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

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# 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**

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# 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.

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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, Motahhareh, 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.**