CANCER CARE EMPLOYEES'

PERCEPTIONS OF RESEARCH –

A QUALITATIVE STUDY

By

JOANNA E.M. SALE, B.A., M.Sc.

A Thesis

Submitted to the School of Graduate Studies

In Partial Fulfillment of the Requirements

For the Degree

Doctor of Philosophy

McMaster University

CANCER CARE EMPLOYEES'
PERCEPTIONS OF RESEARCH

DOCTOR OF PHILOSOPHY (2003)   McMaster University

(Health Research Methodology)   Hamilton, Ontario

TITLE: Cancer Care Employees' Perceptions of Research -

A Qualitative Study

AUTHOR: Joanna E.M. Sale, B.A., M.Sc. (McMaster

University)

SUPERVISOR: Professor H. Shannon

NUMBER OF PAGES: ix, 204

Abstract

This thesis is based on 32 semi-structured phenomenological interviews conducted at a large Canadian ambulatory cancer centre serving 2.3 million people in Ontario. The primary objective of this program of study was to explore cancer care employees' perceptions of a Quality of Work-Life (QWL) Project where they were the subjects of research and their perceptions of clinical research where patients were the subjects of research. Three secondary objectives were to explore: a) perceptions of the participatory approach to research from the perspective of employees on the steering committee of the QWL Project; b) perceptions of the QWL Survey from the perspective of employees who completed the survey; and c) perceptions of clinical trials from the perspective of nurses and radiation therapists who treated trial patients   Findings   had important implications for the conduct of workplace and clinical research in a cancer care environment. Some of the main findings included: a) It may be difficult to conduct participatory research in a work environment given that power and a hierarchy of relationships interfere with employees being considered equal; b) Many QWL issues presented by employees were not captured in the QWL Survey. QWL researchers need to ensure that QWL measures are pertinent to a particular worksite and encompass all meaningful QWL issues of a given work environment; c) Ethical concerns associated with clinical trials suggested that the clinical trials department should review trial procedures; d) Workload concerns associated with clinical trials implied that employees should be credited for their present involvement in trials; and e) Clinical research was perceived to be more important than the QWL Project, party due to the perception that patient interests outweighed those of employees. In general, employees' perceptions of clinical and workplace research suggested that identification with the cancer centre as a clinical research organization contributed significantly to employees' QWL.

Preface

To Mor Mor
(1920-2002)

Having completed this PhD, I am surprised by two things - that my thesis was a qualitative endeavour and that it involved a cancer setting.

I never envisioned doing qualitative research for my thesis. Prior to starting this degree, my work and academic experiences had been limited to quantitative methodology – experimental research, cohort studies, cross-sectional studies, measurement stuff. And I liked these methods because I was pretty confident in their ability to answer research questions. I have since learned that there are no "right" answers and certainly that quantitative methods could not address the thesis questions that were of interest to me.

From 1991-1993, I was a research assistant at the University of British Columbia Cancer Agency in Vancouver. Among other things, I was responsible for 2 breast cancer studies. I found working in a cancer setting to be depressing and humbling and left the cancer environment partly because I did not feel able to cope with death and the horror of the disease. So when I was asked to join the Quality of Work-Life steering committee at the Hamilton Regional Cancer Centre, I hesitated…for a moment. I convinced myself that this experience was going to be different – I would be working with cancer care employees. And it was - very different. (Although my heart sank each time I walked through the radiation therapy waiting room.) I realize now that it takes a certain person to work in cancer care. The employees I met and those who I interviewed for this thesis were special people. I was touched by their insights and appreciation of life. I have no regrets.

Despite access to three work places over the years, I have to admit that the many Toronto Starbucks provided THE setting in which I wrote most of this thesis. Perhaps, I will be awarded a life-time of tall dark roasts by making this admission public. I am grateful for the peace of mind afforded me by my running route through Riverdale and by the lunch breaks made possible by 'All My Children' on those days that I worked from home.

Most of all, I'd like to acknowledge the employees (participants and non-participants of this thesis) and George Browman of the Hamilton Regional Cancer Centre (HRCC); they welcomed me into the organization and made me feel part of the family. I came to realize that oncology employees have a philosophy of life that is unmatched by any other group with which I have worked. I only hope that some of that philosophy was captured in this thesis. Marcia Smoke was, and continues to be, a wonderful friend and colleague who helped and inspired me in so many ways and on so many levels. Virginia Hammill was invaluable – she went out of her way to make my research easier at HRCC and was instrumental with setting up the interviews. I am already saddened that completion of this thesis means that I will not have it as an excuse to visit HRCC and these two people.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Outline of thesis

This thesis follows the format of a sandwich thesis. Chapter 1 describes the context in which this thesis was developed. It then introduces the reader to the author and to the research objectives that are addressed. The assumptions regarding the constructivist paradigm, phenomenology, and the role of theory are also outlined in this chapter. Chapter 2 describes the methodological procedures undertaken to address the research objectives. There is one primary research objective and three related secondary objectives. The secondary research objectives are the focus of Chapters 3, 4, and 5; each objective is addressed in a separate chapter. Consistent with the sandwich thesis guidelines of McMaster University, Chapters 3-5 are meant to be separate publications. Chapter 6 reviews the findings from Chapters 3-5 in order to address the primary research objective. That chapter synthesizes the three publications and discusses their relationship to each other and to the overall purpose of the thesis.

Context

This research was conducted at a Canadian cancer centre. The centre is a large (approximately 450 employees) ambulatory cancer treatment centre that serves over 2.3 million people in Ontario. Approximately, 7,000 new patients are referred to the centre each year and about 500 patients are seen each day for consultations, radiation and chemotherapy treatments and follow-up visits.

Two types of research are currently being conducted at the centre. One type of research involves the patients as the subjects of research (clinical studies

including phase three randomized clinical trials). The other type of research involves the employees as the subjects of research (the Quality of Work-Life Project).

The Clinical Trials Department at the centre is one of the largest of its kind in Canada. There are over 50 studies actively recruiting patients at any time and many more that continue to collect follow-up information on patients who are enrolled in studies. The trials, including, but not limited to, randomized controlled trials (RCTs), affect patients with all types of cancer. These trials test the usefulness of new drugs, new approaches to surgery or radiation therapy, and/or new combinations of treatments.

The Quality of Work-Life (QWL) Project at the cancer centre began in the spring of 2000. It was initiated by the Chief Executive Officer (CEO) of the organization based on anecdotal evidence of low morale and high burnout among staff members. The CEO approached several pharmaceutical companies to solicit funding for the project. In April 2000, Ortho Biotech funded the project for a two-year period. The project fit within Ortho Biotech's mandate that includes research on patient satisfaction and community health in general. With the exception of providing funds for the project, Ortho Biotech has no project involvement. The CEO approached an occupational health scientist and a doctoral student (author of thesis) at the local university for recommendations on how to proceed with a quality of work-life study.

A project coordinator was hired and employees at the centre were asked to volunteer to join a steering committee for the project. The steering committee included representatives from a variety of departments at the centre. Through a participatory approach, the steering committee developed an agenda and timeline

for the project. The first meeting of the steering committee was held on June 19, 2000.

The QWL Project has been promoted in the cancer centre during the last two years and has visible support from the CEO, upper management, and the unions. The steering committee decided that a survey should be administered to employees at the centre in order to gather baseline data on important issues they believed to be related to employees' quality of work-life. Through collaboration between the steering committee and the employees they represented, perceived problem areas in the workplace were identified. These problem areas were translated into four constructs that could be measured: burnout, social support, job satisfaction, and work-family conflict. Tools previously demonstrated to be reliable and valid were selected by the committee to measure each of the four constructs and formed a composite worksite survey. The survey was administered to staff during February 2001. To help fulfill Ortho Biotech's mandate, a patient satisfaction survey was administered at that time to patients at the centre.

Through involvement in the QWL Project, I developed an interest in cancer care employees' perceptions of research in their workplace based on their role in the research process. In a general sense, I was interested in employees' perceptions of clinical research where patients are the subjects of research and their perceptions of the QWL Project where they are the subjects of research. I also became interested in three different groups of employees with varying levels of involvement in research: a) members of the QWL steering committee whom I considered to have an active role in research; b) employees at the centre whose only involvement in research was their completion of the QWL survey – I considered these employees to have a passive role in research; c) nurses and radiation therapists who treat patients enrolled in clinical trials who I considered to have an indirect role in research. Based on the nature of employees'

involvement and the type of research which defined that involvement, it followed that I would explore QWL steering committee members' perceptions of the participatory approach to research, employees' perceptions of the QWL survey, and nurses' and radiation therapists' perceptions of clinical research activities.

Purpose

This thesis explored the following research objectives:

Primary Objective:

The primary objective was to explore cancer care employees' perceptions of the QWL Project where they were the subjects of research and their perceptions of clinical research where patients were the subjects of research. These perceptions were compared based on employees' role in research (active, passive, or indirect).

Secondary Objectives:

There were three secondary objectives:

- to explore perceptions of the participatory approach to research from the perspective of employees who are on the steering committee of the QWL Project and considered to have an active role in research
- to explore perceptions of the QWL Survey from the perspective of employees who completed the survey and had a passive role in research
- to explore perceptions of the clinical trial from the perspective of nurses and radiation therapists who had an indirect role in research.

The Researcher

In qualitative research, it is recommended that the researcher be introduced and that his or her relationship to the phenomenon of study be described (Patton, 2002). My experience and current involvement in research is

especially relevant to the content of this thesis. I have a Bachelor's degree in Psychology and a Master's degree in Health Promotion Research. I started my research career as a research assistant in a psychology lab during my undergraduate years at the University of British Columbia and later became involved in exercise research during my Master's degree. In 1993, I started working as a project coordinator in cancer research at the B.C. Cancer Agency (BCCA) in Vancouver. At BCCA, I was involved in research with breast cancer and skin cancer patients. In 1995, I was hired by the Centre for Health Evaluation Research at the Children's & Women's Health Centre of British Columbia to conduct clinical research in the neonatal intensive care unit (NICU). At the Children's & Women's Health Centre, I was responsible for a national study looking at illness severity, practice variations, and resource consumption in 18 Canadian NICUs. In 1998, I moved to Toronto to pursue my doctoral degree in the Health Research Methodology program at McMaster University. During my doctoral studies, I have been working part-time as a Research Associate at the Institute for Work & Health (IWH) in Toronto. At IWH, I have been involved in a number of projects related to measurement and workplace questionnaires. During the last five years, I have become interested in the methodology of clinical and workplace research and the measurement tools used to collect data. In the spring of 2000, my doctoral supervisor referred me to the QWL Project at the cancer centre. I joined the steering committee for the project, my role being that of methodological consultant. This thesis was developed as a result of my involvement in the QWL Project at the centre and my interest in the centre's research environment.

Assumptions: The Constructivist Paradigm, the Phenomenological Tradition, and the Role of Theory

The primary and secondary objectives of this thesis were addressed using qualitative methods. There are many paradigms of inquiry represented in

qualitative research. A paradigm is a patterned set of assumptions concerning reality (ontology), knowledge of that reality (epistemology), and the particular ways of knowing that reality (methodology) (Guba, 1990). Paradigms of inquiry can influence the research question and the methods associated with the research (Baptiste, 2001; Strauss & Corbin, 1998). There are also several traditions within qualitative research such as ethnography, case studies, phenomenology, grounded theory, and biography (Creswell, 1998). The tradition relied upon in a qualitative investigation is generally dependent upon the research question (Morse, 1994). The role of theory in qualitative research is complicated because theoretical approaches can radically influence what can be found in data and how it can be found there (Honan, Knobel, Baker, & Davies, 2000). Due to the influence of paradigms, traditions, and theoretical approaches, it has been recommended that qualitative researchers clarify assumptions regarding such perspectives (Angen, 2000; Baptiste, 2001; Giorgi, 1989; Giorgi, 1994). This clarification allows the researcher to present a consistent argument for decisions made during the research process.

The Constructivist Paradigm

Qualitative research is linked with many paradigms of inquiry such as interpretivism (Altheide & Johnson, 1994; Kuzel & Like, 1991; Secker, Wimbush, Watson, & Milburn, 1995), positivism (Devers, 1999), post-positivism (Devers, 1999; Marshall, 1990), postmodernism (Creswell, 1998), and critical theory (Creswell, 1998). In this thesis, I assumed that qualitative research was linked with the paradigm of constructivism as proposed by Guba and Lincoln (1994). One assumption made is that multiple realities or multiple truths exist based on one's construction of reality. Reality is socially constructed (Berger, 1966) and so is constantly changing. On an epistemological level, there is no access to reality independent of our minds, no external referent by which to compare the truth (Smith, 1983). The investigator and the object of study are

interactively linked so that findings are mutually created within the context of the situation that shapes the inquiry (Denzin & Lincoln, 1994; Guba et al., 1994). A constructivist believes that one is constructing knowledge and not merely consuming or discovering it (Baptiste, 2001). The constructivist position proposed by von Glasersfeld (von Glasersfeld, 1995) is especially relevant to this thesis; von Glasersfeld's position holds that we can only construct what we know on the basis of our own experience. This assumption is consistent with the phenomenological tradition that is discussed in the next section.

The Phenomenological Tradition

This thesis aimed to explore individual's perceptions of research. The study of individual's perceptions lends itself to the phenomenological tradition (Schwandt, 2001; Sokolowski, 2000). Phenomenology aims to study ordinary experiences of phenomenon in everyday life from the perspective of the person experiencing it (Schwandt, 2001). Consistent with the constructivist paradigm of inquiry, the purpose of a phenomenological study is to obtain "descriptions of the experience under investigation, not to ascertain if these descriptions correspond to an independent reality" (Polkinghorne, 1989), p. 50).

Variants of Phenomenology

Phenomenology was first envisioned as a philosophy by Edmund Husserl (1859-1938). Although Husserl was seen as the founder of this movement, the movement has been adapted and revised by its many followers throughout the 20th century. As a result, many variants or streams of phenomenology exist. The variants commonly reported include eidetic (descriptive), hermeneutic (interpretive), and existential phenomenology. To some extent, this categorization is a simplification as there appears to be some overlap among these variants with the above terms often used interchangeably. For example, van Manen (1990) considers all phenomenology as interpretive and thus refers to

types of phenomenology within this variant. In contrast, von Eckartsberg (1986) appears to classify eidetic and hermeneutic phenomenology under the umbrella of existential phenomenology.

Eidetic (descriptive) phenomenology dates back to the founder of phenomenology, Edmund Husserl. Husserl developed the idea of phenomenology as a philosophy capable of being converting into a rigorous science (Spiegelberg, 1975). Husserl's tradition of phenomenology is epistemologic; it is concerned with the nature of knowledge. It emphasizes the pure description of lived experience with the goal being to describe experience from the perspective of those who have had the experience. As a research method, eidetic phenomenology assumes that there are essential structures to any human experience; these structures constitute that experience (Morse, 1994). The essential structure of a phenomenon is not a single, fixed property by which we know something; rather, it is the certain qualities or properties that make that phenomenon distinguishable from other phenomena (van Manen, 1997). Eidetic phenomenology is now associated with the works of Giorgi (1975; 1989; 1997), Colaizzi (1973; 1978), and Fischer (1984) who have been credited with developing methodological techniques for analyzing phenomenological data.

Hermeneutic (interpretive) phenomenology is ontologic; it is concerned with the nature of being. It assumes that the fundamental dimension of all human consciousness is historical and sociocultural and is expressed through language (Ray, 1994). Hermeneutic phenomenology focuses on the interpretation of experience through textual or symbolic form. The emphasis is on issues of language and the nature and structure of communication (Schwandt, 2001). Because of its focus on interpretation, the researcher must adopt a perspective through which to collect and analyze data; therefore, hermeneutic phenomenologists interpret the meaning of experienced phenomena in terms of a

plausible but contingently adopted theoretical perspective (Giorgi, 1992). From a methodological perspective, hermeneutic phenomenology does not offer a procedural system (van Manen, 1997) making it difficult to apply it to research. In fact, it has been argued that hermeneutics is not a methodology and therefore its application to qualitative inquiry is not easily grasped (Schwandt, 2001). This variant of phenomenology was initially an interpretation of Husserl's phenomenology by Heidegger (1962), a student and critic of Husserl. It later became associated with Gadamer (1975), Ricoeur (1971), van Manen (1990; 1997) and Habermas (1971).

Existential phenomenology is known through the work of Schutz (1967). This variant of phenomenology is "oriented more toward describing the experience of everyday life as it is internalized in the subjective consciousness of individuals" (Schwandt, 2001, p. 192). Inquirers are physically part of the phenomenon they seek to understand and cannot be separated from it. Therefore, the lived experience of the inquirers themselves is a source of knowledge about the phenomenon (Schwandt, 2001). Merleau-Ponty (1964), Sartre (1993), and Heidegger (1962) have influenced and are associated with their own streams within existential phenomenology.

This thesis relied on the eidetic (descriptive) variant of phenomenology. Because eidetic phenomenology focuses on methodological procedures, it is readily applicable to qualitative research. Also, unlike hermeneutic phenomenology, eidetic phenomenology is consistent with the inductive nature of qualitative research because it does not rely on a particular perspective for collecting, analyzing, and interpreting data. Further, I was not interested in contributing my own data (my own perceptions of research) to the findings as is customary with existential phenomenology.

The Role of Theory in Phenomenology

The role of theory in qualitative research is controversial (Ray, 1994). For example, some researchers believe that the validity of qualitative research rests on the assumption that qualitative research is inductive and therefore preconceived theory is absent from it (Glaser & Strauss, 1967; Knafl & Howard, 1984; Strauss & Corbin, 1990). For these researchers, theory should not guide data collection and analysis because it violates the inductive assumption of qualitative research (Morse, 1994). It appears that theoretical frameworks have a substantial role in some variants of phenomenology but not others. As implied in the previous section, it has been proposed that there is minimal or no theory in eidetic (descriptive) phenomenology but that theory is central to hermeneutic (interpretive) phenomenology (Cohen & Omery, 1994; Creswell, 1998; Morse, 1994). As mentioned in the previous section, the assumption of eidetic phenomenology is that all phenomena can be reduced to an essential structure. This assumption, held by Husserl, is now reflected in the several phenomenological analytic techniques that aim to reduce data to the essential structure of the phenomena. Aside from this assumption, the role of theory in the design and procedures of this thesis is minimal. As proposed by Morse (2000) and Strauss and Corbin (1998), the role of theory became important after the analysis was completed and it was necessary to account for the study findings.

Role of the Literature in Phenomenology

When using phenomenological methods, it is appropriate to conduct a literature review either before and/or after data are collected and analyzed (Creswell, 1998). Some qualitative researchers, e.g. Glaser et al., 1967; Strauss et al., 1998, discourage extensive consultation with the literature believing that the researcher can become constrained or stifled by it. Consistent with the eidetic approach, it appears that, as with the role of theory, the role of the literature becomes important after data collection and analysis are completed. At this point,

qualitative researchers then need to place their findings within the context of the work that has already been published in the literature (Morse, 2000).

Before data collection began for the three studies that are the subject of Chapters 3-5, a preliminary literature search was conducted to review the existing research on individual perceptions of research in general as well as individual perceptions of the participatory approach to research, questionnaires as a method of data collection, and clinical trials. I used a variety of strategies to search the literature as the notion of "perception" is not a conventional search term. The most related term was "attitudes" and so my preliminary search was conducted combining the keyword "attitude(s)" with terms such as "research", "workplace studies", "participatory research", "questionnaires", "clinical research", and "clinical trials". As well, I used the textwords "worker participation", "perceptions", and "surveys". If any of these terms mapped to other related terms, the related terms were included in the search. The searches were conducted in Medline, Sociological Abstracts, CINAHL, PsycInfo, and a number of workplace databases including NIOSHTIC-OSH which includes NIOSHTIC, HSELINE, CISILO, and Canadiana. The database at the Institute for Work & Health in Toronto was also searched (I did not target the workplace databases for literature on clinical trials).

A more extensive literature review was conducted after the data were analyzed. The above search strategy was repeated for all years of each database (and later updated to January 2003). I also hand-searched two qualitative journals, Qualitative Health Research and Qualitative Inquiry, and focused on the themes from the findings e.g. labelling theory (Chapter 4), ethics and research (Chapter 5), identity theory (Chapter 6). Many of the articles retrieved were identified from reference lists in articles and books located. I searched the Citation Index on Web of Science for particular authors such as Kathryn Taylor

and Karen Cox who had conducted research that was particularly relevant to my research questions. Experts in the field of measurement, clinical trials, workplace studies, and qualitative research were also contacted by e-mail or in person for potential references. The results of the literature review will be addressed in the corresponding three chapters. However, at this point, it is noted that there appeared to be little reported literature concerning perceptions of research from the perspective of employees (other than physicians) in a clinical environment. The topic of participatory research generated the most search results; for this reason, Chapter 3 contains the longest discussion section.

The apparent gap in the literature regarding perceptions of research was beneficial to this qualitative investigation because it promoted the inductive nature of the research. In other words, it allowed the analyses to be grounded in the data rather than deriving hypotheses from reported literature (Schwandt, 2001). From a phenomenological perspective, the gap in the literature was also beneficial because it implied that there was less that I had to "bracket" before starting data collection. The process of bracketing is described in Chapter 2.

Significance of Thesis

There appeared to be little or no reported literature on employees' perceptions of research in their workplace so the research undertaken was important because it addressed a number of gaps in the literature:

Workplace studies where employees are the subjects of research have been growing in popularity over the last 20 years. However, we do not know how employees perceive these studies. For example, how important is workplace research from the perspective of cancer care employees? What do such studies signify for employees? On the other hand, clinical research where patients are the subjects of research is integral to progress in cancer management and is therefore

an accepted facet of work-life in cancer care. Again, we know very little about how these studies are perceived from the perspective of cancer care employees. Further, do employees' perceptions of research in their work environment differ depending on who is the subject of the research? Do these perceptions vary depending on employees' role in research?

There was also a gap in the literature concerning perceptions of the participatory research approach in the context of a quality of work-life investigation. The QWL Project at the cancer centre evolved through a participatory approach. This approach was intended to give ownership of the project to the employees because employees helped define and implement the research. Anecdotal evidence suggested that, although the project was participatory in its methodology, some members of the steering committee were frustrated about how decisions were made regarding the project and they felt that certain individuals were driving the project's agenda. It was therefore important to verify that those involved in the process perceived the project to be participatory and perceived their contribution to be valued. Chapter 3 explored the extent to which the project was perceived to be participatory by members of the steering committee of the QWL Project.

Questionnaires are a common method of data collection in workplace studies. Although there was some reported literature on interpretations of questionnaires in general, little was reported on health care employees' perceptions and interpretations of questionnaires as a method of data collection in the context of a quality of work-life investigation. As part of the QWL Project at the cancer centre, a survey was developed and administered to employees. Because such questionnaires may imply a promise to improve the quality of working life, it is important to understand how employees perceive the

questionnaires that they are asked to complete. Chapter 4 explored how the 2001 QWL Survey was perceived by employees who completed the survey.

Finally, there was a gap in the literature concerning nurses' and radiation therapists' perceptions of the clinical trial. The clinical trial is integral to progress in cancer management. However, as will be shown, evidence suggested that participation in such studies may result in psychological stress for physicians who are responsible for enrolling trial patients as well as for the patients who are enrolled in trials. It is possible that the presence of trials may also have an impact on other cancer care employees. Although there was some literature on physicians' attitudes to clinical trials, little was known about bedside nurses' and radiation therapists' perceptions of trials. The study addressed in Chapter 5 explored the perceptions of the clinical trial in a cancer care work setting.

Access to the Workplace

In the summer of 2001, I received ethical approval to conduct my thesis research at the cancer centre. Prior to submitting the ethics application, informal access to the centre had been achieved through my involvement in the QWL Project at the centre. During my term as a methodological consultant for the project, I felt that I had gained the steering committee's trust and respect as demonstrated by the following: In September 2000, the steering committee requested that I participate in an educational session and present information on measurement of constructs they wished to assess in the workplace; in October 2000, the committee requested that I organize and lead a one-day retreat for its members so that they could develop a QWL survey for the centre; in January 2001, the committee requested that I take a leading role in the data entry and analysis of the data from the site-wide survey which was to be administered in February 2001; in the summer of 2001, the committee requested that I present the findings of the survey at Grand Rounds that occurred in September 2001.

As part of my role as methodological consultant, I worked very closely with the QWL project coordinator. This relationship proved to be invaluable for several reasons. The coordinator for the project had been employed at the centre for 30 years and had a very high profile there. I believe that my working relationship with her gave credibility to my own research. She also helped me with administrative tasks involved in conducting my research at the centre (such as booking interview rooms and sending out site-wide emails) and with recruitment of some participants for studies #2 and #3 (see Chapter 2). In addition, she introduced me to employees outside the steering committee who also made me feel welcome at the centre.

During the months that I collected data and subsequent to that, I do not believe that the QWL steering committee or other employees felt that my presence at the centre was threatening or disruptive. The committee continued to solicit my help as a methodological consultant and, in November 2001, encouraged me to submit the findings of the survey to an academic journal. They also sought my help and advice with the second QWL survey that was administered in April 2002.

References

Altheide,D.L., & Johnson,J.M. (1994).   Criteria for assessing interpretive validity in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 485-499). Thousand Oaks, CA: Sage Publications.

Angen,M.J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. Qualitative Health Research, 10(3), 378-395.

Baptiste,I. (2001). Qualitative data analysis: Common phases, strategic differences.   Forum Qualitative Sozialforschung/Forum: Qualitative Social Research [On-line Journal], 2(3)

Berger,P.L. (1966). The social construction of reality: A treatise in the sociology of knowledge. Garden City, NY: Doubleday.

Cohen,M.Z., & Omery,A. (1994).   Schools of phenomenology: Implications for research. In J. M. Morse (Ed.), Critical issues in qualitative research methods. (pp. 136-156). Thousand Oaks, CA: Sage Publications.

Colaizzi,P. (1973).   Reflection and research in psychology: A phenomenological study of learning. Dubuque, Iowa: Kendall/Hunt Pub Co.

Colaizzi,P.F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology. (pp. 48-71). New York: Oxford University Press.

Creswell,J.W. (1998).   Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications.

Denzin,N.K., & Lincoln,Y.S. (1994). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 1-17). Thousand Oaks, CA: Sage Publications.

Devers,K.J. (1999). How will we know 'good' qualitative research when we see it? Beginning the dialogue in health services research. Health Services Research, 45(5 Part II), 1153-1188.

Fischer,C. (1984). A phenomenological study of being criminally victimized: Contributions and constraints of qualitative research. Journal of Social Issues, 40(1), 161-178.

Gadamer,H.G. (1975). Truth and method . New York: Seabury Press.

Giorgi,A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer, & E. Murray (Eds.), Duquesne studies in phenomenological psychology. Vol. 3. (pp. 82-103). Pittsburgh, PA: Duquesne University Press.

Giorgi,A. (1989). Some theoretical and practical issues regarding the psychological phenomenological method. Saybrook Review, 7, 71-85.

Giorgi,A. (1992). Description versus interpretation: Competing alternative strategies for qualitative research. Journal of Phenomenological Psychology, 23(2), 119-135.

Giorgi,A. (1994). A phenomenological perspective on certain qualitative methods. Journal of Phenomenological Psychology, 25(2), 190-220.

Giorgi,A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology, 28(2), 235-260.

Glaser,B.G., & Strauss,A.L. (1967). Discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Guba,E.G. (1990). The alternative paradigm dialog. In E. G. Guba (Ed.), The paradigm dialog. (pp. 17-30). Newbury Park, CA: Sage Publications.

Guba,E.G., & Lincoln,Y.S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 105-117). Thousand Oaks, CA: Sage Publications.

Habermas,J. (1971). Knowledge and human interests. Boston: Beacon.

Heidegger,M. (1962). Being and time. London: Blackwell.

Honan,E., Knobel,M., Baker,C., & Davies,B. (2000). Producing possible Hannahs: Theory and the subject of research. Qualitative Inquiry, 6(1), 9-32.

Knafl,K.A., & Howard,M.J. (1984). Interpreting and reporting qualitative research. Research in Nursing and Health, 7, 17-24.

Kuzel,A.J., & Like,R.C. (1991). Standards of trustworthiness for qualitative studies in primary care. In P. G. Norton, M. Steward, F. Tudiver, M. J. Bass, & E. V. Dunn (Eds.), Primary care research. (pp. 138-158). Newbury Park, CA: Sage Publications.

Marshall,C. (1990). Goodness criteria: Are they objective or judgement calls? In E. G. Guba (Ed.), The paradigm dialog. (pp. 188-197). Newbury Park, CA: Sage Publications.

Merleau-Ponty,M. (1964). The primacy of perception. Evanston, IL: Northwestern University Press.

Morse,J.M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 220-235). Thousand Oaks, CA: Sage Publications, Inc.

Morse,J.M. (2000). Theoretical congestion. Qualitative Health Research, 10(6), 715-716.

Patton,M.Q. (2002). Qualitative research & evaluation methods. (3rd ed.). Thousand Oaks, CA: Sage Publications.

Polkinghorne,D.E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology. (pp. 41-60). New York: Plenum Press.

Ray,M.A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), Critical issues in qualitative research methods. (pp. 117-133). Thousand Oaks, CA: Sage Publications.

Ricoeur,P. (1971). The model of the text: Meaningful action considered as a text. Social Research, 38, 529-562.

Sartre,J.-P. (1993). Being and nothingness: A phenomenological essay on ontology. New York: Washington Square Press.

Schutz,A. (1967). The phenomenology of the social world. Evanston, IL: Northwestern University Press.

Schwandt,T.A. (2001). Dictionary of qualitative inquiry. (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Secker,J., Wimbush,E., Watson,J., & Milburn,K. (1995). Qualitative methods in health promotion research: Some criteria for quality. <u>Health Education Journal, 54,</u> 74-87.

Smith,J.K. (1983). Quantitative versus qualitative research: An attempt to clarify the issue. <u>Educational Researcher, 12,</u> 6-13.

Sokolowski,R. (2000). <u>Introduction to Phenomenology.</u> Cambridge: Cambridge University Press.

Spiegelberg,H. (1975). <u>Doing phenomenology: Essays on and in phenomenology.</u> The Hague, Netherlands: Martinus Nijhoff.

Strauss,A., & Corbin,J. (1990). <u>Basics of qualitative research: Grounded theory procedures and techniques.</u> Newbury Park, CA: Sage Publications.

Strauss,A., & Corbin,J. (1998). <u>Basics of qualitative research: Techniques and procedures for developing grounded theory.</u> (2nd ed.). Thousand Oaks, CA: Sage Publications.

van Manen,M. (1990). <u>Researching lived experience: Human science for an action sensitive pedagogy.</u> London, ON: Althouse Press.

van Manen,M. (1997). <u>Researching lived experience: Human science for an action sensitive pedagogy.</u> (2nd ed.). London, ON: Althouse Press.

von Eckartsberg,R. (1986). <u>Life-world experience: Existential-phenomenological research approaches in psychology.</u> Washington, DC: Centre for Advanced Research in Phenomenology, Inc. & University Press of America, Inc.

von Glasersfeld,E. (1995). <u>Radical constructivism: A way of knowing and learning</u>. London: The Falmer Press.

CHAPTER 2

METHODS

There are common procedures integral to the phenomenological tradition. Data collection procedures include purposeful sampling, the process of bracketing or epoche, and the conduct of one-on-one face-to-face interviews. A choice of analytic techniques is also available to phenomenologists. This chapter describes the procedures of the three phenomenological studies that make up this thesis and outlines the steps taken to promote rigor and maintain ethical standards during the research. Unless noted otherwise, the procedures apply to all three studies.

Setting – The workplace

The cancer centre is a large ambulatory cancer treatment centre that serves over 2.3 million people in Ontario. There are approximately 450 employees at the centre. Eighty-two percent of employees are female with the largest proportion of employees working in radiation therapy (19%) and nursing (17%). It is estimated that 7,000 new patients are seen yearly with about 500 patients seen per day. Of the patients seen on any given day, approximately 250-300 patients are treated with radiation therapy.

Sampling

The research methods derived from phenomenology assume that the meaning of phenomena can only by explored by asking individuals who have experienced the phenomena to describe their experiences (Jasper, 1994). The methods also assume that the human experience makes sense to those who live it and that this experience can be verbally expressed (Dukes, 1984; Polkinghorne, 1989). Sampling is therefore purposeful in that individuals who have experienced

the phenomenon and are able to describe their experiences are recruited. To reflect the constructivist perspective, the aim of sampling was to include and explore the diversity of perceptions held by employees.

Sample size

Sample sizes are not meant to be representative or large in number in qualitative studies. For phenomenology, sample sizes of 5-25 (Polkinghorne, 1989) have been suggested. A minimum of 6 (Morse, 1994) and 10 (Creswell, 1998) participants has also been recommended. All participants of the three studies that make up this thesis were employees at the cancer centre. The sample size for study #1 was fixed; there were 15 members on the steering committee of the QWL Project. For studies #2 and #3, it appeared reasonable to recruit a minimum of 10 participants for each study.

As recommended by Lincoln and Guba (1985), sampling for studies #2 and #3 proceeded until information saturation or redundancy was achieved. Saturation or redundancy was achieved when no new information was collected in the interviews. In other words, if no new information was collected during the tenth interview for studies #2 and #3, recruitment was considered to be complete.

Eligibility

This thesis consists of three sub-studies that differ in sampling strategy. Eligible participants for study #1 were the 15 employees who were members of the Quality of Work-Life (QWL) steering committee in February 2001 when the study was introduced to them. These employees were considered to have an active role in research because they were involved in the design and implementation of this project.

Eligible participants for study #2 were those employees who had completed the QWL survey in February 2001. Three-hundred-and-twenty employees completed the QWL survey. Employees recruited for study #2 could not be eligible for study #1 or study #3 (i.e. they could not be members of the steering committee and they could not be a nurse or radiation therapist). These employees were considered to have a passive role in research as it was assumed that their main research involvement was completion of the survey.

Eligible participants for study #3 were nurses or radiation therapists in the centre who treat patients enrolled in clinical trials. There are approximately 100 nurses and radiation therapists in the centre who treat patients enrolled in clinical trials. These employees were considered to have an indirect role in research because they were responsible for conducting extra tests and documenting information related to the trials; they were not directly involved in the design of the trials or with decisions made in regards to them. As with participants in study #2, study #3 employees could not be eligible for study #1.

Recruitment

During a committee meeting in February 2001, the steering committee members were invited to participate in study #1. Members were informed that data collection for the study would commence in the fall of that year. All members present at the meeting informally agreed to participate. A separate e-mail formally inviting all members to participate was sent out in October 2001 (see Appendix A).

Participants for study #2 and study #3 were recruited in a number of ways. A brief site-wide e-mail message was sent out recruiting employees for both studies (see Appendix B). This e-mail had to be approved by a member of senior management at the centre before it was sent out. Approval was granted with no

changes required. The e-mail was generic; it simply described the study as one on employees' perceptions of research in their workplace. Eight employees responded to the site-wide e-mail. Of the eight employees who responded, five were eligible for study #2 and three were eligible for study #3. As not enough participants were recruited by e-mail, two other sampling methods were employed. Additional participants for study #2 and #3 were recruited through the QWL Project coordinator. The QWL Project coordinator had been at the centre for 30 years and had many contacts throughout the centre that allowed her to identify potential participants. Nurse participants recruited for study #1 and #3 were also asked to refer other nurses whom they thought might be interested in participating in the study. This appeared to be the most suitable method to gain access to the nurses at the centre. The technique of using referrals from other participants for recruitment is referred to as snowball sampling.

Bracketing (the Epoche Process)

The process of bracketing, or epoche, is integral to the phenomenological tradition. The term bracketing refers to the setting aside of one's judgments, biases, and preconceived ideas about things (Moustakas, 1994). The goal of this process is to remove one's usual ways of judging, labelling, or comparing (Moustakas, 1994) and to suspend theoretic biases (van Manen, 1997). The bracketing process allows receptivity; it aims to allow the researcher to approach participants and their experiences with an open mind and to accept whatever data are given (Omery, 1983). This state of receptivity is often referred to as an attitude of phenomenological reduction (Giorgi, 1994).

The process of bracketing was practiced throughout the collection and analysis of data. I am a doctoral student at a local university and have a history of involvement in clinical research and workplace studies. My interest in conducting these three qualitative studies was based on my own involvement in the QWL

Project at the cancer centre. Although I had no expectations about what I might discover, it is possible that my knowledge of workplace studies, measurement tools, and clinical research including clinical trials may have influenced my collection and analysis of the data. It was therefore necessary for me to attempt to suspend past knowledge and preconceptions about such research during data collection and analysis. The details of what I attempted to bracket are addressed in Chapters 3-5.

Data Collection

Data were collected through face-to-face semi-structured interviews from September 2001 to March 2002. I was responsible for arranging all the interviews by e-mail and for conducting them. Pilot interviews were conducted with each type of employee to refine the interview questions. One or two representatives from each study's participants were interviewed during the pilot interviews. As each of the studies was a sub-study of the main research objective, the interview protocols for all three studies were similar in format. Because the formats were similar across the studies, four pilot interviews on employees across the three samples were considered adequate (1 for study 1; 2 for study 2; 1 for study 3). At the end of these interviews, participants were asked about their understanding of the questions and whether there were questions that should have been asked. They were told that they were amongst the first group to be interviewed and that any feedback from them would be appreciated. There were no major changes in the interview questions based on the pilot interviews so the pilot interview data were included in the final analysis.

Interview Setting

Participants were given the option of meeting at the workplace, at their home, or at another location that was convenient for them. All participants chose to be interviewed at work. An interview time was scheduled and a meeting place

was assigned. Four participants chose to be interviewed in their offices. The other participants were interviewed in one of the six small meeting rooms at the centre. In order to protect the identity of the participant, prior to the interview, the blinds were closed in the meeting room and the seats were arranged so the participant would sit with his or her back to the door.

Interview Session

Due to time constraints in the workplace, participants were told that the maximum length of the interviews would be approximately 45 minutes. In most cases, participants wanted to talk for a longer period of time and because the room was available, interviews continued for an hour. When participants arrived to be interviewed, they were asked to sign the consent form (see Appendix C) which explained the purpose of the study, the right of the participant to withdraw from the study at any time, the anticipated length of the interview, the fact that the interview was being taped, and an assurance of confidentiality. It was also clarified that the study was not related to the QWL Project at the centre. The information in the consent form was reviewed during the introduction of the interview prior to turning on the tape recorder. This allowed for some social conversation aimed at creating a relaxed atmosphere for the participant.

Interview Protocol

The interviews consisted of three main questions. The opening question was an informal question asking the participants to describe the research activities that they were aware of at the centre. The second question asked participants to address specifically the QWL Project and the clinical research at the centre. Therefore, participants in all three studies were asked about their perceptions of the QWL Project as well as their perceptions of clinical research at the centre. The third question of the interviews differentiated the three studies. Employees on the steering committee of the QWL Project were asked about their perceptions

of the participatory approach to research; employees who completed the workplace survey were asked about their perceptions of the QWL Survey; and nurses and radiation therapists were asked about their perceptions of the clinical trial. To guide the conversation, a typed interview protocol was used with probe questions embedded within the main questions (see Appendix D). Occasionally, participants addressed a subsequent question in a previous response so the questions were not necessarily followed in order. Detailed notes were taken during the interviews.

In order to describe the study samples, four demographic questions were asked at the end of the interview: participants were asked to identify their main activity at the centre, the training they needed for this job, their date of birth, and how many years they had worked at the centre. The sex of the participant was noted.

Upon interview completion, participants were given a gift certificate to a coffee shop (which is located in the workplace as well as in the community at large) in appreciation for their participation. Permission was then requested to contact participants at a later date so that they could review the transcript of their interview and potentially a draft of the research paper.

Once the participant left the interview setting, I read through my notes and filled in as many details as I could remember. This enabled me to capture as much of the interview as possible on paper in the event that the tapes could not be recovered. In addition, I kept a journal for reflecting upon the interviews and the data collected in them.

<u>Data Verification</u>

The interviews were audiotaped and transcribed verbatim into Microsoft Word. As recommended by Kvale (1996), the majority of transcripts were verified against the tapes. Two-thirds of the transcripts were verified in this manner. This process led to discussions with the transcriptionist until I was satisfied with the quality of the transcriptions. Sections of the remaining transcripts were checked when I became concerned that something was missing from them. As I had conducted the interviews, it was apparent when omissions or possible mistakes existed in the transcripts. The transcripts were then sent to the participants for another level of verification (verification is addressed in the next section on trustworthiness/rigour). Once the data had been cleaned, they were downloaded into NVivo (1999). This qualitative software program has flexible features that help organize, code, and retrieve data.

Data Analysis

In qualitative research, data analysis is not a distinct phase of the research process. It is a cyclical and reflective activity that informs data collection, writing, and further data collection (Coffey & Atkinson, 1996; Tesch, 1990). The purpose of phenomenological data analysis is to preserve the uniqueness of each lived experience while permitting an understanding of the meaning of the phenomenon itself (Banonis, 1989). The goal of analysis is to portray the essential nature of the phenomenon experienced (Moustakas, 1994). To achieve this, "every perception is granted equal value; non-repetitive constituents of the experience are linked thematically, and a full description is derived" (Moustakas, 1994, p. 96).

Because different analytic approaches can influence research findings (Honan, Knobel, Baker, & Davies, 2000), it is necessary to describe the analytic techniques followed in this thesis. There are many analytic techniques used by

phenomenologists. Analytic techniques include those by Colaizzi (1973; 1978), Fischer (1984), Giorgi (1975; 1989; 1997), van Kaam (1959; 1969), and Moustakas (1994). The analytic procedures by Giorgi were appealing for a number of reasons:

1. Giorgi proposes procedures that are straightforward and methodological. Researchers such as Fischer (1984) aim toward developing an essential description of the phenomenon but do not provide procedures for arriving at the description. Conversely, the methods proposed by Moustakas are laborious and very detailed.

2. Giorgi does not encourage quantification (content analysis) of results as does van Kaam. Quantification of results is not consistent with the constructivist perspective.

3. Unlike van Kaam (1959; 1969), Giorgi specifically discourages the use of multiple coders during the analysis. This position is consistent with that of other phenomenological experts and qualitative researchers in general (Angen, 2000; Crotty, 1996; Finlay, 2002; Morse, 1994; Sandelowski, 1993). It is also consistent with the constructivist paradigm that allows for multiple interpretations of the data.

4. Giorgi does not rely on large sample sizes; van Kaam (1969), Colaizzi (1973), and Fischer (1984) have reported sample sizes of 365, 50, and 50 respectively.

5. It has been demonstrated that Giorgi preferred to conduct research in the "real world" unlike van Kaam and Colaizzi who conducted much of their research in laboratory-type settings (von Eckartsberg, 1986). Conducting research in the "real world" setting is consistent with the phenomenological approach.

The analytic steps proposed by Giorgi (1975; 1989; 1997) are as follows:

1. The transcripts are read in their entirety to appreciate a sense of the whole data.

2. The transcripts are read more slowly and delineated each time a transition in meaning is perceived.

3. Redundancies are eliminated and the investigator clarifies the meaning units by relating them to each other and to the sense of the whole.

4. The given units are reflected upon as still expressed in the language of the participant.

5. Finally, a consistent description of the essential structure of the phenomenon is synthesized.

Analysis of the data began after the first interview and was an iterative process. Themes and codes were identified and then revised as more interviews were conducted. An editing style approach to coding was applied to the data (Crabtree & Miller, 1992). A coding template was developed to organize the data into meaning units; this template was revised and re-organized numerous times (see Appendix E).

The subsequent chapters provide examples of this analytic process for each study. Direct quotations from the transcripts are given where appropriate to illustrate and/or clarify the findings. The use of quotes also brings a voice to the participants in the study (Creswell, 1998; Morse, 1994; Sandelowski, 1994), allowing participants' views to be expressed in their own words (Patton, 2002).

Trustworthiness/Rigour

In qualitative research, the concept of trustworthiness often appears to be vague and lacking in definition. In this section, I rely heavily on the works of Guba and Lincoln (1982; 1985; 1986) to define a few goals related to

trustworthiness and then describe the procedural steps taken to achieve them. The term "trustworthiness" parallels the term "rigor" used in quantitative research (Lincoln & Guba, 1986). For a qualitative study to achieve trustworthiness, Lincoln and Guba (1986) assert that credibility, transferability and confirmability must be demonstrated. Credibility refers to the believability of the inquirer's analysis, formulations, and interpretations from the perspective of the participants being studied (Guba & Lincoln, 1982). Transferability, or fittingness, refers to the ability of the investigator to transfer or fit the findings of the study to contexts outside the study (Lincoln & Guba, 1985). Confirmability refers to the neutrality of the data (rather than that of the investigator as in quantitative research) (Lincoln & Guba, 1985). Consistent with the constructivist paradigm, the following considerations were made to address the concept of trustworthiness.

Credibility

To achieve credibility, a researcher can engage in member checking, use direct quotations from participants' accounts, and practice prolonged engagement (Guba & Lincoln, 1982; Guba & Lincoln, 1989). Member checking promotes that the descriptions of the experiences are recognized by participants; it allows participants to judge the overall adequacy of the interview, to correct errors of fact or interpretation, to offer additional information, and it puts them 'on record' as having said certain things (Guba & Lincoln, 1989). All participants received a copy of their transcript a few weeks after the interview and were asked to read over their transcript to make sure they were comfortable with its content. Fifteen participants replied after receiving their transcripts. Twelve participants were content with the transcripts as they were; these participants had a few minor comments related to grammar or spelling (e.g., of a person named in the transcript or of a drug or clinical procedure). Three employees sent me written comments to clarify points made in their transcripts. These clarifications were incorporated into the transcripts as the meanings of the text did not appear to be affected by the

changes. Direct quotations from participants' transcripts were then provided to the reader to clarify or demonstrate the findings.

Prolonged engagement at the site allows the researcher to establish rapport with participants, build the trust necessary and facilitates the understanding of the context's culture (Guba & Lincoln, 1989). Prolonged engagement was met to the extent that I was involved in the QWL Project at the cancer centre for almost two years before I conducted my interviews. As I attended QWL meetings at the site regularly (about 1-2 times per month) and was frequently involved in the discussions, I felt that I had established a high degree of rapport with the project's steering committee. I also spent additional time at the centre meeting with other employees and studying in the library and I presented at Rounds in September of 2001. As a result, I felt that my presence was familiar to other employees at the centre.

Transferability

To achieve transferability, a researcher should ensure that he or she leaves an audit trail delineating all methodological steps and decisions made during the research (Guba & Lincoln, 1982). The audit trail allows other researchers to review the steps and decisions made and to assess whether they seem reasonable and similar to those that the reader would have made if he/she had adopted the same viewpoint as articulated by the researcher (Giorgi, 1975). This thesis documents the assumptions of the investigator, the details of the data collection process, the steps of the analysis and the decisions made during the research.

Confirmability

In order to promote confirmability (or neutrality) of the findings, a researcher should practice reflexivity (Guba & Lincoln, 1982). Reflexivity demonstrates a level of integrity in the researcher partly because it allows he or

she to become aware of some of the preconceptions that need to be bracketed (Finlay, 2002). To achieve reflexivity, notes were taken during and after each interview and a journal was kept throughout the research process. By stating my assumptions about qualitative research, the phenomenological approach, and the use of theory, I have clarified my own perspective before conducting this research. As well, I have been open about my own involvement in research and have attempted to bracket preconceptions based on this involvement.

Confirmability can also be sought by verifying the quality of the data collected (Guba & Lincoln, 1982). Two-thirds of the transcripts were checked against the tapes to ensure that I was comfortable with the quality of the transcriptions. Sections of the remaining transcripts were then checked for verification. As mentioned previously, all transcripts were sent to the participants by email and participants had a few weeks to respond with comments.

Ethics

Ethical approval was obtained for this project by the Research Ethics Board of the local university and by the Protocol Review Committee of the cancer centre.

There may appear to be a conflict of interest between my role as a researcher and as a consultant (methodologist) for the QWL Project at the centre. Because I was a member of the project's steering committee, the members of the steering committee who participated in study #1 were my colleagues on the project. I can only document this as a potential source of ethical compromise and note that every effort was made to conduct the interviews in a professional manner. Further, I assured study #1 participants that the content of the interviews would not be disclosed to other committee members. I had no prior relationship with the participants who were recruited for study #2 and study #3. I was

responsible for obtaining consent and for witnessing the consent forms for all three studies.

Participants who wished to withdraw during or after the study were free to do so. Participants were informed that withdrawal from the study would not affect their relationship with their employer. If they wished to withdraw during the interview or if they wished to make a statement off-tape, the tape recorder would be stopped. No-one at the cancer centre would be notified of participants who declined an interview or who withdrew from a study. There were no withdrawals.

Data from the interviews were transcribed, stored, and analyzed off-site at the Institute for Work & Health in Toronto to assure participants that their employers did not have access to their data. The tapes and the transcripts of the interviews were kept in a secure area at the Institute for Work & Health. Data from the transcripts was stored electronically in NVivo (1999). Access to this file was password protected. The interview tapes and transcripts were given unique identification numbers so that individuals were not associated with their data. Participants whose quotations are reported in this thesis are not identified and information in the quotation that might identify them has been omitted. To protect the identity of the centre, the organization has not been named. The interview tapes will be destroyed in seven years as per the policy at the local university and the Institute for Work & Health.

Dissemination

I plan to present the recommendations from Chapters 3 and 4 to the QWL steering committee members because the results in these chapters are most relevant to them. Potentially, the steering committee will devise a strategy to address some of the recommendations regarding the committee in Chapter 3 as

well as engage the decision makers at the centre (managers) to make the relevant changes at the centre recommended in Chapter 4. Chapter 5 will be submitted to the head of the Clinical Trials Department at the centre who has the power to consider the recommendations from that chapter.

This thesis also has implications for workplace and clinical researchers in general. In Chapters 3 and 4, the tenets of participatory research in the context of a workplace setting were challenged. In Chapter 5, some of the limitations of conducting clinical trials in a cancer setting were demonstrated. These three chapters will be submitted to academic journals judged to be appropriate for these messages. The findings may also be interesting to researchers outside the domains of these academic journals and to clinical practitioners in general. At the time this thesis was submitted to Graduate Studies, the findings had been presented at one national conference (Advances in Qualitative Methods) and one international conference (9th International Qualitative Health Research Conference), submitted to two other conferences (6th International Congress on Work Injuries Prevention, Rehabilitation and Compensation; Joint Meeting of the American Society for Bioethics and Humanities and the Canadian Bioethics Society), and presented at Research in Progress Rounds at Women's College Hospital in Toronto. As well, a bioethicist at Cancer Care Ontario (CCO) had requested that the findings of Chapter 5 be addressed by the Radiation Therapy Advisory Committee for CCO.

References

Angen,M.J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. Qualitative Health Research, 10(3), 378-395.

Banonis,B.C. (1989). The lived experience of recovering from addiction: A phenomenological study. Nursing Science Quarterly, 2(1), 37-42.

Coffey,A., & Atkinson,P. (1996). Making sense of qualitative data: Complementary research strategies. Thousand Oaks, CA: Sage Publications.

Colaizzi,P. (1973). Reflection and research in psychology: A phenomenological study of learning. Dubuque, Iowa: Kendall/Hunt Pub Co.

Colaizzi,P.F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology. (pp. 48-71). New York: Oxford University Press.

Crabtree,B.F., & Miller,W.L. (1992). Doing qualitative research. Newbury Park, CA: Sage Publications.

Creswell,J.W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications.

Crotty,M. (1996). Phenomenology and nursing research. South Melbourne, Australia: Churchill Livingstone.

Dukes,S. (1984). Phenomenological methodology in the human sciences. Journal of Religion and Health, 23(3), 197-203.

Finlay,L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. Qualitative Health Research, 12(4), 531-545.

Fischer,C. (1984). A phenomenological study of being criminally victimized: Contributions and constraints of qualitative research. Journal of Social Issues, 40(1), 161-178.

Giorgi,A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer, & E. Murray (Eds.), Duquesne studies in phenomenological psychology. Vol. 3. (pp. 82-103). Pittsburgh, PA: Duquesne University Press.

Giorgi,A. (1989). Some theoretical and practical issues regarding the psychological phenomenological method. Saybrook Review, 7, 71-85.

Giorgi,A. (1994). A phenomenological perspective on certain qualitative methods. Journal of Phenomenological Psychology, 25(2), 190-220.

Giorgi,A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology, 28(2), 235-260.

Guba,E.G., & Lincoln,Y.S. (1982). Epistemological and methodological bases of naturalistic inquiry. Educational Communication and Technology Journal, 30(4), 233-252.

Guba,E.G., & Lincoln,Y.S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage Publications.

Honan,E., Knobel,M., Baker,C., & Davies,B. (2000). Producing possible Hannahs: Theory and the subject of research. Qualitative Inquiry, 6(1), 9-32.

Jasper,M.A. (1994). Issues in phenomenology for researchers of nursing. Journal of Advanced Nursing, 19, 309-314.

Kvale,S. (1996). Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Lincoln,Y.S., & Guba,E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage Publications.

Lincoln,Y.S., & Guba,E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D. D. Williams (Ed.), Naturalistic evaluation. New directions for program evaluation, No. 90. (pp. 78-84). San Francisco: Jossey-Boss.

Morse,J.M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 220-235). Thousand Oaks, CA: Sage Publications, Inc.

Moustakas,C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage Publications.

NVivo [Computer Software]. (1999). Victoria, Australia: Qualitative Solutions and Research Pty Ltd.

Omery,A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5(2), 49-63.

Patton,M.Q. (2002). Qualitative research & evaluation methods. (3rd ed.). Thousand Oaks, CA: Sage Publications.

Polkinghorne,D.E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology. (pp. 41-60). New York: Plenum Press.

Sandelowski,M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.

Sandelowski,M. (1994). The use of quotes in qualitative research. Research in Nursing & Health, 17, 479-482.

Tesch,R. (1990). Qualitative research: Analysis types and software tools. New York: The Falmer Press.

van Kaam,A. (1959). Phenomenal analysis: Exemplified by a study of the experience of 'really feeling understood". Journal of Individual Psychology, 15(1), 66-72.

van Kaam,A. (1969). Existential foundation of psychology. New York: Basic Books.

van Manen,M. (1997). Researching lived experience: Human science for an action sensitive pedagogy. (2nd ed.). London, ON: Althouse Press.

von Eckartsberg,R. (1986). Life-world experience: Existential-phenomenological research approaches in psychology. Washington, DC: Centre for Advanced Research in Phenomenology, Inc. & University Press of America, Inc.

CHAPTER 3

PERCEPTIONS OF THE PARTICIPATORY RESEARCH PROCESS IN A CANCER CENTRE WORKPLACE STUDY

Abstract

This qualitative study explored the perceptions of the participatory research process from the perspective of employees who were on the steering committee of a quality of work-life project at a Canadian cancer centre. The concept of participatory research was developed in the Third World; however, it has been increasingly applied to health research in developed countries. In occupational research, incorporating workers' knowledge is important because workers possess valuable information about their jobs, their working conditions, and their health. The Quality of Work-Life Project at the cancer centre began in the spring of 2000. The project proceeded using a participatory approach to research; the composition of the steering committee was designed to represent the employees at the centre and members collaborated to make decisions about the project. Using a phenomenological approach, the author interviewed 12 of 15 members of the steering committee to explore their perceptions of the participatory approach to the project. The following themes emerged from the analysis: 1) The role of management and senior management was viewed as being important but employees were initially uncomfortable with the presence of management at meetings; 2) The desired composition of the committee was complex and there may have been a natural process by which this composition was attained; 3) Participatory research without action was unacceptable; and 4) Full participation in all aspects of the project was difficult to achieve for a number of reasons. These findings have important implications because they challenge existing

notions in the literature about participatory research in the context of a workplace study.

Objective

This study is part of a larger qualitative study whose objective was to explore cancer care employees' perceptions of a Quality of Work-life (QWL) Project where they were the subjects of research and their perceptions of clinical research where patients were the subjects of research. The objective of the current study was to explore perceptions of the participatory research process from the perspective of employees who were on the steering committee of a QWL Project. The findings from the larger study are not presented in this paper.

Context

This research was conducted at a Canadian cancer centre. The Centre is a large (approximately 450 employees) ambulatory cancer treatment center that serves over 2.3 million people in Ontario. Approximately, 7,000 new patients are referred to the Centre each year with approximately 500 patients seen each day for consultations, radiation and chemotherapy treatments, and follow-up visits. In Canada, health insurance coverage is universal and there are no financial barriers to seeking treatment for cancer.

The QWL Project at the Centre began in the spring of 2000. It was initiated by the Chief Executive Officer (CEO) of the organization based on anecdotal evidence of low morale and high burnout at the Centre. The CEO approached several pharmaceutical companies to solicit funding for the project. In April 2000, Ortho Biotech funded the project for a two-year period. The project fit within Ortho Biotech's mandate that includes research on patient satisfaction and community health in general. With the exception of funding the project, Ortho Biotech had no involvement in the project. The CEO approached

an occupational health scientist and a doctoral student (author) for recommendations on how to proceed with a quality of work-life study.

A part (60%)-time project coordinator was hired by the Centre and employees were asked to volunteer to join a steering committee for the project. The project coordinator was also the chair of the committee (her other role was Patient Education Coordinator at the Centre). The steering committee included representatives from a variety of departments at the Centre. There was an attempt to ensure that representatives from the main employee groups and unions were recruited. The first meeting of the steering committee was held on June 19, 2000. After a series of meetings, the steering committee developed a working agenda to address quality of work-life issues. The committee decided that a survey should be administered to employees at the Centre to gather baseline data on important issues that they believed to be related to employees' quality of work-life. Through collaboration between the steering committee and the employees they represented, perceived problem areas in the workplace were identified. These problem areas were articulated as four constructs that could be measured: burnout, social support, job satisfaction, and work-family conflict. A retreat day was organized to educate the committee about survey methodology and to allow them to select the tools they wanted to include in the survey. During the one-day retreat, measures for each of the four constructs previously demonstrated to be reliable and valid were chosen by the committee - these tools formed a composite worksite survey. The survey was administered to staff during February 2001. To help fulfill Ortho Biotech's mandate, a patient satisfaction survey was administered at that time to patients at the Centre. The patient satisfaction survey was developed by the Supportive Care group at the Centre and is not related to the present study.

The QWL Project has been promoted in the Cancer Centre over the last two years and it has visible support from the CEO, senior management, and the unions. In the past two years, the committee has formally adopted a description of its composition and terms of reference for the Project have also been developed.

The Quality of Work-Life (QWL) Steering Committee

The steering committee includes representatives from a variety of departments at the Cancer Centre. The term for each committee member is 2 years; however, there has been some movement into and out of the committee during the first two years. Five of the original members resigned in the first two years: 2 members resigned from the committee for personal reasons; three others resigned because they were leaving the Cancer Centre to pursue outside employment. Employees from the same department replaced four of the five resigning members. At this point, it was realized that there was over-representation from one department. A department not represented in the committee was approached and an employee from this department was recruited to replace the fifth member.

Participatory Research

There is some evidence that worker participation in workplace interventions has a positive effect on the quality of working life (Coch & French, 1948; Kompier & Cooper, 1999; Kompier, Geurts, Grundemann, Vink, & Smulders, 1998; Kompier, van den Berg, Aust, & Siegrist, 2000) The term "participatory research" encompasses a variety of approaches including Participatory Research, Participatory Action Research, Development Leadership, Rapid Assessment Procedures, and Rapid Ethnographic Assessment (Cornwall & Jewkes, 1995). The concept of participatory research was developed in the Third World (Hall, 1981), however, it has been increasingly applied to health research

in developed countries (Cornwall et al., 1995). According to Cornwall and Jewkes (1995), "participatory research is about respecting and understanding the people with and for whom researchers work. It is about developing a realization that local people are knowledgeable and that they, together with researchers, can work towards analyses, and solutions. Participatory research involves recognizing the rights of those whom research concerns, enabling people to set their own agendas for research and development and so giving them ownership over the process" (p. 1674). In occupational health, participatory research shifts control of the research process away from the professionals to those who actually experience work-related problems (Daykin, 1999). Involving workers' knowledge in the research process is important because workers possess valuable information about their jobs, their working conditions, and their health (Mergler, 1987). There is also an ethical obligation to include workers in research about them. According to Heron (1996), persons as autonomous beings have a moral right to participate in the research decision-making that claims to generate knowledge about them.

The Terms of Reference for the QWL Project at the Cancer Centre states that "The composition of the committee is designed to be representative of the employees at the Centre" and that "Members collaborate to make decisions about the project". Resolution of conflict on decisions is achieved by a majority vote. Although not formally stated in the Terms of Reference, the project was intended to be participatory and has proceeded similarly to Hall's (1981) concept of participatory research. According to Hall, characteristics of the participatory process include:

1. The problem originates in the community or workplace itself;

2. The ultimate goal of the research is fundamental structural transformation and the improvement of the lives of those involved. The beneficiaries are the workers or people concerned.

3. Participatory research involves the people in the workplace or the community in the control of the entire process of the research.

4. Focus of participatory research is on work with a wide range of exploited or oppressed groups e.g. labour

5. Central to participatory research is its role of strengthening the awareness in people of their own abilities and resources

6. The term "researcher" can refer to both the community or workplace persons involved as well as those with specialized training

7. Although those with specialized knowledge/training often come from outside the situation, they are committed participants and learners in a process that leads to militancy rather than detachment

The Researcher's Perspective - The Phenomenological Tradition

This study aims to explore individual perceptions of the participatory research process. The study of individual perceptions lends itself to the phenomenological tradition (Schwandt, 2001; Sokolowski, 2000). Phenomenology aims to study ordinary experiences of phenomena in everyday life from the perspective of the person experiencing it (Schwandt, 2001).

The present study relied on the eidetic (descriptive) variant of phenomenology. As a research method, eidetic phenomenology assumes that there are essential structures to any human experience and that these structures constitute that experience (Morse, 1994).

The Role of Literature in Phenomenology

In phenomenology, it is appropriate to conduct a literature review either before and/or after data are collected and analyzed (Creswell, 1998). Some qualitative researchers (e.g. Strauss & Corbin, 1998) discourage extensive consultation with the literature believing that the researcher can become constrained or stifled by it. Consistent with the eidetic approach, it appears that the role of the literature becomes important after data collection and analysis is completed. At this point, qualitative researchers then need to place their findings within the context of the work that has already been published in the literature (Morse, 2000).

A preliminary literature search was conducted to determine whether other studies had been conducted on employees' perceptions of participatory research in workplace studies. A more extensive literature review was conducted after the data were analyzed. The results of the literature review will be addressed in the discussion section. However, at this point, it is noted that there appeared to be very little literature on perceptions of participatory research in workplace studies from the perspective of those involved in this approach.

Methods

There are common procedures integral to the phenomenological tradition. Data collection procedures include purposeful sampling, bracketing or the epoche process, and the conduct of one-on-one face-to-face interviews. A choice of analytic techniques is also available to phenomenologists.

Sampling

The research method derived from phenomenology assumes that the meaning of phenomena can only be explored by asking individuals who have experienced the phenomena to describe their experiences (Jasper, 1994).

Sampling is therefore purposeful in that individuals who have experienced the phenomena and are able to describe their experiences are recruited.

Recruitment

Eligible participants were the 15 members of the QWL steering committee at the time the present study was introduced to them in February 2001. During a committee meeting in February 2001, the steering committee members were invited to participate in this study. Members were informed that data collection for the study would commence in the fall of that year. All members present at the meeting informally agreed to participate. A separate e-mail formally inviting all members to participate was sent out in October, 2001.

Sample size

In phenomenological studies, sample sizes of 5-25 (Polkinghorne, 1989) have been suggested. A minimum of 6 (Morse, 1994) and 10 (Creswell, 1998) participants has also been recommended. The maximum sample size of the present study was fixed as there were 15 members on the steering committee of the QWL Project.

Bracketing (Epoche)

Bracketing, or the epoche process, is integral to the phenomenological tradition. The term "bracketing" refers to the setting aside of one's judgments, biases, and preconceived ideas about things (Moustakas, 1994). The goal of this process is to remove one's usual ways of judging, labelling, or comparing (Moustakas, 1994) and to suspend theoretic biases (van Manen, 1997).

The process of bracketing was practiced throughout the collection and analysis of data. I am a doctoral student at a local university and have a history of involvement in clinical research and workplace studies. My interest in conducting

this qualitative study was based on my own involvement in the QWL Project at the Centre. I was aware that some committee members were frustrated about how decisions were made regarding the Project. It is possible that my experience with the Project may have influenced my collection and analysis of the data. Although I had never been involved in a QWL Project and had no expectations about the findings of the present study, I am aware that the participatory approach in workplace studies is highly recommended. It was therefore necessary for me to attempt to suspend these preconceptions during data collection and analysis.

Data Collection

Data were collected through face-to-face semi-structured interviews from September 2001 to March 2002. I was responsible for arranging all the interviews by e-mail and for conducting them. Pilot interviews were conducted to refine the interview questions. The interview protocol of the other studies which make up the larger qualitative investigation were similar in format so one or two representatives from each study's sample were interviewed for the pilot interviews. A total of four pilot interviews on employees across the larger study were conducted. One employee from the present study was included in these pilot interviews. There were no major changes in the interview questions based on the pilot interview so the pilot interview data were included in the final analysis.

Interview Setting

Participants were given the option of meeting at the workplace, at home, or at another location that was convenient for them. All participants chose to be interviewed at the workplace. Only one participant requested a 30-minute interview due to a busy work schedule. The remaining interviews lasted 45 minutes to 1 hour. Interview rooms were booked for at least one and a half hours allowing 15-30 minutes for the investigator to prepare for the interview and set up the room. An interview time was scheduled and a meeting room was assigned.

There are six small meeting rooms at the Centre. Three participants chose to be interviewed in their offices.

Interview Session

When participants arrived to the interview, they were asked to sign the consent form which explained the purpose of the study, the right of the participant to withdraw from the study at any time, the anticipated length of the interview, the fact that the interview was being audio-taped, and an assurance of confidentiality. It was also clarified that the study was not part of the QWL Project at the Centre. The information in the consent form was reviewed during the introduction of the interview prior to turning on the tape recorder. This allowed for some social conversation aimed at creating a relaxed atmosphere for the participant.

Interview Protocol

The interview consisted of three main questions. Data from the first two questions are part of the larger qualitative study and are therefore not presented here. The third question of the interview asked participants to talk about their involvement in the QWL Project. When referring to participatory research, the words "team approach" were used as this is how the concept had been introduced to the committee members when they joined the project. To guide the conversation, a typed interview protocol was used with probe questions embedded within the main questions. Detailed notes were taken during the interviews.

In order to describe the study samples, the sex of the participant was noted and then four demographic questions were asked at the end of the interview: participants were asked to identify their main activity at the Centre, the training they needed for this job, their date of birth, and how many years they had worked at the Centre.

Upon completion of the interviews, participants were given a small gift certificate to a restaurant (which is located in the workplace as well as in the community at large) in appreciation for their participation. (Participants were not aware of the gift certificate in advance of the interview.) Permission was then requested to contact participants at a later date so that they could review the transcript of their interview and potentially a draft of the research paper.

Once the participant left the interview setting, I read through my notes and added details based on my memory of the interview. This enabled me to capture as much of the interview as possible on paper in the event that the tapes could not be recovered. In addition, I kept a journal for reflecting upon the interviews and the data collected in them.

Data Verification

The interviews were audiotaped and transcribed verbatim into Microsoft Word. As recommended by Kvale (1996), the majority of transcripts were verified against the tapes. Two-thirds of the transcripts were verified in this manner. This process led to discussions with the transcriptionist until I was satisfied with the quality of the transcriptions. Sections of the remaining transcripts were checked when I became concerned that something was incorrect or missing from them. As I had conducted the interviews, it was apparent when omissions or possible mistakes existed in the transcripts. When I was satisfied with their quality, the transcripts were sent to the participants for another level of verification. Participants were given a few weeks to respond with comments and/or corrections. The transcripts were then downloaded into NVivo (1999). This qualitative software program has flexible features that help organize, code, and retrieve data.

Ethics

Ethical approval by the Research Ethics Board of the local university and by the Protocol Review Committee of the Cancer Centre was obtained for this project.

There may appear to be confusion between my role as the researcher of the present study and as a consultant (methodologist) for the QWL Project at the Centre. Because I was a member of the project's steering committee, the members of the steering committee who participated in this study were my colleagues on the project. However, I was not an employee at the Centre and thus had no voting privileges on the steering committee. I can only document this as a potential source of ethical compromise and note that every effort was made to conduct the interviews in a professional manner. Further, I assured participants that the present study was not part of the QWL Project and that the content of the interviews would not be disclosed to other committee members.

Participants who wished to withdraw during or after the study were free to do so. If they wished to withdraw during the interview or if they wished to make a statement off-tape, the tape recorder was stopped (no-one stopped the tape to make a statement). Participants were informed that no one at the cancer center would be notified if they declined an interview or withdrew from the study (there were no withdrawals). Participants were also informed that withdrawal from the study would not affect their relationship with their employer.

Data from the interviews were transcribed, stored, and analyzed off-site at the Institute for Work & Health (IWH) in Toronto to assure participants that their employers did not have access to their data. The tapes and the transcripts of the interviews were kept under lock and key at IWH. Data from the transcripts was stored electronically in NVivo (1999). Access to this file was password protected.

The interview tapes and transcripts were given a unique identification number so that individuals were not associated with their data and participants whose quotations are reported in this paper were not identified by name. Further, quotes that might compromise the identity of participants were not reported. The interview tapes will be destroyed in seven years as per the policy at the local university and IWH.

Data Analysis

In qualitative research, data analysis is not a distinct phase of the research process. It is a cyclical and reflective activity that informs data collection, writing, and further data collection (Coffey & Atkinson, 1996; Tesch, 1990). The goal of phenomenological analysis is to portray the essential nature of the phenomenon experienced (Moustakas, 1994). The data were analyzed according to Giorgi's (1975; 1989; 1997) procedures. The analytic steps proposed by Giorgi are as follows:

1. The transcripts are read in their entirety to appreciate a sense of the whole data.
2. The transcripts are read more slowly and delineated each time a transition in meaning is perceived.
3. Redundancies are eliminated and the investigator clarifies the meaning units by relating them to each other and to the sense of the whole.
4. The given units are reflected upon as still expressed in the language of the participant.
5. Finally, a consistent description of the essential structure of the phenomenon is synthesized.

Analysis of the data began after the first interview and was an iterative process. An editing style approach to coding was applied to the data (Crabtree &

Miller, 1992). Themes and codes were identified immediately and then revised as more interviews were conducted. According to Giorgi's method, I segregated the text into manageable units referred to as "meaning units". Discrimination between these units was noted throughout the text as I became aware of changes of meaning that were relevant to the study. A coding template was developed to organize the data into these meaning units; this template was revised and re-organized at least 20 times. Twenty-six meaning units emerged from participants' descriptions of the team approach. Meaning units included: participants' role on the committee, workload associated with the QWL Project, committee's lack of knowledge, silent voices on the committee, motivation to be on committee, participants' phases of involvement on the committee, usefulness of the committee, hierarchy on the committee, and group cohesion. Once I was satisfied with the discrimination among these units, I began the process of relating the units to each other and to the sense of the whole.

Results

Of the 15 committee members, 12 members consented to participate in the study. The three remaining members did not respond to three e-mails each that invited them to participate. Two of these members had attended very few committee meetings. For confidentiality reasons, the job titles of the participants are not reported. The majority (n=9) of participants were female and the mean age of the sample was 42 years. Participants had worked at the Centre from 1 to 33 years. Five participants responded with comments after reading their transcripts. The comments were minor and resulted in a few spelling corrections.

At this point, I must address one finding from the interviews. While I referred to the QWL Project as a research project, there were few detailed responses from participants regarding the project as a research project.

Participants preferred to focus on the process of participation in the project as opposed to the research itself.

The following central themes emerged as a result of step 3 of the analysis (relating the meaning units to each other and to the sense of the whole). These themes are reflected in the quotations from 8 of 12 participants. It is acknowledged that these themes are not mutually exclusive and that there is some overlap among them.

1. The role of managers was an issue

Committee members initially expressed discomfort with the presence of management at committee meetings during the interviews. The majority of steering committee members felt that management and senior management should be represented on the committee, however, they were not sure who those representatives should be and how many of them should be on the committee. To date, none of the management representatives has been an immediate supervisor of other members on the committee; however, there was perceived intimidation based on the power that these individuals had at the center and the potential power they had on the committee. As two members initially stated:

"...at times I thought that it [team approach] was driven by just a few members. And sometimes I thought that we were being left on our own to come up with the right direction, but when it didn't go in the right direction, we were quickly refocused by the people that were in charge, in order to make it go where they wanted it to".

"I am somewhat concerned at times that sometimes senior managers tend to try and overshadow the opinions of other committee members. And I think that there is probably some committee members who are strong enough to voice their opinions regardless of who is challenging them. But I also think that perhaps, sometimes, people do not speak their minds, because there are certainly people who are very opinionated, and are afraid to challenge them, and so that is a concern".

Despite the perceived intimidation, most committee members were very positive about the influence that management and senior management had on the committee. They felt that the committee needed such representation in order to have any influence at the Centre and they felt that this influence was beneficial to the committee. This acknowledgement often came up later in the interviews. It was especially important when it came to areas with which the committee was not familiar. For example, two members stated:

"...we all tend to go with [management]. And I'm not sure if it's because we think it is a fabulous idea or because as a whole we just want to defer to [management] for some reason because we are intimidated. But I do find [management] has a lot of pull and maybe it is partly subconscious...and I almost end up agreeing with [management] most of the time and I'm not sure why".

"I think [the committee] should be guided...and I think this is [management's] greatest forte... great at sitting there in a group of people and making them think, and making them come to the conclusion, not come to the conclusion that [management] wants, but...I mean....[management] will throw something up as an idea and it will be, it's a good idea, right, but people will eventually come around and see that's right."

The competence of managers was never questioned. Rather, the perception that managers were highly competent probably contributed to feelings of intimidation among committee members.

2. <u>Desired composition of the committee was complex</u>

This theme was expressed in relation to four issues: the committee required more vocal members; the committee required more "workers"; members needed to be consistent about attending meetings; and there was a transitional phase in which the committee achieved a desired composition.

First, there was concern about the silent voices on the committee. It was felt that quiet members were not contributing to discussion and decisions about the project. Incidentally, both vocal and quiet members voiced this concern. For example:

"You need people who can stand their ground and not in a challenging or an offensive way but certainly in a respectful way to make sure that their issues and concerns and thoughts are taken in to consideration"

One member attributed the silent voices on the committee to the culture of the Centre:

"I think that's a culture thing at the Cancer Centre. Generally, you don't get people who are like secretaries or clerks who will speak up in a meeting at rounds for example, or with physicians or with other people. So I think it is a culture reason why. Certainly not that they don't have anything to say or that they don't speak up in their own groups. When they would go to their own groups, they were fine."

As a potential solution to the problem, one member suggested that:

"I think there needs to be some sort of, if not, interview process, but some sort of up front conversation and dialogue with people who are coming on board to make sure they understand the responsibility that comes with being on the committee. And make sure that they are comfortable with the understanding that sometimes they are going to have thoughts and opinions that will differ from managers, senior managers, executive... And they have to be brave enough to be able to stand there and to express those opinions and if they are not prepared to do that then they are probably wasting their time...It is an awkward position to be in absolutely. And I think it is important for people as they are coming on to the committee to be fully cognizant of the potential awkward situation that they are going to be in, and to try and balance their own personal views with that of the people that they represent and those of management. It is a difficult place to be."

On the other hand, one member felt that it was important not to diminish the contribution of the members who were quiet in meetings:

"Some of them won't speak out at meetings or won't say what they think. And I think it's their nature, that they haven't actually learned those skills. I think there is an intimidation in those meetings, sitting at a table with physicians and physicists who normally they would never sit beside or talk to. But each one of them, when it came to them doing their own presentations at Christmas…well a lot of those people who are not used to getting up in front of people did it. They can do it. They were great at it. So I think everybody bought into the process and everybody did that. Although at meetings they tended to be dominated, sometimes, by one or two people."

Second, some members felt that the committee did not include enough workers. "Workers" were defined as supportive care staff, people that worked at the appointment desks, and clerical staff.

"…you've got a lot of nurses, you've got physicians, you've got radiation technicians, statisticians. But you don't have a lot of workers on that committee".

Third, participants were frustrated that some members consistently did not show up to the committee meetings. One member stated:

"I think if consistently someone is not able to attend a meeting then they should ask somebody else from their department to represent them, not to step in for one meeting but to actually step down and let somebody else take over the position."

Fourth, there appeared to be a transitional process in which the committee developed a desired composition. For example:

"…the dynamics of the group are very interesting. The group's been very fluid. People have come and gone. And at first, there was an awful lot of very strong personalities and very strong personal agendas coming to the table. And it took a while to chip that crust off the top of the group. And that eventually happened. And then once that happened, and the group was kind of finalized, and we got down to brass tacks, I thought the group process was excellent. And lots of really interesting knowledge and good expertise from many areas. There were people who knew a lot about research, right down to people who knew next to nothing about research."

"I think the steering committee, we went through some difficult times at the beginning and I guess I would sum it up by, not everybody was there as a team player and not for their own personal reasons, vendettas, whatever it was. And I think the people who actually didn't like the way the project was going are no longer on the steering committee. They resigned. And so I see it as a cohesive group that are looking at not just their issues but the whole Centre's."

3. Participatory research without action was not acceptable

When discussing "action", committee members referred to interventions based on the results of the QWL survey. The role of the QWL committee was to influence management at the Centre to take action; the committee was never given authority to implement changes in the workplace. However, members on the committee did not focus on their influence on management but rather viewed the success of the project as being gauged by whether action or interventions came of the project:

"From here, do you just wait and every year we just reissue the same survey, and just keep on, you know, generating these results? In which case, people will quickly lose interest in doing it. Because if we're not going anywhere with it, or doing anything with the results, people are going to become less compliant in getting it done. We had such a good response to this survey. But my fear is, if we don't sort of show that we are being pro-active about what we learned, people won't be as quick to do it again."

"...the managers are going to have to work with the departments. They're going to have to have meetings, they're going to have to physically get down and do something with those people. Not just assume that it's going to go away."

Participants were split as to whether the committee should be responsible for interventions that followed from the project results. Some participants expressed frustration that the committee didn't have power to do anything with the results. For example:

"I'm feeling less and less like I like being involved. And I think that may be partly because we're not really doing much right now, I guess. But also because, at the beginning there was sort of the hope that a lot of things could be addressed. And I am starting to believe more and more that the types of problems that were brought up in the data, that there's not much people can do about them."

On the other hand, as discussed in the next theme, some participants admitted that they didn't want to be responsible for action. Those not wanting the responsibility felt that it was management's job to intervene.

4. Full participation in all aspects of the project was difficult to achieve

In theory, the project was supposed to proceed with full participation from all members. However, there were aspects where members did not participate for a number of reasons: a) members did not attend meetings; b) members did not think that they should participate; c) members did not want to participate; d) it was felt that it was not practical for all members to participate.

During the first two years of the project, the union representative attended two meetings. This member's lack of attendance was pointed out during most of the interviews and was a source of frustration for participants. Some participants admitted that it was difficult for them, too, to attend 2-hour project meetings that typically occurred every 1-2 months. For example, the secretaries and the physicians consistently had difficulty arranging their schedules so that they could attend the meetings.

Similarly, those members who were not able to attend the educational retreat at the beginning of the Project felt that they were not able to catch up to the rest of the group on knowledge regarding survey methodology. In addition, members who joined the committee after the retreat day felt that their contribution to the development and administration of the survey was minimal. As one member stated:

"I came into the project late and the developmental work and the actual survey had been administered before I actually became part of the committee. So I really did not have any opportunity to sort of shape the project..."

Despite their physical presence at project meetings, some participants spoke of their attendance metaphorically. These participants referred to their involvement in the project as occurring in phases rather than being consistent. One member described the educational retreat as the highlight of her involvement:

"And I think looking over, looking over the questionnaires, having the retreat, was very useful. That was also a learning experience. As well as being able to pick out what tools we were going to use. By the time we picked out the tools, and finished our retreat day, I felt like the bulk of my work was really done. Because at that point, it just had to be thrown together. I didn't have to do that. And put all the questionnaires together into a package. You know, the distribution and collection of the questionnaires was all you know, done by [member] and her group, and they worked very hard, but I really didn't have very much to do with that either. And then I basically sat back and waited 'til it got analyzed and then I was able to go out and do my little dog-and-pony show for my department and present it."

Another member commented:

"I wasn't able to attend all the meetings. So I lacked a little bit of continuity that the other members had. And there were so many people in the group, and at times, jobs got divided up in such a way that the big picture, for waves at a time, could get lost. And so you know, sometimes the focus was very much on it, as a research project, and then at other times it was very much, you know, this has to get done, this has to get done, and it sort of became a tick list of to do's. And so I found that I was thinking about [the project] in many different ways."

Members on the committee inevitably mentioned the idea of possible interventions based on the results of the survey. However, not all members felt that it was up to the committee to decide or work on these interventions. Two

members felt that this responsibility was beyond the scope of the committee. For example:

"I'm not sure how this whole team approach is going to work now, in terms of intervention strategy. I'm not entirely convinced that the team approach is the best way to do it...I think the intervention strategy possibly should come from the top down and then get discussed in a team environment...I guess my initial hope on this was that, was that these results would go back our CEO who's responsible for guiding the ship that is the Cancer Centre. Like, that's his task. He gets paid big bucks in order to do that. That's his mandate. And that he would come up with what he thought were some large intervention strategies that could be employed...Some people don't see the big picture. They, they're for whatever reason, they don't think of ramifications of decisions. Or they don't have the big picture available to them to make what I would call good, intelligent decisions. And that's not just committees that I've seen here, it's committees that I've seen across the board, in sports, in the work...There are some people that just don't they don't think about the bigger picture and they don't think of ramifications of certain decisions. So I'm not convinced that in a team, that the front line workers would come back with the most effective intervention strategy."

"I don't think that the committee should head up the next step of what we expect people's reactions to be to the results. I don't know if I should say management level or administrative level if they should say we hope at your next meeting that you would discuss the results and decide as a group if you feel any further actions need to be taken. I think people are so bogged down with everything that's going on that it just gets left. Okay, we've seen the results. Okay, we'll just leave it there...because I don't really know if it's our role to do that, I mean the steering committee's role to say who really has ownership of this project I guess is one of the questions it comes down to. Is it the staff? ...or is it administration? Then the next step, should it not come from them for everyone to sort of act. I don't know. I think I'd have to sit and listen to the discussion a bit more before I decide."

As part of the participatory approach, members of the committee were supposed to relay the results of the survey to their own departments. Not everyone wanted to do this and therefore some members ended up conducting most of the presentations. However, this may have been due to some members not being comfortable with presenting. As one member stated:

"I was supposed to be giving the one to the [department] and I couldn't, I couldn't give it and feel comfortable. Because, at that point, I really did not understand what I was doing."

Participants felt that it wasn't practical to participate in all areas of the project. For example, they felt that they lacked awareness and education in topics discussed at the meetings. Comments related to this included:

"You know, I think that if we all were on a level playing field, as far as we all had university education and the quality of work life theories and studies, you know, we'd studied this as a student, we could all come to the table reasonably prepared to argue our point. But the majority of us have a limited understanding, and then there are two or three people who have a much more in-depth understanding."

"At times, I have felt that we come to this meeting and we have some questions that none of us can really answer and instead if this was the agenda, whether it be the chair of the committee or one other person, should be at least coming with some background information to help guide our discussions because sometimes we're trying to have a discussion but nobody really knows what's the right and what's the wrong. I'm not expert in certain areas of research so I expect somebody to bring that to the meeting for me."

"Again, there were a lot of unknowns that we didn't know like where would this data have to be stored? Who could have access to it? How long would you have to keep it for? If somebody else wanted to look at our results or borrow our questionnaire we developed, do we own this? Don't we own this? That's when, I know I would have benefited from having some person who would have known some of that stuff and then we could have decided what we want to do for us."

Essential Description of Employees' Perceptions of the Participatory Research Process

The following description summarizes the perceptions of the participatory research process in the present study: The role of management in participatory research was viewed as being important; however, employees were initially uncomfortable with the physical presence of managers at meetings. The desired composition of the participatory research team was complex; there may have been

a natural process by which this composition was attained for the steering committee. Participatory research without subsequent action was not acceptable to employees; the success of the project was gauged by whether interventions occurred as a result of the project. Full participation in all aspects of the project was difficult to achieve because members did not attend meetings, they did not think they should participate, they did not want to participate, and/or they felt it was not practical for all members to participate.

Discussion

Upon completion of the interviews and analysis of the data, a more detailed review of the literature was conducted. The review uncovered other researchers' experiences with participatory approaches not only in workplace studies but also in evaluation and community research. However, no qualitative studies on participants' perceptions of participatory research were located. The following discussion draws from the literature to address the themes that emerged in the present study. I then revisit Hall's (1981) criteria for participatory research.

In evaluating ten Dutch projects and 11 European case studies aimed at reducing stress, physical workload, and sickness absenteeism in the workplace, Kompier and colleagues (1999; 1998) concluded that sustained commitment of top management support was a key factor to the success of the participative approach. Others (e.g. Israel, Schurman, & Hugentobler, 1992) have found evidence to support the notion of management support. Early in the QWL Project that is the subject of the present study, the chair of the committee made it clear that all meetings of the QWL committee would be scheduled around senior management so that at least 1 of 2 senior managers could attend. At least 1 senior manager was present at every meeting with the exception of one working meeting that was held during the summer of 2001. Based on my observations during the meetings, management has attempted to keep a low profile so as to not dominate

the discussions. However, findings from the present study indicated that committee members were not initially comfortable with the presence of managers on the committee. At the same time, committee members acknowledged that management needed to be represented on the committee.

Elden and Taylor (1983) stress that the participatory research enterprise must be based on power equalization in which all parties share and control the entire research process. In a workplace, this is difficult to achieve as managers clearly have more power than the "workers". As Minkler and Pies (1999) point out, behind the euphemism of participation, the realities of power imbalances often remain. Similarly, Langan-Fox and colleagues (2002) found that participation in an employee participation program was likely to be affected by organizational seniority. There are no apparent solutions to this dilemma. If workplace studies are to include representatives from all levels in an organization, it is inevitable that members at lower levels of the hierarchy may feel intimidated or uncomfortable about expressing their opinions in the presence of work superiors. It also implies that there will always be trust issues between employees and management in such research. Potentially, this barrier to conducting participatory research might be minimized if there was some process in place to assure members of such committees that there will not be repercussions for them based on discussions during the meetings. For example, if the Terms of Reference for the project included an item stating that work on the committee could not be used as a basis for evaluating members' performance at their usual job, trust issues might be alleviated. In the two years that I have been involved with the QWL Project, the atmosphere of the meetings appears to have become more relaxed. Perhaps, it is just a matter of time before members of the group adjust to each other and the presence of managers. There has also been some turnover in members since the interviews for this study were conducted. It is not

clear if the atmosphere of the meetings have changed due to the personalities of new members.

Apart from the role of management, committee members also expressed concern about the makeup of the committee itself. Members were frustrated about committee members who were quiet and those who consistently did not show up to meetings. Some felt that not enough "workers" were on the committee. Israel, Schurman, & Hugentobler (1992) support that committee composition can be a major factor in a workplace project's longevity. These researchers found that their Stress and Wellness committee itself worked to revise its membership so that it was politically appropriate for the organization. It is interesting that members interviewed for the present study noted a transitional process whereby the committee developed a desired composition (the initial composition for the committee had been decided upon by the Chair of the Project). Several months after the interviews for the present study were conducted, an effort was made by the chair of the committee to encourage members who regularly didn't attend meetings to step down. The union representative's lack of attendance was especially noted in one meeting since no reasons had been given to date for this member's lack of attendance. As well, the committee increased in number to 16 and its composition was revised so that it was more reflective of the employee groups at the Centre. It is anticipated that the process of achieving a desired composition will continue to evolve.

Israel, Schulz, Parker, and Becker (1998) discussed the issue of representation in their research on community-based research. They suggest that the community should be represented by respected community members who have credibility and visibility. This implies a different recruitment approach from that of the QWL steering committee in the present study. To date, recruitment of members is voluntary and it is not likely to change despite some members

wishing that an interview process be in place. (It is ironic that members who were recruited by volunteering have suggested an interview process for future members). There are concerns regarding the achievement of a desired committee makeup, whether it is achieved by a natural transition as some members expressed, or as a job interview process as implied by other members. Elden and Taylor (1983) caution that if the group of representatives from the workforce is successful in its research, it could maintain itself and could be seen by others as a new source of power in the workplace. They refer to this as 'the junta problem' (p. 6). Minkler and Pies (1999) similarly discuss how training of participants can alienate those who are involved and make them strangers in the community. One participant of the present study acknowledged the potential problem of the committee attaining an elitist profile. It is the author's opinion that a selection process for recruiting new members may result in such an elitist profile for the committee. There is presently a waiting list to get on the committee so the issue of recruitment may have to be dealt with in the future.

In his experience with participatory research in evaluation, Patton (1997) found that participants regard the process of research more importantly than the findings of research. He argues that "process use", in contrast to "findings use", in participatory research is valuable because the capacity to engage in this type of thinking has more enduring value than a delimited set of findings. Patton suggests that having outcome-oriented goals is an expression of value, itself. The present study found that participatory research without action was not acceptable; in some sense, this is contradictory to Patton's findings. The steering committee was very focused on the QWL survey outcomes and the implications of these outcomes for subsequent action. To date, there has been little focus on processes such as how committee members solicit input from the employees they represent, how the committee deals with the turnover of committee members, how findings of the survey are relayed to management, and what strategies should be in place

for management to respond and intervene based on survey results. These issues have only begun to be addressed. A focus on survey outcomes and subsequent action may be indicative of the focus typically found in clinical research environments. One could argue that clinical research environments are outcome-focused because of the implications these outcomes have for medical practice. If this is the case, the cancer care employees who participated in the present study may have transferred such a value to the QWL Project.

The findings of the present study emphasizing the need for action are more in line with those of Elden and Taylor (1983). These authors argue that a main characteristic of participatory research is an emphasis on local utility of the research results. They claim that the context of participatory research should not be perceived as mere data gathering. As evidence, Israel, Schurman, & Hugentobler (1992) found that committee members of a workplace Stress and Wellness Committee were reluctant to collect additional data because they felt that employees had not seen enough action as a result of the survey. Similar discussions have occurred within our QWL committee and efforts are being made to encourage departmental managers to document in writing the changes they have made, or plan to make, as a result of the survey. At the point of writing this paper, the second annual survey had been administered but formal documentation of managers' responses to the first survey had still not been received by the committee.

The frustration of the committee regarding who should be responsible for action is consistent with Hugentobler, Israel, and Schurman (1992). They found that a variety of barriers limited their own project team's success in achieving goals. When these researchers interviewed team members, they found that less than one-half of the members agreed that the team had the authority to carry out its solutions/recommendations and 55% thought the team had selected problems

that were too large for the group to solve. As implied above, at the time of the interviews for the present study, little action based on the survey results had been taken and committee members expressed frustration about this. According to Israel, Schurman, and Hugentobler (1992), involvement in the participatory research process "may raise expectations that change will occur and when it is slow to happen, feelings of frustration and lack of control may result" (p. 95). Under the Terms of Reference for the QWL project, the committee is supposed to present findings to staff and provide the Chief Executive Officer, senior management, and department managers with a summary of the survey findings; the committee also has the role of facilitating the development and monitoring of follow-up interventions where necessary. However, the process of ensuring that appropriate interventions take place has not been discussed to date at committee meetings. According to Stoeker (1999), organizing action is often the weakest part of a participatory research project.

Patton (1990) advocates that decision makers who are to use the information generated by evaluation research should be involved in every stage of the participatory process. In the context of the present study, decision makers (department managers) have not been involved with the QWL Project. Decision makers have merely received the results of the survey. Perhaps, the lack of consultation with decision makers is why there has been a delay in action subsequent to the survey results being made known.

According to Mergler (1987), in participatory research, worker participation is important in the design and evaluation of all stages of the research process. She argues that data collection, analysis and interpretation of data should be performed by all participants. Other researchers (e.g. Elden et al., 1983; Guba & Lincoln, 1989; Heron, 1996; Park, 1993; Zalk, 2001) concur. Mergler (1987) also stresses the importance of union representation and endorsement of

workplace projects. Based on the present study, this goal is not feasible for reasons previously outlined. It has been acknowledged that full participation is not always met in practice (Brown, 1983; Elden et al., 1983; Heron, 1996). For example, in their experience with a workplace Stress and Wellness Committee, Israel, Schurman, and Hugentobler (1992) reported participation from the committee in almost all aspects of the study but they did not say what aspects of the study were missing participation. However, these authors later acknowledged that they conducted the analyses of the survey and prepared the report to summarize the findings. The difficulty of attaining full participation by members of the QWL steering committee can be traced back to the project's origin; the initial vision for the project came from one person (the Chief Executive Officer of the organization) and funding for the project was acquired by this individual for an initial period of two years (Ortho Biotech has since funded the project for an additional year). Although not discussed in the interviews, members were also not able to participate in data handling and data analysis of the project because the data were confidential.

In reference to co-operative inquiry, a concept similar to participatory research, Heron (1996) reports that it is rare to find full-blown commitment from participants to collaboration about research method. According to Heron (1996), in practice "it may be reduced to no more than seeking fully informed consent of all informants to the researcher's pre-existent or emerging operational plan, and to modifying the plan in order to obtain such consent" (p. 9). In the QWL Project, full participation regarding the analysis was encouraged by the methodological consultant (author) in the first year of the project but the committee voted to have the consultant present potential analysis questions to the committee for approval. If the analysis cannot be conducted collaboratively, Stoeker (1999) recommends such a strategy in community research; this helps to ensure that the analysis is conducted with strict accountability to the community.

The claim that full participation is not feasible should not be mistaken for Minkler and Pies' (1999) concept of "token participation". With "token participation", members are heard but their input is discounted or not heeded. I feel that the opportunity for, and actual, participation in all aspects of the project were not feasible for the QWL steering committee. This is the reality of conducting participatory research in workplace studies. Committee members could not always attend meetings and there were aspects of the project where they did not think they should be involved or they did not want to be involved. It could be argued that the early resignation of a few members from the committee implied that the process was not participatory and that these members' opinions were not respected by the group. However, participants in the present study felt strongly that the members who resigned came to the project with their own agendas and were not interested in working as a team.

The committee itself made it impossible for participation in all aspects of the project to be feasible. Five months into the QWL Project, the committee voted that the QWL survey should be anonymous. To ensure anonymity, only the methodological consultant (author) was allowed access to the raw survey data. As members started to cycle off the committee, new members could not have the same input as original members regarding survey design and methodology. New members may feel a lack of ownership in the project. This issue could be addressed by a yearly retreat to discuss survey methodology and introduce new scales/questions to modify the survey without compromising its rigour. For example, based on staff feedback to the first survey, modifications were made to the second survey; some demographic items were removed and the job description question was made more explicit. New members to the committee were able to take part in these discussions. At the time of writing this paper, the chair of the QWL Committee informed me that a new member had approached

her for some additional duties on the project because she felt that most project tasks had been taken care of by previous and existing members.

The workplace setting makes it difficult for some members to attend project meetings. This may especially be true of health care work environments where it has been shown that having patient responsibilities interferes with members' ability to attend participatory ergonomic team meetings (Bohr, Evanoff, & Wolf, 1997). Similarly, Israel, Schurman, and Hugentobler (1992) found that co-workers of committee members of their workplace project complained when members attended meetings because it created a personnel shortage in their work areas; as a consequence, several members on the project committee agreed that the project had added to their workload and stress level. Although not a dominant theme, this complaint was made by a few participants in the present study. Perhaps challenges in attendance could be alleviated by having more than one representative from areas that experience personnel shortages when an employee (e.g. secretaries, physicians) is absent for a couple of hours. Potentially, representation from such areas may increase if membership is shared among several designated employees. This solution requires the rotating members to communicate with each other. I strongly believe that some representation would be better than no representation from these types of workers.

The benefits of full participation by workers in all aspects of the research process have been questioned. Israel, Schulz, Parker, and Becker (1998) propose that it might be more valuable to focus on involving community members in interpreting and making sense of the data rather than training them in research methodology such as data analysis. Despite the assumption that employees want to be involved in research in their workplace, employees might not want the sort of control that is implied by full participation. This was a message from some participants interviewed. In a study which attempted to increase employees'

control at work by involving them in the day-to-day decisions within their work teams, Reynolds (1997) found that an organizational intervention to improve employees' level of participation and control over their work did not have any impact on their psychological well-being, physical well-being, or absence from work 1-2 years after the intervention was introduced. (It is not clear if the intervention succeeded in giving employees the control intended.)

Was the QWL Project participatory research? While the objective of the present study was not to evaluate the project in this regard, a few comments are in order. Returning to Hall's (1981) criteria for participatory research, I believe that 6 of the 7 characteristics of the participatory process were found in my interviews with study participants: The vision for the project came from the workplace itself with the CEO responding to anecdotal reports of burnout and poor morale; although no action was promised, the ultimate goal of the project was to improve the quality of work-life of employees both on and off the steering committee; the focus of the QWL Project was on work with all employee groups; the QWL Project has strengthened steering committee members' awareness of their own abilities and resources – steering committee members have taken responsibility for many tasks concerning the project including researching topic areas and reporting back to the group as well as presenting the survey results to their own departments; the term "researcher" hasn't been used in the context of the project but I believe that it has been implied that all steering committee members along with the methodological consultant (author) could be considered to be researchers on the project; and the methodological consultant was a committed participant and learner in the process. One of Hall's (1981) characteristics was not met by the QWL Project: based on the present study's findings, participants on the steering committee did not have control of the entire research process. However, this was partly due to feasibility issues previously discussed and the fact that participants did not want control of the entire process. Is "true" participatory

research feasible in a workplace setting? In a sense, the project was as participatory as it could have been. More importantly, it could be argued that the project was as participatory as the workers wanted it to be.

While perhaps not strictly adhering to Hall's concept of participatory research, I believe that the QWL Project adhered as closely to participatory research as is possible for a workplace study. Despite its limitations as a participatory research endeavour, the project was successful in creating 'buy-in' from the Centre for many reasons and appeared to have a positive image at the Centre as a whole. Committee members were keen about it and participated as much as they wished to, and considered themselves able to, participate. Committee meetings were productive and proceeded efficiently - the Chair of the committee was instrumental in making this happen. The minutes of every meeting were available to the Centre and they demonstrate the vast amount of work accomplished by the committee in its tenure. Steering committee members got along and appeared to genuinely like and respect each other. The project gave committee members the opportunity to be involved in research, an opportunity that many of them had not had before. The project also provided a vehicle through which the committee could discuss issues with, and possibly influence, management. Although this was not apparent to all members of the committee, efforts to improve this communication process continue. The consistent support by management for the project is evident by their meeting attendance and participation as well as by continued attempts to secure further funding for the Project. There is a waiting list to join the steering committee; other employees at the Centre are eager to become involved in the project.

Having acknowledged the project's successes, the present study demonstrates that there is room for improvement regarding the steering committee's composition and involvement in the project. Trust issues between

employees and management on the committee might be alleviated if the Terms of Reference for the project included an item stating that work on the committee could not be used as a basis for evaluating members' performance at their usual job. The composition of the committee is not static; the composition needs to be continuously revised so that members can attend and participate in meetings, actively representing their employee groups. One consideration may be to include more than one representative from employees groups that experience personnel shortages when an employee is absent for a couple of hours. The committee needs to be careful that it does not attain an elitist profile at the Centre. In addition, the committee could develop a strategy to involve its waiting list of potential members. The committee needs to focus on setting processes in place that will allow the QWL Project to continue to run smoothly as members leave and new members join. For example, how committee members solicit input from the employees they represent, how findings from the survey are relayed to management, what strategies are in place for management (decision makers at the Centre) to respond and intervene based on the survey results, and how the committee deals with the turnover of committee members (e.g. how to give them ownership in the project) need to be made more explicit. A yearly retreat to discuss modifications to survey content and methods may be one way to engage new members. The role of the committee needs to be clarified to maximize members' time, abilities, and resources. Some project responsibilities may better be addressed by groups or people outside the committee. However, these decisions should be made explicitly by the committee. The steering committee will receive a copy of this paper so that the recommendations made can be considered by its members.

In 1992, Israel and colleagues (1992) reported that there existed little concrete analysis of the issues and dilemmas faced by researchers and participants alike as they learn to assume shared roles in the research process. Over 10 years

later, this still appears to be a gap in the literature. The present workplace study found that: while the role of management in participatory research was viewed as being important, employees were initially uncomfortable with the physical presence of management at meetings; the desired composition of the participatory research team was more complex than simply having representation from workers; involving employees in research about their workplace without subsequent action was not acceptable to them; and participation in all aspects of the project was difficult to achieve. These perceptions are significant because they challenge existing notions in the literature about participatory research.

References

Bohr,P.C., Evanoff,B.A., & Wolf,L.D. (1997). Implementing participatory ergonomics teams among health care workers. American Journal of Industrial Medicine, 32(3), 190-196.

Brown,L.D. (1983). Organizing participatory research: Interfaces for joint inquiry and organizational change. Journal of Occupational Behaviour, 4, 9-19.

Coch,L., & French,J.R.P. (1948). Overcoming resistance to change. Relations, 11, 512-532.

Coffey,A., & Atkinson,P. (1996). Making sense of qualitative data: Complementary research strategies. Thousand Oaks, CA: Sage Publications.

Cornwall,A., & Jewkes,R. (1995). What is participatory research? Social Science & Medicine, 41(12), 1667-1676.

Crabtree,B.F., & Miller,W.L. (1992). Doing qualitative research. Newbury Park, CA: Sage Publications.

Creswell,J.W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications.

Daykin,N. (1999). Introduction: Critical perspectives on health and work. In N. Daykin & L. Doyal (Eds.), Health and work: Critical perspectives. (pp. 1-20). New York: St.Martin's Press, Inc.

Elden,M., & Taylor,J.C. (1983). Participatory research at work: An introduction. Journal of Occupational Behaviour, 4(3), 1-8.

Giorgi,A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer, & E. Murray (Eds.), Duquesne studies in phenomenological psychology. Vol. 3. (pp. 82-103). Pittsburgh, PA: Duquesne University Press.

Giorgi,A. (1989). Some theoretical and practical issues regarding the psychological phenomenological method. Saybrook Review, 7, 71-85.

Giorgi,A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology, 28(2), 235-260.

Guba,E.G., & Lincoln,Y.S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage Publications.

Hall,B.L. (1981). Participatory research, popular knowledge and power: A personal reflection. Convergence, 14(3), 6-17.

Heron,J. (1996). Co-operative inquiry: Research into the human condition. London: Sage Publications.

Hugentobler,M.K., Israel,B.A., & Schurman,S.J. (1992). An action research approach to workplace health: Integrating methods. Health Education Quarterly, 19(1), 55-76.

Israel,B.A., Schulz,A.J., Parker,E.A., & Becker,A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202.

Israel,B.A., Schurman,S.J., & Hugentobler,M.K. (1992). Conducting action research: Relationships between organization members and researchers. Journal of Applied Behavioral Science, 28(1), 74-101.

Jasper,M.A. (1994). Issues in phenomenology for researchers of nursing. Journal of Advanced Nursing, 19, 309-314.

Kompier,M., & Cooper,C. (1999). Stress prevention: European countries and European cases compared. In M. Kompier & C. Cooper (Eds.), Preventing stress, improving productivity: European case studies in the workplace. (pp. 312-336). London: Routledge.

Kompier,M.A.J., Geurts,S.A.E., Grundemann,R.W.M., Vink,P., & Smulders,P.G.W. (1998). Cases in stress prevention: The success of a participative and stepwise approach. Stress Medicine, 14, 155-168.

Kompier,M.A.J., van den Berg,A.-M., Aust,B., & Siegrist,J. (2000). Stress prevention in bus drivers: Evaluation of 13 natural experiments. Journal of Occupational Health Psychology, 5(1), 11-31.

Kvale,S. (1996). Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Langan-Fox,J., Code,S., Gray,R., & Langfield-Smith,K. (2002). Supporting employee participation: Attitudes and perceptions in trainees, employees and teams. Group Processes & Intergroup Relations, 5(1), 53-82.

Mergler,D. (1987). Worker participation in occupational health research: Theory and practice. International Journal of Health Services, 17(1), 151-167.

Minkler,M., & Pies,C. (1999). Ethical issue in community organization and community participation. In M. Minkler (Ed.), Community organizing and community building for health. (pp. 120-136). New Brunswick, New Jersey: Rutgers University Press.

Morse,J.M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 220-235). Thousand Oaks, CA: Sage Publications, Inc.

Morse,J.M. (2000). Theoretical congestion. Qualitative Health Research, 10(6), 715-716.

Moustakas,C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage Publications.

NVivo [Computer Software]. (1999). Victoria, Australia: Qualitative Solutions and Research Pty Ltd.

Park,P. (1993). What is participatory research? A theoretical and methodological perspective. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), Voices of change: Participatory research in the United States and Canada. (pp. 1-20). Toronto, ON: OISE Press.

Patton,M.Q. (1990). Qualitative evaluation and research methods. (2nd ed.). Newbury Park, CA: Sage Publications.

Patton,M.Q. (1997). Discovering process use. Evaluation, 4(2), 225-233.

Polkinghorne,D.E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology. (pp. 41-60). New York: Plenum Press.

Reynolds,S. (1997). Psychological well-being at work: Is prevention better than cure? Journal of Psychosomatic Research, 43(1), 93-102.

Schwandt,T.A. (2001). Dictionary of qualitative inquiry. (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Sokolowski,R. (2000). Introduction to Phenomenology. Cambridge: Cambridge University Press.

Stoeker,R. (1999). Are academics irrelevant? Roles for scholars in participatory research. American Behavioral Scientist, 542(5), 840-854.

Strauss,A., & Corbin,J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory. (2nd ed.). Thousand Oaks, CA: Sage Publications.

Tesch,R. (1990). Qualitative research: Analysis types and software tools. New York: The Falmer Press.

van Manen,M. (1997). Researching lived experience: Human science for an action sensitive pedagogy. (2nd ed.). London, ON: Althouse Press.

Zalk,D.M. (2001). Grassroots ergonomics: Initiating an ergonomics program utilizing participatory techniques. Annals of Occupational Hygiene, 45(4), 283-289.

CHAPTER 4

PERCEPTIONS OF A QUALITY OF WORK-LIFE SURVEY IN A
CANCER CENTRE WORKPLACE STUDY

Abstract

This qualitative study explored the perceptions of a quality of work-life survey
from the perspective of employees at a Canadian cancer centre who completed the
survey. Using a phenomenological approach, the author interviewed 10
employees to explore their perceptions of the survey. The following themes
emerged from the analysis: 1) participants did not remember or incorrectly
recalled the contents of the survey 7-10 months after survey administration; 2)
participants felt that information regarding the survey was withheld from them; 3)
participants varied in their interpretations of the Likert scales and the domains
included in the survey; 4) the impact of the survey was more important than the
survey itself; 5) talking about the survey triggered discussions of quality of work-
life issues most of which were not captured in the survey; 6) participants were
concerned that departments or groups of employees were labelled based on the
survey results. This study has implications for occupational health researchers
who wish to use survey research methods and standardized scales in workplace
studies.

Objective

This study is part of a larger qualitative study that explored cancer care
employees' perceptions of a Quality of Work-life (QWL) Project where they were
the subjects of research and their perceptions of clinical research where patients
were the subjects of research. The current paper explores perceptions of a QWL

survey from the perspective of survey participants. The findings from the larger study are not presented in this paper.

Context

This research was conducted at a Canadian cancer centre. The Centre is a large (approximately 450 employees) ambulatory cancer treatment center that serves over 2.3 million people in Ontario. Approximately, 7,000 new patients are referred to the Centre each year with approximately 500 patients seen each day for consultations, radiation and chemotherapy treatments, and follow-up visits. In Canada, health insurance coverage is universal and there are no financial barriers to seeking treatment for cancer.

The QWL Project at the Centre began in the spring of 2000. It was initiated by the Chief Executive Officer (CEO) of the organization based on anecdotal evidence of low morale and high burnout at the Centre. The CEO approached several pharmaceutical companies to solicit funding for the project. In April 2000, a pharmaceutical company funded the project for a two-year period, but has had no direct involvement in the project. An occupational health scientist and a doctoral student (author) were asked to consult about how to proceed with a quality of work-life study. A part (60%)-time project coordinator was hired by the Centre and employees were asked to volunteer to join a steering committee for the project. The project coordinator was also the chair of the committee (her other role was Patient Education Coordinator at the Centre). The steering committee included representatives from a variety of departments at the Centre. There was an attempt to ensure that representatives from the main employee groups and unions were recruited. The steering committee first met in June, 2000. After a series of meetings, it developed a work agenda to address quality of work-life issues. The committee decided that a survey should be administered to employees at the Centre to gather baseline data on issues that they

believed to be important to employees' quality of work-life. The QWL Project gained visible support from the CEO, senior management, and the unions.

Based on my involvement in the QWL Project and my experience with the development and administration of the QWL survey, I became interested in employees' perceptions of workplace questionnaires as a method of data collection.

The QWL Survey

During the summer of 2000, the steering committee members collaborated with the employee groups they represented to identify perceived problem areas in the workplace. These problem areas were articulated as four domains that could be measured with existing workplace tools: burnout, social support, job satisfaction, and work-family conflict. At a day long retreat in November 2000, committee members learned about survey methodology and decided on a combination of instruments that would be used to measure these four domains. Demographic questions to be included in the survey were also discussed. Prior to the retreat, a package that contained a choice of survey instruments for each of the domains was prepared. Only instruments with demonstrated reliability and validity were considered. Committee members were asked to review the packages before the retreat. During the retreat, members broke out into small groups to discuss the surveys. Each group discussed the comprehensiveness, language, response options, and length of the instruments. After completing a chart identifying the strengths and weaknesses of each instrument and its applicability to a cancer care setting, each group rated the instruments in order of preference. These ratings were collated and the results were presented to the larger group. There were further discussions about the instruments for two domains; the larger group then voted on an instrument for each domain. For one domain (Job Satisfaction), a consensus could not be reached. Therefore, two

instruments and an additional question designed by the steering committee on job satisfaction were included in the survey. The following instruments were chosen: Warr et. al's (1979) Intrinsic and Extrinsic Job Satisfaction scales; the NIOSH (1988) Job Satisfaction scale; one global question on job satisfaction; the Maslach Burnout Inventory (Maslach, Jackson, & Leiter, 1996); the NIOSH (1988) Social Support scales which include social support from supervisors and social support from co-workers; and Netemeyer and Boles' (1996) Work-Family Conflict scale.

During the retreat, anonymity versus confidentiality of survey respondents' data was discussed. I advised the committee of the advantages of confidentiality over anonymity. For example, a confidential survey would allow us to determine who should receive follow-up reminders. A confidential survey would also make it possible for us to link respondents' data over time in the event that future surveys were administered and to link the responses to other employee data such as work absence. Despite my recommendation, the committee decided to administer an anonymous survey.

The survey was distributed to staff during February 2001. Prior to the administration of the survey, staff received a site-wide e-mail that introduced the survey. The survey was accompanied by a letter that described the QWL Steering Committee's interest in measuring quality of work-life as a first step in its effort to improve the working environment at the Cancer Centre.

There was a 78% response rate to the survey. The results of the survey were presented at Rounds at the Centre, as well as at separate departmental meetings, in September 2001. To briefly summarize the results, job satisfaction appeared to be moderately high at the Centre. Burnout measured by emotional exhaustion (loss of energy and general fatigue due to being overworked) and personal accomplishment (feelings of competency and achievement) was

moderate but burnout measured by depersonalization (negative or indifferent attitude to co-workers and/or patients) was low; these values for burnout were comparable to physician and nursing norms for burnout (Maslach et al., 1996). Social support from co-workers was moderately high. Half of the survey respondents reported that work interfered to some extent with their family life; some activity groups at the Centre scored high (i.e. high conflict) in this domain. On average, family-to-work conflict did not appear to be a concern at the Centre; all groups had low conflict scores.

Despite moderate scores for the Centre as a whole, considerable variation among the employee groups was seen for job satisfaction, burnout, social support, and work-family conflict. To maintain anonymity, employees belonging to small departments of less than 10 were combined to form larger employee groups. The results for nine employee groups (some groups were departments) were shown during the presentation but were not specifically addressed. At the end of Rounds presentation, it was emphasized that the survey provided a baseline description of quality of work-life issues and that future annual surveys would monitor changes in the Centre (the second survey was administered during the writing of this paper). A collaborative effort by staff and the QWL Steering Committee was anticipated to address the survey results. The Steering Committee envisioned this collaboration to involve a team approach where feedback would be solicited from departments and staff. If reported levels of job satisfaction, burnout, social support, or work-family conflict in a work unit were undesirable, the possibility of intervention(s) would be discussed.

The Researcher's Perspective - The Phenomenological Tradition

The purpose of this study was to explore individual perceptions of the QWL Survey. The study of individual perceptions lends itself to the phenomenological tradition (Schwandt, 2001; Sokolowski, 2000).

Phenomenology aims to study ordinary experiences of phenomena in everyday life from the perspective of the person experiencing it (Schwandt, 2001).

The present study relied on the eidetic (descriptive) variant of phenomenology. As a research method, eidetic phenomenology assumes that there are essential structures to any human experience and that these structures constitute that experience (Morse, 1994). Other than this assumption, the eidetic approach does not depend on a particular theoretical perspective through which to collect and analyze data.

The Role of Literature in Phenomenology

In phenomenology, it is appropriate to conduct a literature review either before and/or after data are collected and analyzed (Creswell, 1998). A preliminary literature search was conducted to determine whether other studies had been conducted on employees' perceptions of surveys utilized in workplace studies. Consistent with the eidetic approach, a more extensive literature review was conducted after the data were analyzed. The results of the literature review will be addressed in the discussion section. However, at this point, it is noted that there appeared to be very little literature on perceptions of surveys in workplace studies from the perspective of those who have completed them.

Methods
Sampling

The research method derived from phenomenology assumes that the meaning of phenomena can only be explored by asking individuals who have experienced the phenomena to describe their experiences (Jasper, 1994). Sampling is therefore purposeful in that individuals who have experienced the phenomena and are able to describe their experiences are recruited.

Recruitment

Eligible participants were the 320 employees who had completed the QWL Survey and were employed at the Centre in September of 2001. As the survey was anonymous, it was not possible to confirm that participants had completed the survey. The purpose of sampling was to recruit employees who had very little experience with research other than completing the QWL Survey. I assumed that knowledge of survey research might influence participants' perceptions of the QWL Survey. Therefore, participants could not be actively involved in the QWL Project (i.e. they could not be members of the QWL Steering Committee). As well, participants could not be nurses or radiation therapists. Nurses and radiation therapists have a unique experience with clinical research at the Centre because they treat patients enrolled in clinical trials. Nurses and radiation therapists at the Centre are the focus of another investigation that makes up the larger qualitative study mentioned earlier.

Two sampling strategies were employed to recruit employees who fit the above criteria. Employees were introduced to the study in September 2001 by a site-wide e-mail outlining the study and the interview process. In the e-mail, the study was described as a study on employees' perceptions of research. Additional employees were recruited through the coordinator of the QWL Project who has been employed at the centre for 30 years and was considered to be a key informant for referring potential participants.

Sample Size

In phenomenological studies, sample sizes of 5-25 (Polkinghorne, 1989) have been suggested. A minimum of 6 (Morse, 1994) and 10 (Creswell, 1998) participants has also been recommended. The decision was made to recruit a minimum of 10 employees and to then sample until saturation had been achieved.

Saturation was defined as no new thematic information being collected in the interviews.

Bracketing (Epoche)

The process of bracketing (Moustakas, 1994; Omery, 1983) was practiced throughout the collection and analysis of data. I have been involved in workplace studies for a number of years. It is possible that my knowledge of workplace studies may have influenced my collection and analysis of the data. For example, I recently conducted a psychometric assessment of one of the scales included in the survey and feel that this scale is over-used in occupational research. As well, I have completed QWL surveys in my own workplace and have had reservations about the applicability of some of the questions to an academic research environment (e.g., questions that focus on musculoskeletal injuries and physical demands at work). My interest in conducting this study was based on my own involvement in the QWL Project at the Cancer Centre and the development of the QWL Survey that is the subject of this study. I was hopeful that the process of developing the survey would yield a suitable instrument and wanted to evaluate the product from a qualitative perspective. Finally, as I had access to the written comments from the site-wide QWL Survey, I was aware that certain issues had already been raised concerning the survey. It was therefore necessary for me to attempt to suspend past knowledge about, and experience with, survey research during data collection and analysis.

Data Collection

Face-to-face semi-structured interviews were conducted from September 2001 to March 2002. I arranged the interviews by e-mail and conducted them. Pilot interviews were conducted to refine the interview questions. The interview protocol of the other studies which make up the larger qualitative investigation were similar in format so one or two representatives from each study's sample

were interviewed for the pilot interviews. Four pilot interviews with employees across the larger study were conducted. Two employees from the present study were included in these pilot interviews. There were no major changes in the interview questions based on the pilot interview so the pilot interview data were included in the final analysis.

Interview Setting

Although participants were given the option of meeting at the workplace, at home, or at another location that was convenient for them, most chose to be interviewed in an interview room at the workplace and one participant chose to be interviewed in his office. The interviews lasted 45 minutes to 1 hour. Interview rooms were booked for at least one and a half hours allowing 15-30 minutes for me to prepare for the interview and set up the room. In order to protect the identity of participants, prior to the interviews, the interview room blinds were closed and the seats were arranged so participants would sit with their backs to the door.

Interview Session

When participants arrived for the interview, they were asked to sign the consent form which explained the purpose of the study, the right of the participant to withdraw from the study at any time, the anticipated length of the interview, the fact that the interview was being audio-taped, and an assurance of confidentiality. It was also clarified that the study was distinct from the QWL Project at the Centre. This information was reviewed prior to turning on the tape recorder and allowed for some social conversation aimed at creating a relaxed atmosphere for the participant before the interview began.

Interview Protocol

The interview consisted of three main questions. Data from the first two questions are part of the larger qualitative study and are therefore not presented here. The third question of the interview asked participants to talk about the QWL Survey. Participants were encouraged to discuss anything in relation to the survey including the survey findings. To guide the conversation, a typed interview protocol was used with probe questions embedded within the main questions. Eight of the 10 interviews were conducted after the survey results had been presented at Rounds. During these interviews, I also asked participants if they had attended the presentations. Detailed notes were taken during the interviews.

In order to describe the study sample, the sex of the participant was noted. Four demographic questions were asked at the end of the interview: participants were asked to identify their main activity at the Centre, the training they needed for this job, their date of birth, and how many years they had worked at the Centre.

Upon interview completion, the participant was given a small gift certificate to a restaurant (which is located in the workplace as well as in the community at large) in appreciation for their participation. (Participants were not aware of the gift certificate in advance of the interview.) Permission was then requested to contact participants at a later date to review the transcript of their interview, and potentially, a draft of the research paper.

After each interview, I read through my notes and added details based on my memory of the interview. This enabled me to capture as much of the interview as possible on paper in the event of tape failure. In addition, I kept a reflective journal about the interviews and the data collected in them.

<u>Data Verification</u>

The interviews were audiotaped and transcribed verbatim using Microsoft Word. As recommended by Kvale (1996), two-thirds of the transcripts were verified against the tapes. This process led to discussions with the transcriptionist until I was satisfied with the quality of the transcriptions. Sections of the remaining transcripts were checked if I was concerned that something was incorrect or missing from them. As I had conducted the interviews, it was apparent when omissions or possible mistakes existed in the transcripts. When I was satisfied with their quality, the transcripts were sent to the participants for another level of verification. Participants were given a couple of weeks to respond with comments and/or corrections. The transcripts were then downloaded into NVivo (1999). This qualitative software program's flexible features helped to organize, code, and retrieve data during analysis.

Ethics

Ethical approval by the Research Ethics Board of the local university and by the Protocol Review Committee of the Cancer Centre was obtained for this project.

There may be an apparent conflict between my role as consultant on the QWL Steering Committee and my role as researcher for the present study. I was involved in helping the Steering Committee develop the QWL Survey and therefore it may be perceived that I had a stake in its evaluation. I can only document this as a potential conflict of interest and note that there are currently no efforts to formally evaluate or claim ownership of the survey.

Participants were free to withdraw during or after the study. If they wished to withdraw during the interview or if they wished to make a statement

off-tape, the tape recorder was stopped (no-one stopped the tape to make a statement). Participants were informed that no one at the Cancer Centre would be notified if they declined an interview or withdrew from the study (there were no withdrawals). Participants were also informed that withdrawal from the study would not affect their relationship with their employer.

Interviews were transcribed, stored, and analyzed off-site at the Institute for Work & Health (IWH) in Toronto to assure participants that their employers did not have access to their data. The tapes and the transcripts of the interviews were kept under lock and key at IWH. Data from the transcripts was stored electronically in NVivo (1999). Access to this file was password protected. The interview tapes and transcripts were given a unique identification number so that individuals were not associated with their data. Participants whose quotations are reported in this paper are not identified. Quotes that might compromise the identity of participants are not reported.

Data Analysis

Data analysis was a cyclical and reflective activity that informed data collection, writing, and further data collection (Coffey & Atkinson, 1996; Tesch, 1990). The goal of phenomenological analysis is to portray the essential nature of the phenomenon experienced (Moustakas, 1994). The data were analyzed according to Giorgi's (1975; 1989; 1997) procedures:

1. The transcripts were read in their entirety to appreciate a sense of the whole data;
2. The transcripts were read more slowly and delineated each time a transition in meaning was perceived;
3. Redundancies were eliminated and meaning units were clarified;

4. The given units were reflected upon as still expressed in the language of the participants;

5. A consistent description of the essential structure of the phenomenon was synthesized.

Analysis of the data began after the first interview and was an iterative process. An editing style approach to coding was applied to the data (Crabtree & Miller, 1992). Themes and codes were identified immediately and then revised as more interviews were conducted. According to Giorgi's method (1975; 1989; 1997), the text was segregated into manageable units referred to as "meaning units". Discrimination between these units was noted throughout the text as I became aware of changes of meaning that were relevant to the study. A coding template was developed to organize the data into these meaning units; this template was revised and re-organized at least 20 times. Thirty-one meaning units emerged from participants' descriptions of the QWL Survey. Meaning units included: confidentiality concerns, Likert scales, grouping of departments in the survey, sharing of survey results, memory of QWL Survey content, memory of survey results, and rigour. Once I was satisfied with the discrimination among these units, I began the process of relating the units to each other and to the sense of the whole.

Results

Five employees were recruited by the site-wide e-mail. Additional five employees were recruited sequentially until, by the tenth interview, no new thematic information was being presented by participants. At that point, data collection was considered to be complete. Although the intention was to recruit employees with very little experience with research, this turned out to be a challenge. Most employees had some experience with research other than completing the QWL Survey. This involvement included data entry, typing up

grant applications, billing for research expenses and drugs, following up with study patients by telephone, and pulling charts for research studies. In the end, I could only ensure that participants were not on the Steering Committee of the QWL Project and did not treat patients who were enrolled in clinical trials. Due to reasons of confidentiality, the job titles of the participants are not reported. Participants were six females and four males with a mean age of 41 years. Participants had worked at the Centre from 1 to 15 years. Four participants responded with comments after reading their transcripts. Two of the four confirmed that the transcript was satisfactory to them. The remaining two participants sent the transcript back to me that they had edited to remove awkwardness in speech or correct spelling. These revisions were not incorporated as they did not change the content or meaning of the transcript.

Four of the eight participants who were interviewed after the survey results were presented at Rounds had attended Rounds. These participants had the opportunity to refresh their memories about the survey. The four remaining participants either did not know about the Rounds presentation or could not get time off from work to attend it.

The following themes emerged and are reflected in the voices of 7 of the 10 participants:

1. <u>Participants did not remember or incorrectly recalled the contents of the survey</u>
Participants were aware that a survey had been administered at the Centre and that it addressed quality of work-life issues but some participants had difficulty remembering specific information about the survey and its administration. During the interviews, I was asked by a number of participants about the survey:

"Who made up the questions?";

"How long ago did we fill out that survey?";

"I don't know if they asked about how challenging, or how satisfied you are with the actual work that you're doing. Did they ask that? How is the actual job that you're performing, how are you happy about that?"

One participant asked whether access to child day care in the building was included in the survey. Another asked whether respondents were allowed to complete the survey on work time. A few participants could not remember what main activity group they had been part of.

Nine of the ten participants remembered that the survey was anonymous. Interestingly, none of the participants worried that they might be identified in the surveys; they all said that anonymity in the survey was not necessary. However, they all remembered that the demographic questions in the survey could be combined in certain ways to identify employees.

In describing the survey, many participants identified factors that were not part of the survey. For example, participants said the survey included factors such as how much input employees had in their areas, autonomy at work, and insensitivity to fellow workers.

2. Participants felt that information regarding the survey was withheld from them

During the interviews, it became apparent that four participants were unaware that the survey results had been or were being presented to the Centre as well as to their own department group. Lack of knowledge regarding these presentations led these participants to be suspicious of why they hadn't been informed about the presentation of the results.

The fact that the domains in the survey (job satisfaction, burnout, social support, work-family conflict) were not identified with their respective group of questions contributed to the perception that information was being withheld from participants about the survey. This withholding of information was considered to be necessary for the integrity of the survey by one participant. She thought that it was beneficial that the domain titles were hidden; otherwise, respondents could identify which questions belonged to which domains and they'd know what was being measured.

"..aren't you compromising your survey because you're actually giving them the questions and telling them which ones relate to job satisfaction, which ones relate to work/family conflict and stuff. I think that's really compromising the survey tool because you're basically taking all the blinders off."

3. Participants varied in their interpretation of the Likert (Last, 2001; Berk, 1979) scales and the domains included in the survey

Participants clearly recalled two aspects about the survey: the Likert scales and the domains measured. Participants differed in their interpretation of these aspects. The Likert scales (response options) in the survey were mentioned by most participants but described in different ways (no-one actually referred to them as "Likert scales"). One participant talked about multiple choice exams when referring to the Likert scales:

"It's like if you think too hard sometimes about something you just can't see the answer...I think there's a middle road or they can read a little too much in to questions. When I filled mine out, I tried to read the question carefully and then give my answers as I felt it would just come to mind if I had to speak it rather than sit down and go through each A, B, C, or D, or 1, 2, 3, 4, or 5....I always think it's like when I was at [the university] and I was doing my exams and they would give us [multiple] choice. If you thought too hard the nearly right answer and the right answer, you know, you knew the information but I don't know how many times I screwed up because I really didn't do [multiple] choice that well....I'd much rather sit down and write an essay or give my reasonings with

97

my answer...[multiple] choice is no way to test what I know or the way I can think and reason."

One participant complained that the Likert scales did not contain a comparison group or a description of what each response meant. Without a benchmark, the response options were open to interpretation:

"So, you read something and it says, what do you think about this, scale of 1 to 5? Well, what I think is a 4 someone else might think as a 2. It's always going to be subjective. But, is your job dangerous, well a miner is a 5 and something is a 1. Some of the questions, especially since it was the first time through for everyone, it might have been nice to have seen that....I'm thinking also in terms of when you did the rounds and...there were numbers thrown up, this is the average. Well, ok, and I think...that there's no context for those numbers, this group is a 4.3, and so and so is a 4.1. Well, give me an example of a group that I know is really dissatisfied, that everyone knows is dissatisfied, and what number would they be?"

Another participant implied that the Likert scale options were a grading scheme:

"The only contact I've had with the Quality of Work Life really has been a form that they asked us to fill out voluntarily. It kind of got us to grade what we thought of our manager, what we thought of our working area, what we thought of work passing across our desk. It gauged it on, say, 1 to 5. One may be being very important, five not being important."

Some participants spoke more generally about the domains measured as being open to interpretation. For example, one participant spoke about work-family conflict:

"There were also a couple of questions that I just thought were a bit too open to interpretation, and I wasn't sure if I was going to interpret them the same way as the people who were actually writing the survey and trying to interpret them later. And they were things like, does your home life affect your work life, I think that was one of the questions, wasn't it? And vice versa, does work life affect home life? Well ya, of course it does. And at the time some of us [occupational group]

were working longer hours...so there were times when you'd have something that you'd have to be home to take your kid for, either you couldn't or you'd have to make another arrangement, or trade with someone here. So of course it affects, but that's not a question of does it. I guess does it inordinately affect in such a way that it's, makes it difficult for you. So I just thought that it was just too open. Work is supposed to affect your home life. You have to leave home to go to work."

4. The impact of the survey was more important than the survey itself

Participants were not so concerned about the content of the survey as they were with the impact of the survey. The success of the survey was gauged by whether any action had been taken as a result of the survey results. One participant felt that the intent of the survey was to make changes:

"...they're doing the survey for...I mean, basically to make things better, right. Because, you know, a manager, they want to have the best, the best staff working, the best, their output or product to be the best for the least amount of money. So if they can make their working conditions better and make everybody happier and better working, then sure."

Regarding the survey, another said:

"...it's just another thing that management are doing but it's not going to translate in to anything for us. If the Quality of Work Life said if we can master certain points then at the end of it we're going to give you a 20% pay raise, you would have everyone at the centre because it's something tangible...I think a lot of this is really a waste of time."

5. Talking about the survey triggered discussions of quality of work-life issues most of which were not captured in the survey

During the interviews, it was quite apparent that participants were not really interested in talking about the survey (probably because participants could not remember many details). They wanted to discuss their own quality of work life and mentioned issues that affected it that were often unrelated to information captured in the survey:

"I guess because we're at the bottom of the rung I think that it's more important for us to feel we're being heard. We're basically the non-professional part of the Centre which I think does make it a bit more difficult to be heard, I think, sometimes...I think that'll be the same at [the local university]. I'm sure that the handymen and that maybe don't feel they have as much clout as the top professor or something, which they don't and they probably never will."

"I think the one thing with the clerical level of this institution is that we probably have the most tedious jobs, the most repetitive, and probably for the most part, the most boring jobs because a lot of our staff are in the far rooms and maybe all day they'll be ordering blood, and so job satisfaction and that was very important. The lack of variety sometimes in the clerical jobs is one of the more difficult problems, keeping people motivated."

"Because the work load, the volume here, has increased tremendously in the last two years. But the people really haven't [pause], we're taking on more and more and more, and we're not doing what we were doing as well. I even find that I'm just flying by the seat of my pants, and everything is kind of mediocre."

"All the political wrangling and what's going on...I don't care about anymore, because I used to get really quite frustrated and involved when things weren't happening as fast. I find that things are slow to happen here in the building, in terms of change. I find there's too many meetings, too many conferences, too many managers and supervisors at meetings constantly. Sometimes, you can't get hold of them. Death by meetings I call it. Not death by chocolate, but death by meetings."

"Here, people come in for chemotherapy, they come in for radiation therapy. It's got to be correct. There's no margin of error in cancer care. And I think that, the whole genre just, it's just so, it's so dynamic here...I was so excited when I first came here. Oh, this is exactly what I want, you know. I want something where, where there's a lot of action, there's a lot of movement, and, you know, I really liked it. But, you know, you can only take that for so long and it starts to wear you out. It's been three years now, and I haven't stopped running since the day I came here....Here, we see as many cancer patients at Christmas and in the summer as we do any other time of year...times that are traditionally quieter in other environments, are actually busier here, for the people that are here."

"I think health care is a lot busier now...It is busier now, because of all the budget cutbacks and things. You know, you go into an emergency room, it's always

[pause] That used to overwhelm me, how busy it is...sometimes, it feels like a conveyer belt, just get them in, get them out."

One participant spoke about how patients sometimes affected employees' quality of work-life:

"We're the people who see patients every day. The patients tell us things that they may not want to tell a nurse or a doctor, even though we don't want to hear it. We see a lot of anger. We see a lot of resentment. We see a lot of very upset people."

Some participants pointed out that the survey was 'old news' because it had failed to address other factors that influenced the quality of working life. As one participant said:

"Well, I guess the simplest reason would be it's a moving target, the quality of work life...today, for instance, we've just started 14 hour days....So that's probably going to be a larger influence and intervention than I think you could possibly do. So that's why I'm saying it's a moving target, the quality's going to be a moving target as events at the workplace change."

6. **Participants were concerned that departments or groups of employees were labelled based on the survey results**

All four participants who attended Rounds remembered that one department had low QWL scores relative to the rest of the Centre in a number of the domains. A number of these participants were concerned about these results. For example, one participant said:

"I don't like the fact that now it appears that they're labelled that they did the worst, that they have the worst. I don't like that because I think that's a negative association. I don't think that it's right. I don't think it's right from the point of view that they look more burned out or more stressed than anyone or more dissatisfied...I think it's a bad image to have. It just seems negative. It's almost like it marks them. I don't like that....I don't really know what that will accomplish."

Another participant didn't like that her group was labelled with a low score for supervisory social support. She felt that the label was problematic because is didn't convey an accurate picture of her department:

"I don't think it's lower than anywhere else in the Centre. I think that may have not been a very accurate reflection just because I know the people in the department and I know roughly how they would have filled out the form because even though we didn't discuss it, we've all been working with each other pretty much over the years. So, you get to know people pretty well."

Some departments were combined with others to preserve the anonymity of respondents. A senior member of one such group was also concerned that the combined group was labelled as a result of the survey:

"And I think [department group], they scored average, but I think they were just a [little] lower, than the average for the building. And I was a little sensitive to that because I really make a point of being supportive to my staff. I'm always available, you know, come to my door any time."

Essential Description

The following description summarizes the perceptions of the QWL Survey: 1) participants did not remember or remembered incorrectly the contents of the survey; 2) participants perceived that information regarding the survey was withheld from them; 3) participants varied in their interpretations of the domains and Likert scales included in the survey; 4) talking about the survey triggered participants to discuss their own quality of work-life issues which, in most cases, were not captured in the survey; 5) the impact of the survey was more important than the survey itself; 6) participants were concerned that departments or groups of employees were labelled based on the survey results.

Discussion

Upon returning to the literature, I found a number of studies examining respondents' perceptions of surveys. The majority of these studies used techniques to explore respondents' interpretations of survey questions as well as the cognitive processes involved in completing surveys. Such techniques have been referred to as 'think-aloud protocols', 'cognitive interviews', 'verbal report techniques' and 'cognitive science techniques' (e.g. see Conrad, Blair, & Tracy, 1999; Jobe & Mingay, 1990; Kushniruk, Patel, Cimino, & Barrows, 1996; Mallinson, 2002; Willis, Royston, & Bercini, 1991). With these techniques, subjects are encouraged to verbalize their thoughts as they answer survey questions. These procedures assume that concurrent verbalization does not interfere with cognitive processes used to answer the survey questions. Only a few qualitative studies examining respondents' perceptions of survey questions were located (e.g. Barroso & Sandelowski, 2001; Donovan, Frankel, & Eyles, 1993; Masse, 2000). As with the above cognitive interviews, the qualitative interviews were conducted while respondents were completing the surveys. No studies that explored respondents' perceptions of surveys after the survey had been completed were located. None of the surveys examined by cognitive interviews or qualitative methods were workplace surveys.

The present study did not involve participants in the act of completing the QWL survey. Instead, participants were interviewed to explore their perceptions of the survey 7-10 months after it took place. Participants were not able to recall many survey details. This is not surprising given the time that had passed and the fact that employees had completed the survey during work hours and probably did not have a lot of time to think about it. Evidence from psychological experiments suggests that survey recall may be enhanced when survey items are salient (Rajaram, 1998), distinctive (Glover, Plake, & Zimmer, 1982; Rajaram, 1998), bizarre (McDaniel, Einstein, DeLosh, & May, 1995), unexpected (Maki, 1990),

visually presented (Giles, Johnson, Knight, Zammett, & Weinman, 1982), vivid (Collins, Taylor, Wood, & Thompson, 1988; Schiefer, 1986; Tulving, McNulty, & Ozier, 1965), or involve decisions of a high level of difficulty (Glover et al., 1982). However, these findings are pertinent to short-term recall. The factors that influence long-term recall are unclear.

Despite limited recall, there were a few aspects about the survey that participants did remember quite clearly. Most participants remembered that the survey had been anonymous. Participants who remembered that the survey was anonymous appeared to feel that anonymity was not necessary. I had hoped to interview some employees who felt otherwise and would be willing to discuss their concerns about being identified by the survey. I can only conclude that employees with such concerns were not interested in participating in the present study because it entailed a face-to-face interview.

There were two other aspects of the survey that participants remembered. Those participants who attended Rounds in September 2001 were able to recall some of the domains measured in the survey because the results had been reported by domain. And, at some point in the interviews, all participants talked about the Likert scales (response options) to questions in the survey.

There was considerable variation in how participants interpreted the Likert scales. This is not surprising given that interpretation variability with Likert scales has been reported by other researchers (Holden & Edwards, 1989; Jobe et al., 1990; Mallinson, 2002; Weinstein, 1995). For example, it has been found that respondents have difficulty responding to predefined categories (Jobe et al., 1990); respondents often compare themselves with others or with memory of health states at a younger age in order to select a response option (Mallinson, 2002); and respondents who have physical limitations respond more positively

than an external observer because they have adapted to their situation (Mallinson, 2002). Possible solutions to minimize the interpretation of the Likert scales are offered later in this discussion.

Interviewees felt that key information regarding the survey was withheld from them. Factors such as lack of awareness regarding the presentation of survey results to the Centre and the omission of domain titles (e.g. "job satisfaction", "burnout") in the survey contributed to this perception. As a consultant to the steering committee and a participant who was involved in the design of the survey, the perception that information about the survey was deliberately withheld from participants is disturbing to me. I am unsure what can be done about this perception. Firstly, I do not think that the survey domains should be labelled. Evidence of framing effects associated with the wording of individual survey items (Guyatt et al., 1999; Tversky & Kahneman, 1981; Levin, Schnittjer, & Thee, 1988) suggests that labelling a domain may influence respondents' answers to the items of that domain. Secondly, the Rounds and department presentations were advertised by flyers in the Centre and by site-wide e-mails so it is unclear why four participants were unaware of them. Perhaps, there needs to be a deliberate effort by the steering committee to reach all employee groups when advertising the presentation of survey results. Otherwise, there is a danger that these employees will feel alienated and that this will affect the response rates to subsequent surveys. This finding will be brought to the attention of the QWL Committee so that they can develop strategies to improve the announcement of the survey presentations.

Another concern about the survey appeared to be its lack of comprehensiveness and perhaps, relevance. Talking about the survey triggered participants to discuss issues that affected their own QWL but were not reflected in the content of the survey. While it would not have been feasible to include all

these issues in the survey, this finding merits some attention. Barroso and Sandelowski (2001) recommend that surveys "should always be appraised by persons sharing the same kinds of life experience as the ones who will be evaluated using the instrument" (p. 501). Such appraisal may minimize interpretation difficulties with response options as well as enhance the content relevance to the particular work setting. In the development of the QWL survey, the steering committee of the QWL Project collaborated with their employee groups to identify domains to measure. The committee then selected from a variety of instruments those that were most applicable to the Cancer Centre. It is unclear how a survey that was developed in such a manner failed to capture many issues that employees were concerned about. However, one factor that was overlooked in the development of the QWL survey was the pretesting of the survey in employees at the Cancer Centre. Pretesting helps to ensure that the items are understood and interpreted similarly by the group of people who are the recipients of the survey; the subjects in the pretesting stage should be representative of the respondents who will ultimately complete the survey (Streiner & Norman, 1995). The QWL steering committee mistakenly assumed that the survey would be suitable for the Centre because the domain areas had been identified by employees and the scales had then been chosen by committee members who were representative of Centre employees. Although additional time would have been required to pretest the survey, pretesting might have revealed the shortcomings of the survey and allowed the QWL committee to address these shortcomings.

Another explanation for the survey's lack of comprehensivenss and relevance may be that the choice of instruments was limited to what was available in the occupational literature. What was available may not have been suited to oncology workers in this particular work setting. The QWL Project team could address both comprehensives and relevance by developing a Centre-specific

survey. The argument for a Centre-specific survey over a generic one is analogous to the argument for disease-specific health status and quality of life scales over generic ones. While generic scales allow researchers to compare outcomes across different populations and interventions (Patrick & Deyo, 1989), they usually include many questions that are inappropriate or irrelevant to a person suffering from a particular disease (Patrick et al., 1989; Streiner et al., 1995). Generic scales thus contain fewer relevant questions to detect real changes within patients over time (Patrick et al., 1989; Streiner et al., 1995).

The choice of a generic versus disease-specific scale depends on the aims and practical constraints of the investigation (Patrick et al., 1989). The initial purpose of the QWL Survey was to measure baseline QWL and then monitor it over time. A Centre-specific survey would have been appropriate for this purpose. A proposal to develop a Centre-specific survey has been on the agenda of the QWL committee meetings for two years but it has never been seriously addressed due to the time required to develop such an instrument. Developing such a survey might involve conducting focus groups or key informant interviews to devise survey items (Streiner et al., 1995). More recently, however, other cancer centers have been requesting the QWL survey for their own staff. These requests have led the committee to discuss the possibility of comparing QWL data across Canadian cancer centers using the existing generic survey. The purpose of the survey needs to be discussed further before the committee seriously considers directing its efforts toward developing a Centre-specific survey.

The act, itself, of administering a survey has been shown to elicit respondents' expectations concerning the content of the survey. Peck and colleagues (2001) found that the type of instrument used to assess expectations in patients affected the number of expectations elicited as well as the number of unmet expectations reported; patients given a 'long' instrument that asked about

expectations for tests, referrals, and new medications had more expectations of their physician and subsequently reported more unmet expectations than patients given a 'short' instrument measuring general expectations of the visit with the physician. Respondents' expectations were demonstrated in the present investigation. Although no promises of action based on the QWL survey results were made to employees at the Cancer Centre, participants in the present study felt that the impact of the survey was more important than the survey itself. At the same time, they were cynical that changes would be implemented as a result of the survey. They did not share the mantra of performance measurement – 'what gets measured gets done' as proposed by Patton (1997). According to Hartley and Barling (1998), "if staff do not see direct benefits from their taking part in [a] survey (e.g. few or no management actions occur as a result of the organizational problems raised by the survey), then organization-wide cynicism and distrust may increase, jeopardizing the use and benefit of future surveys" (p. 170). As evidence, Brown (1983) showed that workers interpreted the lack of instant solutions to survey results as confirmation of their initial suspicions of management bad faith and researcher manipulation.

Ironically, surveys alone do not generally guide interventions because it is difficult for them to identify the causes and nature of issues (Erickson, Kendall, Anderson, & Kaplan, 1989). According to Hall (1979), survey research alienates respondents and has little likelihood of creating the active and supportive environment essential for change. The QWL steering committee appeared to have no process or strategy in place to address the survey results. Given that employees indicated that the success of the survey was dependent on action, perhaps, the committee was short-sighted in administering the survey without a follow-up plan. It should be noted that the second annual survey was administered during the writing of this paper. The QWL Committee is currently discussing how to focus on intervention strategies to respond to survey findings.

Kompier (2002) takes a more dramatic position concerning action by criticizing the over-use of questionnaires in workplaces. According to Kompier, we do not need further studies based on cross-sectional study designs and employees' self report with regard to psychosocial work environment and health. Although some authors argue that a theoretical basis for workplace interventions is lacking (Goldenhar & Schulte, 1994; Goldenhar & Schulte, 1996), Kompier implies that the administration of such questionnaires adds little value to workplace research and insists that the existing body of workplace knowledge needs to be transformed to prevention and intervention research. However, I would argue that survey data are useful for identifying problem areas that could potentially benefit from interventions. Further, the presence of baseline data makes it easier to assess improvements in QWL, whether or not the improvements occur as a result of the interventions.

Participants of the present study expressed concerned about the labelling of groups who had low QWL based on the survey results. According to Labelling Theory (Becker, 1963; Lemert, 1951), individuals (or groups) who are labelled may react by accepting the label and by getting further entrenched in the behaviour associated with the label. Therefore, once outgroup status has been suggested, "a circular process can be set in motion that reinforces the categorization" (Niemeyer, 1991, p. 259). Labelling Theory, originally developed from studies on deviance, has been applied to mental disorders, drug abuse, infertility, homosexuality, and physical disability (Mason, Carlisle, Watkins, & Whitehead, 2001). In the occupational literature, this theory has been applied to repetition strain injury (Reid, Ewan, & Lowy, 1991) and injured workers in general (Niemeyer, 1991) (who are labelled as "malingerers" or people who take advantage of workers' compensation systems).

I have not come across any literature on Labelling Theory applied to psychosocial constructs associated with workplace surveys. In the context of the present study, Labelling Theory implies that some employee groups may have difficulty overcoming the labels given to them by the QWL Survey. The label may perpetuate unhappiness in those groups labelled as having lower QWL than other groups. The negative effects of labelling are documented. For example, Haynes and colleagues (1978) found that labelling patients as hypertensive led to increased work absenteeism; these authors proposed that the label caused patients to adopt the 'sick role'. In *The Futures of Children*, Hobbs (1975) warns of the consequences of labelling children as different (e.g. emotionally disabled), especially when adequate services to meet the needs of these children are lacking.

Conversely, the labelling of some employee groups as having better QWL raises issues of its own. Findings peripheral to the present study demonstrated the potential problem of labelling groups as having good QWL. Based on feedback during the separate departmental presentations, two groups at the Centre (medical secretaries and the nurses) expected their survey results to be worse. After their presentations, these groups expressed concern that they would be ignored because their QWL scores were satisfactory. The nurses were especially concerned because they felt that they had been putting on a 'show' for their patients at the expense of their own psychosocial health.

The concern about labelling has important implications for the feedback of survey results to staff. One could argue that feedback of survey results is a form of QWL intervention, itself. For example, it was shown that survey feedback led to departmental changes in one workplace study (Elo, Leppanen, & Sillanpaa, 1998). However, in the case of the present study, the presentation of survey results may have had a negative effect on some employees and/or employee groups. The steering committee of the QWL Project tried to be sensitive about

the concerns from specific employee groups by presenting detailed departmental results to the respective departments only; these separate presentations were conducted so that departmental concerns would not be made known to the rest of the Centre. However, it is possible that the committee was doing more 'harm' than 'good' by presenting the results even in this format. Should occupational researchers reveal survey results to employee groups? Should occupational researchers administer surveys in the first place? How do we address QWL if no "evidence" exists to warrant addressing it? The potentially negative effect of labelling based on survey results needs to be explored further.

Assuming that occupational researchers choose to measure QWL and report the findings to employees, the present study demonstrated an interesting relationship between the perception of labelling and the need for action. Findings of this study implied that all groups, regardless of their QWL scores, wanted action and saw action as determining the success of the survey. As researchers, we need to think about how we can address workplace groups who appear to do well, or are labelled as doing well, on surveys. What interventions are appropriate for these groups?

Before closing, I want to acknowledge that participants' perceptions of the QWL survey were fairly negative. Despite their negative perceptions of the survey, most participants were able to distinguish between the survey and the QWL Project in general. While not so positive about the survey, they were positive about the Project. The Project was not the focus of this paper so data about it has not been presented. However, participants felt that the Project indicated that management cared about the employees at the Centre and participants were pleased that input from employees was being solicited even if it was in the form of a survey.

According to Barroso and Sandelowski (2001), qualitative data gathered during the use and evaluation of a quantitative instrument "can illuminate and partly close the gaps between meaning and measurement" (p. 502). The present qualitative study that explored employees' perceptions of a QWL Survey they completed appeared to be significant because it addressed some aspects of the meaning-measurement gap. This study found that: participants did not remember or incorrectly recalled the contents of the survey; participants perceived that information regarding certain aspects of the survey was withheld from them; participants varied in their interpretations of the domains and Likert scales included in the survey; talking about the survey triggered participants to discuss their own quality of work-life issues most of which were not captured in the survey; the impact of the survey was more important than the survey itself; and participants were concerned that departments or groups of employees were labelled based on the survey results. As demonstrated in this study, occupational health researchers who wish to use surveys in workplace studies may face a number of challenges. Surveys should be pretested in a sample of employees to solicit feedback regarding their content. If the survey results are to be presented to employees, deliberate efforts need to be made to advertise, or make known, the results of the survey. An action plan should be in place to respond to survey results and this action plan should be articulated to employees in advance of the survey administration. Finally, intervention strategies should address all employee groups regardless of whether their QWL scores raised concerns or not.

References

Barroso, J. & Sandelowski, M. (2001). In the field with the Beck Depression Inventory. Qualitative Health Research, 11, 491-504.

Becker, H. S. (1963). Outsiders: Studies in the sociology of deviance. London: Free Press of Glencoe.

Berk, R. A. (1979). The construction of rating instruments for faculty evaluation: A review of methodological issues. Journal of Higher Education, 50, 650-669.

Brown, L. D. (1983). Organizing participatory research: Interfaces for joint inquiry and organizational change. Journal of Occupational Behaviour, 4, 9-19.

Coffey, A. & Atkinson, P. (1996). Making sense of qualitative data: Complementary research strategies. Thousand Oaks, CA: Sage Publications.

Collins, R. L., Taylor, S. E., Wood, J. V., & Thompson, S. C. (1988). The vividness effect: Elusive or illusory? Journal of Experimental Social Psychology, 24, 1-18.

Conrad, F., Blair, J., & Tracy, E. (1999). Verbal reports are data! A theoretical approach to cognitive interviews Washington, D.C.: Bureau of Labor Statistics.

Crabtree, B. F. & Miller, W. L. (1992). Doing qualitative research. (Vols. 3) Newbury Park, CA: Sage Publications.

Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications.

Donovan, J. L., Frankel, S. J., & Eyles, J. D. (1993). Assessing the need for health status measures. Journal of Epidemiology and Community Health, 47, 158-162.

Elo, A.-L., Leppanen, A., & Sillanpaa, P. (1998). Applicability of survey feedback for an occupational health method in stress management. Occupational Medicine, 48, 181-188.

Erickson, P., Kendall, E. A., Anderson, J. P., & Kaplan, R. M. (1989). Using composite health status measures to assess the nation's health. Medical Care, 27, S66-S76.

Giles, R. M., Johnson, M. R., Knight, K. E., Zammett, S., & Weinman, J. (1982). Recall of lecture information: A question of what, when and where. Medical Education, 16, 264-268.

Giorgi, A. (1975). An application of phenomenological method in psychology. In A.Giorgi, C. Fischer, & E. Murray (Eds.), Duquesne studies in phenomenological psychology. Vol. 3 (pp. 82-103). Pittsburgh, PA: Duquesne University Press.

Giorgi, A. (1989). Some theoretical and practical issues regarding the psychological phenomenological method. Saybrook Review, 7, 71-85.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology, 28, 235-260.

Glover, J. A., Plake, B. S., & Zimmer, J. W. (1982). Distinctiveness of encoding and memory for learning tasks. Journal of Educational Psychology, 74, 189-198.

Goldenhar, L. M. & Schulte, P. A. (1994). Intervention research in occupational health and safety. Journal of Occupational Medicine, 36, 763-775.

Goldenhar, L. M. & Schulte, P. A. (1996). Methodological issues for intervention research in occupational health and medicine. American Journal of Industrial Medicine, 29, 289-294.

Guyatt, G. H., Cook, D. J., King, D., Norman, G. R., Kane, S. L., & van Ineveld, C. (1999). Effect of the framing of questionnaire items regarding satisfaction with training on residents' responses. Academic Medicine, 74, 192-194.

Hall, B. L. (1979). Knowledge as a commodity and participatory research. Prospects, 9, 393-408.

Hartley, J. & Barling, J. (1998). Employee attitude surveys. In K. Whitfield & G. Strauss (Eds.), Researching the world of work: Strategies and methods in studying industrial relations (pp. 157-170). Ithaca, NY: Cornell University Press.

Haynes, R. B., Sackett, D. L., Taylor, D. W., Gibson, E. S., & Johnson, A. L. (1978). Increased absenteeism from work after detection and labeling of hypertensive patients. New England Journal of Medicine, 299, 741-744.

Hobbs, N. (1975). The futures of children. San Francisco, CA: Jossey-Bass Publishers.

Holden, G. W. & Edwards, L. A. (1989). Parental attitudes toward childrearing: Instruments, issues, and implications. Psychological Bulletin, 106, 29-58.

Jasper, M. A. (1994). Issues in phenomenology for researchers of nursing. Journal of Advanced Nursing, 19, 309-314.

Jobe, J. B. & Mingay, D. J. (1990). Cognitive laboratory approach to designing questionnaires for surveys of the elderly. Public Health Reports, 105, 518-524.

Kompier, M. (2002). The psychosocial work environment and health - What do we know and where should we go? Scandinavian Journal of Work, Environment & Health, 28, 1-4.

Kushniruk, A., Patel, V., Cimino, J. J., & Barrows, R. A. (1996). Cognitive evaluation of the user interface and vocabulary of an outpatient information system. Proceedings of the AMIA Annual Fall Symposium 22-26.

Kvale, S. (1996). Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Last, J. M. (2001). A dictionary of epidemiology. (4th ed.) New York: Oxford University Press.

Lemert, E. (1951). Social pathology: A systematic approach to the theory of sociopathic behavior. New York: McGraw-Hill.

Levin, I. P., Schnittjer, S. K., & Thee, S. L. (1988). Information framing effects in social and personal decisions. Journal of Experimental Social Psychology, 24, 520-529.

Maki, R. H. (1990). Memory for script actions: Effects of relevance and detail expectancy. Memory & Cognition, 18, 5-14.

Mallinson, S. (2002). Listening to respondents: A qualitative assessment of the Short-Form 36 Health Status Questionnaire. Social Science & Medicine, 54, 11-21.

Maslach, C., Jackson, S. E., & Leiter, M. P. (1996). Maslach Burnout Inventory (3rd edition) Palo Alto, CA: Consulting Psychologists Press, Inc.

Mason, T., Carlisle, C., Watkins, C., & Whitehead, E. (2001). Introduction. In T.Mason, C. Carlisle, C. Watkins, & E. Whitehead (Eds.), Stigma and social exclusion in healthcare (pp. 1-13). London: Routledge.

Masse, R. (2000). Qualitative and quantitative analyses of psychological distress: Methodological complementarity and ontological incommensurability. Qualitative Health Research, 10, 411-423.

McDaniel, M. A., Einstein, G. O., DeLosh, E. L., & May, C. P. (1995). The bizareness effect: It's not surprising, it's complex. Journal of Experimental Psychology: Learning, Memory, & Cognition, 21, 422-435.

Morse, J. M. (1994). Designing funded qualitative research. In N.K.Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 220-235). Thousand Oaks, CA: Sage Publications, Inc.

Moustakas, C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage Publications.

Netemeyer, R. G. & Boles, J. S. (1996). Development and validation of work-family conflict and family-work conflict scales. Journal of Applied Psychology, 81, 400-410.

Niemeyer, L. O. (1991). Social labeling, stereotyping, and observer bias in workers' compensation: The impact of provider-interaction on outcome. Journal of Occupational Rehabilitation, 1, 251-269.

NIOSH (1988). NIOSH Generic Job Stress Questionnaire Cincinnati, Ohio: National Institute for Occupational Safety and Health.

NVivo (1999). (Version 1.0) [Computer software]. Victoria, Australia: Qualitative Solutions and Research Pty Ltd.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5, 49-63.

Patrick, D. L. & Deyo, R. A. (1989). Generic and disease-specific measures in assessing health status and quality of life. Medical Care, 27, s217-s232.

Patton, M. Q. (1997). Discovering process use. Evaluation, 4, 225-233.

Peck, B. M., Asch, D. A., Goold, S. D., Roter, D. L., Ubel, P. A., McIntyre, L. M., Abbott, K. H., Hoff, J. A., Koropchak, C. M., & Tulsky, J. A. (2001). Measuring patient expectations: Does the instrument affect satisfaction or expectations? Medical Care, 39, 100-108.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R.S.Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology (pp. 41-60). New York: Plenum Press.

Rajaram, S. (1998). The effects of conceptual salience and perceptual distinctiveness on conscious recollection. Psychonomic Bulletin & Review, 5, 71-78.

Reid, J., Ewan, C., & Lowy, E. (1991). Pilgramage of pain: The illness experiences of women with repetition strain injury and the search for credibility. Social Science & Medicine, 32, 601-612.

Schiefer, H. J. (1986). Effect of verbal and nonverbal vividness on students' information-processing. Perceptual & Motor Skills, 63, 1106.

Schwandt, T. A. (2001). Dictionary of qualitative inquiry. (2nd ed.) Thousand Oaks, CA: Sage Publications, Inc.

Sokolowski, R. (2000). Introduction to Phenomenology. Cambridge: Cambridge University Press.

Streiner, D. L. & Norman, G. R. (1995). Health measurement scales: A practical guide to their development and use. (2nd ed.) New York: Oxford University Press.

Tesch, R. (1990). Qualitative research: Analysis types and software tools. New York: The Falmer Press.

Tulving, E., McNulty, J. A., & Ozier, M. (1965). Vividness of words and learning in free-recall learning. Canadian Journal of Psychology, 19, 242-252.

Tversky, A. & Kahneman, D. (1981). The framing of decisions and the psychology of choice. Science, 211, 453-458.

Warr, P., Cook, J., & Wall, T. (1979). Scales for the measurement of some work attitudes and aspects of psychological well-being. Journal of Occupational Psychology, 52, 129-148.

Weinstein, M. (1995). Methodological issues in comparative industrial relations and human resource management survey research. In Proceedings of the Forty-seventh Meeting of the Industrial Relations Research Association (pp. 169-177). Madison, Wisconsin: Industrial Relations Research Association.

Willis, G. B., Royston, P., & Bercini, D. (1991). The use of verbal report methods in the development and testing of survey questionnaires. Applied Cognitive Psychology, 5, 251-267.

CHAPTER 5

PERCEPTIONS OF CLINICAL TRIALS IN A CANADIAN CANCER CENTRE

Abstract

Clinical trials are integral to progress in cancer management; many cancer drugs and treatments cannot be approved without being subjected to the clinical trial process. However, there is evidence to suggest that participation in trials may be stressful for physicians who are involved in trials. While physicians' attitudes to clinical trials have been documented, there is little or no literature on the perception of trials from the perspective of other clinicians who treat trial patients. The purpose of this phenomenological study was to explore nurses' and radiation therapists' perceptions of clinical trials in their workplace. This study was conducted in a Canadian cancer centre where there are over 50 clinical trials actively recruiting patients at any one time. The following themes emerged from the analysis: 1) nurses and radiation therapists perceived a variety of ethical concerns associated with clinical trials; 2) treating patients enrolled in clinical trials was perceived to add to the workload of radiation therapists; 3) nurses and radiation therapists did not perceive meaningful involvement in clinical trials as an option; and 4) the additional workload and ethical concerns associated with trials were off-set by the view that patients' interests outweighed those of nurses and radiation therapists. This study implies that nurses and radiation therapists should be invited to provide input regarding trial procedures and be acknowledged for their work associated with clinical trials.

Objective

This study is part of a larger qualitative study whose objective was to explore cancer care employees' perceptions of a Quality of Work-life (QWL)

Project where they were the subjects of research and their perceptions of clinical research where patients were the subjects of research. The objective of the current study was to explore nurses' and radiation therapists' (RTs') perceptions of the clinical trial. The findings from the larger study are not presented in this paper.

Context

       This research was conducted at a large (approximately 450 employees) Canadian ambulatory cancer treatment centre that serves over 2.3 million people in Ontario. Approximately, 7,000 new patients are referred to the Centre each year with approximately 500 patients seen each day for consultations, radiation and chemotherapy treatments, and follow-up visits. In Canada, health insurance coverage is universal and there are no financial barriers to seeking treatment for cancer.

       I became involved with the Cancer Centre through a Quality of Work-Life (QWL) Project that began in the spring of 2000. During the 3 years that I have been a member of the steering committee of the QWL Project, I developed a general interest in employees' perceptions of clinical research; over time, I became interested in nurses' and RTs' perceptions of clinical trials.

Clinical Trials at the Centre

       The Clinical Trials Department at the Cancer Centre is one of the largest such departments in Canada. It is a member of the National Cancer Institute of Canada Clinical Trials Group, the Radiation Therapy Oncology Group, and participates in Pediatric Oncology Group studies and Ontario Clinical Oncology Group studies. The department works closely with a number of industry partners who fund approximately half of the trials. Over 50 studies actively recruit patients at any time and many more studies continue to collect information on

recruited patients. These trials test the usefulness of new drugs, new approaches to surgery or radiation therapy, or new combinations of treatments. They address a variety of topics including cancer prevention, early cancer detection, and quality of life. Approximately 50% of the clinical trials at the Centre are Phase III trials, most of which are randomized controlled trials (RCTs). Phase III trials are typically effectiveness trials because they seek to compare a new drug or management strategy with an existing drug or intervention known to be effective (Jadad & Rennie, 1998). The remaining trials at the Centre are Phase I and II trials. Phase I trials are the first studies conducted in humans to evaluate a new drug or treatment; in Phase II trials, the new drug or treatment is given to small groups of patients with a given condition to establish the efficacy of different doses and frequencies of administration (Jadad et al., 1998). Most Phase II trials are not randomized. Generally, in cancer, Phase I and II trials are evaluated in patients who have progressing terminal disease and cannot be cured by conventional methods (Cox, 2000a).

The Researcher's Perspective - The Phenomenological Tradition

The purpose of this study was to explore nurses' and RTs' perceptions of clinical trials. The study of individual perceptions lends itself to the phenomenological tradition (Schwandt, 2001; Sokolowski, 2000). Phenomenology aims to study ordinary experiences of phenomena in everyday life from the perspective of the person experiencing it (Schwandt, 2001).

The present study relied on the eidetic (descriptive) variant of phenomenology. As a research method, eidetic phenomenology assumes that there are essential structures to any human experience and that these structures constitute that experience (Morse, 1994). Other than this assumption, the eidetic approach does not depend on a particular theoretical perspective through which to collect and analyze data.

The Role of Literature in Phenomenology

In phenomenology, a literature review may be conducted either before and/or after data are collected and analyzed (Creswell, 1998). Consistent with the eidetic approach, the role of the literature becomes important after data collection and analysis are completed. At this point, researchers then need to place their findings within the context of the work that has already been published in the literature (Morse, 2000).

A preliminary literature search was conducted to determine whether other studies had been conducted on health care employees' perceptions of clinical trials. A more extensive literature review was conducted after the data were analyzed. The results of the literature review will be addressed in the discussion section. However, at this point, it is noted that while physicians' perceptions of clinical trials have been documented (McColl, Smith, White, & Field, 1998; Ross et al., 1999; Taylor, 1992; Taylor et al., 1994; Taylor & Kelner, 1987b; Taylor & Kelner, 1987a; Taylor, Margolese, & Soskolne, 1984), there appeared to be very little or no literature on perceptions of clinical trials from the perspective of other health care clinicians.

Methods

The research method derived from phenomenology assumes that the meaning of phenomena can only be explored by asking individuals who have experienced the phenomena to describe their experiences (Jasper, 1994).

<u>Recruitment</u>

There are approximately 40 primary care nurses, 10 clinical trial nurses, and 70 RTs at the Cancer Centre. A variety of sampling techniques were used to recruit employees from the nursing and radiation therapy groups. Nurses and RTs were introduced to the study by a site-wide email outlining the study and the interview process. The study was described as one on employees' perceptions of research in their workplace. Additional RTs were recruited through the coordinator of the Quality of Work-Life (QWL) Project, an RT who was a long-term employee of the Centre and was considered to be a key informant for referring potential participants. Additional nurses were recruited through two nurses on the QWL Project Steering Committee.

Sample sizes of 5-25 (Polkinghorne, 1989) have been suggested for phenomenological studies. A minimum of 6 (Morse, 1994) and 10 (Creswell, 1998) participants has also been recommended. The decision was made to recruit a minimum of 10 employees and to then sample until saturation had been achieved. Saturation was achieved when no new information was collected in the interviews.

<u>Bracketing (Epoche)</u>

The term "bracketing" refers to the setting aside of one's judgments, biases, and preconceived ideas about things (Moustakas, 1994). The process of bracketing was practiced throughout the collection and analysis of data. I am a doctoral student at a local university and have a history of involvement in clinical

research. During the last four years, I have been involved in a number of studies examining the health of health care providers, particularly nurses. My experience with clinical research and my more recent involvement at the Cancer Centre led me to question whether clinical research had an effect on the quality of work-life of health care providers. I suspected that providers might not be supportive of clinical research activities because they interfered with their work responsibilities. It was therefore necessary for me to attempt to suspend this predisposition toward clinical trials during data collection and analysis.

Data Collection

Data were collected through face-to-face semi-structured interviews from September 2001 to March 2002. I arranged and conducted the interviews. Pilot interviews were conducted to refine the interview questions. The interview protocol of the other studies that make up the larger qualitative investigation were similar in format so one or two representatives from each study's sample were interviewed for the pilot interviews. A total of four pilot interviews with employees across the larger study were conducted. One participant from the present study was included in these pilot interviews. There were no major changes in the interview questions based on the pilot interview so the pilot interview data were included in the final analysis.

Interview Setting

Although given the option of meeting at the workplace, at home, or at another location that was convenient for them, all participants chose to be interviewed at the workplace. Interviews took place in one of the six small meeting rooms at the Centre and lasted 45 minutes to 1 hour. Interview rooms were booked for at least one and a half hours to allow me 15-30 minutes to prepare for the interview and set up the room.

Interview Session

When participants arrived for the interview, the information in the consent form was reviewed. They were asked to sign a consent form which described the purpose of the study, the right of the participant to withdraw from the study at any time, the anticipated length of the interview, the fact that the interviews were audio-taped, and an assurance of confidentiality. I again clarified that the study was not part of the Quality of Work-life Project at the Centre (in case participants associated me with the Project). This allowed for some social conversation aimed at creating a relaxed atmosphere for the participant before taping began.

Interview Protocol

The interview consisted of three main questions. To guide the conversation, a typed interview protocol was used with probe questions embedded within the main questions. Detailed notes were taken during the interviews. Data from the first two questions are part of the larger qualitative study and are therefore not presented here. The third question of the interview asked participants to talk about clinical trials at the Centre.

In order to describe the study samples, the sex of the participant was noted. Four demographic questions were asked at the end of the interview: participants were asked to identify their main activity at the Centre, the training they needed for this job, their date of birth, and how many years they had worked at the Centre.

Upon completion of the interviews, participants received a small gift certificate to a restaurant (which is located in the workplace as well as in the community at large) in appreciation for their participation. (Participants were not aware of the gift certificate in advance of the interview.) Permission was then

requested to contact participants at a later date so that they could review the transcript of their interview and potentially a draft of the research paper.

Once the participant left the interview setting, I read through my notes and added details based on my memory of the interview. This enabled me to capture as much of the interview as possible on paper in the event that the tapes could not be recovered. In addition, I kept a journal for reflecting upon the interviews and the data collected in them.

Data Verification

The interviews were transcribed verbatim into Microsoft Word. As recommended by Kvale (1996), two-thirds of the transcripts were verified against the tapes. This process led to discussions with the transcriptionist until I was satisfied with the quality of the transcriptions. Sections of the remaining transcripts were checked when I became concerned that something was incorrect or missing from them. As I had conducted the interviews, it was apparent when omissions or possible mistakes existed in the transcripts. When I was satisfied with their quality, the transcripts were sent to the participants for another level of verification. Participants were given a few weeks to respond with comments and/or corrections. The transcripts were then downloaded into NVivo (1999) to assist in organizing, coding and data retrieval.

Ethics

Ethical approval by the Research Ethics Board of the local university and by the Protocol Review Committee of the Cancer Centre was obtained for this project.

Participants who wished to withdraw during or after the study were free to do so. If they wished to withdraw during the interview or if they wished to make

a statement off-tape, the tape recorder was stopped (no-one stopped the tape to make a statement). Participants were informed that no one at the Cancer Center would be notified if they declined an interview or withdrew from the study (there were no withdrawals). Participants were also informed that withdrawal from the study would not affect their relationship with their employer.

Data from the interviews were transcribed, stored, and analyzed off-site at the Institute for Work & Health (IWH) in Toronto to assure participants that their employers did not have access to their data. The tapes and the transcripts of the interviews were kept in a secure location at IWH and given a unique identification number so that individuals were not associated with their data. Data from the transcripts was stored electronically in NVivo (1999). Access to this file was password protected. Participants whose quotations are reported in this paper are not identified by name. Quotes that might compromise the identity of participants were not reported. The interview tapes will be destroyed in seven years as per the policy at the university and IWH.

Data Analysis

The goal of phenomenological analysis is to portray the essential nature of the phenomenon experienced (Moustakas, 1994). Analysis of the data began after the first interview and was an iterative process. The data were analyzed according to Giorgi's (1975; 1989; 1997) procedures. After reading the transcripts in their entirety, they were re-read and segregated into manageable units referred to as "meaning units". I eliminated redundancies and developed a coding template to organize the meaning units; this template was revised and re-organized at least 20 times. Fifty-six meaning units emerged from participants' descriptions of clinical trials at the Centre. Meaning units included: research changes practice, trials affect workload, trials provide hope to patients, trial patients jump the waiting list, involvement in trials is not an option, coordination of trial patients' care,

recruitment of patients, and employees don't get credit for involvement in trials. Once I was satisfied with the discrimination among these units, I began the process of relating the units to each other and to the sense of the whole. Finally, a description of the essential structure of the phenomenon was synthesized.

Results

Two RTs and one clinical trials nurse responded to the site-wide e-mail. Five other RTs were recruited through the Quality of Work-Life coordinator. Three primary care nurses and two other clinical trials nurses were recruited through the nurses on the Quality of Work-Life Steering Committee. During the interviews with nurses, I discovered that clinical trial nurses had a very different role in research from that of the primary care nurses and RTs at the Centre. The trial nurses were responsible for recruiting, treating, and monitoring patients in clinical trials - they only interacted with trial patients. The jobs of these nurses were dependent on the existence of the trials and recruitment of patients to them. They were wholly supportive of the clinical trial process, they mostly spoke about their work responsibilities with trials, and they did not raise the same issues as those of the primary care nurses and RTs. Based on this finding, I decided not to include the data from the interviews with trial nurses in the final analysis. By the tenth interview with the sample of primary care nurses and RTs, no new thematic information was being presented by participants so data collection was considered to be complete. Of the 10 participants, 7 were RTs and 3 were primary care nurses. Participants were 8 females and 2 males with a mean age of 40.6 years. Participants had worked at the Centre from 6 months to 27 years. Two participants responded with comments after reading their transcripts: one confirmed that the transcript was satisfactory to him; the other participant clarified the meaning of one response in the transcript and this revision was incorporated in the transcript.

The following themes emerged and are reflected in the voices of 9 of 10 participants:

1. <u>Nurses and RTs perceived a variety of ethical concerns associated with clinical trials</u>

A variety of ethical concerns associated with clinical trials were discussed by participants. One concern was that study patients were scheduled to jump the waiting lists for treatment and for other treatment-related tests such as blood tests and CT scans:

"We have a multitude of patients in the system to start treatment, and if you're a clinical trials patient generally, you will get a predetermined, you have to start treatment on this date or this date or this date, so those patients are given a date to start treatment, and prioritized through the system to be top of the pile, so to speak...They will jump the waiting list."

"They're [non-trial patients] waiting, say, two weeks. 'You're going to be starting your treatment in two weeks.' And all of a sudden, they tell them 'it's going to be in three weeks now', and it's the booking ladies up at the front that receive these phone calls, 'How come I'm being bumped up?', and try to explain it to someone. It's just not a nice thing because everybody is in the same boat. They all have cancer and they're all trying to get on treatment."

"...they have special CT scans because they have to get [study] patients CT'd by such and such a date and ...the rest of us are waiting six weeks to get a CT scan and they've got spots saved but I mean studies are studies. So the patient will get in much quicker and they'll get their answers much quicker where another patient may have to wait five weeks before they can actually have the CT scan until we know what we're doing with further treatment."

Similarly, participants expressed concern about study patients being given priority when treatment machines broke down:

"...if one of our machines breaks, clinical trial patients are prioritized to be treated ahead of other patients. We have a list that orders how these patients should be treated."

Preferential treatment of study patients appeared to affect some disease sites more than others simply because more patients were eligible for studies in these disease sites:

"If you speak to a nurse who's in breast and prostate clinic, she'll likely be really adamant or angry about the fact that the clinical trials' patients are getting on before her patients are, just because her patients have to wait 3 to 4 months before they get on."

The concern about patients jumping the waiting lists was heightened by the fact that some of these patients withdrew from trials:

"...sometimes, we have patients that start off in a trial then refuse the trial but they're already booked [for] treatment....They don't get cancelled. We won't cancel them."

A second ethical concern expressed was the possibility that patients might not be aware of what they were consenting to when enrolling in a trial. Participants questioned the concept of informed consent.

"A lot of the patients that are on clinical trials when they're on treatment, we sometimes question if they actually knew what they were letting themselves in for because they have to have, say, more x-rays taken or there's a little bit more to their simulation than a normal, standard patient. Sometimes you hear patients say 'if I'd known I had to go through all this, I wouldn't have gone on the study'. I've heard that before...and I've heard therapists say that afterwards about their patients...It's like, has it really been explained to them what it means to be in this study?....As far as we're concerned, patients, when they first come in the door - and we see patients for six, seven weeks – we get to know these patients. They start to open up to you, and we've always known that it doesn't matter what the doctor or nurse say to them when they come through the front door, they could go through clinic, they could go in their simulation, and they won't actually realize what's happening to them until perhaps the second week of treatment."

Some participants did not think it was ethical to ask patients to decide if they wanted to be in a clinical trial after they had been diagnosed with cancer. As one RT said,

"Some patients have anxiety because they have to choose something. Or they're randomized to something. Right. And you, when you're getting treatment you know, you want the best, to give you the best chances of survival and here they're quoting you, well if you do this you have a 50/50 chance. If you do this, we think it's going to be better, but we don't know, we haven't proven it. So, it's like okay, what do I do?"

In making a decision to enroll or not enroll, one participant felt that patients did not always have all of the facts about treatment to make an informed decision:

"Or some of them, I think, don't fully understand. Like they perceive having more radiation is better, when in actual fact, that's not always the case."

Another ethical concern brought up was the perception that patients were administered placebo pills that did not contain an active ingredient. These participants thought that patients were being given sugar pills:

"...you're taking medication and one would get the placebo, it might be just like sugar, and then the other one would get the real thing, and they don't know what they're getting...I don't know how they do it, when they find out at the end they took the placebo. Wow! That must be quite a shock. I think I would feel used."

2. Treating patients enrolled in clinical trials was perceived to add to the workload of an RT

In describing their perceptions of clinical trials, the RTs brought up the added work associated with treating patients enrolled in clinical trials:

"Usually, to be honest, sometimes we [joke] about it. We always say these trials tend to be more work for us a lot of times. I don't know if it's more work or it's

sort of a break in your normal routine because a lot of times these trials have a little bit of a different spin on them as far as the way you have to treat them [the patients]...like I might say this is a real pain I've got to do this and I've got to remind the patient to do this and I got to set this up, so suddenly, I think it's a little bit bothersome."

Such additional work was not an issue for the primary care nurses because, once patients enrolled in a study, their care was taken over by the clinical trial nurses.

In speaking about one of the protocols currently being followed in the radiation therapy department, one therapist said:

"In this particular protocol, the patients basically had to do the whole procedure twice...Sometimes you almost get mad at the person who's bringing this down [from the clinical trials department] because you're like, oh yeah, I have to do this. You're just telling me to do this. You get to walk away from this whole thing and we're the ones having to do this almost basically twice."

Treating patients enrolled in clinical trials meant that the RTs had to keep up with the numerous trial protocols:

"Sometimes, for example, we had one [a patient] that we did a couple of weeks ago, it was a clinical trial. We didn't know it was a clinical trial, so we should have sent him for a contour and we didn't, so he's had to come back for a contour...there was no information on the pink sheet. I didn't know, or it'll say a prostate, I don't know, 90-11. Okay, that means nothing to me. I could have known that three weeks ago, but today, I don't know what that means. You know, and we don't have like something to look it up quickly and say, oh this is what you have to do, like step one, two, three, four."

Keeping up with trial protocols appeared to be particularly problematic for part-time RTs. Approximately, twenty percent of the RTs at the Centre are part-time.

"Some people, they are part-time or so, and they have a different machine every day so then it's kind of hard because you cannot know all the protocols and all the patients. What kind of study they are at or something like that. That can be difficult for the therapists."

Therapists felt that reading up on the protocols was an added stress. After being asked whether she read the protocols, one therapist said:

"Yes. We kind of have to [read them] because certain protocols have patients going for blood tests. Certain protocols require you check films every so often. So, we kind of should. We do have to know what the protocol is about."

Because trial patients had to adhere to strict protocols, this created time pressures for the RTs who had to make sure that these patients' care was coordinated with other treatments and/or tests at the Centre:

"And in some cases, like the head/neck protocol, we have to treat the patients an hour after they've received their chemo, so that, you know, you're dependent on chemotherapy being given at a certain time. Like we're such a regimented schedule that if chemotherapy's running behind, then you're running behind. Once they've missed that 15-minute appointment, you can't make up for that later on. So, you're basically double-booked, or triple-booked. So it causes increased pressure."

RTs were also concerned that their role and/or responsibility in the clinical trials was not always clear to them. One RT spoke at length about this concern:

"...sometimes, it's not very clear if you're supposed to write down, you know, what time you've done it, or if the patient is on which branch, you know, do you do the same things for both? So, I think the instructions in terms of delivering, like for my case, radiation therapy, is sometimes very vague...and we have several clinical trials that go on at the same time. But some are sporadic, like we'll have one patient and then a few weeks later we'll have another patient. Plus, we rotate from one unit to another. So the same people who are doing that first person will not be doing the next person. So, it's like starting from scratch. And if you look at the clinical trial information...it would say, deliver this dose to this target volume, you know, in this amount of time. But it doesn't say the little

gritty things that you have to do....what we would really need would be like a sheet of paper that says this is the type of trial, and this says what the therapist's responsibilities are. Because we don't have time to go through the whole thing, and see, okay, what do we have to do. And some things are not explicit, and so we have to go ask her [trial coordinator]. And then this will be one week and next week when it's someone else, we'll have to go ask her again because they have no clue."

In addition to the lack of clarity regarding trial instructions and the stress of keeping up with trial protocols and coping with the time pressures of coordinating treatment for study patients, therapists were disappointed that their work with trial patients was not acknowledged. Some of the therapists who participated in the interviews were unhappy that they weren't given credit for the work they did with trial patients. As the above therapist said:

"...we just do the work and we don't get any credit."

3. <u>Nurses and RTs did not perceive meaningful involvement in clinical trials as an option</u>

Both RTs and the primary care nurses were dissatisfied with their role in clinical trials. For the RTs, there simply wasn't enough time to become more involved in the trials. Their workload was already affected by trials:

"...like our profession's chronically short of radiation therapists. You tend not to be able to participate [in research] because you're always short staffed and you're, you know, you're trying to do the front line work."

"...we have shifts and we have extended hours and things like that could come into play where there isn't any time for [therapists] to do anything extra, really. It's busy on the floor. To get away to meetings or to do anything on your own, let's say you want to go to the library or other things, they'll support you on it here but you're probably putting your colleagues out a little bit by leaving."

In talking about wanting to get more involved in clinical trials, one RT said:

"How much more of my own time do I want to put in, when I'm in here doing, you know, eight hours plus overtime, and then go home and have little kids, you know? For my career and you know, my brain, that [being more involved] would be great. I would really enjoy that. But for my life, my kids and my husband, I don't know...Because I don't know if I'm willing to go that extra mile....At this point...I don't think they could spare any therapist to let them do research, yeah. I mean, it would be great to have a research department, other centres have it. They have full-time therapists doing research."

Being involved in clinical trials was perceived as a privilege. One nurse talked about being reprimanded for trying to give patients a little information about a particular trial that she thought they might be eligible for:

"I mention a little bit about the study, just to see if they're interested in talking to someone but I have been told by clinical trials that that is not my role to do that...they don't want me to say anything about the study. [Just] 'there's a study. I think you're eligible...Are you interested in a study? Well, what's the study about? I can't tell you. Would you like to talk to someone about the study?' So, I've had my fingers rapped for mentioning a little bit about [the study]."

Another nurse felt that primary care nurses who wanted more involvement in trials were limited to the option of becoming a clinical trials nurse.

One therapist felt that the therapists, in general, were not meaningfully involved in clinical trials because there wasn't an infrastructure to create awareness of how to become involved:

"I think one reason is maybe a lot of therapists may not know that it's an option for them to look into research, possibly....I'm not sure myself, to be honest. So that's why I think that could be that maybe they don't know that's an option to do or they haven't been informed or enlightened about, you know, if you want to take something on your own, what channels to go through, who to talk to. So I

don't know if that's an educational thing or an information thing that's maybe lacking on the floor."

According to another RT:

"We have so many things on the floor that we can do [research] with. It's just we aren't at the mindset..."

Once patients were identified as eligible for, and then enrolled in, a clinical trial, their care at the Centre was taken over by the clinical trials nurse. Some of the primary care nurse participants pointed out that this made them feel like bystanders in the patients' care. For example, one nurse said:

"It's hard because the clinical trials nurses kind of take over the patients...so that's kind of hard because we're not really in the care, like we are with the patients who are not on the study."

In general, both RTs and nurses felt segregated from the clinical research at the Centre because they were not able to have more involvement in clinical trials. One RT felt that some therapists might not buy into the trials at the Centre because they were excluded from trials. This therapist felt that the RT department needed to be integrated more into the studies that their patients were enrolled in so that clinical research could be a more collaborative process.

4. The increased workload and the ethical concerns associated with trials were offset by the view that patients' interests came first

Despite the perception that clinical trials were associated with additional work for RTs as well as presenting a variety of ethical concerns for all interviewees, they were overwhelmingly in support of trials. Overall, the nurses and RTs felt that the trials benefited patients whose interests came before their own. In some interviews, participants downplayed the ethical concerns and/or workload when they started to talk about their patients.

"To me, it takes two seconds to do whatever, to tell them [the patients] to go for blood tests or 'let's have a talk for the next two minutes. How are you feeling?' I think it's just part of our job...That's why you're here, you're here for the patient, so for you to do a little extra for the patient isn't a big deal."

"I think they're [clinical trials are] necessary. I think they're good. I don't know how we can make changes where they're necessary if we don't do these different studies. They're necessary and it's excellent that there are people that really want to do this, initiate and see the trials through..."

"I think that patients have the right to the best treatment, they have the right if they want to be involved in any sort of clinical trial...as long as the patient is getting good care, then I feel that my role as patient advocate has been met."

Trial results might imply that shorter treatments were necessary for patients meaning that more patients could be treated. As one RT said:

"...because of the resources being so limited, these trials have helped. I mean, if you can treat breast, and, you know, maintain long-term control with 16 factions versus 25, then you can ultimately treat more patients in a, you know, in a time period."

As well, trial patients were perceived as getting more attention, and this was viewed positively:

"I think it's great because patients are so well taken care of...they're well cared for because obviously they have to on a weekly basis make sure things are going okay."

Most participants talked about trial patients as having more contact with their nurses and being more informed:

"I think they [trial patients] ask more questions. Other patients just kind of come in and do their thing and that's it. These patients, for some reason, they've been talked to so much that, it's not that it's their right, because it is their right to talk

or ask question, but they feel like they can talk about it because that's what they've done all this time. They'll come in and ask about medications or they'll ask about just anything. I think they do talk more maybe because right from the start, they've been talked to and they've been allowed to ask questions as opposed to the other ones."

As one nurse said:

"...they [clinical trial nurses] can schedule their appointments with their patients according to the patient's schedule but they take their calendar and book those patients in to when they can see them around their time schedule. Myself, I'm assigned to the clinic so it's not my personal visit with the patients that I've booked. I'm in a clinic with 19 or 20 patients plus answering the phone or whatever. So the quality of time that the [study] patient gets with the clinical trials nurse, I think, is blocked off and less interrupted."

Finally, clinical trials were also seen positively because they drove the field of cancer care; this ultimately was a benefit to patients. According to one RT:

"To me, that's what drives our profession, the clinical trials. Without clinical trials, you can't move forward and have change in a treatment area...And without the clinical trials, you wouldn't make advances for treatment, cures. So, you know what I mean, really, it's a very important part of the whole cancer environment."

Essential Description

Nurses and RTs perceived a variety of ethical concerns associated with clinical trials; these concerns included the fact that study patients were scheduled to jump the waiting list and/or were prioritized for cancer treatment, patients were not aware of what they were consenting to when enrolling in trials, and that patients might be given inactive placebos for treatment. Treating patients enrolled in trials was perceived to add to the workload of RTs; treating trial patients, coordinating their care, and reading the study protocols were time consuming. As well, the lack of clarity regarding their role in trials and the lack of credit for their

role in trials appeared to be a concern for RTs. Nurses and RTs did not perceive meaningful involvement in trials as an option for them; involvement in trials was perceived to be a privilege. The additional workload and the ethical concerns associated with trials were offset by the view that patients' interests outweighed those of the nurses and RTs interviewed.

Discussion

Randomized controlled trials (RCTs) are often considered to be the gold standard of research designs (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) and hailed as providing the highest level of evidence in clinical research (Guyatt et al., 2000). Further, regardless of group assignment, cancer patients who participate in clinical trials appear to have higher survival rates (Stiller, 1994) and better outcomes (Schmidt, Gillie, Caco, Roberts, & Roberts, 1999) than patients not participating in clinical trials. This phenomenon has been referred to as the "inclusion benefit" (Lantos, 1999).

Recently, clinical trials have been criticized for being vulnerable to multiple types of bias such as publication bias and time lag bias (Jadad et al., 1998) and for being exploited as marketing tools for new drugs (Horton & Smith, 1999). Trials have also been criticized by feminist researchers for their dependence on chance rather than choice in the allocation of treatment and for false claims of informed consent (Oakley, 1989).

Many drugs and treatments cannot be approved without being evaluated in clinical trials. Although trials are integral to progress in many clinical areas, reports in the literature on how trials are viewed in clinical work environments are limited to physicians (e.g. see McColl et al., 1998; Ross et al., 1999; Taylor, 1992; Taylor et al., 1994; Taylor et al., 1987b; Taylor et al., 1987a; Taylor et al., 1984); these studies are often motivated by low accrual rates. There is little

literature on the perceptions of clinical trials from the perspective of other clinical staff who treat patients enrolled in trials.

The nurses and RTs who participated in the present study perceived a variety of ethical concerns about clinical trials. Participants were not comfortable with the fact that study patients were scheduled to jump the waiting list for radiation therapy and other tests and that they received priority for treatment after mechanical equipment failures. Some participants were also concerned that patients enrolled in studies were given a placebo or "sugar pill". These participants did not appear to be aware that the comparison group in clinical trials for life-threatening diseases is usually the standard treatment for that condition (Streiner & Norman, 1996). This is the policy practiced in trials at the Cancer Centre.

There does not appear to be any literature on physicians', nurses', or RTs' concerns about administering placebos in clinical trials or the prioritization of study patients during resource shortages. The concern about patients jumping the waiting list for radiation treatment has only become a concern in recent years at the Cancer Centre because resources have been scarce; increased patient populations, a shortage of RTs, and aging radiation machines have contributed to the shortage of resources. The Canadian Association of Radiation Oncologists (CARO) recommends that patients should not wait more than four week for radiation therapy from decision to treat (Broadbear, 2000). At the time of conducting the present study, waits of 7 to 15 weeks for radiation treatment existed at the Cancer Centre.

The Cancer Centre is both a health care and research institution so it is not surprising that participants perceived a conflict of interest between the Centre's role in research and patient care. The situation presents a complex resource

allocation dilemma because knowledge generation from trials in this setting is closely tied to future patient care. At the same time, clinical trials at the Centre is perceived to be disadvantageous to non-trial patients, especially when long treatment waiting lists exist. Clearly, the prioritization of trial patients over non-trial patients in such circumstances needs to be reviewed.

The staff interviewed also expressed concern that patients were not capable of giving informed consent due to the context within which informed consent was attained (after being diagnosed with cancer). (Informed consent refers to voluntary consent by a subject to participate in a study after being informed of the purpose, methods, procedures, benefits and risks, and when relevant, the degree of uncertainty about outcome (Last, 2001)). Their concerns are similar to physicians' and patients' attitudes to the informed consent process that have been documented in the literature, suggesting that the nurses' and RTs' concerns in the present study were warranted.

Most of the existing literature on attitudes to informed consent is survey-based. For example, Taylor and Kelner (1987a) found that 95% of physicians reported that informed consent was an intrusion into the doctor-patient relationship and 61% said that they preferred to tell patients about their diagnoses in small installments, arguing that patients needed time to absorb the shock of diagnosis before hearing a detailed description of the uncertainty of treatment options. Although most of the surveys targeting health care providers focus on physicians, some of the samples include other clinicians. Kodish and colleagues (1998) found that a sample of physicians and nurses reported that the greatest barrier to the informed consent process for enrolling children in pediatric oncology trials was the parents' state of shock regarding the child's diagnosis of cancer. These authors concluded that informed consent as currently practiced in pediatric oncology may be overwhelming and unduly burdensome for parents

who are asked to permit clinical trial entry on behalf of their child. In a more recent study by Cox (2000b), physician and nurses of a cancer clinical trials unit acknowledged difficulty in asking patients to make a decision about a trial after telling them that there was nothing more that could be done for them.

Perceived difficulties with the informed consent process are shared by patients who enroll in clinical trials. Cox and Avis (1996) explored the psychosocial aspects of patients' participation in early anticancer drug trials. Though the consultation had taken place only a few days prior to the interview, patients interviewed had poor recall of the initial consultation about the trial they were enrolled in. Participants reported feeling overloaded with the information presented to them and said that there had been very little time to digest what they had been told. Reasons for participating in trials included hope of getting better, a desire to help others and a feeling that they had no other choice. Patients described this hope in terms of being given a chance for life and a feeling that the doctor had not given up on them. However, while the majority of patients recognized that they had a choice about trial participation, they expressed that, in reality, "they had no choice because not participating was equated with death" (p. 182).

In interviewing Phase I and II trial patients about their views at the beginning, during, and after trial participation, Cox (2000a) found that prior to being offered the trial, many patients experienced an increased sense of feeling helpless and distressed. Nearly 80% of the patients interviewed wanted the health care professional to present them with all the information and then to advise them what to do. When patients acknowledged that the choice to participate rested with them, it was clear that such a decision provoked anxiety. Patients who accepted immediately felt that there was no other option and believed that the doctor would not offer them something that was not in their best interest. "The offer of trial

treatment was, therefore, seen as a turning point for these patients" and the trial was described as the "light at the end of the tunnel" because of the hope it offered (p. 316). Less than one-third of the patients were able to describe the purpose of the trial they had been offered.

Featherstone and Donovan (2002) found that eligible patients struggled to make sense of their participation in clinical trials implying that there is a need for clinicians to provide clearer written information or time to discuss the trial with patients. These authors interviewed patients to explore their recall and understanding of trial information and their reasoning about how they were allocated to a treatment. Those patients who agreed to participate felt they were allocated to treatment based on all the tests they had completed and the questionnaires they had filled out; some thought they were assigned to treatment based on rationing; others thought their allocation to treatment was based on fate or destiny. In other words, the concept of randomization was confusing and difficult to patients and many of them formed alternative accounts to explain the treatment allocation.

Concerns about informed consent in the present study suggest that informed consent procedures at the Centre need to be reviewed; staff not involved in this process should contribute to the discussions. Revisions to the procedures such as allowing the nurses to talk about the trials with patients might alleviate nurses', and potentially, patients' concerns. Interestingly, no interviewee suggested that the informed consent should disclose to patients that trial entry might expedite cancer treatment.

The present study found that treating trial patients was associated with an increased workload for the RTs. More time was required to treat trial than non-trial patients and there were time pressures to coordinate radiation treatment with

144

other tests for these patients. As well, the RTs did not always have time to read the trial protocols; this was especially difficult for part-time RTs who constituted 20% of the department. There was also a psychological element to the additional workload. Although RTs were expected to adhere to strict protocols for treating trial patients, it wasn't always clear to them what their role or responsibilities were regarding treatment. One RT felt that some trial data might be compromised because trial instructions were not always explicit regarding the treatment of trial patients.

Trial processes such as obtaining informed consent, recruiting and following up on patients are bothersome to physicians who complain about time constraints as well as administrative hassles (Ross et al., 1999; Taylor, 1992; Taylor et al., 1987a; Taylor et al., 1984). Taylor and Kelner (1984) found that 38% of physicians involved in a trial claimed that they weren't entering all eligible patients into the trial because obtaining informed consent was an arduous task. The physicians complained that the "time required to explain procedures to patients, the rigid rules governing eligibility, the inflexibility of the prescribed treatment formulas…were…insurmountable barriers to enrollment" (p. 1366). It is not surprising that in the present study clinical trials were found to have a workload impact for the RTs whose jobs involved treating trial patients. Although the RTs were not responsible for obtaining informed consent or for recruiting and following up on trial patients, they were required to adhere to strict protocols when treating trial patients.

I had expected that there might be workload issues associated with the treatment of trial patients but I found that most of the conversations about workload were initiated only by the RTs interviewed. When I asked the nurses about workload issues, they explained that primary care nurses at the Centre did not treat trial patients during a trial; they were primarily responsible for non-trial

patients at the Centre. Primary care nurses resumed the care of trial patients only during follow-up visits. At this point, the additional workload of caring for trial patients was minimal.

The additional workload and stress of treating trial patients for the RTs who participated in the present study appeared to be compounded by the fact that RTs were not given credit for their work with trial patients. Besides wanting clearer instructions regarding the care of trial patients, the message from RTs was that they wanted some recognition or acknowledgement for their role in the care of trial patients. This appears to be a reasonable expectation given that the RTs' role is crucial in the conduct of clinical trials. Interestingly, no-one brought up the financial incentives that principal investigators receive for conducting industry trials at the Centre. Perhaps, a portion of such funds should be distributed to the RT department to acknowledge their role in trials.

Another finding of the present study was the perception that meaningful involvement in clinical trials was not an option for both nurses and RTs. Although not articulated by participants, I understood involvement to refer to the design phases of clinical trials. Involvement was not an option primarily because there was no time to get involved in trials. Lack of time as a barrier to being involved in research is not an unusual finding. For example, a study of Ontario nurses' attitudes and interest in nursing research found that a major barrier to conducting research for nurses was lack of time due to nursing shortages, heavy workloads, and direct patient care activities that took priority over research activities (Alcock, Carroll, & Goodman, 1990). Some of the literature on the time commitment required by physicians to conduct clinical trials has already been discussed.

Perhaps more significant than the finding that lack of time was a barrier, was the finding that involvement in trials research was not an option for RTs because no infrastructure enabled RTs' involvement. Due to the large number of trials in radiation therapy, there was a full-time trial coordinator in the department who was solely responsible for these trials. While there was no infrastructure enabling RTs to become involved in trials, the existing infrastructure appeared to be a barrier to primary care nurses. The infrastructure regarding nursing care at the Cancer Centre dictated that patients who became trial patients were transferred from the care of primary care nurses to that of clinical trial nurses for the study period.

In the context of a cancer care environment where clinical trials are plentiful, it is unfortunate that some health care professionals who treat trial patients feel that they do not have opportunities to pursue meaningful involvement in trials. Because nurses and RTs are front line workers and are familiar with treatment procedures and patient needs, it is possible that their input could improve the treatments tested and/or how trials are conducted. It was evident that primary care nurses and RTs were disappointed that they did not have a more meaningful role in research activities. One participant talked about the need to mobilize RTs so that they could learn about and get involved in research studies. This participant felt that having their own research agenda would give recognition to and advance the profession and practice of radiation therapy. As I did not specifically ask nurses or RTs what involvement they would find meaningful, details of possible types of involvement need to be explored in future studies.

Participants' desire to have meaningful involvement in research at the Cancer Centre may have a more serious implication than the desire to participate solely for the sake of conducting research. From an occupational health

147

perspective, groups that are not able to participate in research in an environment that values clinical research, may have lower quality of work-life. Perhaps, the RTs and nurses wanted meaningful involvement in research because they did not feel that their work at the Centre was appropriately valued. The recent Quality of Work-Life Project at the Centre showed that, as a group, the RTs had the lowest quality of work-life scores of all groups of employees on a number of domains including job satisfaction and social support. (There was nothing remarkable about the nursing group scores.)

The current RT shortage and the existing waiting lists for radiation treatment may make it difficult to increase involvement of RTs in trials in the near future. The roles that RTs (or nurses) wanted were not determined so the potential impact of research involvement on existing workload cannot be assessed. It is possible that if RTs felt that they were able to influence decisions concerning trials and if they were acknowledged for their existing work with trial patients, they might be less concerned about the additional workload associated with treating trial patients.

While the participants in the present study associated clinical trials with ethical concerns and increased workload, their concerns were offset by the perception that the interests of cancer patients were paramount and that trials were integral to progress in cancer management. When referring to patient interests in clinical trials, the distinction between present and future patients is important. The participants in the present study appeared to be talking about benefits to both present and future cancer patients, although I did not think to clarify this with them. Many health care providers are unaware that trials are primarily conducted to improve the treatment of future patients (Joffe, Cook, Cleary, Clark, & Weeks, 2001). The interpretation that trials directly benefit the patients enrolled in them has been termed the "therapeutic misconception" (Appelbaum, Roth, Lidz,

Benson, & Winslade, 1987). Evidence suggests that physicians and nurses directly involved in a cancer trials academic unit value the importance of future patients over present patients while non-academic clinicians who are not part of a trials unit hold the reverse view (Cox, 2000b).

A number of recommendations can be made as a result of the findings of the present study. The prioritization of trial patients over non-trial patients at the Cancer Centre needs to be reviewed, especially when treatment waiting lists exist. Nurses and RTs should be informed about the processes used in clinical trials at the Centre to decrease misconceptions about procedures such as the administration of placebos and the purpose of trials (generally intended to improve the treatment of future, rather than present, patients). Other employees at the Centre might benefit from this information as well. The clinical trials department in the Cancer Centre should be made aware of the added workload to RTs who treat study patients and RTs and nurses should be acknowledged for their role in the trial process. A fairer distribution of the incentive funds received for industry trials might be considered to compensate nurses and RTs for their involvement. The trials department should also attempt to involve nurses and RTs in trials so that members of these two professions feel that they can contribute meaningfully to the process. The type of involvement that nurses and RTs desired was not determined in the present study and therefore needs to be clarified. However, it appeared that meaningful involvement might allow nurses and RTs to provide advice on practical issues regarding trial procedures. Further, if nurses were allowed to discuss trial information and the informed consent procedure with patients, this might alleviate their ethical concerns and also provide continuity in care for patients who are considering trial enrolment. Future studies that examine nurses' and RTs' perceptions of clinical trials should separate nurses and RTs as findings from the present study implied that different issues may be of priority to these two groups. It would also be interesting for

future studies to explore the perceptions of clinical trial nurses whose jobs depend on the existence of clinical trials.

References

Alcock,D., Carroll,G., & Goodman,M. (1990). Staff nurses' perceptions of factors influencing their role in research. The Canadian Journal of Nursing Research, 22(4), 7-18.

Appelbaum,P.S., Roth,L.H., Lidz,C.W., Benson,P., & Winslade,W. (1987). False hopes and best data: Consent to research and the therapeutic misconception. Hastings Center Report, 17, 20-24.

Broadbear,S. Smoke, M. (2000). Canadian Association of Radiation Oncologists (CARO), Business Secretary.

Cox,K. (2000a). Enhancing cancer clinical trial management: Recommendations from a qualitative study of trial participants' experiences. Psycho-Oncology, 9, 314-322.

Cox,K. (2000b). Setting the context for research: Exploring the philosophy and environment of a cancer clinical trials unit. Journal of Advanced Nursing, 32(5), 1058-1065.

Cox,K., & Avis,M. (1996). Psychosocial aspects of participation in early anticancer drug trials. Cancer Nursing, 19(3), 177-186.

Creswell,J.W. (1998). Qualitative inquiry and research design: Choosing among five traditions . Thousand Oaks, CA: Sage Publications.

Featherstone,K., & Donovan,J.L. (2002). "Why don't they just tell me straight, why allocate it?" The struggle to make sense of participating in a randomised controlled trial. Social Science & Medicine , 55, 709-719.

Giorgi,A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer, & E. Murray (Eds.), Duquesne studies in

phenomenological psychology. Vol. 3. (pp. 82-103). Pittsburgh, PA: Duquesne University Press.

Giorgi,A. (1989). Some theoretical and practical issues regarding the psyhological phenomenological method. Saybrook Review, 7, 71-85.

Giorgi,A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology, 28(2), 235-260.

Guyatt,G.H., Haynes,R.B., Jaeschke,R.Z., Cook,D.J., Green,L., Naylor,C.D., Wilson,M.C., & Richardson,W.S. (2000). Users' guide to the medical literature: XXV. Evidence-based medicine: Principles for applying the users' guides to patient care. JAMA, 284(10), 1290-1296.

Horton,R., & Smith,R. (1999). Time to register randomised trials. The Lancet, 354(1138), 1139

Jadad,A.R., & Rennie,D. (1998). The randomized controlled trial gets a middle-aged checkup. JAMA, 279(4), 319-320.

Jasper,M.A. (1994). Issues in phenomenology for researchers of nursing. Journal of Advanced Nursing, 19, 309-314.

Joffe,S., Cook,E.F., Cleary,P.D., Clark,J.W., & Weeks,J.C. (2001). Quality of informed consent in cancer clinical trials: A cross-sectional survey. The Lancet, 358, 1772-1777.

Kodish,E.D., Pentz,R.D., Noll,R.B., Ruccione,K., Buckley,J., Lange,B.J., & for the Childrens Cancer Group. (1998). Informed consent in the Childrens Cancer Group. Cancer, 82(12), 2467-2481.

Kvale,S. (1996). Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Lantos,J.D. (1999). The "inclusion benefit" in clinical trials. The Journal of Pediatrics, 134(2), 130-131.

Last,J.M. (2001). A dictionary of epidemiology. (4th ed.). New York: Oxford University Press.

McColl,A., Smith,H., White,P., & Field,J. (1998). General practitioners' perceptions of the route to evidence based medicine: A questionnaire survey. BMJ, 316, 361-365.

Morse,J.M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. (pp. 220-235). Thousand Oaks, CA: Sage Publications, Inc.

Morse,J.M. (2000). Theoretical congestion. Qualitative Health Research, 10(6), 715-716.

Moustakas,C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage Publications.

NVivo [Computer Software]. (1999). Victoria, Australia: Qualitative Solutions and Research Pty Ltd.

Oakley,A. (1989). Who's afraid of the randomized controlled trial? Some dilemmas of the scientific method and "good" research practice. Women & Health, 15(4), 25-59.

Polkinghorne,D.E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology. (pp. 41-60). New York: Plenum Press.

Ross,S., Grant,A. , Counsell,C., Gillepsie,W., Russell,I., & Prescott,R. (1999). Barriers to participation in randomised controlled trials: A systematic review. Journal of Clinical Epidemiology, 52(12), 1143-1156.

Sackett,D.L., Rosenberg,W.M.C., Gray,J.A.M., Haynes,R.B., & Richardson,W.S. (1996). Evidence based medicine: What is is and what it isn't: It's about integrating individual clinical expertise and the best external evidence. BMJ, 312(7023), 71-72.

Schmidt,B., Gillie,P., Caco,C., Roberts,J., & Roberts,R. (1999). Do sick newborn infants benefit from participation in a randomized clinical trial? The Journal of Pediatrics, 134(2), 151-155.

Schwandt,T.A. (2001). Dictionary of qualitative inquiry. (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Sokolowski,R. (2000). Introduction to Phenomenology. Cambridge: Cambridge University Press.

Stiller,C.A. (1994). Centralised treatment, entry to trials and survival. British Journal of Cancer, 70(2), 352-362.

Streiner,D.L., & Norman,G.R. (1996). PDQ epidemiology. (2nd ed.). St. Louis, Missouri: Mosby.

Taylor,K.M. (1992). Physician participation in a randomized clinical trial for ocular melanoma. Annals of Ophthalmology, 24, 337-344.

Taylor,K.M., Feldstein,M.L., Skeel,R.T., Pandya,K.J., Ng,P., & Carbone,P.P. (1994). Fundamental dilemmas of the randomized clinical trial process: Results of a survey of the 1,737 Eastern Cooperative Oncology Group investigators. Journal of Clinical Oncology, 12(9), 1796-1805.

Taylor,K.M., & Kelner,M. (1987a). Informed consent: The physicians' perspective. Social Science & Medicine, 24(2), 135-143.

Taylor,K.M., & Kelner,M. (1987b). Interpreting physician participation in randomized clinical trials: The physician orientation profile. Journal of Health and Social Behavior, 28, 389-400.

Taylor,K.M., Margolese,R.G., & Soskolne,C.L. (1984). Physicians' reasons for not entering eligible patients in a randomized clinical trial of surgery for breast cancer. New England Journal of Medicine, 310(21), 1363-1367.

CHAPTER 6

SYNTHESIS: PERCEPTIONS OF
WORKPLACE AND CLINICAL RESEARCH
AMONG CANCER CARE EMPLOYEES

Purpose of Chapter

In this chapter, I address the primary objective of this thesis and synthesize the findings from Chapters 3-5 that are relevant to this objective. The primary objective of this thesis was to explore employees' perceptions of: a) the Quality of Work-Life Project (QWL) where they were the subjects of research; and b) clinical research where patients were the subjects of research. These perceptions were compared based on the extent of employees' involvement in research. I then review the methodological implications and the implications for various stakeholders at the Cancer Centre based on the findings of Chapters 3-5. In addition, my overall impression of the findings is discussed.

Data Collection

The findings presented in this chapter are based on the 32 interviews that were conducted at the Cancer Centre between September 2001 and March 2002. Twelve employees participated in the study on the participatory process in research (Chapter 3), 10 participated in the study on the Quality of Work-Life (QWL) Survey (Chapter 4), and 10 participated in the study on clinical trials (Chapter 5). As an introduction to the interviews, all participants were asked about their perceptions of clinical research and the QWL Project at the Cancer Centre. These questions were aimed at introducing the topic of research at the centre and they encouraged participants to reflect on both clinical and workplace

research in general. These questions eventually led to discussions concerning the secondary questions that were the focus of Chapters 3-5.

From this point forward, I refer to the three study samples as: the Participatory Group (participants on the QWL steering committee); the Survey Group (participants who completed the QWL Survey); and the Trials Group (nurses and RTs who treated patients enrolled in clinical trials).

Primary Objective of Thesis: Themes Across the Three Study Samples

Many of the following themes are consistent with the findings presented in Chapters 3-5 and so are only briefly addressed here. As might be expected, findings that were not directly related to the primary (or secondary) objectives of this thesis emerged from the interviews. Two such themes are also discussed in this section. Quotations from 17 of the 32 participants are reported.

Themes related to the primary objective

There was a status difference in the research at the centre

Participants appeared to value clinical research and patient interests over the QWL Project and their own interests; in other words, the subject of research (patients versus employees) determined the importance of that research. Those who considered the QWL Project as research perceived this Project to be of secondary importance at the centre. For example,

"I definitely see it [QWL Project] as lesser research. Well, to be honest, not as important as, you know, from basic research to clinical trials because, I mean, that is our business..."

"...if we had a society of limited funds, and one was to be cut [clinical research versus QWL Project] and the other wasn't, then I would choose clinical research above research of the workplace. That's just the way I'm programmed. We do everything for the patients and the things that affect the patients most directly I think are most important."

The QWL Project was often praised not for its benefit to employees but rather its ultimate benefit to patients. This link had been promoted at the centre. However, the Project was still considered to be less important than the clinical research at the centre that had a direct link with patient interests. Laboratory research conducted at the centre was similarly less valued. Most participants were aware that laboratory research was conducted on the fourth floor of the centre (only a few were able to describe that research). The general impression was that laboratory research wasn't truly important until it was transferred into clinical research.

The perceived status difference of research was partly attributed to the perception that medical staff that treated patients had an elitist attitude and that they were valued more than the non-clinical staff:

"...from what I've seen, these health care workers have a real, for the most part, prima donna attitude about themselves, because they touch the patients and they're allowed to, and I think that's very unfortunate..."

The valuing of clinical research over the QWL Project was also evident in the tone that participants used when speaking about these two types of research. In general, participants were overwhelmingly supportive of the clinical research at the centre and they highlighted the benefits of clinical research. Although supportive of the QWL Project, participants tended to focus on the negative aspects of this project. As demonstrated in this thesis, the Survey Group raised many negative issues related to the QWL Survey.

One Trials Group participant who acknowledged her own preference for clinical research over the QWL Project was concerned that clinical research was valued over workplace research:

"The focus is always on patients. It's never necessarily on staff...All the staff here will not do anything to compromise a patient's treatment. For a lot of the staff, treatment of a patient is reward enough, but that only lasts so long for some people. So, you've got to research into how you can make things better for the staff."

Ironically, no one judged the two types of research (clinical versus workplace) using life and death terminology. Clinical research was perceived as more important because it dealt with patients rather than staff; this valuing of clinical research was not discussed in relation to life and death. Perhaps, participants felt that it was too obvious to make such a distinction between the QWL Project and the clinical research at the centre.

Meaningful involvement in clinical and workplace research was perceived to be a privilege

Given the overall support for clinical research at the centre, it is not surprising that participants wanted meaningful involvement in that research. During the interviews, participants were asked to describe their involvement in research at the centre. I clarified that the term "research" included both clinical research and the QWL Project. Most participants had varying levels of clinical research involvement. Despite this involvement, most participants indicated that they wanted more involvement and that they wanted to know more about this type of research. This was probably due to the fact that participants were aware of the extent of the research at the centre and that they were involved in only a small part of that research. This finding was vocalized more by the Survey and Trials Group participants. (It could be argued that the members of the Participatory Group were able to fulfill the desire to be more involved in clinical research by participating in the QWL Project at the centre.) Participants who felt alienated from the clinical research at the centre described themselves as "not actively

counted among the researchers", "on the outer circle", and "from the outside looking in".

The privilege of being involved in clinical research was addressed in Chapter 5. As shown by the Trials Group interviewees, meaningful involvement in clinical trials was perceived to be an option not available to them. The privilege of being involved in workplace research was implied in both Chapters 3 and 4. As demonstrated in Chapter 4, not all participants were aware that the survey results were being presented to the centre at large as well as to their individual departments. Further, not everyone who knew about the presentations was able to attend them. These findings were interpreted as lack of access to research at the centre. Despite the involvement in research allowed by the QWL Project, QWL steering committee members were not able to participate in all aspects of the Project. For example, as reported in Chapter 3, some groups represented on the committee were not guaranteed time-off from their regular duties to attend QWL meetings.

One participant in the Survey Group also perceived involvement in the QWL Project itself as a privilege. This participant had expressed an interest to be on the committee and had been turned down because the committee was full. This participant felt denied involvement in the QWL Project. (Concern that the QWL Committee might attain an elitist profile was discussed in Chapter 3.)

There were challenges to the notion of participatory research as the term is traditionally understood

As demonstrated in Chapters 3 and 4, the participatory research process applied to the QWL Project at the Cancer Centre posed many challenges. The Participatory Group questioned the *process* of participatory research; the Survey Group questioned the *product* of that participatory research (the QWL Survey).

The Survey Group felt that the survey failed to address QWL issues that were important to them. These findings led me to question the communication process between the QWL steering committee members and the employee groups they represented. This communication was supposed to occur so that the steering committee could identify problem areas that could be addressed in the survey. How had steering committee members solicited input? Findings from Chapter 4 also led me to question the extent to which members of the Steering Committee were representative of the employee groups at the centre.

Some suggestions on how to improve the participatory nature of the Project in a workplace setting were made in Chapter 3. For example, trust issues between employees and management on the QWL steering committee warrant attention and difficulties experienced by some members in attending project meetings need to be addressed.

Strictly speaking, as discussed in Chapter 3, the QWL Project was not participatory research as the term is traditionally understood (the Project was compared with Hall's (1979) criteria for participatory research). However, the question of whether true participatory research was feasible in a workplace setting was also raised. To date, participatory research has been successful in community settings, however, such settings might be conducive to its success. Given that a formal structure of power, relationships, and salaries exist in workplaces, participatory research may not be appropriate for workplace settings - the structure of the setting may over-ride the aims of this method. If this is the case, occupational researchers may want to reconsider using participatory research methods in workplaces.

Hidden costs of conducting clinical research

Chapter 5 focused on some of the perceived costs of conducting clinical trials at the centre. The workload associated with clinical trials for RTs was highlighted in that chapter. The RTs in the Participatory Group also perceived that treating patients enrolled in trials increased their workload. Workload associated with clinical research was discussed by participants across all samples. Because clinical research was integral to most participants' jobs at the centre, there were workload implications for being involved in various aspects of this research. There was work associated with the paperwork, billing for study medication, pulling charts in health records, and dispensing medication to study patients. There were also workload implications associated with the outcomes of clinical research. For example, some RTs in the Trials Group talked about the results of studies leading to an increase or decrease in the time it took to treat each patient.

While the work associated with clinical research was most often part of participants' job descriptions, participants on the QWL Project held voluntary positions on the Steering Committee. Interestingly, while participants on the Steering Committee did not complain about the additional work associated with the Project, those from several employee groups acknowledged that they could not always attend meetings or did not have the time to take on additional tasks related to the Project because of their existing workload. Therefore, existing workload prevented participants from being involved in all aspects of the QWL Project but participation in the Project itself was not perceived as work.

The ethical concerns associated with clinical trials emerged as a theme from the Chapter 5 interviews. Although not everyone interviewed for Chapters 3 and 4 was aware that study patients jumped the waiting lists for radiation therapy, ethical concerns about clinical research, including the adequacy of informed

consent, were discussed by participants across the three samples. For example, one member from the Participatory Group said:

"...we're currently doing a study where you know, a woman who's recently diagnosed with breast cancer comes to discuss chemotherapy with medical oncologists. So, at that visit, she may discuss why she needs chemotherapy versus why she may not choose to take it. And then, if she decided to take it, she has to have another big discussion about a 3-arm randomized clinical trial for chemotherapy. That discussion takes at least 45 more minutes, and that woman you know, is already overloaded with information before she even walks into our building. And by the time she comes for that consult and spends 90 minutes and learns all the things that we propose, and then needs to make a decision about a clinical trial, I think that puts her under a great deal of stress and strain. I think it's impossible to make an informed decision under those circumstances and I feel really strongly that you know, that's a real negative to clinical trials."

Other ethical concerns were also expressed. For example, one participant spoke of the ethics of *not* doing research and the potential impact on patients:

"I think that some of the research that we are doing is so ethical because a lot of it is around efficiency of services and so if we actually do not do that, we cannot improve our own system...We did a study on giving radiation for a shorter period, and if we did not do that study, we would have disadvantaged a much broader group of patients by using longer treatments."

Another participant felt that the ends justified the means when it came to the ethical dilemmas of conducting clinical research. This participant felt that the ultimate benefit of trials outweighed the ethical dilemma of having trial patients jump the waiting list for radiation therapy. Although this participant was also concerned about the waiting lists, the perception about the overall benefits of trials was similar to that of the Trials Group:

"I think the value in the trial is...more important than adhering strictly to the waiting lists."

Hidden costs associated with research methodology were also discussed in the interviews. Misunderstandings about methodology applied to both clinical and workplace research. There were some misunderstandings about the survey process and the clinical trials process. Participants who had completed the QWL Survey wanted a more transparent survey that labelled domains of interest. As noted in Chapter 5, one participant was concerned about the administration of placebos in clinical trials not knowing that placebos were only usually used if there was no standard therapy for patients. A few participants in the Chapter 3 and 4 groups also expressed concern about placebos being given to patients. Again, it appeared that these participants were not aware of when placebos were appropriate.

The success of research was gauged by action

Participants in all three samples perceived that the success of both workplace and clinical research was gauged by action. Themes related to use of research to inform action were discussed in Chapters 3 and 4: in Chapter 3, participants felt that being involved in participatory research without having power to implement changes in the workplace was unacceptable; in Chapter 4, participants felt that the impact of the survey was more important than the survey itself. I will not spend much time on this theme as the reader can refer to Chapters 3 and 4 for a more detailed discussion. The perceived lack of action concerning the QWL Project probably contributed to the valuing of clinical research above workplace research at the centre; compared with the QWL Project, clinical research was seen as having definite outcomes and direct action associated with those outcomes. This impact difference was discussed by one participant:

"...this drug didn't work because this agent is not useful, but we learned something from it. Whereas, if nothing comes out of the quality of work-life survey that we're doing, then people will say, oh, that's just system and

bureaucracy and...I guess the whole scenario around negative results for clinical research is something that you learn from and move on... in this organization, change happens so slowly...it can take a year or more to make a decision on something. And most people have forgotten about it by the time it's resurrected yet again."

<u>The interests of patients outweighed those of employees</u>

One finding in Chapter 5 was that the interests of patients were perceived to outweigh those of nurses and RTs. A similar theme resonated for all participants interviewed for this thesis. Despite the workload and ethical concerns associated with clinical research, participants perceived continuously improving patient care as *the* priority at the Cancer Centre and they appeared to be supportive of both clinical and workplace research because of its ultimate impact on patients. The reader can refer to Chapter 5 for a more detailed discussion on this theme.

Themes not related to the primary objective

<u>There was a research culture at the Cancer Centre</u>

There were many similarities among the three samples interviewed for this thesis, probably attributable to the reality that clinical research was part of the working lives of all participants. As alluded to previously, secretaries typed grant proposals and were responsible for data entry, health records employees pulled study charts, radiation therapists and nurses treated patients enrolled in clinical trials, physicists conducted research related to the application of treatment technology, finance employees billed pharmaceutical companies for study medication, and pharmacy employees dispensed medication to trial patients. Since the spring of 2000, the QWL Project has been part of the working lives of approximately 20 employees. Participants interviewed for this thesis were involved, or perceived themselves to be involved, in research in some way (not necessarily meaningful involvement) and viewed the Cancer Centre as a very research-oriented environment. As one interviewee said:

"...if you don't buy into research and you don't buy into evidence-based practice, this is a very difficult place to work"

The Cancer Centre has a national and international reputation for conducting cancer research. Most participants were aware of this and their pride in the centre was evident. Because the Cancer Centre is a research institution as well as a patient care facility, some participants felt that the centre engaged in activities that were not done elsewhere e.g. adopting research into practice. One participant spoke about what it meant to be part of such a research culture:

"Last week...a big research paper was published in the New England Journal of Medicine. And we had a meeting at 5 o'clock in the afternoon about this new paper and what it was going to mean to our work. And I don't think that there's very many places in the world where you could work, where you could actually review a big important paper on the day that it was published, to try to decide how it would influence your clinical practice. I was very proud of that."

Perceptions of research were framed in the context of clinical research

Participants' perceptions of research appeared to be framed in the context of clinical research. The term "research" was often interpreted as "clinical research" rather than "workplace research". Many participants who were involved in research other than clinical research denied knowledge of research at the centre because they had equated the term "research" with "clinical research". Their own research was a minor aspect of the research at the centre and they did not assign the same importance to it as they did to the clinical research at the centre.

Participants' framing of research in the context of clinical research especially became evident when participants described their perceptions of the QWL Project. One positive aspect of the QWL Project was that it "wasn't so invasive [i.e. did not involve giving blood samples or taking medications]". The

weaknesses of the project were that it lacked a "control group", a "benchmark", or a "gold standard". One participant spoke about the danger of giving employees too much information about the QWL Project because that meant that the "blinders" would be taken off. (This contradicts the finding that other interviewees in the Survey Group wanted the domains of the QWL Survey identified.)

Employees' perceptions of the QWL Project as a research endeavour were influenced by the clinical research environment to which they were accustomed. The project was not viewed as traditional research: it was perceived as not having an interesting or focused research question and there were no pre-determined outcomes. Some employees referred to the project as "qualitative research". One participant referred to it as "philosophical research".

Finally, not all employees perceived the QWL Project as research. When asked to describe the research at the centre, not everyone acknowledged the QWL Project as part of that research. When prompted by me to specifically talk about the QWL Project as a research project, some participants still did not perceive it as research:

"I never really thought of that [QWL Project] as part of the research, but it's certainly a good idea because it gives people a chance to voice areas of concern more than anything and it can be justified because it's actually hard data or it's done officially."

The Project was referred to as a "quick fix for morale", a "union project", and a "management project". One participant referred to the Project as a human resources endeavour:

"I see [the] Quality of Work-Life [Project] as really being, very frankly being, of a human resources type of thing."

Comparison of Employees' Perceptions of Research Based on their Role in Research

The three samples in this thesis were selected based on the extent of their involvement in research: the Participatory Group was considered to have an <u>active</u> role in research because it was involved in the design and implementation of the QWL Project; the Survey Group was considered to have a <u>passive</u> role because its main involvement in research consisted of completing the survey – these employees did not have direct involvement in the design of the survey; the Trials Group was considered to have an <u>indirect</u> role in research because its nurses and RTs did not participate in the design or reporting of the research – they simply treated patients enrolled in trials.

During the interviews, it became apparent that participants in the three categories shared more similarities than differences in their perceptions of clinical and workplace research. For example, although the nurses and RTs who were on the QWL steering committee were more aware of the details of the QWL Project and more knowledgeable about research methodology primarily due to instructional sessions during committee meetings, they reported similar perceptions of research to those of the Trials Group. And although the Survey Group was less informed about the details of clinical research and the QWL Project than the Participatory and Trials Groups, this group's perceptions of research did not differ substantially from those of other participants. As a result, the previous section focused on the general findings across all three samples regarding their perceptions of clinical research and the QWL Project at the Cancer Centre.

One difference among the nurses interviewed for Chapters 3 and 5 is worth noting; the nurses on the QWL steering committee perceived that they had

more involvement in clinical research than did the nurses in Chapter 5. I am not sure if this was a matter of perception or whether these nurses were an exception to primary care nurses in general at the centre. Nurses on the committee did appear to have more involvement in various projects or research teams than other nurses at the centre even if they did not necessarily have direct involvement in clinical trials. Such perceptions of involvement might also be reflective of a broader definition of research held by the nurses on the steering committee. For example, one nurse on the committee thought that she was involved in the clinical research at the centre because she helped to identify potential patients to the clinical trials nurses; another nurse on the steering committee considered her role in looking after follow-up patients in clinical trials as part of the clinical trials research at the centre. The nurses interviewed for Chapter 5 did not perceive these two activities as involvement in research.

Implications of Thesis for Research Methodology

As a student in Health Research Methodology, I feel that it is necessary for me to comment on the main implications that this thesis had for me as a researcher.

Process of conducting research in a small workplace and the issue of confidentiality

There were about 450 employees at the centre at the time I conducted the interviews for this thesis. Having spent a fair amount of time at the centre and having given many presentations regarding the QWL Project (including Grand Rounds for 2001 and 2002), I felt that I had become a familiar face to employees. Throughout my interviews, I worried endlessly about compromising the identity of participants who might be seen with me in the hallways or meeting with me in the interview rooms. During the interviews, I made an effort to close window blinds and to seat participants with their backs to the door. However, no-one

appeared to be concerned that they might be seen as an interviewee: all participants chose to be interviewed at the centre (rather than at their homes or at another location that was convenient for them); some participants preferred me to interview them in their offices; further, all participants asked me to e-mail their transcripts to their work email address (when, in principle, employers had the right to read their emails). Employees whom I had interviewed acknowledged that they knew who I was in front of their colleagues; they approached me to say "hello" and/or to ask how my research was going. I concluded that those who volunteered to participate in the interviews were not concerned about being identified as a participant in my study and that they had accepted my assurances that they would not be identifiable in the written manuscripts.

Confidentiality was maintained when participants talked about specific issues that were not public knowledge. For example, some participants had specific workload concerns; others disclosed information that only a few people at the centre would have access to. This information was extremely difficult to report and in most cases, was not reported to avoid others identifying the speaker from the quotation or from a description of the quotation.

Ironically, qualitative research can generate findings that are rich in context and depth. In the studies that make up this thesis, a lot of the "rich" data were "watered down" and quotations not reported in order to protect the identity of participants. In a single small workplace, this is unavoidable. The loss of some richness in data reporting might have been reduced if there had been larger employee groups at the centre from which to draw interviewees or if I had sampled from a number of cancer centres in Ontario.

Did this research contribute to participants' expectations of change as a result?

Over the course of the interviews, I became concerned that perhaps my own research was conveying a certain expectation to participants. Participants were very open about their own QWL issues and some were very vocal about the changes they desired in their work environment. For example, the participants who completed the QWL Survey wanted action concerning the results of the survey; they also wanted the survey domains to be labelled. The RTs in the Trials Group expected clarification about their role in trials and they expected to be credited for their work with trial patients.

At the beginning of each interview session, I told participants that my research was not related to the QWL Project. Still, most participants knew that I was involved in the QWL Project at the centre. Although this potential conflict of interest was discussed in Chapter 2, it didn't really become a conflict for me until later in the thesis. My continued involvement in the QWL Project and the corresponding desire to improve QWL at the centre made me feel guilty about keeping the findings from my thesis research to myself. I felt a strong obligation to disseminate such findings to those who had the authority to make the appropriate changes. The feelings of obligation were also likely due to the personal contact I had with participants; while analyzing the data and writing this thesis, I could associate most complaints and/or concerns with the person who voiced them. I look forward to relaying the findings back to the steering committee and to the centre as a whole (see Chapter 2 for dissemination plans).

My "non-bracketed" assumptions were challenged

During the course of my research, I began to realize that I held numerous assumptions other than those that were bracketed in Chapters 2-5. Many of these assumptions were challenged. For example, I assumed that participants, especially nurses and RTs, would know what "randomized controlled trials"

(RCTs) were. However, I discovered that this was not a term that participants were familiar with; RCTs were known as "clinical trials" or "Phase III trials" to the nurses and RTs. I assumed that clinical trial nurses and the primary care nurses would hold the same views about clinical trials but they turned out to hold different perceptions. As a result, the data from the clinical trial nurses were summarized briefly but otherwise excluded from Chapter 5 and the final analyses. I assumed that employees would consider the QWL Project as research but not all participants perceived the Project as a research endeavour. I assumed that I could report demographic information such as the job titles of participants in the three study samples but it became clear early on in the interviews that this might compromise the identity of participants. I assumed that I could separate employees' involvement in research to "active", "passive", and "indirect" but this distinction did not affect participants' perceptions of research as I had expected. In fact, it was difficult to find participants whose involvement in research consisted solely of completing the QWL survey.

I was especially optimistic that participants would arrive to the interviews on time. Because the Cancer Centre is a busy place, I assumed that participants would be prompt. This assumption was over-optimistic. About 80% of participants were late; some were 20-30 minutes late. Several participants had forgotten about the interview and I had to locate them. As the theme concerning the status difference of research at the centre began to emerge, I became acutely aware that my own research was even less important than the workplace research at the centre. Fortunately, I generally allowed enough time between any two successive interviews so only in one case did a participants' lateness interfere with the following interview.

Another non-bracketed assumption that I held concerned the definition of research. I consider research to be a purposeful and systematic process aimed at

generating knowledge. The process can be inductive (inferences from observations to theories) and/or deductive (predictions based on theories). While this definition is quite broad, I learned that participants had a variety of views about what constituted research (see section "Perceptions of research were framed in the context of clinical research"), some of which did not include the QWL Project. If we had shared a similar definition of the term "research", the content of the interviews may have been different. In retrospect, it would have been interesting to ask all participants to define research at some point during the interview. Although the interview protocol included the probe "What do you understand by the term 'research'?", this question only came up in approximately half of the interviews. Even then, it was a difficult question for participants to answer so not much time was spent on it.

The process of conducting three qualitative studies simultaneously

When I first drafted up the proposal for this thesis, I had not thought about the implications of conducting three qualitative studies simultaneously. Fortunately, with the exception of sampling techniques, the procedures for the three studies were similar. For the first couple of months, I tried to design the data collection so that I would focus on interviewing participants for each sample separately. However, I realized that this was not feasible for a number of reasons. Firstly, I could not recruit enough participants for each sample quickly enough. Secondly, I had to be flexible to ensure that I interviewed participants for Chapter 3 before they rotated off the QWL Steering Committee. Finally, because the interviews entailed for me a 2.5 hour commute each way, I tried to schedule two interviews per trip. This often meant scheduling participants from two different samples on the same day. (I believe that scheduling two interviews in a given day did not compromise the quality of the data collected because I scheduled at least 30 minutes between the interviews to allow myself time to take detailed notes and to reflect on the interviews.)

In order to maximize my productivity in conducting the three studies, I developed the following organizational strategy. I kept a separate file on each sample/chapter; my notes and the relevant literature were incorporated into this filing system. I also separated the three samples in NVivo. This software package has the capability of grouping record numbers into sets. In this way, I was able to look at all samples together when working on the primary objective of this thesis but I was also able to separate the samples when I wanted to work on an individual chapter.

In the late analyses stages, the benefit of having conducted the three studies simultaneously became apparent to me. Despite the organizational challenge, the simultaneous data collection and analyses had allowed me more time to ruminate on each of the chapters and to pull them together to make sense of the whole. In other words, my reflections on the 'whole' had helped me with my reflections on the 'parts', and vice versa. However, once I began the formal writing process, I had to narrow my focus so that I could concentrate on the subject of each chapter as well as the literature and implications for that chapter. Focusing on each chapter in turn at this point made sense to me, as the readers of each chapter (in its published version) would not have the context of the whole study to which they could refer. However, I acknowledge that while conducting data collection and analyses simultaneously was advantageous to synthesizing the thesis results, it may have been disadvantageous to my work on each chapter; when working on a particular chapter, knowledge of the other chapters likely had an influence.

Implications of Findings from Chapters 3-5

This section reviews the implications of Chapters 3-5 for the various stakeholders at the Cancer Centre.

Implications for employees

- Treating patients enrolled in clinical trials was perceived to add to the workload of RTs in the Trials Group who had to keep up with numerous protocols and adhere to strict timelines for treatment. These findings suggest that health care professionals such as nurses and RTs who are employed in a cancer centre that participates heavily in clinical trials should be prepared for the additional work responsibilities associated with participating in clinical research.

Implications for the Quality of Work-Life Steering Committee

- The Participatory Group felt that while the role of management in participatory research was important, it was initially uncomfortable with the physical presence of management at meetings. Greater trust between employees and management on the Steering Committee might be promoted if the committee's Terms of Reference included a statement that work on the committee could not be used as a basis for evaluating members' performance at their usual job.

- Several members of the Participatory Group pointed out that they were not able to attend QWL Project meetings due to personnel shortages that resulted when they left their work area for a couple of hours. I suggested that the steering committee recruit more than one representative from employee groups that experienced personnel shortages when an employee was absent for a couple of hours. This might improve representation from such groups and would also allow members to rotate their attendance at meetings so that the additional work resulting from an employee's absence would not always be left to the same individuals.

- Talking about the QWL Survey led the Survey Group to discuss their own QWL issues; many issues presented by these participants were not captured in

the QWL Survey. I recommended that the Steering Committee pretest the survey in employees at the centre in order to evaluate, and potentially improve, its comprehensiveness and applicability.

Implications for managers

- As mentioned, some members of the Participatory Group were not able to attend QWL Project meetings due to personnel shortages in their work areas when they were absent. In order to maximize the potential of the QWL Project, managers should support meeting attendance from employees who are on the QWL Steering Committee. It is the responsibility of managers to develop strategies to handle personnel shortages that might occur as a result of a staff member being absent for a couple of hours.

- Many staff members gauged the success of the QWL Project by whether changes were made as a result of the project. As the QWL Project is an ongoing endeavour, managers have an obligation to develop formal strategies to respond and intervene based on the survey results.

- The Survey Group expressed concerns that departments or groups of employees were labelled based on the QWL Survey results. I proposed that those groups labelled as having good QWL might be overlooked by QWL intervention strategies. It is important that managers respond to the QWL Survey results regardless of whether their group had low or high QWL scores.

- Managers should inform new clinical staff members that participation in clinical research at the Cancer Centre may have an impact on their job responsibilities.

Implications for the clinical trials department

- The finding concerning clinical trials and workload issues for RTs suggests that the clinical trials department should review the impact of trials on

employees who treat study patients and give credit to them for their present roles in trial procedures.

- Although caring for trial patients, nurses and RTs in the Trials Group did not perceive meaningful involvement in clinical trials as an option for them. I recommended that the trials department should find ways for nurses and RTs to contribute meaningfully to the trial process. Because frontline workers have a better understanding of clinician-patient interactions, their contribution might improve the trial process and ultimately patient care.

- The Trials Group raised ethical concerns about the informed consent process. In collaboration with staff, the clinical trials department should consider reviewing informed consent procedures to ensure that patients understand to what they have consented. The informed consent process might appear less intrusive to patients if other health care providers such as the primary care nurses and RTs were allowed to discuss the process with them.

- When study patients are scheduled to jump the waiting list for radiation therapy and other treatment-related tests, there may be an ethical obligation for the clinical trials department to acknowledge in the informed consent process that trial enrolment might expedite cancer treatment.

Implications for QWL Researchers

- QWL researchers need to ensure that 'off the shelf' measures are pertinent to a particular worksite and encompass all meaningful QWL issues of a given work environment.

- It may be difficult to conduct participatory research in a work environment given that power and a hierarchy of relationships interfere with employees being considered 'equal'.

Implications for the Cancer Centre

- Some members of the Trials Group were misinformed about clinical research processes such as the use of placebos in clinical trials. It is important that such processes are carefully explained to staff so that misconceptions about them are reduced.

Implications for Cancer Care Ontario/policy makers

- The Trials Group concern about study patients jumping the waiting lists for cancer treatment implies that preferential treatment of these patients in this context needs to be reviewed. This is especially important given the present resource constraints in cancer treatment.

My Overall Impression of Thesis Findings

In exploring participants' perceptions of clinical and workplace research, I discovered that research was a part of all their working lives and that participants perceived that meaningful involvement in that research (clinical and workplace research) was a privilege. Clinical research was especially integral to participants' working lives. Despite the workload and ethical concerns associated with clinical research, clinical research was perceived to be more important than the QWL Project. The perceived greater value of clinical research over workplace research was partly due to the perception that patient interests outweighed those of employee interests. This status difference was also attributed to the perception that clinical research led to action whereas participants doubted that action would come about as a result of the QWL Project.

Gini's (2001) discussion on the notion of 'you are what you do' appears to be central to participants' perceptions of research. According to Gini, "where we work, what we do at work, and the general climate and culture of the workplace indelibly mark us for life" (p. 2). The role of work in shaping one's identity has

been discussed earlier by other researchers as well (e.g. see Ashforth & Mael, 1989; Borrero & Rivera, 1980). One's work identity may be defined by the particular type of job that one holds and/or by the organization for which one works (Chatman, Bell, & Staw, 1986). Throughout the interviews for this thesis, participants' perceptions of clinical and workplace research appeared to be linked more to *where* they worked rather than to *what* they did at work. In other words, many of the general findings of this thesis appear to be related to participants' identification with the Cancer Centre as an organization rather than their particular jobs at the centre.

Many possible factors can lead an individual to identify with his or her organization. For example, it has been proposed that the distinctiveness of the group's values and practices lead to identification (Oakes & Turner, 1986). The distinctiveness hypothesis holds that novelty attracts individuals to group membership (Taylor & Fiske, 1978). The prestige of the group may also lead to identification (Chatman et al., 1986). According to Ashforth and Mael (1989), "individuals often identify themselves with a 'winner'" (p. 25). There was a strong demonstration that participants interviewed for this thesis identified and "bought into" the research culture at the Cancer Centre. They were aware of the centre's reputation for clinical research and they were proud to be working in such an organization. The prestige and distinctiveness of the clinical research at the Cancer Centre as well as the ultimate impact this research had on patient care appeared to all play a role in participants' identification with the centre.

Participants did not perceive the dual roles of the Cancer Centre as a site of work and research as incompatible. Ironically, although participants valued clinical research over the QWL Project at the centre, the existence of clinical research appeared to contribute to employees' QWL on a profound level; it appeared to have a greater impact on participants' quality of work-life than did

the QWL Project. Although there were many unresolved QWL issues for participants, overall, participants were very supportive of the Cancer Centre as an organization - this identification was strongly linked to the clinical research conducted there.

It has been proposed that people in organizations are engaged in a search for meaning (Gioia, 1986) and that employees identify with their organization to fulfill the need to feel valuable, worthy, competent, and effective (Stets & Burke, 2000). Identification with the Cancer Centre as a research organization (and a patient care facility) appeared to give meaning to the lives of employees who participated in this thesis. The majority of participants felt connected to the clinical research at the centre through their work. Perhaps, having meaningful involvement in that research was perceived to be a privilege because it allowed participants to feel part of the research community, thus contributing to patient care.

Given the status of the clinical research at the centre, it is highly unlikely that the QWL Project will be considered its equal for some time, and indeed may never happen. In a sense, this may be equivalent to asking employees to put their own interests ahead of those of patients. However, employees' support of clinical research probably evolved over time so it is possible that employees will eventually accept the QWL Project as part of the research at the centre as well. In the meantime, the QWL steering committee might consider incorporating employee attitudes toward clinical research as part of the QWL Survey in future years. Such a domain may be important to consider when interpreting QWL in a cancer setting.

The proposal that identification with the centre as a clinical research organization contributes to employees' QWL has important implications. This

may be helpful for managers seeking changes to improve QWL at the centre. For example, involving employees in clinical research may enhance identification and thus, improve QWL. Similarly, acknowledging those employees who are already directly and indirectly involved in that research might improve their QWL. Participants' identification with the centre is beneficial to the organization as a whole. Such identification may elicit loyalty and commitment to the organization, facilitate the internalization of organizational values and beliefs, and be associated with pride in the organization and its activities (Ashforth et al., 1989). This suggests an opportunity for the Cancer Centre to not only contribute to its mission of serving patients but to also improving the QWL of its employees.

References

Ashforth,B.E., & Mael,F. (1989). Social identity theory and the organization. Academy of Management Review, 14(1), 20-39.

Borrero,M., & Rivera,H.A. (1980). Toward a meaning of work. Journal of Sociology and Social Welfare, 7(6), 880-894.

Chatman,J.A., Bell,N.E., & Staw,B.M. (1986). The managed thought: The role of self-justification and impression management in organizational settings. In H. P. Sims, D. A. Gioia, & Associates (Eds.), The thinking organization: Dynamics of organizational social cognition. (pp. 191-214). San Francisco, CA : Jossey-Bass Inc.

Gini,A. (2001). My job, my self. New York: Routledge.

Gioia,D.A. (1986). Symbols, scripts, and sensemaking: Creating meaning in the organizational experience. In H. P. Sims, D. A. Gioia, & Associates (Eds.), The thinking organization: Dynamics of organizational social cognition. (pp. 49-74). San Francisco, CA: Jossey-Bass Inc.

Hall,B.L. (1981). Participatory research, popular knowledge and power: A personal reflection. Convergence, 14(3), 6-17.

Oakes,P., & Turner,J.C. (1986). Distinctiveness and the salience of social category memberships: Is there an automatic perceptual bias towards novelty? European Journal of Social Psychology, 16, 325-344.

Stets,J.E., & Burke,P.J. (2000). Identity theory and social identity theory. Social Psychology Quarterly, 63(3), 224-237.

Taylor,S.E., & Fiske,S.T. (1978). Salience, attention and attribution: Top of the head phenomena. In L. Berkowitz (Ed.), <u>Advances in Experimental Social Psychology, Vol. 11</u>. New York: Academic Press.

APPENDIX A

EMAIL TO QUALITY OF WORK-LIFE STEERING COMMITTEE

Joanna Sale

Hi everyone,

As some of you may know already, I've started the interviews related to my thesis. (I sent out a site-wide email through Marcia some time ago recruiting participants in general from the centre.) As mentioned in one of our previous QWL meetings, I was hoping to interview most of you on the steering committee (I've interviewed a couple of you already). The interviews take roughly 45 minutes to 1 hour. Please let me know if you'd be interested in participating and I'll get back to you with alternatives for dates. In particular, I'll be at the centre this Thursday (November 1) and have a room booked for the following times:

10-1
3:30-4:30

Are any of you available during these times for an interview?

Thanks.

Joanna

APPENDIX B

SITE-WIDE EMAIL TO RECRUIT PARTICIPANTS
FOR STUDIES #2 AND #3

Joanna Sale

Dear [Centre] Employee,

I am recruiting participants for a study which looks at how [centre] employees view research in their workplace. For this study, I am conducting interviews which take approximately 45 minutes to 1 hour. The interviews will be scheduled at your convenience; if you like, I can arrange to conduct them during work hours at [the centre] or we can choose another location outside of work hours. This study is not affiliated with [the centre] – it is for my PhD dissertation.

If you are interested in participating, please email me at:
jsale@iwh.on.ca

Thanks!

Joanna Sale

APPENDIX C

CONSENT FORMS

<u>**Consent Form for Study #1**</u>

Perceptions of research among employees at the Hamilton Regional Cancer Centre

The following information is provided for you to decide whether you wish to participate in the present study. You are free to decide not to participate and you may withdraw from this study at any time without any impact on your employment.

The purpose of this study is to explore the perceptions of research as described by employees at HRCC who are on the steering committee of the Quality of Work-life Project. Data will be collected in this 30-45 minute interview and will be based on your responses to questions posed by the researcher. The interview will be tape recorded so that the researcher can listen to your responses without being distracted. Tape recording the interviews also decreases the chances of the researcher misinterpreting anything that you say. In order to confirm that the researcher has not misinterpreted anything that you say, you may be asked at a later time to read over the transcript of this interview as well as a draft of the final paper.

Please ask any questions about the study either before participating or during the time that you are participating. If you are interested in a copy of the findings after the research is completed, please contact Joanna Sale at the below address/phone number.

Your name will not be associated with the research findings in any way, and your identity as a participant will be known only to the researcher. If any study results are published, you will not be identified. Your answers are confidential and will not be shared with your employer. The tapes, transcripts from the interviews, and participants' names and study identification numbers will be kept under lock and key off-site at the Institute for Work & Health in Toronto.

There are no known risks and/or discomforts associated with this study.

Please sign your consent to acknowledge your awareness of the nature and purpose of the study procedures and to acknowledge receipt of a signed copy of this consent form.

If you have any questions, please contact:

Joanna Sale, Institute for Work & Health
250 Bloor Street East – Suite #702
Toronto, ON M4W 1E6
phone: (416) 927-2027 Ext. 2145
fax: (416) 927-4167
email: jsale@iwh.on.ca

_____	_____	_____
Name of participant	Signature of participant	Date
(please print)		
	_____	_____
	Signature of witness	Date

Consent Form for Study #2

<on HRCC letterhead>
Perceptions of research among employees at the Hamilton Regional Cancer Centre

The following information is provided for you to decide whether you wish to participate in the present study. You are free to decide not to participate and you may withdraw from this study at any time without any impact on your employment.

The purpose of this study is to explore the perceptions of research as described by employees at HRCC who have completed the Quality of Work-life Project survey. Data will be collected in this 30-45 minute interview and will be based on your responses to questions posed by the researcher. The interview will be tape recorded so that the researcher can listen to your responses without being distracted. Tape recording the interviews also decreases the chances of the researcher misinterpreting anything that you say. In order to confirm that the researcher has not misinterpreted anything that you say, you may be asked at a later time to read over the transcript of this interview as well as a draft of the final paper.

Please ask any questions about the study either before participating or during the time that you are participating. If you are interested in a copy of the findings after the research is completed, please contact Joanna Sale at the below address/phone number.

Your name will not be associated with the research findings in any way, and your identity as a participant will be known only to the researcher. If any study results are published, you will not be identified. Your answers are confidential and will not be shared with your employer. The tapes, transcripts from the interviews, and participants' names and study identification numbers will be kept under lock and key off-site at the Institute for Work & Health in Toronto.

There are no known risks and/or discomforts associated with this study.

Please sign your consent to acknowledge your awareness of the nature and purpose of the study procedures and to acknowledge receipt of a signed copy of this consent form.

If you have any questions, please contact:

Joanna Sale, Institute for Work & Health
250 Bloor Street East – Suite #702
Toronto, ON M4W 1E6
phone: (416) 927-2027 Ext. 2145
fax: (416) 927-4167
email: jsale@iwh.on.ca

Name of participant (please print)	Signature of participant	Date
	Signature of witness	Date

<u>Consent Form for Study #3</u>

<on HRCC letterhead>
Perceptions of research among employees at the Hamilton Regional Cancer Centre

The following information is provided for you to decide whether you wish to participate in the present study. You are free to decide not to participate and you may withdraw from this study at any time without any impact on your employment.

The purpose of this study is to explore the perceptions of research as described by nurses and radiation therapists at HRCC. Data will be collected in this 30-45 minute interview and will be based on your responses to questions posed by the researcher. The interview will be tape recorded so that the researcher can listen to your responses without being distracted. Tape recording the interviews also decreases the chances of the researcher misinterpreting anything that you say. In order to confirm that the researcher has not misinterpreted anything that you say, you may be asked at a later time to read over the transcript of this interview as well as a draft of the final paper.

Please ask any questions about the study either before participating or during the time that you are participating. If you are interested in a copy of the findings after the research is completed, please contact Joanna Sale at the below address/phone number.

Your name will not be associated with the research findings in any way, and your identity as a participant will be known only to the researcher. If any study results are published, you will not be identified. Your answers are confidential and will not be shared with your employer. The tapes, transcripts from the interviews, and participants' names and study identification numbers will be kept under lock and key off-site at the Institute for Work & Health in Toronto.

There are no known risks and/or discomforts associated with this study.

Please sign your consent to acknowledge your awareness of the nature and purpose of the study procedures and to acknowledge receipt of a signed copy of this consent form.

If you have any questions, please contact:

Joanna Sale, Institute for Work & Health
250 Bloor Street East – Suite #702
Toronto, ON M4W 1E6
phone: (416) 927-2027 Ext. 2145
fax: (416) 927-4167
email: jsale@iwh.on.ca

_____	_____	_____
Name of participant	Signature of participant	Date
(please print)		
	_____	_____
	Signature of witness	Date

APPENDIX D

INTERVIEW PROTOCOLS

<u>**Study #1 – Perceptions of research and the participatory approach**</u>

<after consent form signed>

Introduction
This study is part of my PhD thesis. The purpose of the study is to look at how HRCC employees view research in their workplace. The interview will take approximately 45 minutes. I will be taping the interview so that I can listen to you without being distracted. Taping the interview also decreases the chances that I misinterpret or change anything that you say. Is it ok to proceed?

<turn on tape recorder>

Interview Questions*:

1. **Tell me about the research activities that are occurring in your workplace.**
   probe: What do you understand by the term "research"?
   probe: You didn't mention the Quality of Work-life Project. Why?
   probe: You didn't mention the clinical research that goes on at the centre. Why?

2. **What do you think about the research activities that are occurring in your workplace? i.e. How do you feel about them?**
   probe: What experiences have shaped your views about such research? e.g. Have you or a family member ever been a participant in a research study? Tell me about your/their experiences. What was/has been good? What was/has been bad?
   probe: How have your views about research changed as a result of these experiences?
   probe: What do you think about the Quality of Work-life project?
   probe: What do you think about the clinical research?
   probe: Do you see any differences between the Quality of Work-life Project and the clinical research that goes on at the centre? What differences do you see? How important are they? Why? How are they alike?

3. **Tell me about your involvement in the Quality of Work-life Project.**
   probe: Tell me more about your role in this project? What has your role been?
   probe: What's been good and bad about your experience in this role?
   probe: What's your understanding of the team approach? How well has it worked?
   probe: How, if at all, has the project affected your own work life? Helped? Hindered?
   probe: How do you feel you have contributed to the project?
   probe: Do you feel your contribution is important? Explain

<turn off tape recorder>

Now, I'm going to ask you a few questions about yourself:

1. What best describes your main activity at HRCC? _____
2. What training did you need for this job? Did you have to go to university?
3. Note: Female __ Male __
4. What is your date of birth
5. How many years have you worked here? _____ years

Thank you very much for participating. As mentioned in the consent form, I may contact you at a later date and ask you to read over the transcript of this interview and/or a draft of the final paper. Would this be ok? What is the best way to get hold of you?
<coupon>

Study #2 – Perceptions of research and questionnaires as a method of data collection

<after consent form signed>

Introduction
This study is part of my PhD thesis. The purpose of the study is to look at how HRCC employees view research in their workplace. The interview will take approximately 45 minutes. I will be taping the interview so that I can listen to you without being distracted. Taping the interview also decreases the chances that I misinterpret or change anything that you say. Is it ok to proceed? *<turn on tape recorder>*

Interview Questions*:

1. Tell me about the research activities that are occurring in your workplace.
> *probe:* What do you understand by the term "research"?
> *probe:* You didn't mention the Quality of Work-life Project. Why?
> *probe:* You didn't mention the clinical research that goes on at the centre. Why?

2. What do you think about the research activities that are occurring in your workplace? i.e. How do you feel about them?
> *probe:* What experiences have shaped your views about such research? e.g. Have you or a family member ever been a participant in a research study? Tell me about your/their experiences. What was/has been good? What was/has been bad?
> *probe:* How have your views about research changed as a result of these experiences?
> *probe:* What do you think about the Quality of Work-life project?
> *probe:* What do you think about the clinical research?
> *probe:* Do you see any differences between the Quality of Work-life Project and the clinical research that goes on at the centre? What differences do you see? How important are they? Why? How are they alike?

3. Tell me more about the Quality of Work-life Project.
> *probe:* What do you know about the steering committee?
> *probe:* You were asked to complete a survey for the QWL project. Do you remember the survey? What did you think of the survey? Were you concerned about confidentiality? Why/why not?
> *probe:* What do you remember about the questions (or scales)?
> *probe:* Were there any important questions which didn't get asked? What kinds of questions? Why are they important?
> *probe:* Did you see completing the survey as important to the project? Why/why not?
> *probe:* Do you feel your contribution is important? Explain.
> *probe:* How, if at all, has the project affected your own work life? Helped? Hindered?

<turn off tape recorder>

Now, I'm going to ask you a few questions about yourself:

1. What best describes your main activity at HRCC? _____
2. What training did you need for this job? Did you have to go to university?
3. Note: Female __ Male __
4. What is your date of birth
5. How many years have you worked here? _____years

Thank you very much for participating. As mentioned in the consent form, I may contact you at a later date and ask you to read over the transcript of this interview and/or a draft of the final paper. Would this be ok? What is the best way to get hold of you?
<coupon>

Study #3 – Perceptions of research and the clinical trial

<after consent form signed>

Introduction
This study is part of my PhD thesis. The purpose of the study is to look at how HRCC employees view research in their workplace. The interview will take approximately 45 minutes. I will be taping the interview so that I can listen to you without being distracted. Taping the interview also decreases the chances that I misinterpret or change anything that you say. Is it ok to proceed?

<turn on tape recorder>

Interview Questions*:

1. **Tell me about the research activities that are occurring in your workplace.**
   probe: What do you understand by the term "research"?
   probe: You didn't mention the Quality of Work-life Project. Why?
   probe: You didn't mention the clinical research that goes on at the centre. Why?

2. **What do you think about the research activities that are occurring in your workplace? i.e. How do you feel about them?**
   probe: What experiences have shaped your views about such research? e.g. Have you or a family member ever been a participant in a research study? Tell me about your/their experiences. What was/has been good? What was/has been bad?
   probe: How have your views about research changed as a result of these experiences?
   probe: What do you think about the Quality of Work-life project?
   probe: What do you think about the clinical research?
   probe: Do you see any differences between the Quality of Work-life Project and the clinical research that goes on at the centre? What differences do you see? How important are they? Why? How are they alike?

3. **Tell me about the clinical trials that go on at the centre.**
   probe: You routinely see patients who are part of clinical trials. What do you think about these trials? Good or bad aspects for you? For patients? (Do you ever think about them?)
   probe: What do you know or understand about clinical trials?
   probe: How, if at all, have these clinical studies/trials affected your own work life? Helped? Hindered?
   probe: How are you involved in these studies? Would you like that to be different?
   probe: How, if at all, do these studies affect your patients?
   probe: How, if at all, do these studies affect your relationship with your patients?

<turn off tape recorder>

Now, I'm going to ask you a few questions about yourself:

1. What best describes your main activity at HRCC? _____
2. What training did you need for this job? Did you have to go to university?
3. Note: Female __ Male __
4. What is your date of birth
5. How many years have you worked here? _____years

Thank you very much for participating. As mentioned in the consent form, I may contact you at a later date and ask you to read over the transcript of this interview and/or a draft of the final paper. Would this be ok? What is the best way to get hold of you?
<coupon>

APPENDIX E

CODING TEMPLATE

Quality of work-life project
QWL survey
- ❑ confidentiality
- ❑ criticisms/limitations of QWL survey
  - sharing of results
  - labelling – negatively and positively
  - grouping of departments
  - open to interpretation
  - cross-sectional nature – e.g. QWL changes from day to day
  - incomplete picture
  - no standards/relativity
  - process too long
  - Likert scales
  - presentation of results
  - survey too long
  - no vision re data utilization
  - missing domains
  - results don't make sense
  - union discouragement
- ❑ benefits of QWL survey
  - felt contributed
  - effort to develop it
  - can compare to the literature
  - makes the subjective objective
  - good length
  - rigor
  - provides evidence of QWL
- ❑ memory of QWL survey
  - the process
  - content
  - reaction/response to (e.g. is completed it, feelings about it)
- ❑ memory of survey results
- ❑ feelings about survey results

QWL project in general
- ❑ criticisms/limitations of QWL
  - lack of awareness
  - centre's attitude to project
  - disillusionment
  - subjective
  - no action/changes
  - no promises made
- ❑ benefits of QWL
  - learning opportunity
  - gesture by management
  - ultimate impact on patients
  - results over-ride complainers
  - participation allows a voice

- will fix things
- helps retention of employees
- allows a focus on the workplace
- gives employees ownership/power
- bargaining chip
- accessible
- potential for change
- ❏ expectations of QWL/QWL results
- ❏ feelings about steering committee
- ❏ knowledge of steering committee
- ❏ intervention suggestions
- ❏ external factors influence QWL
- ❏ wants to know more about QWL project
- ❏ gauging success of QWL survey/project
- ❏ reputation due to QWL
- ❏ recruitment to QWL committee

team approach
- team approach suggested
- views of team approach
- role on committee
- experience on committee
- contribution to QWL project
- ownership of data
- recruitment to committee
- workload associated with QWL
- committee's lack of knowledge
- CEO on committee
- education of committee/learning opportunity/research opportunity
- pride
- silent voices/no shows (i.e. union people not attending)
- motivation to be on committee
- usefulness of committee
- inaction
- phases of involvement
- too close to project to evaluate it
- hierarchy on committee
- creates buy-in
- role of committee
- active members
- time pressure
- group cohesion
- role model for the organization e.g. the team approach filters through workplace and provides example of how to approach problems in general
- helper role

Clinical research
clinical trials
recruitment flyers
benefits of clinical research/trials
- ❑ sharing of knowledge
- ❑ study patients receive treatment within recommended timelines
- ❑ study patients receive more attention
- ❑ education spin-off
- ❑ first-hand knowledge of new treatment
- ❑ alternate treatment available
- ❑ contribution to science
- ❑ reputation due to clinical research
- ❑ get to know patients
- ❑ well-prepared studies
- ❑ research has an impact
- ❑ research changes practice
- ❑ research creates knowledge
- ❑ effect on patient care
- ❑ effect on workload for caregivers
- ❑ drives the profession e.g. job depends on it
- ❑ patient feels contributing
- ❑ hope to patient
- ❑ breaks monotony

limitations/criticisms of clinical research/trials
- ❑ cost of clinical research
- ❑ ethics of trials/clinical research e.g. re informed consent
- ❑ trial patients jump waiting list
- ❑ care taken over by trials nurse/ownership of patients
- ❑ some caregivers are just bystanders
- ❑ patients are willing but not eligible
- ❑ time commitment needed by patients
- ❑ waiting list to get on trial
- ❑ no guarantees
- ❑ trial patients take up patient rooms
- ❑ resource issues
- ❑ disseminating results (to patients and caregivers)
- ❑ clinical research involvement not an option
- ❑ getting in the wrong group – e.g. re choosing options, randomization
- ❑ coordinating care
- ❑ side effects
- ❑ perception from outside HRCC
- ❑ rigid rules
- ❑ integration of
- ❑ clarifying instructions and employees' role
- ❑ employees don't get any credit
- ❑ changing practice

knowledge of clinical research process
- ❑ knowledge allows involvement in process

workload associated with clinical research/trials
experience of patients
clinical research involvement not an option
relationship with study/trial patients
research activity depends on disease site

202

recruitment of patients
being monitored (as a trials nurse)
patients are more informed
admiration of patients
research associated with a group/profession
- ❏ RT research
- ❏ RT study
- ❏ supportive care research
- ❏ physics research
- ❏ medical oncology study
- ❏ genetic counselling research
- ❏ pharmacy research
- ❏ nursing research
- ❏ name of researcher
- ❏ 4th floor/lab research

research associated with presentations

HRCC research website

my thesis research
motivation to participate in

other research

another workplace study
expectations of another workplace study

definition of research
definition of good research
novelty of research
hierarchy of research

experience with general research
involvement in research through school
not want more involvement in research
wants to know more about research
wants more involvement with research
involved in research but not know it
indifference to research
research imposed on you
denies knowledge of research
family member in research study
research requires a mind set
experience as subject of research
motivation to participate in research
experience with surveys in general
research is a privilege
team approach in other research

did not mention QWL project (part of hierarchy of research/defn of research)

comparing clinical and workplace studies

203

hierarchy of research (i.e. status of QWL)
impact of clinical trials vs. QWL

feelings about current job or own QWL
comparison to old job
feelings about boss
male-female issues
politics at HRCC
feelings about CEO
comparison to QWL outside HRCC

personal life