

**A Comparison of Patients' and Nurses' Perceptions  
of Cancer Patients' Quality of Life:  
A Mixed Research Approach**

**Masoud Bahrami**

Dip Biol, BSc (Nursing), MSN (Med-Sur Nursing)

A thesis submitted in the fulfilment of the requirements for the degree of  
Doctor of Philosophy

School of Nursing and Midwifery  
Faculty of Health Sciences  
Flinders University, Adelaide, Australia

July 2008

# **DEDICATION**

**To my dear wife, Mahtab and son, Mohammad**

**And my daughter, Motahhareh**

**And to my dear parents**

**You are the centre for my life**

**You are always shining for me**

**I would love to shine for you**

# TABLE OF CONTENTS

<b>TABLE OF CONTENTS</b> .....	<b>I</b>
<b>LIST OF TABLES</b> .....	<b>VII</b>
<b>LIST OF FIGURES</b> .....	<b>VIII</b>
<b>ABSTRACT</b> .....	<b>IX</b>
<b>DECLARATION</b> .....	<b>XI</b>
<b>ACKNOWLEDGEMENTS</b> .....	<b>XII</b>
<b>LIST OF PUBLICATIONS AND PRESENTATION</b> .....	<b>XV</b>
<b>CHAPTER ONE: INTRODUCTION AND BACKGROUND: GROUNDING THE QUESTION</b> .....	<b>1</b>
Introduction .....	1
The significance of cancer .....	1
The significance of QoL research in cancer care .....	3
Cancer patients and QoL .....	3
Health care professionals, policy makers, and QoL .....	4
Who can provide the best information about patients' QoL? .....	5
Significance of nurses' perceptions of cancer patients' QoL .....	6
The gap in QoL research.....	8
The researcher's experience and background .....	9
The significance of the research study for health care in Iran .....	12
The research questions.....	14
Methodology.....	15
Thesis structure .....	15
Conclusion.....	16
<b>CHAPTER TWO: LITERATURE REVIEW: SITUATING THE STUDY IN RELATION TO OTHER RESEARCH AND ASSOCIATED THEORY</b> .....	<b>18</b>

<b>Introduction .....</b>	<b>18</b>
<b>Concept of Quality of Life (QoL) .....</b>	<b>18</b>
Development of the QoL concept .....	18
Early times .....	19
From the late 1940s to the 1960s .....	19
From the 1960s to the present .....	20
Development of QoL concept in cancer care .....	22
QoL definitions.....	24
Quality of Life domains .....	26
Differences between Quality of Life (QoL) and Health Related Quality of Life (HRQoL) .....	29
<b>Implications of QoL information .....</b>	<b>30</b>
1-Clinical trials of treatment with curative intent .....	31
2-Clinical trials of treatment with palliative intent .....	33
3-Improving symptom relief, care or rehabilitation .....	35
4-Facilitating communication with patients.....	36
5-Patient preferences.....	37
6- Late problems of psychological adaptation .....	39
7-Medical decision making.....	40
<b>Variables influencing agreement between patients and nurses about cancer patients' QoL.....</b>	<b>41</b>
Patients' and proxies' demographics.....	41
Patients' health status .....	43
Contact time between patients and proxies .....	44
Proxies' burden.....	45
QoL domain.....	46
<b>Conclusion.....</b>	<b>47</b>
<b>CHAPTER THREE: METHODOLOGY.....</b>	<b>49</b>
<b>Introduction .....</b>	<b>49</b>
<b>The methodology of the whole thesis: a mixed research approach .....</b>	<b>50</b>
<b>The methodology and the philosophical issues underpinning the first phase .....</b>	<b>53</b>
Positivism .....	54
Positivism and the issue of realism .....	55
Positivism and the issue of objectivism .....	56
Positivism and the issue of experimentalism .....	56
<b>The methodology and philosophical issues underpinning the second phase .....</b>	<b>57</b>
The rationales for choosing processes and principles of grounded theory.....	58
1-Finding conceptual categories that inform practice .....	58
2-Lack of knowledge about the reasons, outcomes, and implications of agreement.....	59
3-Focus of the research study on patients-nurses interactions .....	59
4-To incorporate findings of the first phase into the construction of the second phase .....	62
5- Researcher's philosophical view and background.....	62
<b>Conclusion.....</b>	<b>65</b>
<b>CHAPTER 4: METHODS OF THE FIRST PHASE .....</b>	<b>67</b>

<b>Introduction .....</b>	<b>67</b>
<b>Aims of the first phase.....</b>	<b>67</b>
<b>Research Design and procedure .....</b>	<b>68</b>
Instrument.....	68
Classification of the WHOQoL-BREF questionnaire .....	68
Patient and proxy versions of the WHOQoL-BREF questionnaire and instructions .....	70
Rationales for selecting the WHOQoL-BREF questionnaire.....	70
Data Collection.....	76
Inclusion and exclusion criteria for the participants .....	77
Ethical considerations.....	78
<b>Data sampling .....</b>	<b>79</b>
<b>Conclusion.....</b>	<b>81</b>
<b>CHAPTER FIVE: RESULTS OF THE FIRST PHASE.....</b>	<b>82</b>
<b>Introduction .....</b>	<b>82</b>
<b>Preparing the SPSS file .....</b>	<b>83</b>
<b>Data analysis and results.....</b>	<b>84</b>
Outcomes of descriptive tests relating to missing data .....	85
Outcomes of descriptive tests related to patients' demographic and clinical variables.....	89
Outcomes of descriptive tests related to nurses' responses based on their clinical and demographic variables .....	95
Outcomes of assessing the reliability of the WHOQoL-BREF questionnaire (patients and nurses).....	99
Outcomes of measuring the level of agreement between patients and nurses about cancer patients' QoL .....	100
Correlations (r and ICC) .....	100
The proportion of exact agreement between patients and nurses.....	103
Bland-Altman test .....	104
Paired t-test for comparing means of two group responses.....	109
Outcomes of assessing the relationship/effect of demographic and clinical variables of patients and nurses on the level of agreement using Bivariate and Multivariate analysis .....	110
Outcomes of the exploratory factor analysis showing the structure of domains of the WHOQoL-BREF questionnaire completed by cancer patients.....	114
<b>Conclusion.....</b>	<b>115</b>
<b>CHAPTER SIX: METHODS OF THE SECOND PHASE.....</b>	<b>117</b>
<b>Introduction .....</b>	<b>117</b>
<b>Aim of the second phase.....</b>	<b>117</b>
<b>Research methods.....</b>	<b>117</b>
Data collection.....	118
Why use interviews.....	118

Ethical considerations .....	119
Interview questions and strategies used in the research study .....	120
Participants.....	123
The sampling strategies.....	124
Theoretical sampling .....	125
Theoretical sensitivity .....	126
Theoretical saturation.....	127
Inclusion and exclusion criteria .....	128
The interview process .....	128
<b>Data analysis.....</b>	<b>129</b>
Transcribing the interviews.....	129
Using NVivo software to facilitate the data analysis .....	130
Comparative data analysis .....	131
<b>Conclusion.....</b>	<b>137</b>

## **CHAPTER SEVEN: RESULTS OF THE SECOND PHASE .....138**

<b>Introduction .....</b>	<b>138</b>
<b>Results.....</b>	<b>138</b>
QoL aspects .....	139
QoL meanings .....	145
Cues-based QoL assessment .....	149
1) Just simple cues .....	150
2) Assessment with uncertainty .....	152
Purpose-based QoL assessment.....	155
Facilitators of QoL assessment.....	158
1) Relationship and rapport.....	158
2) Doing a QoL assessment .....	169
3) Nurses' experiences .....	172
4) Nurses' education and training .....	175
5) Using alternative criteria.....	175
Barriers to QoL assessment.....	177
1) Focus on tasks.....	177
2) Time limitation .....	178
3) Fragmentation .....	179
<b>Conclusion.....</b>	<b>181</b>

## **CHAPTER EIGHT: DISCUSSION OF THE RESULTS .....183**

<b>Introduction .....</b>	<b>183</b>
<b>Question One: What differences and/or similarities are there between cancer patients' and nurses' perceptions of cancer patients' QoL? .....</b>	<b>184</b>
(a) At the individual level, the level of agreement ranges from poor in the social relationship domain up to moderate in the physical domain.....	184
(b) At the group level, nurses' mean domain scores are similar to those of patients in physical and psychological domains .....	190
(c) At the group level, nurses underestimated patients' QoL in the social relationship and environmental domains .....	191
<b>Question Two: Why do differences and/or similarities exist between cancer patients' and nurses' perceptions about cancer patients' QoL?.....</b>	<b>194</b>
(a) Emergence of spirituality.....	194
(b) How do nurses assess cancer patients' QoL? .....	198

(c) Barriers to QoL assessment .....	200
(d) Patients' and nurses' clinical and demographic characteristics .....	201
<b>Limitations .....</b>	<b>207</b>
Limitations of the first phase .....	207
Limitations of the second phase .....	209
<b>Conclusion .....</b>	<b>210</b>
<b>CHAPTER NINE: CONCLUSION.....</b>	<b>211</b>
Introduction .....	211
Nurses' assessment of cancer patients' QoL in the clinical area .....	211
Nurses as proxies in QoL research studies .....	213
Nurses' education support .....	214
Future research studies .....	216
The QoL concept.....	219
Conclusion.....	220
<b>APPENDICES .....</b>	<b>221</b>
Appendix A: The relevant article accepted for publication in <i>Contemporary Nurse</i> , vol. 29, no. 1, pp. 67- 69. ....	221
Appendix B: The detailed process of one strategy for data collection in the first phase .....	243
Appendix C: Participant Information Sheet (Patient specific for the second phase) .....	245
Appendix D: Participant Information Sheet (Nurse specific for the second phase) .....	247
Appendix E: The patient clinical and demographic characteristics form .....	249
Appendix F: The WHOQoL-BREF questionnaire for patients.....	250
Appendix G: The nurse characteristics form.....	253
Appendix H: The WHOQoL-BREF questionnaire to be completed by nurses for a patient.....	254
Appendix I: Labelling the WHOQoL-BREF items and calculating the mean domains for patients and nurses as proxies .....	257
Appendix J: Outcomes of SPSS for reliability testing (patients and nurses) .....	258
Appendix K: The ICC between patients' and nurses' scores for all 26 items on the WHOQoL-BREF questionnaire .....	262
Appendix L: The proportion of exact agreement between patients' and nurses' scores for all 26 items on the WHOQoL-BREF questionnaire .....	263
Appendix M: Bland-Altman test for measuring agreement between patients and nurses.....	264

**REFERENCES .....266**



# LIST OF TABLES

TABLE 2-1: DESCRIPTION OF ASPECTS OF THE WHOQOL-BREF QUESTIONNAIRE EXPRESSED AS DOMAINS AND FACETS OF QOL.....	28
TABLE 4-1: ESTIMATING MEANS AND STANDARD DEVIATIONS (IGNORING THE SIGN OF THE DIFFERENCES) FOR CALCULATING THE SAMPLE SIZE .....	81
TABLE 5-1: THE NUMBER OF MISSING DATA BASED ON QOL ITEMS OF THE WHOQOL-BREF QUESTIONNAIRE FOR PATIENTS AND NURSES .....	87
TABLE 5-2: THE NUMBER OF MISSING DATA BASED ON PATIENTS' DEMOGRAPHIC AND CLINICAL VARIABLES .....	88
TABLE 5-3: THE NUMBER OF MISSING DATA BASED ON NURSES' DEMOGRAPHIC AND CLINICAL VARIABLES.....	88
TABLE 5-4: DISTRIBUTION OF PATIENTS BASED ON THEIR NUMBER AND THEIR AGE 95	
TABLE 5-5: DISTRIBUTION OF NURSES' RESPONSES BASED ON THEIR NUMBER, THEIR CLINICAL EXPERIENCE AND TIME THEY SPENT WITH CANCER PATIENTS/SHIFT99	
TABLE 5-6: TEST OF RELIABILITY OF THE WHOQOL-BREF QUESTIONNAIRE COMPLETED BY PATIENTS AND NURSES BASED ON QOL MEAN DOMAIN SCORES .....	100
TABLE 5-7: PEARSON CORRELATIONS BETWEEN DIFFERENT MEAN DOMAIN SCORES OF PATIENTS AND NURSES.....	102
TABLE 5-8: INTRACLASS CORRELATIONS BETWEEN QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES.....	102
TABLE 5-9: THE PROPORTION OF EXACT AGREEMENT FOR DIFFERENT QOL DOMAINS BETWEEN PATIENTS AND NURSES.....	104
TABLE 5-10: PAIRED SAMPLES T-TEST VALUES BETWEEN QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES.....	110
TABLE 5-11: BIVARIATE AND MULTIVARIATE CORRELATIONS BETWEEN PATIENTS' AND NURSES' CLINICAL AND DEMOGRAPHIC VARIABLES AND ABSOLUTE DIFFERENCE BETWEEN PATIENTS AND NURSES QOL MEAN DOMAIN SCORES..	113
TABLE 5-12: THE EIGENVALUES OVER ONE AND RELATED VARIANCES FOR THE WHOQOL-BREF QUESTIONNAIRE COMPLETED BY PATIENTS .....	115
TABLE 8-1: THREE FACTORS INFLUENCING THE LEVEL OF AGREEMENT BETWEEN PATIENTS AND NURSES ABOUT CANCER PATIENTS' QOL.....	203

## LIST OF FIGURES

FIGURE 5-1: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR GENDER.....	89
FIGURE 5-2: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR FIRST LANGUAGE USE.....	89
FIGURE 5-3: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR MARITAL STATUS .....	90
FIGURE 5-4: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR HIGHEST LEVEL OF EDUCATION .....	90
FIGURE 5-5: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR CURRENT TREATMENT .....	91
FIGURE 5-6: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR TREATMENT SETTING.....	92
FIGURE 5-7: THE NUMBER OF PATIENTS INVOLVED BASED ON PATIENTS' PERFORMANCE STATUS .....	93
FIGURE 5-8: THE NUMBER OF PATIENTS INVOLVED BASED ON THEIR CANCER DIAGNOSIS.....	94
FIGURE 5-9: THE NUMBER OF NURSES' RESPONSES BASED ON THEIR GENDER .....	95
FIGURE 5-10: THE NUMBER OF NURSES' RESPONSES BASED ON THEIR FIRST LANGUAGE .....	96
FIGURE 5-11: THE NUMBER OF NURSES' RESPONSES BASED ON THEIR MARITAL STATUS .....	96
FIGURE 5-12: THE NUMBER OF NURSES' RESPONSES BASED ON NURSES' HIGHEST LEVEL OF EDUCATION.....	97
FIGURE 5-13: THE NUMBER OF NURSES' RESPONSES BASED ON THEIR RATING OF THEIR OWN QUALITY OF LIFE .....	98
FIGURE 5-14: BLAND-ALTMAN PLOT INDICATING AVERAGE PHYSICAL QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES AGAINST DIFFERENCES IN THEIR MEAN DOMAIN SCORES .....	105
FIGURE 5-15: BLAND-ALTMAN PLOT INDICATING AVERAGE PSYCHOLOGICAL QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES AGAINST DIFFERENCES IN THEIR MEAN DOMAIN SCORES.....	106
FIGURE 5-16: BLAND-ALTMAN PLOT INDICATING AVERAGE SOCIAL RELATIONSHIP QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES AGAINST DIFFERENCES IN THEIR MEAN DOMAIN SCORES.....	107
FIGURE 5-17: BLAND-ALTMAN PLOT INDICATING AVERAGE ENVIRONMENTAL QOL MEAN DOMAIN SCORES OF PATIENTS AND NURSES AGAINST DIFFERENCES IN THEIR MEAN DOMAIN SCORES.....	108
FIGURE 6-1: OPEN CODING PROCESS .....	135
FIGURE 6-2: SELECTIVE CODING PROCESS .....	136

## ABSTRACT

In attempting to give more years of life to cancer patients, their Quality of Life (QoL) during this time has frequently been compromised. Assessment of patients' QoL provide nurses with an opportunity to know about the whole range of patients' needs and desires. These information would be potentially very useful for health care professionals particularly nurses for planning, conducting and evaluating the nursing care of cancer patients.

Questionnaire survey research carried out in countries other than Australia identified a varied amount of agreement between cancer patients and nurses about cancer patients' QoL. However, based on the literature review, no research study has been found in Australia that provides a detailed understanding of how nurses and cancer patients are similar or different in their perceptions of cancer patients' QoL. A research study, therefore, was conducted to answer the following key questions: (a) what differences and/or similarities are there between patients' and nurses' perceptions of cancer patients' QoL; (b) why do these differences and/or similarities exist?

A research study with a mixed approach was undertaken to answer the research questions. In the first phase, a survey by questionnaire was conducted. The main aims were to identify: (a) the level of agreement between cancer patients' and nurses' scores on the World Health Organisation's Quality of Life Brief questionnaire (WHOQoL-BREF); and (b) variables that may influence the level of agreement between them. Each patient and nurse was invited to complete the WHOQoL-BREF questionnaire, which was considered as an appropriate tool for evaluating cancer patients' QoL. This questionnaire considers QoL across four domains or dimensions: physical, psychological, social relationship and environmental.

In the first phase of the study, 166 cancer patients and 95 nurses were recruited from three major hospitals in Adelaide, South Australia. The patients had a range of cancer diagnoses with breast cancer being the most prevalent. Most patients were being treated as inpatients with chemotherapy being their primary treatment. The mean age

of nurses was approximately 37 years and their clinical experience with cancer patients averaged approximately eight years. Intraclass Correlation Coefficient (ICC) between patients' and nurses' scores ranged from 'poor' in the social relationship and psychological domains up to 'moderate' in the physical domain indicating that generally nurses were different in their perceptions from those of cancer patients. Another major finding of this phase was that nurses underestimated cancer patients' QoL in the social relationship and environmental aspects, which consisted of more personal and private issues.

Having finished the first phase, the second phase was conducted based on the principles of a classical version or mode of grounded theory. The aim here was to include an interpretive perspective and explore the reasons why nurses may differ in their perceptions about cancer patients' QoL in comparison to cancer patients. In this phase, three cancer patients and 10 nurses took part in semi-structured interviews. Participants were selected from different inpatient and outpatient oncology services and a palliative setting.

Differences in patients' and nurses' perceptions about cancer patients' QoL and their implications for nursing clinical practice were discussed further in the light of six important categories found in the second phase including: QoL meanings, QoL aspects, Cues-based QoL assessment; Purpose-based QoL assessment; Facilitators of QoL assessment; and Barriers to QoL assessment. It emerged that QoL has individualised meanings and nurses generally have difficulties understanding their patients' personal perspective or definition of QoL. Another interpretive outcome that may explain why nurses differed in their perceptions when compared with cancer patients is that nurses' assessment of cancer patients' QoL in oncology wards is mainly made during their interaction with patients when providing care. Such an assessment has a focus on physical cues and may not facilitate nurses developing a more holistic picture of cancer patients' QoL. Participants in the interpretive phase indicated that time limitations, focus on care tasks, and discontinuity of care, all work against nurses developing a more accurate understanding of cancer patients' QoL. Conversely, it was found that building a relationship and stronger rapport with patients is the main facilitator in improving nurses' understanding of cancer patients' QoL.

## DECLARATION

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

Signed:..... Masoud Bahrami .....

Date:.....

## ACKNOWLEDGEMENTS

Firstly, thanks to God for providing me with this opportunity to come abroad and to experience one of the most challenging phases of my life so far. I have been requesting God that this PhD journey develops my knowledge and practice. I wish this PhD thesis to be useful for cancer patients, and to be considered by respected examiners as a good scientific piece of work. This PhD has not been simply studying and investigation in an ideal situation leading to a degree even though Adelaide is one of the well-known cities in the world. It proved to be a very challenging experience with uncertainty throughout the process and having to confront a number of problems. I worked through them and I am glad because it has opened a new approach to my life.

My deep indebtedness goes to my supervisors:

Professor Paul Arbon, School of Nursing and Midwifery, Flinders University, who has been very supportive. He commented generously on different aspects of the research thesis particularly the methodological issues. He taught me to be open to new ideas and thoughts and was familiar with the complexities of PhD research.

Doctor Steve Parker, School of Nursing and Midwifery, Flinders University, who has given me valuable comments in the second phase of the research study. He taught me to be more critical and independent. He was available to answer and solve a number of technological questions and problems that I have faced regarding computer software programs such as Endnote and NVivo.

Doctor Ian Blackman, School of Nursing and Midwifery, Flinders University, who spent much time with me during the first phase and provided extensive advice concerning statistical issues. He encouraged me to focus more on the clinical issues so that the outcomes will be more beneficial for cancer patients and their nurses.

My special thanks to the many people who supported me and provided me with a shoulder to cry on. These include but not limited to: Dr Salah Kutieleh for his

general comments; Professor John Keeves and Ms Kylie Lange for their comments and advice about the statistical issues; and many PhD travellers who became more than just colleagues.

Thanks also go to the Ministry of Health and Medical Education of Iran (Islamic Republic) and Isfahan University of Medical Sciences, Isfahan, Iran (Islamic Republic) for granting me a scholarship to complete my PhD abroad. Without their financial support I could never afford to pay the living and studying expenses in Australia. I hope I can compensate this offer by performing my professional responsibilities at the best level and by conducting useful research studies, particularly in the clinical area of cancer patients.

I want to appreciate the efforts of my wife, Mahtab. Mahtab means ‘moon’s light’ in English and she was really like the moon in this PhD journey. Without her it was impossible to complete my PhD. She is a mathematics teacher in Iran. Years ago she went to a school in a rural area called ‘*Agcheh*’, and had very limited facilities to teach students. She managed to do her teaching duties successfully despite the inherent difficulties. Years later, she came with me to ‘*Adelaide*’. *Adelaide* is completely different from *Agcheh* in terms of its facilities. She encountered numerous pressures like English language problems, and looking after our children in addition to other responsibilities. She was really patient and persistent. Despite being in tears on occasions, she remained supportive. *Agcheh* and *Adelaide* are very far from each other but for us they are a reminder of a similar experience: ‘*a very close relationship and love*’. I asked Mahtab to write some of her memories which can be named ‘*from Agcheh to Adelaide*’ to document what I believe to be a frustrating, isolating but productive and educative experience.

Mohammad, my son, tolerated me in my dual role as a father and a student. He needed, like any other child of his age, to play. This was not always possible as I was preoccupied with my research most of the time. I apologise to him. I hope the experience in Adelaide will be beneficial for the future. The same applies to my little girl, Motahhreh, known as Holy, who was born in Adelaide and grew up here at the same time as thesis took shape. Mahtab shared some lonely times with her. While I was writing the final chapter of my thesis, she began the first chapter of a very

promising life.

I am grateful to my parents. They were not beside me but I am sure they supported me through their prayers. My siblings and friends in Iran deserve more than a thank you. I am also thankful to the support provided by my in-laws and promise them to always be a loyal son-in-law.



## LIST OF PUBLICATIONS AND PRESENTATION

As a result of working on this topic, the following presentations and publications were produced:

1-Bahrami, M (2005) Nurses evaluation of cancer patients' quality of life (QoL), poster presented at the Research Summit: Building Capacity for Nursing Research, Stamford Hotel, Glenelg, Adelaide, SA.

2-Bahrami, M (22-24 March 2006) A comparison of patients' and nurses' understandings of cancer patients' quality of life, paper presented at the Haematology Oncology Nurses: Conference, Christchurch, NZ.

3-Bahrami, M. Parker, S. and Blackman, I (2008) Patients' quality of life: A comparison of patient and nurse perceptions. *Contemporary Nurse*, vol. 29, no. 1, pp. 67-69.

The article submitted to *Contemporary Nurse* is still in press. The final version of the article accepted for publication on 16 January 2008 is shown in **Appendix A**.