzheimer's Disease International, 2010). Unpaid family caregivers experience financial strain due to their reduced ability to concurrently manage paid work and care; the cost of which is often underestimated by policy-makers (Wimo, et al., 2011).

Social Policy and Implications for Dementia Care

Social policy focuses on improving human welfare through meeting the needs for education, health, housing and social security (Blakemore & Warwick-Booth, 2013). Social policy aims to improve people's wellbeing, and especially focuses on the welfare of those who are disadvantaged (McClelland & Smyth, 2014). Social policy has three meanings: *output, discipline* and *process*. As an *output*, social policy refers to a policy or set of policies, as well as the arrangements and organisations to achieve the policy objectives. As a *discipline*, it refers to a field of study. As a *process*, it is an action to improve societal welfare (McClelland & Smyth, 2014). Social policies are modelled on political ideologies for the welfare of individuals, families and societies, and accordingly, they mainly focus on meeting human needs for education, health, housing and social security. Such policies formally represent the goals, intentions and ideas of governments for quality of life for their citizens (Blakemore & Warwick-Booth, 2013).

Social policy is a foundation of citizenship (Ketola & Nordensyard, 2018). There are three types of citizenship rights: social, civil and political. Social rights, for instance, focus on access to a minimum of economic welfare and security guaranteed through the provision of education, housing, healthcare and pensions (Cole & Marshall, 1951; Ketola & Nordensyard, 2018). Rights to employment, health, housing, education, social care and social security are critically important for human wellbeing (Dean, 2014). Social policy is the granting of social citizenship rights associated with welfare services to members of a certain political community on equity, equality and need basis (Ketola & Nordensyard, 2018).

Social policies are formulated in response to empirically recognised human needs and problems or based on the societal and cultural perceptions of those needs and problems. Various theoretical models have evolved to solve these problems, and recent concepts and models are more empirical and comprehensive. In the context of disability, the universal design (UD) and the social model of disability (SMOD) are noteworthy. These models provide theoretical underpinnings for social policies on equity, equality and need basis (Ketola & Nordensyard, 2018) and provide the theoretical basis for this thesis. The UD is a political strategy that focuses on reducing disabling barriers and promoting enabling environments with the underlying democratic principle that recognises all people as equal (Lid, 2013). The UD assimilates the values of non-discrimination, participation, equality and equal opportunities, and has clear implications for the planning and manufacturing of goods and services to be useable by all people to their fullest (Lid, 2013). The SMOD was developed in response to the limitations of the medical model of disability (MMOD). The MMOD views disability arising from individual's bio-sensory impairment which reduces the person to a collection of symptoms largely focusing on what the person is unable to do (Hughes, 2010).

In contrast, SMOD recognises that limitations result from negative external attitudes and lack of access to services or supports. SMOD argues that the factors that hinder people from accessing services are the barriers caused by society, not by their impairment (Hughes, 2010). It conceptualises disability as existing on a continuum shifting between the individual and their environment and focuses much on their abilities and capacities (Owens, 2015). It challenges discrimination and exclusion, and links civil rights and political activism (Owens, 2015). Both the UD and the SMOD have supplementary implications for dementia social policy. The UD guides dementia-friendly housing and services, and thus supports people living with dementia to maintain community independence (Grey, 2015). Additionally, the SMOD promotes positive attitudes, non-discrimination, respect and dignity to people living with dementia and their families (Thomas & Milligan, 2018).

Social policies ensure that social services reflect international and domestic human rights laws and complement objective enforcement of such laws. Historically, a legal basis for recognising and protecting the human rights of people with disability is described in the *Universal Declaration of Human Rights*, *1948*. Article 2 of the declaration states "everyone is entitled to all rights and freedoms set forth in this declaration without discrimination of any kind, such as race, colour ... birth or other status" (Universal Declaration of Human Rights 1948 [UN, p.2]). It guarantees life, liberty and security of all people. The united nations conventions on the rights of persons with disability was specifically promulgated with the purpose of promoting, protecting and ensuring the full and equal enjoyments of all human rights and fundamental freedoms by all people with disability (United Nations Convention on the Rights of Persons with Disability [UNCRPD] 2006 [UN]). It encapsulates the SMOD in its eight faceted principles under Article 3: respect for inherent dignity; non-discrimination; participation and inclusion; respect for difference; equality of opportunity; accessibility; equality between genders; and respect for the evolving capacities of persons with disability (United Nations Convention on the Rights of Persons with Disability [UNCRPD] 2006 [UN]). These principles oblige the signatory nations to formulate social policies to promote the rights of people with disability or dementia in their contexts (Owens, 2015).

Changes and adaptations to social policy can significantly impact the lives of citizens (Blakemore & Warwick-Booth, 2013). Many countries have developed policies in response to dementia underpinned by the principles and provisions inherent in Universal Declaration of Human Rights, 1948 and the UNCRPD, 2006. Dementia activism and research progressively establishes the basis to identify dementia as a disability (Thomas & Milligan, 2018). Associated secondary effects of dementia such as loss of confidence, negative reactions from others, activity limitation and participation restriction line up with the consequences of disability. Such experience of disability by people living with dementia confers them the right to services and supports as guaranteed in the UNCRPD (Clare, 2017).

Dementia Policy

Social policy specific to dementia is an important part of a national response to dementia. Dementia is recognised as a *global health priority* (Alzheimer's Disease International and World Health Organization [ADI &WHO], 2012; DeWitt & Ploeg, 2016). In 2012, the World Health Organization (WHO) and Alzheimer's Disease International (ADI) released a landmark report urging international action on dementia given its increasing threat to global health (Chen et al., 2017). Countries globally have developed different approaches to respond to dementia needs focusing particularly on the quality of life of people living with dementia and their caregivers. Some have launched policies, others have developed plans, strategies or frameworks (ADI &WHO, 2012). For instance, England has a strategy: *Living well with dementia: A national dementia* *strategy* (ADI &WHO, 2012; Leeds Department of Health, 2009). It has a three-pronged purpose: (1) to provide a framework for quality improvements to dementia services and addressing health inequalities; (2) to provide advice, guidance and support to all relevant stakeholders; and (3) to provide a guide to the content of high-quality health and social care services (Leeds Department of Health, 2009).

In 1992 Sweden developed a social policy on dementia with an argument for *normalization process.* The policy argues that people with dementia should have a normal life, identical to that of all citizens in society. This marked a paradigm shift from previous theories (Eriksson, 2010; WHO, 2012). Sweden has also devised specified national guidelines for dementia (WHO, 2012). Some other countries in Europe, such as Belgium, Cyprus, Finland have recognised dementia as a priority and have initiated steps towards dementia policy formulation (WHO, 2012). Similarly, India and China are currently developing national approaches to address dementia impact (WHO, 2012). Australia, Canada, Switzerland and the USA have developed state or regional policies to decentralize health and social care (WHO, 2012).

Mostly high income countries seemed to be concerned with dementia issues even before WHO proclaimed dementia as public health priority in 2012. This could also be inferred from Prince et.al. (2008) that despite the need for social protection, access to good quality age-appropriate healthcare, and addressing the disability problem, dementia policy-making is under-prioritised in the LMICs regions. However, some significant achievements made even in LMICs over time are worth appreciating. According to ADI (2018), 13% of the dementia plans already developed and 67% of the plans being developed are from

LMICs. By contrast, 87% of the plans developed and 33% of the plans being developed are from high income countries (ADI, 2018). This data also indicates that not all high-income countries do have dementia plans; nor are all LMICs indifferent to dementia policy-making. The difference between high income countries and LMICs lies in proportion. Similarly, the WHO's dementia action plan 2017-2025 is appealing to both high income countries and LMICs (ADI, 2018). Thus, increased attention to dementia is being given globally which practically sets dementia as a public health priority. Yet given the problem of early diagnosis due to awareness lacking and stigma, and lack of improved and expanded community dementia services in LMICs (Fam et al., 2019), the LMICs regions have to do much more through policy-making.

Person-Centred Care

Drawn on the work of a humanistic psychologist Carl Rogers, Tom Kitwood propounded the philosophy of person-centred care in relation to people with dementia against the biomedical responses to dementia care that undermine personhood. Rogers focused on an empathetic understanding of a person's underlying desire and the endeavour to communicate that desire (Rogers, 1992; Brooker, 2004; Røsvik et al.,2013). Therefore, the aim of person-centred care is to bring together ideas and ways of working with emphasis on communication and relationships that would maintain personhood through recognition, respect, and trust (Kitwood & Bredin, 1992; Bone et al., 2010; Røsvik et al.,2013). Also known as individualised or relationship-based care, Person centred care embraces the uniqueness of an individual (Kitwood & Bredin, 1992; Bone et al., 2010). Personhood, being at the core of person-centred care as a standing or status, emerges in a social context being bestowed upon by the presence of others

(Kitwood & Bredin, 1992). Personhood promotes a more positive interaction and encourages wellbeing and a sense of belonging unique to each person (Hobson, 2019).

The practice of person-centred care is said to have begun in the UK. Later, it was expanded to other regions and countries, such as Europe, North America, and Australia (Evardsson et al., 2010). It has expanded almost across the world as an overarching philosophy of dementia care.

Various frameworks seem to have been conceptualised to deliver person centred care in dementia care settings in best possible ways. According to Hobson (2019), for example, as a holistic approach, person centred care to dementia draws on a five-dimensional attribute: personality, biography, neurological impairment, social psychology, and physical health status in relation to the person with dementia. Alluding to Tom Kitwood, Vernooij-Dassen and Moniz-Cook (2016) argue that the notion of personhood has three attributes: humanistic perspective on people with dementia, treating them with deep respect, and recognition of their sense of self which would underpin and embrace dementia care within relationships, interconnectedness and communication between people. Similarly, Brooker (2004) encapsulates person centredness in the framework of the VIPS: *valuing* people with dementia and carers, treating people as *individuals*, using the *perspective* of the person with dementia, and a positive *social* environment (Edvardsson et al., 2010; Røsvik et al.,2013). However, Edvardsson et al. (2010), critiquing Brooker's framework as subjectively conceptualised, claim to have come with the empirically verified aspects of person centredness. They are knowing the person, welcoming family, providing meaningful activities, being in a personalised environment, and experiencing flexibility and continuity (Edvrdsson et al., 2010).

The incorporation of person-centred care in dementia services is more likely to yield significant benefits for people with dementia, such as continuation of self and normality (Edvrdsson et al., 2010), recognition, respect and trust (Vernooij-Dassen & Moniz-Cook, 2016), positive beliefs about personhood influencing empathy with people with dementia (Hunter et al., 2016), perception of undesirable behaviours as form of communication indicating needs (Hancock et al., 2006; Bone et al., 2010), and promotion of collaboration and facilitation in caring for people with dementia (Mitchell & Agnelli, 2015).

The literature reveals that with a long legacy, the application of person-centred care is broadly expanding and rapidly growing over time, there could be many frameworks of person-centred care, and it does have significant benefits for people with dementia. Vernooij-Dassen and Moniz-Cook (2016), therefore, conclude that person-centred care may become a facilitator for people with dementia to live life as fully as possible given that their interests, pleasure and capacity utilisation are more facilitated than compensating only for what they cannot do.

Informal Caregiving

Informal caregiving for people living with dementia is common predominantly where cultural and religious values promote family responsibility for elder care (Camden et al., 2011). Informal caregiving is any unpaid care services provided by a family member, friend or neighbour or by volunteer caregivers organized by formal services (Alzheimer’s Australia, 2015). Globally, 40% of caregiving to people living with dementia is incurred by informal caregivers (Alzheimer's Australia, 2015; Alzheimer's Disease International, 2015). Therefore, the role of informal caregivers is crucial (Gaugler et al. 2000; SCRGSP, 2018).

The significance of the informal caregiver role is well-recognised; care at home can reduce care costs and improve health outcomes of the care recipients (SCRGSP, 2018). Informal care delivery further reduces the care costs of the governments by delaying entry to institutional care (SCRGSP, 2018). For example, in Australia 70% of institutional care costs can be reduced if people living with dementia are supported to stay at home for longer (SCRGSP, 2018). Informal caregiving also improves the health outcomes of the care recipients as their preferences to age in place can more often be met (SCRGSP, 2018). Informal caregiving can help people living with dementia stay connected to a range of socio-cultural contexts such as neighbourhood, community, church or cultural groups (Wiles et al., 2012). Informal caregiving can also contribute to the sense of personal fulfillment which can be realized only in the context of social relationships assimilated into familial, communal and religious belonging (Doron & Foster, 2016).

Despite the individual and societal benefits of informal caregiving, caregivers themselves can experience negative consequences from providing care (SCRGSP, 2018; Teahan et al., 2018). These include poor physical, mental and social outcomes (Brodaty & Donkin, 2009; Teahan et al., 2018). A meta-analysis by Pinquart and Sorensen (2003) found that dementia family caregivers are more stressed than non-dementia caregivers, and report significantly greater depressive symptoms and physical problems (Cheng, 2017; Pinquart & Sorensen, 2003).

Another study found that 34% and 44% of family caregivers report depression and anxiety symptoms, respectively (Sallim et al., 2015). Family caregivers experience poorer mental health and lower levels of general wellbeing compared to their non-caring counterparts (Cooper et al., 2007; Pinquart &Sorensen, 2003; Teahan et al., 2018).

Ongoing caregiver distress and burden can have repercussions on care recipients themselves through early placement into long-term care and relinquishment of the caregiver role (Cheng, 2017; Eska et al., 2013; Gauler et al., 2011); potential caregiver apathy (Dowling et al., 2014; Pinquart & Sorensen, 2007; Wong et al., 2012); and abusive behaviours (Camden et al., 2011; Cooper et al., 2010). people living with dementia are at high-risk for domestic violence. Risk factors include high level of dependence on family caregivers, aggressive and violent behaviour, caregiver depression and psychological stress and caregiving burden (Dyer et al., 2000; Hansberry et al., 2005; Matsuda, 2007; Wang, 2006). For these reasons, evidence-based interventions tailored for caregivers are necessary to promote positive outcomes for both caregivers and the people for whom they provide care (SCRGSP, 2018).

Informal Caregiver Support Programs and Policy Recognition

In order to maximise positive outcomes of informal caregiving, promoting caregivers' wellbeing is essential (Zwaanswijk et al., 2013). Informal caregivers' psychosocial support needs can change at different stages of dementia, and tailored support is required throughout the period of caregiving (Zwaanswijk et al., 2013). A broad range of empirically verified interventions has been documented including *case management*, *education and skill building*, *counselling* and *respite* (SCRGSP, 2018).

Case management focuses on the identification of the needs of the people living with dementia and their caregivers and planning and coordination of the necessary care. A recent Cochrane review reported that case management is effective in coordinating support between different agencies in community and can meet some of the needs of the people living with dementia and caregiver (Reilly et al., 2017). *Education and skills building* aim to build caregivers' knowledge about dementia and available resources and support them to develop skills to manage the role of caregiver, including that specific to people living with dementia (such as managing difficult behaviours). Evidence suggests that education and skill building approaches/interventions are effective in building knowledge, developing awareness and managing behavioural and psychological symptoms among caregivers (SCRGSP, 2018).

Counselling involves emotion-orientated or education-based counselling, including individual, family and group therapy. Counselling, particularly tailored to the individual needs of the caregiver, helps to build resistance and coping strategies (SCRGSP, 2018). Similarly, another review highlights that psychological interventions specifically designed to target depressive symptoms in caregivers, such as cognitive behaviour therapy (CBT) have positive effects in reducing caregiver depression (Akarsu et al., 2019).

Finally, *respite* care involves temporary care services provided to the person with dementia to provide a break for the caregiver (SCRGSP, 2018). Caregivers value respite programs because they report spending large amounts of time in their caregiving role, limiting the opportunity to participate in physical activity, and contributing to stress (McKeown, 2018). Another study demonstrates that the use of respite services by caregivers extends the length of time people with dementia can remain living in the community with family support (Phillipson et al., 2014).

Dementia Care and Dementia Policy in Nepal

Despite the effectiveness of various informal caregiver focused interventions, Nepal at present has no formal arrangements or policy for dementia diagnosis, treatment and support for caregivers of people living with dementia (Jha & Sapkota, 2013). This contrasts with other nations. For example, dementia was formally included in Australia's health priority areas in 2012. The National Framework for Action on Dementia 2015-2019 was subsequently developed which guides actions, plans and policies to reduce the risk of dementia and improve outcomes. The framework recognises the vital role played by informal caregivers (SCRGSP, 2018). The lack of such policy in Nepal is a key barrier to delivery of caregiver support (Pathak & Montgomery, 2015).

There is a very limited awareness of dementia and its associated problems both at the local and national level in Nepal, and there is no existing epidemiological survey of dementia (Hamal et al., 2014). Professional and policy-maker awareness and understanding of dementia is low (Pathak & Montgomery, 2015) and the issues of an ageing population in Nepal have not gained priority despite the potential of social and economic consequences (Sapkota, 2015). Parker et al. (2014) highlight that Nepal has very limited resources and finances to allocate for research in ageing issues.

The elderly population in Nepal increased from 1.5 million in 2001 to 2.7 million in 2011. Older people account for 9% of the total population with a 3.4% growth rate, while the annual growth rate of the general population is 2.1% (Sapkota, 2015). Population ageing is attributed to steadily improving life expectancy and a decreasing population growth rate (Shrestha, 2014). The life expectancy in 1991 and 2011 was measured as 54 and 66.6 years respectively, whereas birth rates in 2001 and 2011 were 2.25% and 1.35% (UNFPA Nepal, 2017). Almost 80% of older adults depend on their family members for their care support, and most of these care providers have little knowledge about certain age associated conditions, such as dementia (Hamal et al., 2014). A status report on older adults in Nepal recounts that most do not want to separate from their adult children or family, implying that care support from the family is an important contributor of elderly wellbeing (Hamal et al., 2014; Status Reports on Elderly People in Nepal, 2010). The Nepalese Government is committed to providing financial subsidies in medical treatment charges for the older population (Sapkota, 2015). The Senior Citizen Act 2006 ensures 50% subsidy in health-related treatment to all eligible older adults (Senior Citizen Act [2063] 2006 [NPL]). However, no such formal arrangement has been made for dementia care (Pathak & Montgomery, 2015; Sapkota, 2013). An estimated population of 100,000 people living with dementia live in Nepal, and the projection in the next two decades is 132,000 (Jha & Sapkota, 2013). Research shows that family members caring for their elderly relatives tend to perceive dementia symptoms as a normal part of ageing (Hamal et al., 2014; Jha & Sapkota, 2013). In Nepal, even the college and medical students seem to have a very limited knowledge about Alzheimer's disease and dementia. A study on general college students reveals that their knowledge level on Alzheimer’s disease is below moderate (Baral and Pradhan, 2020). Another study by Sharma et.al. (2018) on the knowledge of medical students found their knowledge to be average. Both the studies used Alzheimer`s Disease knowledge Scale (ADKS) to assess the students’ knowledge on various dementia aspects. ADKS is said to be consisting of 30 true/false items with the resulting score being the numbers answered correctly.

Policy is crucial to implementing evidence-based practices. It is an authoritative response to a public issue which is intentional, structured, political, and all about making decisions and achieving objectives (Althaus et al., 2013). As a legitimate instrument of governance, it specifies the direction of public resources (Althaus et al., 2013). It also reflects the respective government's commitment to international and domestic laws; has clear purpose, goals and strategies based on evidences; delegates responsible personnel and institutions for action; and is underpinned by certain theories, principles and values. It clearly directs services in practice. It also promises innovations in response to changing scenario and evaluation outcomes. Nepal ratified the UNCRPD in 2010 (CIL Kathmandu, 2019). Basic health service is also recognised as a fundamental right in its 2015 constitution (Regmi et al., 2017). There were also recommendations from Hamal et al. (2014) to make dementia policy including the provision of various forms of caregiving. However, Nepal is still lagging behind in dementia policy formulation.

Purpose of the Study

The purpose of the study is to analyse the nature and content of policy provisions designed for informal caregivers of people living with dementia in seven selected countries and draw out policy implications for Nepal. The selected countries were Australia, the United Kingdom (UK), the United States of America (US), Canada, Korea, India and China. The specific objectives of the study were as follows:

(a) To analyse the shared and unique features of dementia care policies within Australia, the UK, the USA, Canada, South Korea, India, and China.

(b) To analyse specific policy provisions for informal caregivers of people living with dementia in those countries.

(c) To draw on the outcomes of these policies to understand potential implications for Nepal.

Selection of Countries

There were two criteria for selection of countries: publication of at least one journal article on dementia and geographical proximity to Nepal. The number of research studies on dementia can influence dementia policy development, innovation and implementation, and policy development in neighbouring countries may impact each other due to local knowledge spill over (Marrocu et al., 2013). Selected countries met at least one of the criteria.

For the first criterion, the 'AgeLine' was chosen as a more comprehensive and widely used database for ageing literature. Then a basic search was employed with the search term *dementia care policy* limiting to journal articles within the time range 2000 to 2018. Of 28 journal articles that were identified, six could not directly be accessed in full. Among the remaining 15, seven articles focused on the UK, three of them on the USA, and the remaining were from Australia, Canada, India, and Korea. Thus, these countries were chosen for inclusion. Under geographical proximity criterion, India and China were chosen as they border Nepal (Baral & Pyakurel, 2015). India met both criteria.

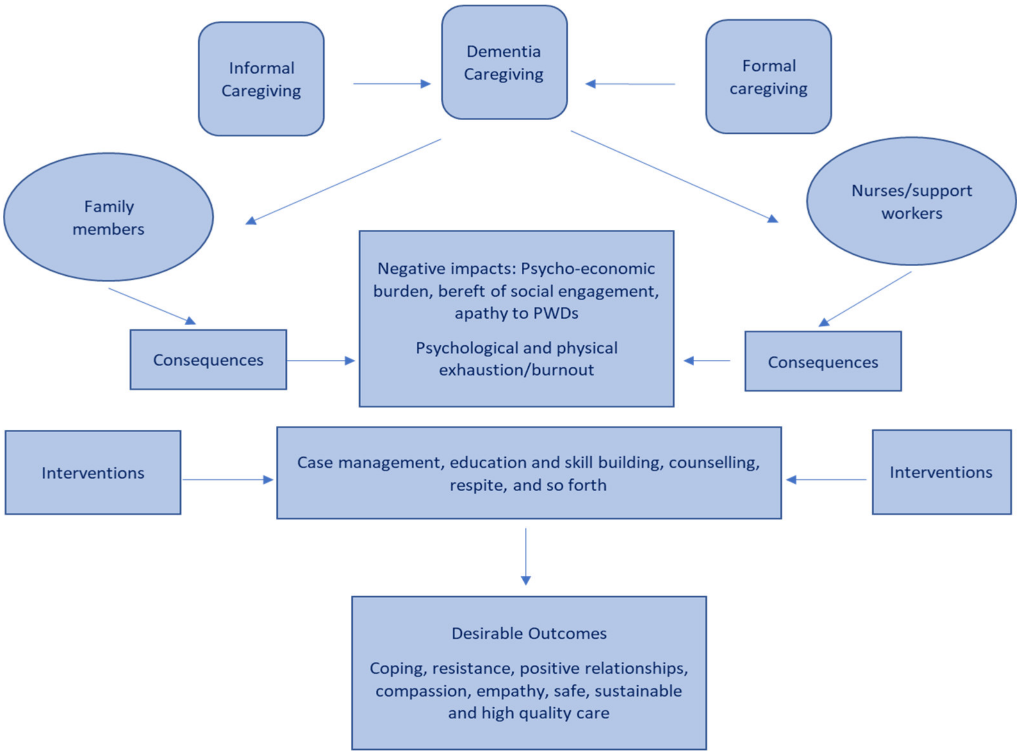
Conceptual Framework

In light of the literature review, the framework below (Figure 2.1) is conceptualised (Adapted from Cheng, 2017; SCRGSP, 2018; Teahan et al., 2018;

Wiles et al., 2012) to capture the fact that caregiving to people living with dementia can be delivered both informally by family members and formally by health care professionals. Caregiving tends to pose numerous negative consequences to caregivers. However, evidence-based interventions can yield positive outcomes.

Figure 2. 1.

Dementia caregiving-consequences-interventions-desirable outcomes



Chapter 3: Methodology

This study adopted a conventional, directed, abductive, latent, manifest qualitative content analysis (CA) methodology. CA can be quantitative or qualitative in nature (Bengtsson, 2016); can be conventional, directed or summative by approach; can be deductive, inductive, abductive in reasoning or inferencing (Graneheim et al., 2017; Krippendorff, 2018); and can be manifest or latent by the level of analysis (Elo & Kyngäs, 2008; Bengtsson, 2016). These concepts are elaborated in the subsequent sections.

Content Analysis

CA has a long historical basis of application in research. Broadly, CA is a technique of inferencing by systematically and objectively identifying specific characteristics of messages (Haggarty, 1996; Holsti, 1969). Despite its inception for the analysis of quantitative communication content, later researchers broadened its scope and meaning applying for both quantitative and qualitative study (Bengtsson, 2016). CA is applied so that generalisations can be made in relation to the categories of interest to the researcher (Haggarty, 1996). It enables researchers to make replicable and valid inferences from texts to the context of their use (Bengtsson, 2016; Krippendorff, 2018). CA is highly flexible and can be used with a wide variety of data sources, such as visual, audio and textual (Stemler, 2015). Much of the flexibility also underlies the fact that researchers can develop their own theory of its application to suit their research interests (Stemler, 2015).

Content analysis is a systematic, objective, and reliable approach to data analysis (Guthrie et al., 2004). It involves codifying information or data into pre-defined categories for deriving patterns in the presentation and reporting of information. For effective CA, certain technical aspects need to be considered prior to analysis. First, categories of classification must be operationally defined; second, the analyst must objectively identify whether an item belongs to or does not belong to a particular category; third, the information needs to be quantifiable; fourth, coding should be reliable (Guthrie et al., 2004). CA also requires the selection of unit of analysis which could be words, sentences or paragraphs (Guthrie et al., 2004).

Content analysis is guided by scientific principles: objectivity, systematicity and generality. Objectivity implies that the analysis must be undertaken based on explicitly formulated rules that will enable or allow two or more persons to obtain the identical results from the identical documents (Haggarty, 1996; Holsti, 1969). Systematicity refers to the consistently applied criteria of selection that govern the inclusion and exclusion of content or categories (Haggarty, 1996; Holsti, 1969). Generality implies that the analytical findings must bear theoretical relevance. Purely descriptive information about content, unrelated to other attributes of content or to the characteristics of the sender or recipient of the message, is of little scientific value (Haggarty, 1996; Holsti, 1969). In order to maintain objectivity and systematicity, this study applied systematic criteria to selection of countries, inclusion of policy documents, specification of study objectives, and coding. Results are reported explicitly to understand implications for Nepal, thus maximising generality.

Approaches to Qualitative Content Analysis

There are three approaches to qualitative CA: *conventional*, *directed* and *summative*. *Conventional* qualitative CA is used with a study design that aims to describe a phenomenon. It avoids the use of preconceived or pre-determined categories, instead allows the categories and their names to flow from the data. Researchers are immersed in the data and allow new insights to emerge (Hsieh & Shannon, 2005; Kondracki & Wellman, 2002). In *directed* qualitative CA, the researcher tends to use the existing theory or a prior research about phenomenon that is incomplete or would benefit from further description or interpretation (Hsieh & Shannon, 2005). Directed CA is guided by a more structured process (Hickey & Kipping, 1996; Hsieh & Shannon, 2005). With the use of prior research, researchers begin by identifying key concepts or variables as initial coding categories (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999). A study using a *summative* approach to qualitative content analysis begins with the identification and quantification of certain words or content in text for understanding the contextual use of the words or content. The quantification is not to infer meaning but to explore usage (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999). In this study, firstly, the Australian documents were analysed with the conventional approach so as to let the coding themes or categories emerge from the data itself. Those conventionally developed coding categories were later used also to code information from other country documents as of the directed approach.

In addition to these approaches, analytical inferences made during CA can be either deductive, inductive, or abductive (Graneheim et al., 2017; Krippendorff, 2018). *Deductive* inferences proceed from general to specific and are logically conclusive (Krippendorff, 2018). For example, if all children are interested in playing, then Babu, being a child must be interested in playing. Using a deductive approach, the researcher moves from a more abstract and general level to a more concrete and specific one (Graneheim et al., 2017). By contrast, *inductive* inferences proceed from specific to general (Krippendorff, 2018). For example, if people in my community speak English, then all people in the world can speak it. An inductive approach to inferencing or reasoning is characterised by a search for patterns, for example, similarities or differences in the data (Graneheim et al., 2017). *Abductive* inferences proceed across distinct domains from specific information of one kind to specific information of another kind according to the analysts' interest and questions (Krippendorff, 2018). For example, one might infer the date of a document from its vocabulary or one might infer a writer's attitude from the images used in her prose (Krippendorff, 2018). Also known as complementary, combined or fuzzy logic, abductive inference can be used for a complete understanding and can move back and forth between deductive and inductive approaches to inferencing (Graneheim et al., 2017). This study applied an abductive approach (both inductive and deductive) to inferencing. Initially general themes were inductively developed from the Australian documents and then those general themes were deductively applied to the subsequently analysed documents from other countries.

Finally, there are two levels of reporting in qualitative CA: manifest and latent. In a manifest CA, the researcher describes what the informants actually say, stays very close to the text, uses the words themselves, and describes the visible and obvious in the text. In contrast, latent CA is extended to an interpretive level in which the researcher seeks to find the underlying meaning of the text: what the text implies or is talking about (Bengtsson, 2016). Both of these levels require interpretation but interpretations will vary in depth and level of abstraction (Graneheim et al., 2017). The present study adopted both latent (with interpretations) and manifest (with original quotes in *italics*) levels of analysis.

In sum, a *conventional, directed, abductive, latent, manifest qualitative* content analysis was applied for this research project.

Validity and Reliability in Content Analysis

Content analysis is a social scientific methodology which requires researchers to make a strong case for the validity and reliability of their data (Potter & Levine-Donnerstein, 1999). *Reliability* in CA concerns with the way that two or more persons achieve the same results from analysing the same documents or data. It needs to be a check of both coder (the person involved in coding) and coding categories. It is important to have the information or data coded by another researcher and to test inter-coder agreement (Haggarty, 1996). In order to maximise reliability of the present study, data search was piloted and inclusion of the data was confirmed in consensus by three research team members. Policy documents from one country (Australia) were coded twice with broad context coding in NVivo, and the two sheets of information references (reference in NVivo is a bit of information selected) were compared. The information from both the sheets was almost identical.

In CA, *validity* of analysis could be captured in three aspects of its meaning: concept validity, empirical validity, and phenomenological validity. The *concept validity* addresses the issue of whether the categories reflect the ideas they claim to reflect. The *empirical validity* addresses the issue of whether there is any external evidence which can be used to confirm what is being suggested in the CA. The *phenomenological validity* is whether the researcher interprets what is said in the way the participants had intended (Haggarty, 1996). The use of conventional coding, in which categories emerge from the policy documents, maximises the concept validity of this work. The empirical validity of the findings is justified in the discussion (chapter 5) below, with reference to other evidences (Haggarty, 1996).

Strengths and Limitations of Content Analysis

Content analysis has a long historical base. It is a highly versatile technique that can be used with a wide variety of data sources for both quantitative and qualitative analysis (Stemler, 2015). Researchers can adapt CA to suit their interest of analysis. Textually it can be used to analyse trend and frequency across a wide range of texts for future predictions and implications (Stemler, 2015).

Despite these strengths, CA has some important limitations. It can be vulnerable to researcher subjectivity and biases which can affect the collection, analysis and interpretation of data (Kolbe &Burnett, 1991). It can also be time-consuming, and time constraints can lead to superficial analysis (Bauer, 2007). However, the researcher attempted to mitigate such limitations in this study by adhering to the theoretical principles and methodology specified *a priori*.

Data Collection

Data Inclusion and Exclusion Criteria

Documents were included for analysis:

(a) if they belonged to one of the selected seven countries published by either the country government or by peak body organisations,

(b) if they mentioned dementia caregiver services or interventions,

(c) if they were published between 1981 and 2019, and

(d) whether they were policy or non-policy documents given that they mentioned dementia caregiver services or interventions.

This timeframe was chosen because 1981 was proclaimed by the United Nations as the International Year of Disabled Persons (Ruskin, 1981). The underlying purpose of the announcement was to encourage nations to take actions to support a happy life for people with disability (O'Flaherty, 1981). The proclamation was the culmination of the disability rights movement which framed the SMOD from the 1970s onwards. 2019 was the year in which this research was undertaken. This study included both policy (such as acts, frameworks, guidelines, plans, and strategies) and non-policy documents (such as reports) both from governments and peak bodies as long as they mentioned dementia caregiver services or interventions. The sole purpose was to reach the comprehensive body of information and then to draw reliable conclusions.

Documents were excluded if they:

(a) discussed only direct medical or pharmacological interventions for people living with dementia,

(b) did not include anything about informal caregivers, and

(c) were not written in English

Procedure

Data were initially accessed through an advanced Google search using the terms *policy, regulation, strategy, service, plan, framework, guideline, intervention, statement, report, evaluation,* with *dementia* or *dementia caregiver or dementia caregiving* and *the respective country name*. The health-related government sites of the selected countries and those of dementia-related peak body organisation of each country were also separately searched to locate any policy or report mentioning dementia caregiver services. Further, snowball sampling was employed by reviewing the reference list of the accessed documents for further documents that met inclusion criteria (Yingling, 2015). Finally, the World Health Organization, Alzheimer's Disease International, Dementia Alliance International, and other advocacy organisations were also searched for reports that focus on dementia caregiver services in the selected countries.

Coding

As stated earlier, both conventional and directed approaches were used for finalising coding categories. In the conventional approach, the coding categories and subcategories emerge as the documents to be content-analysed are examined or scanned through (Hsieh & Shannon, 2005; Kondracki & Wellman, 2002), whereas in the directed approach, such categories are pre-conceived or adapted from previous studies (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999). First, the Australian documents were conventionally coded. Next, the same coding categories conventionally established with the Australia documents were used also to code information from other country documents, in line with a directed approach.

There were 17 coding categories that emerged from the analysis of documents from the first country (Australia). They were caregiver definition and recognition, cultural or linguistic backgrounds, impacts of caregiver services, indicators of dementia friendly communities, institutions or stakeholders involved, key enablers, policy objectives or goals, peak bodies and other agencies, plan or policy outcomes for caregivers, policy recognition of caregiver burden, principles, priorities, research, resources or funding, service delivery mechanism or care path, services, and vision statement. These were later reduced to 10 categories and further limited to two broad categories with sub-categories of each. Finally, the two broad categories with their sub-categories were decided as the coding categories of the policy documents from all countries. The two broad categories were*: shared and unique features of dementia caregiving policies* and *informal caregiver focused provisions or services*. These two broad categories and associated sub-categories emerged inductively with the application of conventional approach to coding, and the same categories were later deductively used to code information references from other country documents theoretically in line with a directed approach to coding (Hsieh & Shannon, 2005; Kondracki & Wellman, 2002).

Coding Procedure

Documents from each country that met inclusion criteria were given special code names so that they could easily be located or tracked back whenever needed (Appendix A). The major types of documents included were acts, frameworks, guidelines, action plans, reports and strategies. Data analysis was completed using NVivo version 12, a software program that supports fine-grained and in-depth qualitative analysis (Richard, 1999). In NVivo, codes or themes or coding categories are referred to as nodes and sub-categories as child nodes. Chunks of information selected or coded under coding categories are referred to as references. All the information references were assembled under the coding categories as mentioned above (under coding). Broad context coding was followed by re-coding for refinement of categories and themes (Richard, 1999). There were 352 broad codes which were then refined to 93 codes and 419 references (Table 4.3).

Chapter 4: Results

The purpose of the study was to analyse the nature and implications of policy provisions designed for informal caregivers of people living with dementia and consider policy implications for Nepal. The specific objectives were three-fold: first to explore and analyse the shared and unique features of dementia care policies; second to explore and analyse the policy provisions for the informal caregivers of people living with dementia, and third to draw implications for dementia care policies in Nepal. The *shared and unique features* in this study refer to the policy aspects that are likely to guide and influence the provisions for informal caregivers of people living with dementia and their implementation.

Data Characteristics

Of 132 policy documents accessed, only 105 met inclusion criteria (Refer to Table 4.1). The oldest documents included dated 2003 despite the inclusion criterion from 1981(Refer to Table 4.2). No primary policy documents were found of China and South Korea possibly because they were made inaccessible from the Google Search. However, some secondary information about South Korea was available in four reports released by Alzheimer’s Disease International (ADI; peak body representing all dementia advocacy organisations worldwide). The rest of the documents were excluded as they did not contain any relevant information on informal caregiving.

Table 4. 1.

Number of policy/non-policy documents

Country	Accessed	Included
Australia	28	23
Canada	35	30
China	00	00
India	04	04
South Korea	00	00
UK	31	22
US	20	14
ADI/WHO	14	12
Total	132	105

Table 4.2 below summarises the type and number of documents included of the six countries with the publication timeline. The references and code names of all the documents are presented in *Appendix A*.

Table 4. 2.

The policy/non-policy documents from selected countries and international peak bodies

Countries and international peak bodies	Type of documents (*n*)	Publication year range	Total documents
Australia	Acts (1), frameworks (5), guidelines (3), plans (2), reports (12)	2004-2018	23
Canada	Acts (1), frameworks (2), guidelines (4), plans (3), reports (16), strategies (4)	2011-2019	30
India	Acts (1), reports (3)	2009-2018	4
South Korea	-	-	0
UK	Frameworks (1), guidelines (5), plans (2), reports (12), strategies (2)	2004-2019	22
US	Plans (6), reports (7), strategies (1)	2003-2017	14
WHO and ADI	Reports	2009-2019	12

Table 4.3 below presents the NVivo analysis of two-phased coding of information from the documents of five countries and ADI and WHO as above (Refer to Table 4.2). The second phase codes and references were considered for the reason of succinctness and precision to further analyse, interpret and summarise the findings.

Table 4. 3.

Coding outcomes: codes and references

Countries or peak bodies	First phase coding	Second phase coding	
	Codes	Codes	References
Australia	107	17	92
Canada	109	18	105
India	08	09	28
South Korea [a]	00	06	11
UK	99	21	109
US	74	15	57
ADI/WHO	55	07	17
Total	352	93	419

[a] As no primary documents were accessed from South Korea, some information was coded from ADI documents during the second phase only. Hence, there were no codes about Korean policy documents from the first phase.

Themes

Aim 1: Shared and Unique Features of Dementia Care Policies

Policy Visions

The overarching visions clearly stated or implied common to several policies broadly aim for *dementia friendly world*. The policies envision a community in which people living with dementia, their caregivers and families are recognised, respected, valued, included, connected, well-supported and strengthened through properly organised support systems. Public and professionals alike are well-informed about dementia. Dementia-associated stigma and fear are eliminated, and dementia research is prioritised.

In the Canadian context, this overarching vision is described in several policies as an integrated, whole-person care in the community with sustainable quality services that meet people living with dementia families' needs. The vision focuses on being respectful to people living with dementia, their caregivers and families; support for their informed choices, optimisation of the quality of their life; and understanding, prevention and effective treatment of dementia:

> *…. a vision for Integrated, Whole-Person Care in the Community. The Ministry of Health has committed to a system-wide plan for innovation and strategic change to ensure the health system delivers quality services that meet families' needs in a manner that is sustainable in the long term (p1-CA,2012, p.4,Gov)*
>
> *The core vision for developing the dementia strategy is to make sure that all Ontarians with dementia, along with their families and care partners, are treated with respect, have the tools to make informed choices about their care, and are living well (R10-CA,2016, p.4, Gov)*

Canadian policies equally emphasise the recognition, resiliency, and supportive resources for caregivers and appropriate balance of prevention and care with the right care, in the right place, at the right time through coordination and integration.

Australian policies also envision a dementia-friendly community where coordinated services, partnerships, enablers and outcomes are available, and people living with dementia, their caregivers and families are valued, respected, supported and encouraged. Priorities encompass improving the quality of life for people living with dementia, caregivers and families and their support networks, funding and supporting high quality, high impact research and translation initiatives to facilitate positive outcomes:

> *.... develop a vision of what we want to achieve, such as seeing the whole person and not the disease of dementia alone, coordinated services, partnerships, enablers and outcomes (p1-Aus,2012, p.23, Gov)*
>
> *.... a shared vision that seeks a better quality of life for people with dementia, their carers and families and identifies achievable goals for all Australian governments that will make a positive difference (F4-Aus,2006, p.1, Gov)*

Similarly, policies from the UK and the USA have a common vision for a system where all people living with dementia have access to care and support, their families are aware of referral pathways, all the public are well-informed and dementia-associated fear and stigma reduced, and the quality of care remains high and equally available everywhere:

> *Our vision is for a system where all people with dementia have access to care and support that they would benefit from. As the Strategy is implemented, we look to a time when the public and professionals alike are well informed, and where the fear and stigma associated with dementia have been decreased. It will be a system where families affected by dementia know where to go for help and what services to expect, where the quality of care is high and equal wherever they might live, and where people seek help early for problems with memory and are encouraged to do so (R11-UK,2011, p.7, Non-Gov).*

Some USA policies envision a nation free of AD/ADRD which implies the equalisation of opportunities for people with AD/ADRD and their families and the lessoning of their burden to the optimum:

> *In consultation with stakeholders both inside and outside of the Federal Government, this National Plan represents the blueprint for achieving the vision of a nation free of AD/ADRD. Central to and guiding the National Plan are the people most intimately impacted by AD/ADRD (p1-US, 2017, p.5, Gov)*

The vision of the Indian dementia strategy focuses mostly on the procedural aspects in responding to dementia, such as diagnosis, rehabilitation, and supports:

> *Ensure comprehensive sustainable dementia diagnosis, care, rehabilitation, and support services across the country (R3-India, 2018, p.1, Non-Gov)*

The South Korean campaign *War on dementia* implies the vision of having a dementia friendly Korea through coordinating and focusing the resources and programmes on raising awareness, reducing stigma and minimising the impacts of dementia on people living with dementia, their caregivers and families (R3-ADI). Similarly, the 3rd National Dementia Plan of South Korea 2016 envisions a dementia friendly society, where people living with dementia and their carers live well, focusing on community-based prevention and management of dementia; diagnosis, treatment and care for people living with dementia; the reduction of care burden and support for dementia research.

In the context of India, no policies with dementia-specific vision statements could be accessed or found. However, there were some efforts initiated in the past which would suggest the direction of India for dementia policies, programmes and services. For example, the theme of the National

Dementia Strategy Consultative Meeting in 2009 was known as *'integrated dementia care',* and the unprecedented Dementia Report 2010, also proclaimed as ambitious and visionary, calls for the government and policy-makers to recognize dementia as a health and social welfare priority by developing a National Dementia Strategy.

Policy Objectives

The objectives of several dementia care policies are to provide specific services to people living with dementia, their caregivers and families, as well as transforming system and society through awareness, collaboration and integration, capacity-building, policy-making and research. The objectives stated in each document are displayed in *Appendix B*.

Most policy objectives (Appendix B) focus on the *process and procedures* for services. They specifically focus on multi-sectoral collaboration, integration of services, policy guidance, reducing stigma, identification of interventions, and capacity building of health care professionals and other service providers:

> *….to promote collaboration between dementia care researchers, service providers and consumers with the objective of improving the quality of dementia care through the rapid dissemination and uptake of research evidence (R10-Aus, 2011, p.10, Gov)*
>
> *to integrate healthcare and community services while strengthening the informal care network and providing information, coaching, and emotional support to caregivers (R4-ADI, 2017, p.38, Non-Gov)*

Objectives that are directly concerned with *services and consumers* focus on addressing applicable unmet needs of caregivers, empowering people living with dementia and their caregivers, improving wellbeing of people living with dementia, providing counselling, education and flexible respite and reducing the risk of dementia:

At the centre of the model is the key objective that the Framework strives to ensure that the person living with a dementia, their families and carers, can live well with dementia (F2-UK, 2016, p.13, Non-Gov)

The overall objective of the four sets of recommendations put forward in Part 4 of this Discussion Paper is to increase flexibility in the provision of respite care (R11-Aus, 2009, p.8, Non-Gov)

…its stated objective is to provide support to caregivers so they are able to maintain their usual relationship with the home care clients (R13-CA, 2016, p.11, Non-Gov)

Another common objective is to promote a dementia-friendly society, ensuring a person-centred philosophy of care, improving system sustainability, and establishing care and referral pathways:

> *The 3rd National Dementia Plan of 2016 aims to create a dementia friendly society to enable people with dementia and their carers live well (R4-ADI, 2017, p.101, Non-Gov)*
>
> *Its overall objective was to create positive change for people living with dementia as well as their families and caregivers (S4-CA, 2015, p.5, Gov)*
>
> *The first and most important objective is to ensure that a person-centred philosophy of care is well understood and put into practice (G1-CA, 2011, p.9, Non-Gov)*

Policy Priorities and Recommendations

The priorities identified in dementia policy differ in terms of policy and country contexts. The policy context here refers to the policy type and the time when the policy was developed. Similarly, policy priorities differ on basis of the areas of focus. For example, some policies emphasise the importance of research while others put emphasis on early diagnosis and early intervention, awareness, and service delivery. Additionally, some others tend to focus specifically on caregiver-focused supports.

> *Focus on priorities for care-givers - access to continuity of support, access to good-quality information about dementia and local help available (pr-India, 2009, p.4, Non-Gov)*

Nonetheless, this part summarises articulated priorities set across policies in general irrespective of time and specific priority. Common key priorities are research, awareness, early assessment and diagnosis, flexible care and support services, policies and programs, strengthening capacity and system, monitoring and evaluation, and human rights-based and person-centred care approach.

Several policies emphasise the importance of robust dementia *research* through increasing funding and collaborating between researchers nationally, regionally and internationally. The research goals should be directed primarily towards assessment and diagnosis, quality of care, and delivery of care. Foci of the identified research priorities include assessment and diagnosis focused goals, which stress the importance of identifying interventions to promote timely diagnosis and assessment of dementia and the needs of people living with dementia, their caregivers and families. Quality-focused research goals aim to determine the most effective interventions for educating, training and supporting caregivers; maximising patients' quality of life and reducing caregiver burden; developing and evaluating policies, investments and plans for increasing the capacity, knowledge, skills and interest of the health and social care workforce; and establishing norms and standards for the high quality of care. Delivery-focused goals recommend evaluation of the effectiveness of existing policies and services or the identification of optimal models of care and support. Other examples of delivery-focussed research goals include understanding the role of assistive and technological devices, such as e-health and mobile health strategies. Other priority areas recommended for research include identification of measures for prevention, risk reduction and delaying the onset of dementia; building the evidence base for effective interventions, increase of system supports, and strengthening of system capacity and accountability:

> *…continue to seek funding for research projects that fit into the housing and dementia research consortium (HDRC) research priorities (R10-UK, 2017, p.68, Non-Gov)*
>
> *Research is focusing on better understanding the causal links between social determinants and health outcomes, and on which policies might lead to better health outcomes (R4-Aus, 2016, p.138, Gov)*

Another common policy priority is expanding and increasing *awareness* of dementia in communities and societies through the equitable availability of evidence-based and culturally-appropriate educational and informational resources. The awareness should strategically focus on promoting public understanding about dementia; eliminating stereotypes and stigma; improving attitudes and interactions; facilitating easy and safe access to forums, networks and services such as diagnosis and post diagnosis supports (seamless transition and referral pathways); and understanding measures for modifiable risk, prevention and delaying the onset of dementia:

> *As part of this campaign, the national Alzheimer association coordinated training programmes in an effort to raise awareness and reduce stigma (R3-ADI, 2018, p.20, Non-Gov)*

Early assessment and diagnosis of dementia and associated needs are emphasised across policies. Importance is laid on the need for affordable, accessible and safe procedures, and trained and skilled workforce for early and reliable assessment and diagnosis on ongoing basis to respond to the changing needs of people living with dementia, their caregivers and families. The outcomes of assessment and diagnosis enable tailoring individualised support services at a specific and/or broader level to form the basis of policies, plans and programs from a consumer perspective:

> *Early assessments would help to identify seniors at risk (R9-CA, 2012, p.23, Gov)*
>
> *Programs should therefore include an assessment component (formal or informal) to determine the individual needs of caregivers… (R6-CA, 2011, p.17, Non-Gov)*
>
> *The strategy contained 44 recommendations ...promoting early assessment and diagnosis… (F2-UK, 2016, p.8, Non-Gov)*

Several policies recommend that, following assessment and diagnosis, *flexible care and evidence-based support services* should be delivered to people living with dementia, their caregivers and families:

> *Develop & disseminate evidence-based interventions for people with AD/ADRD & their caregivers (P2-US, 2016, p.45, Gov)*

Care and support services should be provided by skilled workforce and promote physical, psychological, social and economic wellbeing of people living with dementia, their caregivers and families. Policies and reports equally emphasise the co-design of policies and programs with the involvement of people living with dementia, their caregivers and families. Services should recognise the unique needs of people living with dementia and their caregivers; establish a comprehensive dementia care system and dementia friendly communities; regulate safe delivery of services, allocate human and financial resources to support people living with dementia and their caregivers; and promote recovery oriented long-term care system embedding cultural safety and diversity:

> *This includes providing recommendations about education, cultural safety, diversity, support for caregivers and service providers, and service delivery models (G3-CA, 2018, p.19, Gov)*

Strengthening workforce capacity and overall care system is another common priority. Overall care system in this case, refers to dementia care institutions and broader communities. Health and social care professionals require adequate training, education and information to enhance their capacity for high quality dementia care:

> *Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers… (R6-US, 2016, p.8, Non-Gov)*

Similarly, legal, financial and human resource mechanisms should be established to ensure safe, sustainable, seamless, and smooth transition dementia care pathways, with effective leadership, good governance and accountability. Beyond the immediate workforce, members of broader communities such as employers of working caregivers should also be informed of dementia and the needs of dementia caregivers.

Another common priority is *monitoring and evaluation*. Several policies advise to monitor and evaluate policies, programs, services and overall care system on ongoing basis to determine their effectiveness, impacts and outcomes and to introduce innovations in dementia care system:

> *Continue to monitor the impact of factors that may reduce the prevalence of dementia… (R9-UK, 2014, p.xix, Non-Gov)*

Human rights-based and person-centred care approaches are common to priorities, policies and programs. This approach recognises the rights of people living with dementia, their caregivers, and therefore, sets obligations on government, business and non-profit sectors to respond to the unique needs of people living with dementia, their caregivers and families. The outcomes guided by this approach will be individualised support system that articulates their dignity, respect, freedom and choice:

> *Services are provided within a consumer-directed care philosophy, delivered in a person-centred way… (F1-Aus, 2015, p.3, Gov)*
>
> *Human rights lens: A person-centred approach that focuses on respecting and preserving an individual's rights, autonomy and dignity in alignment with Canada's human rights commitments (S2-CA, 2019, p.7, Gov)*

Recognition of Caregivers

Most of the policies recognise informal caregiving of people living with dementia as a key component of dementia care. Some countries like Australia have introduced legislation, whereas others have provided space in policies and policy visions for recognising the valuable contribution these caregivers make to society:

> *The object of this Act is to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society (A1-Aus, 2010, p.2, Gov)*

Subsequently, the term referring to a caregiving person varies across countries. In Australia, a caregiver (or 'carer') is any individual providing support to the needy:

> *A carer is an individual who provides personal care, support and assistance to another individual who needs (A1-Aus, 2010, p.3, Gov)*

Canadian documents specify a more detailed definition of caregiver:

> *Caregiver is a member of the immediate or extended family, a friend or a neighbour who provides support, care and assistance, without pay, to an adult or child who is in need of support* (R11-CA, 2011, p.4, Non-Gov)

However, the definition of a caregiver tends to vary in different programmatic and service contexts even within a particular country. For instance, the Caregiver Benefit Program Policy in Canada defines a caregiver as any individual (not necessarily a family member, friend or neighbour) who is providing unpaid assistance with activities of daily living and instrumental activities of daily living to a family member or friend. This implies that caregiver definition can be specific to the contexts of time, space and services.

Many policy documents note that caregivers play a critical and unique role in supporting people living with dementia, ranging from support to activities of daily living (ADLs), management of care, to provision social and emotional support. They deliver support for cooking, shopping, housework and home maintenance; bathing, dressing, using the toilet and grooming; arranging for and ensuring delivery of formal and informal services; and arranging, enabling and participating in social events. Their unique role supports family members, friends and neighbours to live at home and remain connected to their communities:

> *Carers play a vitally important role in supporting family members, friends and neighbours to live at home and remain connected to their communities (G1-Aus, 2016, p.2, Gov)*

Caregivers make valuable contributions to society which result in positive social and economic outcomes such as delaying the institutionalisation of care and reducing care cost, supporting in the sustainability of publicly funded health programs, connecting people living with dementia to family and friends for optimising their optimistic family and social life:

> *The valuable social and economic contribution that carers make to society should be recognised and supported (A1-Aus,2010, p.3, Gov)*
>
> *The South Australian Carers Recognition Act 2005 and the Carers Policy enshrines into legislation the Carers Charter which seeks to recognise and support un-paid carers for their community and economic contributions (P2-Aus, 2009, p.5, Gov)*

Several policies acknowledge that dementia caregivers experience more negative physical, emotional, psychological, social and financial consequences and strains compared to caregivers of people without dementia. Stages or severity of dementia also determine the level of such consequences or strains:

> *As the disease progresses and care needs increase, caregivers may feel overwhelmed (G2-CA, 2016, p.11, Gov)*

The heightened demands of care have an impact on the physical and emotional health of the caregivers, sometimes resulting in disruption of sleep and tiredness, and in caregiver burn out. Behavioural and psychological symptoms of dementia (for example, aggressive or agitated behaviour; BPSD) can cause significant emotional burden for caregivers. Documents highlight that caregivers have high rates of distress, depression, anxiety and frustration, and have poor health outcomes. They may also report feeling guilty, sad, grieved and pessimistic. Fear of stigma compounds these psychological problems. Caregiving can cause isolation from family, friends and community, as the person can lose opportunities for shared activities, communication and social life. Employed family caregivers also experience work interruptions, lower productivity and reduced opportunity for paid work; further exacerbating financial pressures:

> *The caregiver is at risk for stress, depression, general health deterioration, and loss of productivity at work (p1-CA, 2012, p.10, Gov)*
>
> *Being a carer is like being on an emotional roller coaster (F4-Aus, 2006, p.5, Gov)*
>
> *Many carers experience negative effects on their emotional, psychological and physical health, social activities and support networks, ability to work and finances (R5-Aus, 2015, p.4, Non-gov).*

Every policy recognises the uniqueness of the needs of caregivers due to their own personal circumstances and the uniqueness of the individuals they are supporting. Caregivers vary in age, caregiving experience, knowledge and skills, and the degree of care they are required to provide to those they support. They need individualised support structures put in place to address their varying physical, emotional, psychological, social, practical and informational needs so that they can continue their support to people living with dementia. Some of them may also need flexibility in work hours and support from their co-workers:

> *The 2012 dementia action plan recognized the important and unique needs of caregivers while working to improve care for people living with dementia (G2-CA, 2016, p.5, Gov)*
>
> *Family caregivers vary in age – with largest proportion (23%) between 45 and 54 years old. Of the balance, 11% are over the age of 65 and 19% are 55-64 and 17% are 15 to 24 years old (F1-CA, 2017, p.6, Non-Gov)*

Several policies further recognise caregivers as major stakeholders in system-level dementia care policy and planning. Their input is valuable at all stages and levels of decision-making for the translation of effective dementia care services supporting the wellbeing of both caregivers and care recipients:

> *The World Health Organization suggests that family caregivers can make important contributions to the mental health system by being involved in system-level roles, such as strategic planning for the organization, service planning, implementation, delivery and evaluation (G4-CA, 2013, p.37, Gov).*

In order to facilitate their effective and meaningful participation, family caregivers can be provided with orientation to the mental health system and organisation's operations. Similarly, they can be linked to various networks and forums.

Stakeholders and Support Networks for Advocacy and Service Coordination

Several policies acknowledge that dementia caregiving requires interdisciplinary, multi-dimensional and multi-componential supports from a broad range of stakeholders and support networks. At an organisational or institutional level stakeholders include government departments, businesses, non-profit organisations such as trade organisations and peak bodies, and academic institutions such as universities. Of these, peak bodies and departments of health and social services are key institutional stakeholders.

The peak bodies identified in the countries included in this study include Dementia Australia (formerly Alzheimer's Australia), Alzheimer's Society of Canada and Canadian Caregiver Coalition, Dementia Action Alliance and Age UK, Alzheimer's Association & Dementia friendly America, Agewell Foundation and Alzheimer's and Related Disorders Society of India, and Alzheimer's Association Korea (Refer to Appendix C). The role of peak bodies in promoting the wellbeing of caregivers is articulated in several documents. Peak bodies develop communities supportive to people living with dementia and their caregivers, build meaningful partnerships and working collaboratively with organisations, and establish and lead support networks, advocating and creating platform for dialogue and uniting people living with dementia and their caregivers:

> *Canadian Caregiver Coalition (CCC) is a virtual coalition of over forty diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada (S1-CA, 2015, p.1, Non-Gov)*

> *Dementia Friendly America (DFA) is a multi-sector, national collaborative of cross sector organizations and individuals seeking to foster communities across the United States that are equipped to support people living with dementia and their caregivers (P1-US, 2017, p.25, Gov). The Dementia Action Alliance (DAA) brings together over 150 organisations across England to connect, share best practice and take action on dementia (R10-UK, 2017, p.6, Non-Gov).*

Similarly, some reports highlight the existence of a range of support networks and their effectiveness. These networks could range from small-scale support groups (such as caregivers' self-help groups) to larger networks (such as Caregiver Advocacy Groups Canada, Carers Australia, Family Caregiver Alliance US, and Crossroads Care Britain). These networks also help connect people living with dementia, caregivers and researchers focused on developing, conducting and disseminating person-centred dementia research. They provide caregivers with opportunities for webinars, consultation and to better serve themselves:

> *Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy (R2-US, 2016 p.., Gov).*

Summary

The policies explored share in common the vision of dementia friendly communities where people living with dementia, their caregivers and families are recognised, valued, and included. The objectives of the policies focus on specific services to people living with dementia, their caregivers, and families and transformation of system and society. Priorities and recommendations include research, awareness, early assessment and diagnosis, flexible care and support services, policies and programs, strengthening capacity and system, monitoring and evaluation, and human rights-based and person-centred care approach. Several policies recognise caregivers of people living with dementia as a key component of dementia caregiving. Some policies also acknowledge the involvement of a broad range of stakeholders and support networks for effective dementia care outcomes.

Aim 2: Informal Caregiver-Focused Services or Provisions

A range of services or interventions are available for informal caregivers of people living with dementia. Several documents highlight that interventions and supports that contribute to health, financial and social aspects of caregivers are necessary to promote positive outcomes:

> *Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role (F1-Aus, 2015, p.14, Gov)*
>
> *The absence of such supports, on the other hand, can lead to negative effects for family caregivers that jeopardize both their capacity to provide care and their own health and well-being (G4-CA, 2013, p.2, Gov)*
>
> *…the support and maintenance of relationships between carers and care recipients by facilitating access to information, respite care and other*

> *support appropriate to both the carer's and the care recipient's needs and circumstances (R3-Aus, 2012, p.194, Gov)*

The informal caregiver-focused services and interventions discussed in the documents included five categories: informational; assessment; direct support; multi-component; and system level.

Informational Supports

Informational support benefits caregivers in building their confidence and capacity to care. Some policies imply that the lack of information or poor communication increases caregiver uncertainty and stress. Suitable information and advice can include why they need support services; how they can identify and assess their needs; what services, arrangements, programs and initiatives are in place; and where and how they can access them. For keeping informal caregivers informed and supported, practical caregiver guides, information centres, and toll-free helplines are available. For example, Carelink Centres in Australia provide caregivers access to information, and HelpAge India has initiated a toll-free senior citizen helpline:

> *As a carer I found it quite difficult to find what services were available at the different stages of the dementia journey, so the guide is put together in a roadmap format (G2-Aus,n.d., p.3, Non-Gov)*
>
> *Caregiver resources have been developed or updated, such as "A Guide for the Caregiver: Information and Resources for Caregivers of Older Adults (F3-CA, n.d., p.13, Gov)*
>
> *'Support for Carers', a practical guide to services for families and friends of people with dementia (G2-Aus, n.d., p.1, Non-Gov)*
>
> *Elderly helpline: A toll-free senior citizen helpline has been initiated by*

> *HelpAge to service queries of elders, provide information and address issues related to isolation, abuse and neglect (R1-India, 2010, p.56, Non-Gov)*
>
> *Ensure that people living with dementia and their carers know how to get more information and who from if their needs change (G1-UK, 2019, p.13, Non-Gov)*

Procedural Supports

Procedural services refer to procedures adopted to identify the needs of caregivers and to provide referrals in their contexts. Some policies inform that a *one-size-fits-all* philosophy is not always generalisable and applicable. As mentioned earlier, caregiver needs vary with regard to their individual care contexts which can be influenced by age, gender, role in the family, experiences and skills of caregiving, financial conditions, and the stages or psychosocial complexity of their care recipients. Some policies emphasise the importance of services such as case management, needs assessment and referral to social workers and health care professionals. In the current context, *case management* is a broad procedural intervention that can include both needs assessment as well as care planning and coordination:

> *FCS offers each client a tailored comprehensive care package for a period of 8–12 weeks which comprises intensive case management by experienced social workers (R2-Aus, 2006, p.2, Gov)*
>
> *A holistic assessment identifies the strengths and capacities of the client as well as deficits (G3-Aus, 2013, p.19, Gov)*
>
> *...a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health, an assessment of*

> *their need for short breaks and other respite care (G1-UK, 2019, p.32, Non-Gov)*

Direct Supports

Direct supports are services and interventions that directly address the needs of informal caregivers of people living with dementia and support them to live a normal life while they are continuing their caregiving role. Several policies highlight that despite great joy and pleasure many families take in providing care to their loved family members with dementia, the physical, emotional and financial consequences of caregiving can be overwhelming without some concrete intervention such as respite. The key direct support services recommended include respite, education and training, counselling, and financial support. These services are found to be significant and effective in assisting informal caregivers to maintain a normal life in their dementia care journey.

Respite is a planned or emergency temporary break provided to the family or informal caregivers of people living with dementia. Respite provision provides a short-term break to support and maintain their primary care relationships. It gives them a break from their caring responsibilities as well as providing them important opportunities for social engagement for people living with dementia:

> *Respite care is designed to give you a break from your caring responsibilities for a period of time as well as providing important opportunities for social engagement for the person with dementia (G2-Aus, n.d., p.24, Non-Gov)*

Respite programs are effective in reducing caregiver burden, depression and other associated health problems, and caregivers are reportedly satisfied with respite services. Respite is considered a major contributor to family caregiver sustainability:

> *Respite programmes might reduce carer burden, depression and carers' reported health problems (R6-UK, 2004, p.1, Non-Gov)*
>
> *Carers reported high levels of satisfaction with in- home respite services (R11-Aus, 2009, p.61, Non-Gov)*

In the Indian province of Kerala, though not directly focused on caregivers, the first ever respite service called Harmony Home Respite Care Centre was established in August 2005 which provides respite care to people with dementia:

> *The centre provides round the clock care to people with dementia with respite care service and day care service (R1-India, 2010, p.53, Non-Gov)*

In the USA, large grants are provided for a wide range of respite services for caregivers of people living with dementia and most states have respite services for them:

> *NYSDOH allotted $1.5 million to fund a wide range of caregiver support and respite services for caregivers of individuals with AD/ADRD (P1-US, 2017, p.37, Gov)*

Flexibility and choice principles are an important aspect of respite services, such as time flexibility and place flexibility:

> *There are an increasing range of respite options including in-home, residential, overnight/weekend stays in day centres or cottages, mobile services, emergency respite, respite for working carers, as well as social outings, holiday programs and weekend retreats that may include carers/ family (F3-Aus, 2010, p.46, Gov)*

Some countries offer consumer directed and volunteer respite. Consumer directed respite care services focus on choice and control principles. Such care packages allow both the caregivers and the care recipients control over the design and delivery of respite services. Both of them can make choices about the types of services including how and when they are delivered:

> *Consumer Directed Respite Care (CDRC) packages can give the person receiving care and you a greater say and more control over the design and delivery of respite services provided to you. This means with your support the person receiving care can make choices about the types of respite services (G2-Aus, n.d., p.25, Non-Gov)*

Volunteer respite is designed to increase the availability and scope of respite within a community setting. It is not supposed to replace formal respite services or paid respite providers. Instead, it is aimed at maximising opportunities for caregivers to take a break from their caregiving activities:

> *In part, volunteer respite schemes are a response to the recognition that funded respite services are insufficiently resourced to meet demand (F2-Aus, 2017, p.41, Gov)*

Another direct component service is *financial support*. This can be provided in the form of cash or tax deduction or tax exemption provided to the families or informal caregivers of people living with dementia to tackle the financial consequences that result from the high cost of caregiving to their family member with dementia. Financial support to caregivers can help to alleviate their burden, and keep people living with dementia living in the community longer. As a growing domain of income security policy, most of the countries provide financial support to caregivers of people living with dementia in different modalities:

> *Financial support to caregivers will help alleviate the burden individuals and families experience, keep individuals with dementia in the community longer and meet Canadians' stated desire to age at home (R2-CA, 2016, p.11, Non-Gov)*

In India, the State Government of Kerala provides a support scheme called *Aswasakiranam* with monthly in-cash support for people with dementia and caregivers:

> *This scheme provides financial support to bedridden and mentally challenged patients, their families and primary caregivers; a monthly assistance of ₹ 525 is being provided under the scheme to caregivers of all bedridden patients who need a full-time care (R1-India, 2010, p.59, Non-Gov)*

In the US, financial support to family caregivers of people living with dementia is one of the recommended priorities to help the affected families deal with the high cost of caregiving and long-term care. The Alzheimer's Disease Demonstration Grants to the States program is available in all states, offering financial support mainly through tax credit, long-term care insurance and deductible insurance premiums.

Canadian policies deliver financial support to family or informal caregivers in three different ways: direct financial support; indirect financial support and labour policies. Direct financial support includes cash benefits in the form of an allowance directly paid. There are four specific models of direct financial support to caregivers identified in terms of who and why receives these benefits:

> *They are consumer-directed personal budgets that allow older people to employ their caregivers; care allowances paid to the care receiver, who has complete freedom to decide how they are to be used; care allowances paid directly to the family caregiver; and payments to family and friend caregivers who substitute for formal service providers (R11-CA, 2011, p.18, Non-Gov)*

Indirect financial support includes delayed monetary support such as pension security or some forms of tax relief. This includes the compassionate care benefit, an employer-employee-contribution-funded program which allows eligible employees to take up to eight weeks leave. Labour policies also allow employed informal caregivers to have flexible working hours for mitigating the negative consequences of job interruption, reduced income and lower retirement pensions.

In Australia, there are two cash benefit programs. The Caregiver Payment is paid as income support to individuals who have left their income jobs due to caregiving responsibilities. The Carer Allowance, on the other hand, is provided to carers of people with a disability or medical condition who need additional care and attention. In the UK, the support scheme called *Carer Allowance* provides direct payments to eligible caregivers via the local council for self-arranging care.

Another direct component service *education and training* is recommended for both caregivers and the workforce.

Increased knowledge assists people living with dementia and caregivers a better understanding of dementia, its progression, treatment options, and available supports which enable them to make informed decisions about their care and to plan for the future. They are also found effective in reducing the BPSD related burden and impact on the caregiver:

> *Providing evidence-based education and training to help people better understand dementia, its progression, treatment options, and available supports can enable them to make informed decisions about their care and plan for the future (R14-CA, 2018, p.22, Gov)*
>
> *Carer support such as increasing time available to carers and providing carer education and training in relation to BPSD may be effective in decreasing burden and reducing the impact on the carer (F1-Aus, 2015, p.19, Gov)*

Education and training interventions are tailored and delivered through a range of programmes across nations. Canadian education programs focus on standardised educational information about the disease process, disruptive behaviours, and caregiving to enhance the ability of the caregiver to manage the problematic behaviours. One of the major components of a *planning framework for improving supports to caregivers (F1-CA)* is *caregiver education* which focuses on expanding the delivery of caregiver education and training resources in order to increase caregivers' skills, confidence and resiliency.

Indian policies do not include caregiver specific education and training programmes. However, these policies introduce some training institutes for dementia care and focus on training caregivers to manage related behavioural symptoms in a way their stress reduces:

> *A 10-month certificate course in care-giving recognized by the Rehabilitation Council of India is being conducted with the support from Help Age India (R1-India, 2010, p.53, Non-Gov)*

> *They can also be trained to appropriately manage most of the common behavioural symptoms in such a way that the frequency of symptoms and/or the strain experienced by the carer are reduced (R2-India, 2017, p.6, Non-Gov)*

In the USA, federal agencies are advised to offer educational efforts to improve care providers' ability to recognise early signs of dementia. The outcome of such supports is the deferral of nursing facility placement for people living with dementia and decrease in depression and distress among caregivers:

> *Training related to quality dementia care should be included in curricula and continuing education sessions for health professionals (P1-US, 2017, p.69, Gov)*
>
> *Federal agencies should offer and support educational efforts that improve health care providers' ability to recognize early signs of dementia, including AD/ADRD, and to offer counselling to individuals and their caregivers, as well as connect them to local services and resources (P1-US, 2017, p.69, Gov)*

The other education and training embedded initiatives are: cultural infusion in dementia training; translation of care of people living with dementia in their environments in a publicly-funded home care program; and Alzheimer's disease caregiver support initiative (ADCSI):

> *The State of Minnesota is creating a dementia-capability online training that is infused with culturally specific information to reflect the norms and values of diverse cultural groups (P1-US, 2017, p.40, Gov)*
>
> *Grounded in an effective model program developed by New York University (NYU) and others, Alzheimer's Disease Caregiver Support*

> *Initiative (ADCSI) promotes early diagnosis and has a protocol for providing education, care consultation, and a plan for medical and social services to persons living with Alzheimer's and their caregivers (S1-US, 2017, p.4, Gov)*

In the context of UK, opportunities for caregiver education and training are guided by right-based approach. Hence, several policies inform the commissioning, development and provision of appropriate continuing education and training programmes by assimilating the needs of education and training for dementia care workforce including caregivers. Such programmes need to treat them as care partners and enable to plan and make decisions about the future. The UK Department of Health offers caregivers of people living with dementia a psychoeducation and skills training intervention on educating about dementia, its symptoms and prognosis, developing strategies and building carer skills and adapting communication skills. For example, the department commissioned and funded Dementia Core Skills Education and Training Framework.

> *People with dementia and their carers have the right to access opportunities for community education and lifelong learning (G5-UK,2009, p.5, Non-Gov)*
>
> *Inform the commissioning, development and provision of appropriate continuing education and training programmes (F2-UK, 2016, P.9, Non-Gov)*
>
> *We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future (R10-UK, 2017, p.4, Non-Gov)*

> *Offer carers of people living with dementia a psychoeducation and skills training intervention that includes: education about dementia, its symptoms and the changes to expect as the condition progresses (G1-UK, 2019, p.31, Non-Gov)*

Policies also advise that dementia related education and training programmes be developed with the participation of people living with dementia, their families and caregivers.

> *The provision of dementia related education and training across the sectors should be developed with people with lived experience, families and carers (p1-UK, 2018, p.29, Gov)*

An additional direct service is *counselling*. Counselling is an emotion-oriented or education-based intervention that can also include individual, family and group therapies. Several policies include counselling as a key intervention to support caregivers of people living with dementia. Given the significant strain, stress and psychological illness experienced by caregivers, counselling is found to reduce their depressive symptoms and address their needs. Counselling provides a safe space for caregivers to share their concerns and enhances their personal growth, decision-making, capacity to take on new roles and self-confidence despite their reduced connectivity and a loss of shared activities and conversation. Furthermore, counselling services encourage caregivers to utilise other essential services and delay long-term care placement of people living with dementia:

> *…by building an effective therapeutic relationship, therapy can provide a 'bridging' relationship and a 'safe space' for carers to disclose and share concerns … carers in therapy appeared to demonstrate personal growth, decision making, capacity to take on new roles and improved self-*

> *confidence; even whilst they were experiencing a loss of conversation, reduced connectivity and a loss of shared activities (R8-UK, 2016, p.61, Non-Gov)*

Policies state or imply the availability of the provision of counselling services for caregivers of people living with dementia in all the countries. For example, in Korea, *the Dementia Management Act 2012 (R4-ADI)* includes the provision of establishing dementia counselling centres in every public health centre. In India, Alzheimer's Disease and Related Dementia Society of India (ARDSI) and Nightingale Medical Trust (NMT) provide counselling services to caregivers both individually and in a group:

> *ARDSI also organizes caregiver's meetings, individual and group counselling, lectures on various methods of care-giving and related issues (R1-India, 2010, p.53, Non-Gov)*

In Australia, the National Carer Counselling Program, Carers Australia and the Psychotherapy and Counselling Federation of Australia provide counselling services to caregivers of people living with dementia. In the UK and US, there are no specific laws or organisations providing counselling services, but policies imply that such provisions are available sporadically in these countries. In the UK, caregivers of people living with dementia are provided with counselling and psychological therapies to alleviate depression and promote their psychological wellbeing:

> *Individual or family counselling is frequently provided for carers of people with dementia and there is evidence that it is helpful in alleviating depression (R7-UK, n.d., p.3, Non-Gov)*

In Canada, counselling and psychoeducational programs focus on the psychological and informational needs of caregivers. Trained counsellors identify caregivers' needs and facilitate increased understanding of such issues. Counselling services are provided either in groups or individually:

> *Counsellors with specific training identify caregivers' needs and facilitate increased understanding of such issues as the problematic behaviours of care recipients. The counselling is given in groups or one-on-one, and generally individualized, rather than standardized, information is provided (R6-CA, 2011, p.7, Non-Gov)*

Some multicomponent services combine two or more of the other types of direct services as mentioned above. Evidence demonstrates that structured multicomponent psychoeducational and psychosocial interventions tend to display the most significant improvements in caregiver outcomes. For example, they maintain caregiver mood and morale, reduce caregiver strain, and delay and reduce rates of transition into care homes.

> *Caregiver multicomponent interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain (R6-ADI, 2015, p.5, Non-Gov)*
>
> *There is a strong evidence-base that such interventions are highly effective in reducing caregiver strain, and delay and reduce rates of transition into care homes (R6-ADI, 2015, p.11, Non-Gov)*

For example, in the USA context, caregiver support services provided through Community and Home Options to Institutionalised Care for the Elderly and Persons with Disabilities (CHOICE) are considered as multicomponent services:

> *Among caregiver support services that may be included in a CHOICE*

> *care plan are respite care, "other services" (including home modifications or adaptive aids) and training (R2-US, 2003, p.114, Non-Gov)*

System or Systemic Level Supports

System level supports to caregivers of people living with dementia consider the macro-level of dementia caregiving such as the perspective of the system, coordination between ministries at federal, provincial and local level, and broad level programs. Some policies describe the use of a *co-design* process to determine the system level perspective, the caregiver required services and the modality of service delivery. They emphasise that besides consulting literature for evidence-based data, the system level principles and values should be established also from consultations with the families and caregivers of people living with dementia. They also acknowledge that family caregivers can make significant system-level contributions when provided with strategic roles:

> *This planning framework is broad in scope, and intended to provide a system-level perspective on improving supports to caregivers. Drawing upon the ideas generated during the co-design sessions held in the Central LHIN (F1-CA, 2017, p.10, Non-Gov)*
>
> *Health Organization suggests that family caregivers can make important contributions to the mental health system by being involved in system-level roles, such as strategic planning for the organization, service planning, implementation, delivery and evaluation (G4-CA, 2013, p.37, Gov*)

Some policies also suggest that particular caregiver issues require supports beyond an individual and organisational level:

> *The consultations highlighted the fact that there are broad caregiver support issues that cannot be effectively addressed at an individual or organizational level. These include wider public issues as well as those that involve multiple provincial ministries such as health, community and social services, education, housing and transportation, and involve various levels of government such as provincial, municipal and federal (R8-CA, 2017, p.15, Non-Gov)*

System level programs should target broad public issues that affect caregivers of people living with dementia. Some of the widely agreed-upon initiatives are conducting public education and awareness programs and increasing knowledge among health care and other service providers about the role, value and active engagement of caregivers. Caregiver support policies should target systemic burden on caregivers and provide opportunities to interact with a wider range of service providers:

> *There was widespread agreement that caregiver supports at the system level need to include the following four initiatives: conduct public education and awareness programs; increase knowledge among health care and other service providers about the role, value and active engagement of caregivers; advise on improved caregiver support policies and legislation; and advise on and participate in caregiver research (R8-CA, 2017, p.16, Non-Gov)*

Spiritual Support and Cultural Considerations

Caregivers and families of people living with dementia tend to suffer multiple negative consequences such as stress from the dementia onset to the post-death of people living with dementia. For example, the death of people living with dementia can cause significant loss and grief to caregivers, including the loss of their caregiving role. Spiritual support throughout both pre-death and post-death periods can decrease the risks of stress and grief, attain and sustain wellbeing for people living with dementia, their families and caregivers. Evidence also indicates that many caregivers seek spiritual support when they experience stress or a loss:

> *A person's well-being may be determined by their physical health as well as psychological, social and spiritual needs. Consideration of these needs are important in attaining and sustaining well-being for people living with a dementia, their families and carers (F2-UK, 2016, p.35, Non-Gov)*
>
> *One third of Alzheimer's caregivers (33%) have gone to a professional or spiritual counselor to try to deal with caregiving stress, compared to just 22% of other caregivers… (R8-US, 2004, p.3, Non-Gov)*

While providing support services, service providers need to be culturally competent in delivering the service. They should be aware of how their own beliefs and values might influence service providing. They need to recognise cultural, spiritual and religious differences with reference to the context of their own and in the context of caregiver-care recipient:

> *Consider own beliefs and values and reflect on how these may influence care giving. Outline the values, customs, spiritual beliefs and practices of individuals/groups to exercise culturally competent practice (F2-UK, 2016, p.49, Non-Gov)*
>
> *Health care is delivered in a culturally appropriate way that respects the individual's cultural, linguistic and spiritual needs. Person-centred care also respects the importance and value of family and friends (G2-CA,*

2016, p.6, Gov)

Summary

The major services available in countries explored within the scope of this study are informational, procedural, direct, system level, and spiritual supports. The informational supports, for example caregiver guides, can increase the care confidence and capacity of caregivers. The procedural supports, explicitly the needs assessment and referral, can ensure caregivers' access to appropriate supports. The direct supports, in particular respite and counselling, can mitigate negative consequences of caregiving such as stress, depression, and grief. The system level services, namely public education, can build an informed society where the caregiving role will be valued. In sum, several policies indicate that the arrangement of those services, with cultural considerations, can yield better outcomes for people living with dementia, their caregivers, and families.

Chapter 5: Discussion and Implications

This study identified and synthesised previously implemented dementia policy documents from Australia, Canada, India, South Korea, the UK, the USA and national and international peak bodies. Included in the study were 105 policy documents (including acts, frameworks, guidelines, plans, reports, and strategies) dated from 2003 to 2019 despite the time range for inclusion criterion beginning 1981. This chapter summarises the findings, describes study strengths and limitations, and discusses implications for dementia policy in Nepal.

Main Findings

Policy Vision, Objectives, and Priorities for Informal Caregivers of people living with dementia

The most common vision described across documents is a *dementia-friendly* society where dementia policies, procedures and trained workforce are in place and where people living with dementia and their caregivers are recognised, valued, included, connected, well-supported and strengthened through properly organised support systems. This vision is also echoed in the Maltese dementia strategy (Scerri, 2016) and is consistent with the vision of WHO's Global Action Plan on the Public Health Response to Dementia 2017-2025 (World Health Organisation, 2017). Moreover, Lin and Lewis (2015) recommend that polices also draw on the concepts of *dementia-capable* and *dementia-positive* society through proactively committing resources with the participation of people living with dementia and their families. These concepts respectively denote the ability to create infrastructure for the growing number of people living with dementia and their social inclusion (Lin & Lewis, 2015). There are some differences in policy visions across countries. For example, Australia and Canada emphasise person-centred care in the community settings, prioritising individual choices and preferences, whereas the UK and the USA focus respectively on addressing the systemic and societal barriers and improving equity of opportunities for people living with dementia and their caregivers. Both approaches, and the recommendation of Lin and Lewis (2015), align with the principles of the UD, SMOD, and UNCRPD (Grey, 2015; Thomas & Milligan, 2018; UN, 2006).

There are three types of objectives across documents: process and procedure; service and consumer; and society and system. The *process and* *procedure* objectives include multi-sectoral collaboration, integration of services, conquering stigma, identification of interventions, and capacity building of health care professionals. These objectives are consistent with research demonstrating that family caregiving requires collaboration to ensure formal supports are adjusted in line with stages of dementia and changing care needs (Lethin et al., 2016). *Service and consumer*-focused objectives consist of addressing unmet needs of caregivers, empowering caregivers and their care recipients, and providing counselling, education, and flexible respite. The *society and system* objectives take account of ensuring person-centred care, improving system sustainability, establishing care and referral pathways. These objectives are consistent with the principles of the UNCRPD (United Nations Convention on the Rights of Persons with Disability [UNCRPD] 2006 [UN]) and are also reiterated in other countries' dementia policies. For example, Taiwan's policy also focuses on diagnosis, treatment and care management, and supporting caregivers with integrated services (Hsiao et al., 2019).

Seven common priorities and recommendations emerge from the included documents: research, awareness; early assessment and early diagnosis; flexible care and support services; policies and programs; strengthening capacity and system; monitoring and evaluation; and human rights-based and person-centred care approach. Several documents recommend research focusing on assessment and diagnosis, quality of care, public awareness and monitoring, and delivery of care. This is consistent with the study by Shah et al. (2016), in which prevention, identification, and reduction of dementia and delivery and quality of care for people living with dementia and their caregivers were three of the ten research priorities agreed by a consensus of global dementia experts. The research priorities described in the documents included here also highlight calls for additional work designing and testing high-quality interventions and implementation studies of promising interventions and policies (Mitchell et al., 2012)

Policy Perception or Recognition of Informal Caregivers

The findings illustrate that there are some terminological variations across countries such as *carer* in Australia and the UK, *caregiver* in Canada and the USA, and either of the terms interchangeably elsewhere. However, all countries recognise caregivers of people living with dementia as key stakeholders in dementia care and their participation in all care procedures as significant. Several policies explicitly cite research demonstrating that caregivers' contributions lead to delayed institutionalisation of care, sustainability of publicly funded health programs, and optimisation of family and social life of people living with dementia (Wiles et al., 2012; Doron & Foster, 2016; SCRGSP, 2018). Nevertheless, policies also acknowledge that along the care journey, caregivers are most likely to experience negative physical, emotional, psychosocial and financial consequences and their needs vary according to their contexts (Dowling et al., 2014; Sallim et al., 2015; Teahan et a.; 2018; Zwaanswijk et al., 2013).

Stakeholders and Support Networks for Advocacy and Service Coordination

The importance of interdisciplinary networks to support caregivers is a key theme emerging from this study. This is consistent with the study of Heinrich et al. (2016) who report that stakeholders play a key role in coordinating and optimising services for people living with dementia and their caregivers (Heinrich et al., 2016). Several policies recognise the involvement of stakeholders and other support networks for resourcing, managing and coordinating services for dyads.

Caregivers themselves, their care recipients, family and friends, neighbours, health care professionals are individual stakeholders whereas, respective public departments of health and social care, peak bodies, other relevant non-profit sectors and universities are institutional stakeholders. All these stakeholders and networks can help assess the needs of caregivers, create forums for caregivers to exchange their experiences, provide information about dementia services or advocate for caregivers' needs and rights.

Services for Informal Caregivers and Cultural Consideration

Caregiver wellbeing is essential for positive outcomes of caregiving (Zwaanswijk et al., 2013). The emotional toll of caregiving, in addition to time demands, financial strain, and occasionally lack of information is likely to cause increased stress and health problems of caregivers (Andersen et al., 2019). Therefore, they require supports for their wellbeing as well as confidence and capacity for caregiving. The findings of the current study reveal the six types of supports recommended across countries for informal caregivers. These are *informational, procedural, direct, multi-component, system level, and spiritual* supports.

The timely *information* on why, what, how, and where aspects of supports can decrease caregiver uncertainty and stress and enhance their capacity and confidence for positive outcomes. Research also indicates that informational support improves caregiver health and resource utilisation (Lucero, 2019). Some of the informational resources found in the current study are practical caregiver guides, information centres, and toll-free helplines which can supplement the informational needs of caregivers. However, the findings do not include technology-based supplements for informational support to caregivers, despite recent research that suggests more caregivers can benefit from eHealth informational programmes (Christie, et al., 2018).

Caregivers need certain *procedural* supports such as case management, needs assessment and referral aligned with their care contexts in order to supplement their needs with appropriate supports. All three procedures are significant for the seamless transition of dyads and need to be carried out by skilled social and health care professionals. For instance, Jensen-Hart (2018) highlights that social workers can provide assistance for the wellbeing of people living with dementia and their families through addressing dementia-related practical problems such as navigating services. However, documents are not specific about which personnel are to be involved at different points of transition and referral. For example, in case of people living with dementia, Lipton and Marshall (2013) advise that the primary care doctor makes a referral to the specialist dementia doctor in their nearest geographic area (Lipton & Marshall, 2013).

The findings reveal that caregivers benefit from a range of specific direct services. The four types of direct support services found are: respite; financial; education and training; and counselling. All these services are made available in almost all the countries, with some differences in the focus and implementation models, and are replicated in every single policy. *Respite* provides caregivers with a temporary break from their caring responsibilities and opportunities for social engagement. Though effective in reducing caregiver burden and other associated health problems, respite implementation strategies vary significantly across countries. For example, in Australia respite is delivered nationally through the Commonwealth home support programme, whereas in the USA, respite is grants-based and therefore not universally available.

Financial support is helpful in alleviating caregiver burden, keeping people living with dementia in the community longer and meeting an older person's desire to age in place. Modalities of financial support also vary across countries. For example, the Indian State of Kerala provides monthly in-cash support, and in Australia financial support is delivered through two cash benefits programmes. In Canada, there is the provision of both direct cash support and indirect financial support through flexible working hours for employed family caregivers. Despite the lack of recent research demonstrating the benefits of financial support, through his study, Hughes (2007) points out the positive consequences of financial support to informal caregivers, such as their continuity to caregiving.

The findings also highlight that *education and training* services to both caregivers and other professionals in the workforce are much emphasised in all countries and are delivered through various programmes. *Education and training* to the professionals such as GPs, nurses, homecare managers and staff can prepare skilled and knowledgeable workforce for people living with dementia and their caregivers. Education programs for caregivers increase their caregiving knowledge and skills, confidence, and resiliency (Bailey & Harrist, 2018). *Education and training* services in Australia focus on knowledge, skills and capacity of the workforce. Likewise, UK programs take a rights-based approach for similar caregiver gains.

Counselling appears equally emphasised across all countries with the intent of reducing caregiver depressive symptoms, providing an opportunity to share their concerns, enhancement of personal growth, self-confidence, and decision-making capacity and increasing or maintaining capacity to manage the role. Meichsner et al. (2019) argue that the gradual loss confronted by people living with dementia can adversely affect caregivers' health. Thus, *counselling* can help caregivers cope with stress, loss, and potential grief.

System level supports were also emphasised across documents. These provide direction towards creating a dementia-friendly society and include coordination between ministries, broad level programmes, and service systems. It has been suggested greater collaboration with the education, housing, and transportation sectors would better support the universal design (UD) of services (Ketola & Nordensyard, 2018; Lid, 2013). The commonly recommended *system level supports* include: conducting public education and awareness programs; increasing knowledge among health care and other service providers about the role, value and active engagement of caregivers; advising on improved caregiver support policies and legislation; and informing and participating in caregiver research. Some policies recommend a co-design approach to determine the system level perspective, the caregiver required services and the modality of service delivery. Co-design has a range of benefits such as improved focus on customers, better idea generation and decision-making, improved creativity and innovations, higher quality of service, and positive public relations (Steen et al., 2011).

A final theme to emerge across documents was that many caregivers seek *spiritual support* to cope with negative consequences of both caregiving and loss of caregiving to people living with dementia, such as stress and grief. Spiritual support throughout both pre-death and post-death periods can decrease the risks of stress and grief, attain and sustain wellbeing for people living with dementia, their families and caregivers. Such benefits of spiritual supports have long been established (Kaye & Robinson, 1994; Wright et al., 1985), and the latter research has also conformed to them (Bormann et al., 2009; Dilworth-Anderson et al., 2007; Hebert et al., 2007). The findings also caution that spiritual support providers need to be aware of the cultural values and beliefs of the caregivers.

Despite the primary focus of this study being on supports for informal caregivers specifically, the outcomes affect both caregivers and those for whom they provide care. Services focused on either of them should aim at better outcomes for both. Making an allowance for this, it is always advisable to provide and adapt supports for caregivers in response to their care contexts. Research demonstrates that interventions simultaneously targeting both people living with dementia and their caregivers are more beneficial to them (Van't Leven et al., 2018). Therefore, supports for caregivers must consider the needs of people living with dementia concurrently.

Aim 3: Implications for Nepal

Nepal is a multi-ethnic, multilingual federal democratic republic country which has constitutionally recognised health as a basic human right and articulated its commitment to public health (Pathak & Montgomery, 2015; Regmi et al., 2017). Similarly, it has ratified UNCRPD (CIL Kathmandu, 2019) and is committed to the sustainable development goals (SDGs) and attempting to graduate from the status of *least developed country* by 2022 (Dhimal et al., 2017). Despite reportedly significant achievements in public health sector (Dhimal et al., 2017) and formal recognition of mental health in 2006, Pathak and Montgomery (2015) imply that Nepal is yet to establish policies to address issues arising from dementia and the recognition of informal caregiver burden is still afar. There are approximately 100,000 people living with dementia in Nepal (Jha & Sapkota, 2013; Pathak & Montgomery, 2015) which doubles every 20 years and the projected increase in incidence will be substantial in developing countries (Cheng, 2014). This affirms that on the one hand, Nepal needs to operationalise its international and national commitment to promoting public health through comprehensive policies and programs as also recommended by Regmi et al., (2017) for the elaboration of existing health system. On the other hand, it needs to be prepared to tackle the imminent challenges of increasing dementia prevalence through specific policies as a constituent of the elaborated public health system.

The findings of this study have significant implications for Nepal. Initially, the results of this study suggest that Nepal should set dementia as a public health priority. At that juncture, the responsible ministries such as the Ministry of Health and Population (MOHP) and the Ministry of Women, Children, and Senior Citizens (MOWCSC) need to coordinate with each other, and with other relevant stakeholders to develop policies based on the principles of SMOD and UD (Ketola & Nordensyard, 2018; Lid, 2013). The MOHP is responsible for public health policy and the MOWCSC for older citizens' policies and programs (MOWCSC, 2018). Under the auspices of those ministries, Nepal can establish a vision and sub-priorities for people living with dementia, their caregivers, and families at the national level informed by provincial and local level consultations, including relevant stakeholders and peak bodies such as the National Senior Citizens Federation (NASCIF), Alzheimer's and Related Dementia Society of Nepal (ARDSN). The vision of Nepal ought to be to create a society that is dementia-friendly, dementia-positive and dementia-capable (Lin & Lewis, 2015).

The dementia policy priorities identified here (research, awareness, assessment and early diagnosis, flexible care and support services, policies and programs, strengthening capacity and systems, monitoring and evaluation, and human rights-based and person-centred care approach) are largely evidence-based and can be adapted in the context of Nepal. Implementation of these priorities must be leveraged through financial, infrastructural and human resource policies under the sectoral ministries up to local levels. For example, for research, in the USA, research grants can be established as in the USA, and collaboration and partnership with universities can be promoted as in the UK. Resembling the countries included in this study, research can be directed towards finding out potential dementia policy priorities and issues of people living with dementia, their caregivers, and families and their interventions in the context of Nepal.

Extensive *collaboration* is required to inform dementia priority and policy development and to underpin subsequent implementation. Szebeko (2010) argues that health care adaptation and innovation is a complex undertaking which, therefore, requires contributions from many different stakeholders such as governments, professionals, carers, patients and the general public. Given that dementia is a global health priority (De Witt & Ploeg, 2016), every individual and institution may have a role to undertake to support the establishment of a dementia friendly society. The current findings establish people living with dementia and their caregivers as key stakeholders whose involvement and contributions are fundamental at all levels of policy-making and implementation. In the early stages, the Ministry of Women, Children, and Senior Citizens

(MOWCSC) can play a part in identification of other relevant stakeholders in the context of Nepal. They could conduct stakeholder analysis and describe the expected roles and contributions of such stakeholders at national, provincial and local levels. In turn, this may facilitate collaboration between stakeholders and participation in priority setting, policy-making, and implementation at all levels.

The findings of the current study additionally infer some action priorities for Nepal. Policies and programmes, awareness, education and training from workforce, specific supports for informal caregivers and families of people living with dementia, and ongoing research are proposed as action priorities for the MOWCSC in collaboration with the MOHP and other delineated stakeholders. Dementia specific policies and programs need to be developed at all levels of governance with clear guidelines for programmes and implementing stakeholders. Policies could also involve system and societal level changes supportive of caregivers and families of people living with dementia such as subsidies for chargeable public services, and tax deductions for caregivers.

Despite being a promising initiative for the elderly, the provision within the *National Senior Citizen Act, 2006* that renders adult children responsible for the care of their ageing parents (Bhattarai, 2013) is likely to pose additional risk and burden to adult children of people living with dementia. Research has shown that dementia family caregivers are more stressed than non-dementia family caregivers and have greater depressive symptoms and physical problems (Cheng, 2017; Pinquart & Sorensen, 2003). Therefore, such a provision necessitates reconsideration in how this is enacted at a practical level and polices focused on supporting older adults need to apply an equity principle that perhaps assigns greater priority on people living with dementia and their families.

Programs developed could target a broader audience through awareness raising and public education, in conjunction with specific support and training developed for caregivers, families of people living with dementia, health and social care professionals and other related stakeholders. Awareness programs can focus on reducing stigma and discrimination, and illuminate information regarding the impacts and consequences of dementia, burdens on families and caregivers, role of the public, risk modifiability, and available services. Education and training also require a focus on improving health and social care professional capacity, to better assess and respond to the concerns of caregivers and families of people living with dementia. For example, as often the first point of public contact, GPs at public hospitals (Pathak & Montgomery, 2015) and professionals at primary health posts (Bhattarai, 2013) could be offered such training as an early priority. Training and education to caregivers needs to enhance their knowledge and skills of caregiving and self-caring. Wherever feasible, education and training contents should be guided by research outcomes and based on best practice evidence; potentially initiated and led by the ARDSN.

Based on the findings of this study, it is proposed that a range of appropriate support services need to be developed and implemented in Nepal. Some examples of informational supports might include audio-visual materials, caregiver guides, or a dementia help desk or telephone service that can be established at local level primary health posts. Procedural supports such as case management, need assessment, and referrals could be introduced into primary health posts or local units of the MOWCSC with the involvement of trained health and social care professionals. Based on the initial assessment and preference of the caregivers, they can be referred to further specialised services.

The requirement of direct services such as counselling, respite, and financial support can be decided upon the initial assessment at the local units of the MOWCSC. The government could foster environments that encourage caregivers to proactively seek counselling services through ensuring outcome awareness, safety and confidentiality. Despite the benefit of respite-like supports from extended family networks (Skordis, 2019), respite has not gained formal recognition in Nepal (Geriatric Centre Nepal, 2010).

With the exception of some in-cash support via universal old-age allowance and some medical subsidies for the elderly (Bhattarai, 2013; Geriatric Centre Nepal, 2010), there is no financial provision strategy planned to respond to increasing demand for dementia care. Financial support is delivered through various programmes in other countries. Considering the financial consequences and associated comorbidities dementia can pose to caregivers and families of people living with dementia, it is advisable for Nepal to consider allocation of some financial supports for caregivers in whatever model possible. Given the resource limitations (Parker, 2014) and family support practices (Skordis, 2019), many of the supports and programmes can be aligned with existing programmes and family caregiving practices. For example, the universal old-age allowance can be increased for older people living with dementia on the basis of equity, also with some special additional provisions for their caregivers and people with younger onset dementia. As research can stimulate awareness, inform evidence-based policy-making, and service development (Prince et al., 2008), in the context of Nepal, research on dementia should be a priority for continuous change, adaptation, and innovation of dementia policies and practices. Besides collaboration with universities, aspiring young scientists and researchers could be encouraged to undertake dementia related research through various schemes such as research grants (Dhimal et al., 2017). As Nepal is a multicultural, multilingual country a recognised space for cultural and linguistic diversity should be provided across policies and programmes.

Formal policy recognition of dementia as a public health priority is key to the consideration and implementation of an appropriate response within Nepal. This necessitates involvement of a range of community and professional stakeholders to advocate and support the Nepalese government to initiate and develop high quality, appropriate and formal dementia policy and priorities.

Conclusion

Informal caregivers of people living with dementia make significant contributions through their role in the community. Globally they incur 40% of caregiving to people living with dementia (Alzheimer's Australia, 2015). Their contributions reduce care cost, improve health outcomes, delay institutional care, and help to stay connected with their socio-cultural contexts (SCRGSP, 2018; Wiles et al., 2012). However, caregiving can cause stress, anxiety, depression, and loss of jobs (Cheng, 2017; Sallim et.al., 2015; SCRGSP, 2018; Teahan et al., 2018). Such consequences may lead to caregivers opting for institutionalisation of people living with dementia, caregiver apathy, and abusive behaviours towards people living with dementia (Cheng, 2017; Cooper et al., 2010; Gauler et al., 2011; Pinquart & Sorensen, 2007). For these reasons, evidence-based interventions tailored for caregivers are necessary to promote positive outcomes for both caregivers and the people for whom they provide care (SCRGSP, 2018).

Alongside the WHO declaration of dementia as a global health priority in 2012 (ADI &WHO, 2012; De Witt & Ploeg, 2016), many countries in the world have developed policies focusing on the quality of life of people living with dementia, their caregivers, and their families. Despite an increasing prevalence of dementia in Nepal, there are no formal policies to address dementia issues (Jha & Sapkota, 2013; Pathak & Montegomery, 2015). There appears a very limited awareness of dementia and its associated issues both at the local and national level (Hamal et al., 2014). Even professional and policy-maker awareness and understanding of dementia are very low (Pathak & Montgomery, 2015). Many families or adult children assume care for their older family member or parent perceiving their dementia symptoms as a normal part of ageing (Chalise & Brightman, 2006; Hamal et al., 2014). There is an urgent need of formal support for families or informal caregivers of people living with dementia in Nepal.

Therefore, this study had a three-pronged purpose: to analyse the shared and unique features of dementia policies that are likely to influence the supports for caregivers; to analyse the support provisions for informal caregivers of people living with dementia articulated in these policies; and to draw on these outcomes to consider implications for Nepal. There were 105 policy documents accessed of six countries: Australia, Canada, India, South Korea, the UK, and the USA. These policy documents were analysed with conventional, directed, abductive, latent, manifest qualitative content analysis.

Despite some terminological variations, most policies envision a dementia-friendly society, recognise caregivers as a key component in dementia recovery journey, and acknowledge the involvement of multiple stakeholders to coordinate supports for caregivers and families of people living with dementia. There were six types of supports recommended for positive outcomes of informal caregiving. One of them, for example, was the direct support which includes respite, education and training, counselling, and financial supports. Most of these recommendations are evidence-based in that they are consistent with research literature that mention effective services for caregivers. (Christie, et al., 2018; Heinrich et al., 2016; SCRGSP, 2018; Porock et al., 2015; Shah et al., 2016; Van't Leven, De Lange, Prick, and Pot, 2019; Zwaanswijk et al., 2013).

These research findings have significant implications for Nepal. The respective responsible ministries of Nepal can adapt the findings to frame policies and actions for informal caregivers or families of people living with dementia in Nepal. This could fulfil their commitments to adhere to international and domestic laws as well as promote positive outcomes for people living with dementia, their caregivers, and families. Some of the priorities worth considering are dementia research for the identification of important issues and policy priorities, adaptation and innovation of policies, and caregiver support provisions in the context of Nepal. Similarly, some of the evidence-based support services such as informational and financial supports can be of great assistance to caregivers and families of people living with dementia and reduce burden on expensive formal support services in the long-term. Informational support can allow caregivers to develop caregiving knowledge and skills and access available resources, allowing them to care effectively for longer. Financial supports can provide relief from financial burden and anxiety and better assist with their financial needs. In the context of Nepal's ratification of the UNCRPD (CIL Kathmandu, 2019), the findings can also serve as the basis of advocacy for the quality of life of people living with dementia, their caregivers, and families in Nepal.

This study also stimulates and provides avenues for future research both in the contexts of Nepal and other LMICs. Future research can focus on the modalities of providing informal caregiver supports in those contexts. Especially in Nepal, research work can focus on the experiences, expectations, and needs of people living with dementia and their families; the potential for service co-design; identification of potential stakeholders and resources for services; cultural and religious perception of dementia and their impacts on people living with dementia and their families.

Innovative dementia policy and practice is proliferating in developed countries. These provide an evidence-base that can inform policy development in LMICs like Nepal. Additionally, the Nepalese Government's policy initiatives will ultimately benefit the quality of life of people living with dementia, their caregivers, and families in their contexts.

Study Strengths and Limitations

To the author's knowledge, this is the first study to explore and summarise policy provisions for informal caregivers of people living with dementia. A large number of heterogeneous dementia policy documents have been included from a diverse range of nations. All the data were the implemented policies and high-quality reports from both developed and developing countries with time range 2003 to 2019. This study has succinctly replicated the key aspects and foci of dementia policies from as many as 105 documents. It has explored, analysed, and summarised from such as large number of documents policy priorities, visions and policy objectives, stakeholders and networks, and key caregiver services available or recommended. This study has also attempted to summarise the sub-aspects of all those aspects in terms of the reasons for, and ways of, their arrangements. For example, one of the policy priorities specifically is regarding research needed for identification of needs and interventions, quality of care, and delivery of care, which can be facilitated through increased funding and collaboration.

This study moreover gives insights into who are and who could be stakeholders for supporting caregivers of people living with dementia. The support provisions for caregivers are summarised succinctly in terms of what, why and how aspects. This study can have a large number of potential beneficiaries. Even though this study was undertaken for policy implications in Nepal, any country attempting to introduce policies especially for informal caregivers of people living with dementia may benefit from the findings. The study outcomes may also be of value to academics, professionals, researchers and policy-makers interested in dementia policies and policy provisions for informal caregivers.

Despite these strengths, this study has some limitations. It included the policy documents from only six countries: Australia; Canada; India; South Korea; the UK; and the USA. No primary documents were accessed for South Korea and the number of documents from India was very low. In all probability, the Korean documents may have been either in the native Korean language or made inaccessible via the Google Search. The significantly low number of Indian documents suggests there may be less formal dementia policy developed in comparison to other countries. Next, this study included many heterogeneous documents for the finding of available or recommended key common informal caregiver services. Despite efforts to maximise consistency and objectivity in the study methodology, some key information may possibly have been missed during coding due to document heterogeneity.

Further, the study focused merely on implemented caregiver provisions without reference to probable philosophical, political, civil or economic influences of those provisions in each country context which could differ by country. Therefore, it is not possible to comprehensively generalise on basis of this study's findings. Similarly, this study summarised caregiver provisions without specific focus on the caregiver needs specific to the stages of dementia, which will likely vary across the care continuum. Brodaty et al. (2003) have mentioned seven-tiers of dementia care. On the tier continuum, tier one is the most normal condition, whereas the tier seven is the most complex care situation. Nor were the findings analysed from the perspectives of other variables such as age, gender, education, and income of caregivers and their attachment. For example, research shows that caregivers' attachment and sense of coherence with care recipients lessens their burden of caregiving (Stensletten et al, 2016). Future researchers have the opportunity to overcome these limitations and widen the scope of their studies by including additional countries for a more comprehensive and robust evidence base. Their studies can also focus on synthesising homogenous documents and their theoretical foundations which can establish more consistent and reliable evidence base of the available services, and the theories that can guide the establishment of better services. Correspondingly, supports needed for caregivers at various dementia stages in consideration of the variables such as their age, education, gender, income, and attachment level with their care recipients can be a significant arena of future research inquiry.

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Appendix A

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Appendix B

Key common objectives extracted of policy documents in *appendix* A

Focus	Policy objectives
Process and procedure	-To champion a multi-sector collaborative movement focused on improving quality of life for people living with dementia and their caregivers, using a Dementia-Friendly Communities model -To conquer negative stigma associated with dementia through research and publications -To guide the development and implementation of actions, plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers -To guide system planners, policy makers and service providers in planning, implementing and evaluating mental health care services that recognize and address the unique needs of family caregivers - To identify what interventions to support carers of older people living with dementia are effective in preventing or delaying entry into residential aged care

Focus	Policy objectives
	-To improve diagnosis, care and support, and research
	-To improve health-care professional and caregiver knowledge and ability to deliver safe, well-informed dementia care using best practices
	-To increase the capacity of communities, carers, families and service providers as well as to create new services where required
	- To increase public awareness and recognition of the value and contributions of caregivers
	-To increase access to information about dementia, resources and services.
	-To integrate healthcare and community services while strengthening the informal care network and providing information, coaching, and emotional support to caregivers
	-To promote collaboration between dementia care researchers, service providers and consumers with the objective of improving the quality of dementia care through the rapid dissemination and uptake of research evidence
	-To promote the vision of a better quality of life for people living with dementia and their carers and families

Focus	Policy objectives
Service and customer	-To provide a framework for policy makers to begin estimating costs and benefits of policies and programs aimed to help caregivers - To support all health and social care staff to deliver better care to people living with a dementia, their families and carers regardless of the settings -To work together to improve the care and services for those individuals with dementia, and to better support their caregivers, families and health care professionals -To address the unmet needs of carers of people with dementia. -To empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected. - To enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life - To ensure that people who provide unpaid care are supported to look after their own health and wellbeing - To ensure that the person living with a dementia, their families and carers, can live well with dementia -To identify the needs of carers of people with dementia.

Focus	Policy objectives
	-To improve the lives of people living with dementia, their families and caregivers. -To improve the experience of family caregivers - To improve wellbeing of people with dementia -To improving post-diagnostic support for people living with dementia from seldom heard groups, including the LGBT community, prisoners and people with learning disabilities -To increase support for caregivers -To provides services and supports to carers so that they can continue to provide care - To increase flexibility in the provision of respite care -To promote counselling services and education and awareness programs to carers of people with dementia at all stages of care continuum. - To provide support to caregivers so they are able to maintain their usual relationship with the home care clients -To reduce the risk of dementia -To support families

Focus	Policy objectives
System and society	- To assess the evidence on pathways of people with dementia into and through the health and aged care system and implications of these for the quality of life of people with dementia and their families and carers -To create a dementia friendly society to enable people with dementia and their carers live well - To create positive change for people living with dementia as well as their families and caregivers - To deliver major improvements in dementia care and research - To encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour - To ensure that risk reduction messages are included in relevant public health policies and programmes -To ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care -To ensure that a person-centred philosophy of care is well understood and put into practice - To provide referral to any service appropriate to the needs of the individual with cognitive impairment and their family/carer(s)

Focus	**Policy objectives**
	-To improving health outcomes and the sustainability of the health system -To reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer's disease and other dementias

Appendix C

Government and Non-Government agencies (Peak bodies)

Countries	Government and Non-Government agencies (Peak bodies)
Australia	*Non-government*: Alzheimer's Australia, Dementia Australia, Carer Australia *Government*: Australian Institute of Health and Welfare (Mostly government involvement)
Canada	*Non-government*: Alzheimer's Society of Canada, Canadian Academy of Health Sciences, Canadian Caregiver Coalition, Canadian Gerontological Nursing Association, Canadian Nurse Association, Change Foundation, Covenant Health, McMaster Health Forum, Mental Health commission of Canada, National Institute of Ageing, Saint Elizabeth, Speech Language and Audiology Canada, Public Health Agency of Canada; *Government:* Ministry of Health

UK	*Non-government:* Age UK, Alzheimer's Society, Alzheimer's Disease International, British Association for Counselling and Psychotherapy, Age Watch, British Psychological Society, Care UK, Dementia Action Alliance, Dementia Action Alliance, Dementia Together, Mental Health Foundation, National Collaborating Center for Mental Health, National Institute for Health and Care Excellence, RAND Corporation, University of Birmingham, University of Worcester University of York *Government:* Department of Health
US	*Non-government:* Alzheimer's Association & National Alliance for Caregiving, American Society of Ageing, Family Caregiver Alliance, National Alliance for Caregiving, National Academy of Sciences, Youth Against Alzheimer's *Government:* U.S. Department of Health and Human Services,
India	*Non-government:* Alzheimer's and Related Disorders Society of India *Government:* Ministry of Social Justice and Empowerment
South Korea	*Non-government:* Alzheimer's Association Korea, neurology/psychiatry associations, nurses' associations and the media;

Government: Ministry of Health and Welfare