

Influence of the Research Frame on Qualitatively Derived Health Science Knowledge

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Abstract:

Although qualitative researchers generally acknowledge that their theoretical location and methodological orientation will influence the findings of their inquiries, it has been less well understood how the body of knowledge within a substantive field might be shaped by these factors. In this article, the authors draw on insights obtained from their experiences attempting to synthesize qualitative research findings. From that reflective process, they raise questions about the manner in which qualitatively derived knowledge d from various orientations can be interpreted and understood.

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While it is well recognized that the lens with which a qualitative researcher views a research problem will play a significant role in the outcome of the ensuing research, it is more difficult to work out precisely how those research results should influence our understanding of the state of the art knowledge in the particular field to which that study attempts to make a contribution. In this article, we examine many of the facets that comprise a researcher's angles of vision, or frame of reference, within a qualitative study, in an attempt to further elucidate the effects such lenses have on qualitatively derived knowledge in the health sciences. We draw on two meta-study projects in which we have been involved, one on chronic illness experience and the other on fatigue, in which the available body of qualitative research was rigorously and systematically examined for patterns and themes in the process and products of knowledge. On the basis of insights derived from these projects, we intend to challenge qualitative researchers to more accurately recognize and effectively account for the influence of their research frame on their findings, thereby strengthening the contributions that qualitatively derived knowledge can ultimately make to the health sciences and health care.

Background to our Analytic Process

Although results from our qualitative meta-study projects are reported elsewhere (Paterson, 2001; Paterson, Thorne & Dewis, 1998; Thorne & Paterson, 1998; Thorne, Paterson, Acorn, Canam, Joachim & Jillings, in press), some background will be useful to contextualize our particular insights. Using an adaptation of approaches evolved in sociology for meta-analysis across theoretical orientations (Ritzer, 1992; Zhao, 1991), we extended meta-theory, meta-method, and meta-data analysis strategies into a meta-synthesis approach called meta-study (Paterson, Thorne, Canam & Jillings, 2001). With a team of colleagues, we engaged in an extensive meta-study of all available research published between 1980 and 1996 on some aspect

of living with a chronic disease. Systematically analyzing the implications of theoretical orientation, methodological strategy, and data interpretation for the 292 published reports that met our study criteria (see Appendix A), we were able to challenge many of the current and rather static conceptualizations of chronic illness experience and propose more comprehensive and inclusive interpretations that would better represent the spectrum of experience that persons with chronic illness report (Paterson, 2001). In a second meta-study of research conducted before 1999, we examined qualitative investigations into the phenomenon of fatigue within chronic illness. Using similar methods to categorize and interpret the 33 available studies (see Appendix B), we concluded that a number of distinct conceptualizations of fatigue existed within the researchers' orientation to the phenomenon and, at least in part, explained discrepancies and contradictions within the body of findings (Paterson, Canam, Joachim & Thorne, in review).

In both meta-study projects, we had the opportunity to deconstruct current knowledge claims made on the basis of qualitative research by examining and interpreting the theoretical and methodological foundations on which they were made. While many qualitative researchers seemed to surround their designs with epistemological claims consistent with subjectivism and social construction, they also typically expressed their findings in the language of 'truth value' and advocated application of their results as if they were fundamental to a shared reality.

Because of this, we found ourselves increasingly disquieted by what qualitative health researchers are claiming their findings to represent, and we were inspired to reconsider the knowledge claims that are derived from the body of work as it evolves and develops over time. In this discussion, we draw from our experience with both of these studies to reflect on the implications of four distinct aspects of the research frame: its historical location, the manner in

which the disciplinary orientation influences its logic, the theoretical and philosophical positions in which it is grounded, and the methodological strategy by which it has generated its findings.

Historical Location

While research related to health issues has been conducted in the social sciences for generations, the rapid proliferation of qualitative approaches in the health sciences began in the early 1980s. During the ensuing decades, nurses, physicians, social workers, and rehabilitation therapists have found that qualitative approaches provide an opportunity to address a wide range of health questions that are not amenable to inquiry using quantitative approaches. Throughout this relatively recent period of history, there have been tremendous shifts in how qualitative research is understood in the health sciences, the number and nature of methodological approaches that are available to investigators, and the expectations of a reading audience with regard to how methodology is located and explained.

These historical trends are important to understanding the style and form of research reports, and also for evaluating the quality of findings on the basis of reported aspects of the inquiry process. Because qualitative studies in the social sciences were traditionally understood to use methods that conformed to the standards of each discipline, many of the early health research reports included almost no discussion of the method that was used and how it was applied. In contrast, in the health sciences, qualitative researchers of the same era were attempting to publish their research reports in an academic climate in which deviations from traditional quantitative methods were not well understood and therefore required extensive explanation and documentation, not only of the methods themselves but also of the epistemological underpinnings from which they were derived.

During this same two decade period, there have been recognizable trends within the health fields related to which topics are commonly understood to warrant inquiry and how such topics are conceptualized. For example, in the early 1980s, an understanding of chronic illness as a discrete theoretical entity unto itself was still in its infancy, and the majority of studies concerned with chronic illness bounded their inquiries into discrete disease categories, occasionally but not necessarily linking their findings with those that might be relevant to other chronic diseases. As the body of research evolved, many researchers built their own inquiries on the designs and methods of others, and certain methods became more closely aligned with studies relating to certain diseases. For example, those studying diabetes were drawn to grounded theory methodology, while those studying multiple sclerosis seemed more likely to employ narrative inquiry methods. These patterns of how certain questions were considered in turn influenced what researchers thought might be interesting about various diseases and what factors or features they might be alerted to as they generated their subsequent investigations.

Over the course of this timeframe, some studies came to be held up as exemplars in the field, and became a standard foundation on which subsequent studies were grounded. For example, Charmaz's early work on loss and suffering in chronic illness (Charmaz, 1983) dominated the field for a decade or more until it was countered with equally compelling images of health within illness (Thorne & Paterson, 1998). Strauss' (1975) classic work on chronic illness trajectory depicted a pattern of experiential progression that was widely adopted as universally applicable until more complex conceptualizations began to emerge from the synthesis of the body of work (Paterson, 2001). This pattern of theoretical linkages, on which subsequent studies were expected

to build, also occurred in relation to the conceptualizations used to study specific diseases. For instance, the early work linking epilepsy with stigma (Scambler & Hopkins, 1986; Schneider & Conrad, 1983) became almost ‘industry standard’ so that even today there are few alternative interpretations available in the body of qualitative research on epilepsy. Thus, although stigma is widely recognized as the appropriate conceptual representation associated with epilepsy, we know little about whether that linkage remains true within the current social context in which other diseases that evoke different judgements may have shifted the social context in which epilepsy is experienced.

In the case of other diseases, shifting trends in the popular conceptualizations associated with particular chronic conditions rose and fell in popularity over time in a discernable pattern. For example, although the traditional conceptualization linked with breast cancer was body image disturbance (Cohen, Kahn & Steeves, 1998; Thorne & Murray, 2000), the past two decades of inquiry have witnessed a shift to framing breast cancer first as a disease characterized by uncertainty (Hilton, 1988; Nelson, 1996) and later as one characterized by spiritual transformation (Coward, 1990; Peluzsi, 1997). Thus, in some diseases, certain prototypical conceptualizations seem to remain unchallenged over time while, in others, researchers interpret similar data into findings characterized by quite different conceptual structures.

As various diseases come to be identified with particular experiential concepts over time, these concepts often orient the next generation of inquiries and become the theoretical lens through which the disease is understood. So, for example, while it is difficult to discuss epilepsy without the reader assuming you are referring to stigma, the body of literature on stigma tends to be

relatively silent on conditions that one might logically presume to have stigmatizing potential, such as psoriasis. Similarly, while sexuality and body image are typically presumed by health care providers to be a critical component of the breast cancer experience, it is much less likely that persons with inflammatory bowel disease or end-stage renal failure will be recognized as requiring support for sexuality and body image challenges. And, although fatigue has finally achieved some recognition as a prominent experiential element of chronic illness, it tends to be studied in relation to primary fatigue syndromes (such as CFS) and in the context of therapeutic interventions (such as breast cancer chemotherapy), rather than in diseases such as multiple sclerosis or rheumatoid arthritis, in which clinicians well recognize that fatigue is a pervasive characteristic of the chronic illness experience.

Another complication of the historical context of qualitative science in this field is the various degrees of affinity for interdisciplinarity that have evolved within the scholarship as compared to a disciplinary ethnocentricity. While some researchers explicitly read and report on the research of scientists from a range of disciplines, others focus almost exclusively on the work that derives from their own discipline. And while some researchers manage to explore research from a global perspective, others apparently limit their exploration to studies from a single nation, language group, or subset of journals. While linguistic boundaries account for this problem to some extent, it also seems likely that the Atlantic Ocean presents a much more conceptual divide than necessary, especially in this era of electronic communication.

From our analysis of these bodies of qualitative research, therefore, it seems apparent that the historical context into which each individual qualitative study emerges plays a significant role in

determining what is considered relevant and interesting, which bodies of knowledge are recognised as foundational, how one ought to approach a research problem, which methodological strategies one should draw upon, and how research findings will be reported. Thus, when we try to understand the way in which the findings of any particular qualitative study contribute to our general understanding of any phenomenon, there are a number of critically important historical and contextual factors that must be thoughtfully considered.

Disciplinary Orientation

One prominent form of theoretical variation that becomes apparent when one reviews research reports across the health and social sciences is the powerful impact of the disciplinary lens that is applied to studies, even when investigators have used similar methods to study similar topics. In some instances, the disciplinary orientation of the author(s) is made explicit in the author credits, or can be implied from the intended audience of the journal in which the research is published. However, as researchers are increasingly working and writing outside their discipline, the disciplinary orientation of a specific published report may be difficult to discern. A critical read of the reference list for which authors have been cited and which others have not may be illuminating; in many instances, it will suggest that the logic of a particular discipline has been recognized as foundational background knowledge. In addition to cited references, cues in the way in which language is used and/or implicit assumptions within the research report can also reveal information about the disciplinary orientation that is being expressed in any particular study. At times, this level of scrutiny may reveal a departure from the discipline that one might have assumed from the author's academic preparation or home department; for example, health care professionals with social science training might be writing in the style of one discipline or the other or a unique application of both. The obscurity of the disciplinary perspective in many

of the published qualitative research reports adds a layer of complexity to the process of analyzing their relative biases and to making sense of how those biases may have influenced the findings that are claimed as a result of the research.

The disciplinary orientation of any qualitative research study can have a profound influence on the way the research problem is framed, the way the research questions are posed, the data that are gathered and analyzed, and the findings that are produced (Thorne, 2001). As might be expected, psychologists tend to be oriented by the assumption that documenting processes of cognition and emotion are the ultimate aim of this kind of research. In contrast, sociologists tend to be unconcerned with what the individual cognitive processes might look like and focus instead on the interactional structures of behavioral patterns, social expectations, and cultural rules within health care (Gerhardt, 1990). Anthropologists tend to document patterns within beliefs about health and illness, and to locate them within the larger context of social, cultural and ethnic organizational frameworks. While the language, methods and questions deriving from these disciplines might appear to represent similar kinds of inquiry, our experiences of trying to interpret across the disciplinary divides have convinced us that research reports are strongly shaped by what the researcher understands to be the point of gaining new knowledge from a disciplinary perspective. Given the same interview or observation, each social scientist would likely 'see' it differently and use different reasoning processes in analyzing not only what is meaningful but also what meaning can be made of it.

In contrast to the social science disciplines, researchers working from a disciplinary perspective in the health sciences tend to generate and conduct their investigations from the perspective of

gaining knowledge for application to clinical practice. Where they link their questions and interpretations to social science theoretical structures, they generally do so with a rather different intent than that of the social scientists (Wellard, 1998). As many of their research reports reveal, health science researchers tend to assume that the alpha and omega of each research project is indeed the clinical context (Miller & Crabtree, 1999). Thus, they use, and rely on, general theoretical and social science ideas, but in a manner that is considerably less theoretical and more applied than the usual standards of social science research might dictate. They might acknowledge and build on theoretical principles and common understandings, but express them with an identifiable attention to the unique and particular variations that constitute the cases on which these theoretical understandings would be applied in practice. Thus, many qualitative researchers working from a health science orientation are considerably more hesitant than their colleagues in the social sciences to align their inquiries with grand theoretical projects. As a result, their research results may be regarded with scepticism by their more theoretically inclined colleagues.

Interestingly, with the trend toward increasingly large and interdisciplinary research teams, many studies explicitly capitalize on the perspectives of different social and health science disciplines, and in some cases, the research reports reflect that hybrid species of varying orientations. Our investigations into disciplinary perspectives has therefore also led us to consider the effect that disciplinary publication standards have had on the form and style of research reports as well as on the way that authors frame their work in order to make them acceptable for publication and dissemination. For example, some social science journals have long traditions of discouraging detailed discussion of the application of method, especially when the methodologies inherent to

the discipline can be assumed. The written reports of research in such journals can create a serious challenge to those with different disciplinary backgrounds attempting to audit the reasoning process by which the authors have reached their conclusions. Some health science journals, in contrast, typically demand a critical reflection on all aspects of the research process, such that reports seemed to provide considerably more detail about the researcher as instrument than about the findings of the research. Thus, in trying to critically interpret what sense can be made of the findings of any particular study, the astute reader must be able to appreciate not only the nature of the disciplinary grounding of any study, but also the traditions of that discipline's scholarly conventions.

Theoretical and Philosophical Grounding

Although it has become commonplace to articulate a primary distinction between qualitative and quantitative methods in health research, this classification sometimes blurs the wide range of epistemological and ontological variations within and between the methods that are considered qualitative (Frankel, 1999). Such variations arise in relation to the manner in which a study is grounded within existing literature, the assumptions that are made with regard to what constitutes knowledge, and the claims that can be justified on the basis of research findings. While disciplinary orientation represents an important theoretical and philosophical foundation that helps us understand the meaning of findings from specific qualitative studies, it is typically embedded within a much larger variety of theoretical and philosophical positionings that influence the research process and product. Thus, having established that scholars from various disciplines decidedly do not think alike, we can now turn to similarly powerful variations in thinking that may be independent of discipline. Each of these theoretical and philosophical frames can strongly influence the research. By understanding their influence, we are in a position

to consider more critically the meaning of what has been studied and the claims about what is and is not known.

Proponents of qualitative methods differ with regard to the degree to which they expect a study to be grounded in prior theoretical and research literature (Sandelowski, 1993). In some instances, it is assumed that a study will build on all knowledge within a substantive field of study (such as illness-related fatigue). In others, it is recognized that an appreciation for existing empirical knowledge is essential to locating any new research question. However, various authors may interpret this requirement as including only research-based papers (such as those using a particular fatigue measure), or only qualitative investigations (such as those that have explored the experience of fatigue as articulated by those who know it first-hand) as relevant to the foundation of any new inquiry. Finally, there are some methods for which it is recommended that the researcher avoid serious attention to the pre-existing knowledge for fear of biasing the inductive reasoning processes that might occur during data collection and analysis. For example, some species of existential phenomenology and heuristics suggest bracketing all preconceptions to the extent possible and exploring the topic with a fresh perspective rather than running the risk of recreating the conceptualizations that have been argued by others (Schwandt, 1997). Because of these significant theoretical variations, it can be difficult for proponents of one method to recognize the credibility and value of findings of another, and to interpret the results of a particular study in the context of those deriving from different approaches (Smith, 1990).

Within and between disciplines, there is also considerable variation with regard to the way in which various authors understand the proper use of theory. Depending on method, discipline, and

personal preference (or perhaps that of the dissertation supervisor!), some qualitative researchers explicitly locate their inquiries within a particular strand of theoretical development, and sustain that orientation throughout the report. Others seem reluctant to contaminate the originality of their findings by providing an overly detailed theoretical location from which their study was launched. Still others provide clues as to theoretical leanings, but insufficient information for the reader to fully understand the manner in which theory may have been integrated. In some instances, authors justify their studies on the basis that nothing is known about the phenomenon under question, and therefore qualitative methods are warranted. Unfortunately, such claims often ignore the presence of scholarly writing on certain aspects of the phenomenon that may take a different form, derive from a different discipline, or use different inquiry methods than those chosen by the author for the current review.

An even more curious feature of the theoretical orientation of qualitative research is that some authors explicitly locate their inquiries within a particular position in theory development and then apparently abandon all efforts to link, apply, or interpret their findings in that context. Thus, in some instances, theory may be useful for defending that a particular study is justifiable within a discipline's knowledge development regardless of whether that theory represents a grounding to which the researcher actually ascribes. Thus, a critical observer is well advised to thoughtfully consider not only which theory has been used to ground the research but also how it has or has not shaped the research process (Sandelowski, 1993).

A more subtle, but equally potent, theoretical grounding arises from the fundamental epistemological and ontological positions that the researcher takes in relation to the nature of the

phenomenon under study and knowledge about it. In particular, the relative meaning and importance of objective and subjective knowledge has a critical impact on the questions, designs, and interpretations of qualitative research. If a researcher is engaged in fieldwork, interviewing persons afflicted by fatigue due to a particular health condition for example, the subjective impressions offered by such persons might variously be interpreted as evidence of objective reality, as an intersubjective construction between the researcher and the researched, or as their unique experience of a dominant socially constructed discourse. Different researchers take very different philosophical positions on such questions as where truth resides and whether there is an objective truth to be had in relation to the phenomenon (Altheide & Johnson, 1994; Kvale, 1995; Lincoln, 1995). For example, while one might assume that pain or fatigue are real simply because someone claims them to be, another might depend on clinical measures or behavioral signs to corroborate subjective reports. Such distinctions can sometimes be found in the overt claims that researchers make about their philosophical positionings, and at other times they can be inferred from their methodological choices, such as claiming uninterpreted raw data as findings, or using member-checks to validate their theoretical interpretations.

Thus, in understanding the potential contribution of a particular qualitative study, the explicit and implicit theoretical and philosophical positionings of the author can explain a great deal about why the findings are articulated and explained in the manner that they are and what sense the author believes one might make of them. Whether the author is presenting the reader with a truth claim or an alternative way of understanding a phenomenon makes an important difference in the way the research results can be interpreted and applied to ongoing inquiry or to practice.

Methodological Strategy

While the methodological approach adopted by any qualitative researcher is inevitably highly dependent on his or her historical location, disciplinary orientation, and philosophical perspective, there are aspects of the research method that warrant further consideration in trying to make sense of the contributions that several studies might make to a particular substantive field. In our chronic illness meta-study, we scrutinized almost 300 qualitative studies on some aspect of adult chronic illness experience. Within the social sciences, we found that most researchers adhered to the methods most common in their discipline, so that psychologists used phenomenological methods and anthropologists used ethnographic approaches and so on.

Within health sciences research, we found interesting patterns and trends in the use of various methods to address various questions, and noted that those patterns had indeed shifted over time as various claims gained theoretical dominance and popularity. Of those studies that explicitly claimed a methodological direction (64 percent of the total sample), 29 percent were grounded theory studies, 25 percent were phenomenologies, and 13 percent were ethnographies. Another 33 percent used a wide range of less prominent methods, such as narrative analysis, qualitative case analysis, discourse analysis, participatory action research, naturalistic inquiry, feminist methodology, and biographical analysis. While it was quite common in the 1980s in both the social and health sciences to publish 'generic' qualitative research, or studies in which the method was not specified, there is a decided preference for 'named' methods as the fields mature.

As one explores the relationships between method and study focus, design and findings, other insights emerge. For example, we have observed that narrative analysis methods are quite often used to study a particular constellation of diseases (such as HIV/AIDS, MS and cancer) but almost never in relation to other diseases such as diabetes, despite the fact that a disproportionate share of the chronic illness research derives from this population. Such observations caused us to question assumptions about who ‘has a story to tell’ about their illness as opposed to whose disease is understood to be more mundane or straightforward. One can also notice fascinating slippages between methods, so that some researchers explicitly apply grounded theory methods to studies of ‘lived experience’ and some phenomenologies are explicitly grounded within social theory. Thus, ethnographies do not necessarily contribute to sociocultural theory, grounded theories do not necessarily contribute knowledge of basic social processes, and phenomenologies do not necessarily tap subjective or phenomenal understanding. Further, we have noticed that studies purportedly using quite different methodological direction can be remarkably similar in their design. In particular, studies in the health sciences often apply general interpretive description approaches (Thorne, Reimer Kirkham & MacDonald-Emes, 1997) regardless of their methodological claims, searching for common patterns and themes within shared elements of a chronic illness experience, and theorizing the application of those common themes to an infinite set of unique cases.

Although all aspects of qualitative research are influential on the product, sampling perhaps deserves special attention with regard to how it creates the frame on which research findings are reported. In many instances, the unstated disciplinary, theoretical, and philosophical orientations that a researcher brings to an inquiry can be extrapolated by his or her sampling logic. For

example, we were intrigued by how various researchers defined their samples when their intent was to study chronic illness in a general sense. In some instances, they drew from a mixed population, perhaps including individuals with such conditions as rheumatic, cardiovascular, and endocrine disorders. In other instances, they studied individuals with one disease and theorized a relationship to other diseases. Some studies included individuals with physical disabilities while others explicitly exclude these. Rarely were persons with chronic mental disorders unrelated to the physical illness included in these kinds of studies. Until fairly recently, most studies of chronic illness drew upon samples of persons whose diseases were not understood as ‘terminal.’ As technological and other scientific advances have changed the trajectory of many such diseases through the 1990s, cancer and HIV/AIDS have started to appear quite regularly in the constellation of diseases that researchers consider chronic (Paterson et al., 2001).

To illustrate this issue further, we have noticed that some chronic diseases attract a disproportionate share of qualitative research interest, and therefore contribute more strongly than do other diseases to general chronic illness theorizing. As Bland (1999) noted, there has been almost no research enthusiasm for discovering what it is like to live with a chronic venous leg ulcer, despite its prevalence, the inherent chronicity of the condition, and the powerful degree to which it influences all aspects of a person’s life. Similarly, Chronic Obstructive Pulmonary Disease and hypertension are rarely a focus of qualitative inquiry, while asthma and cardiovascular disease are quite popular. Among the most commonly studied chronic diseases are breast cancer and diabetes (both Type I and Type II), and while they clearly comprise significant subgroups within the chronic illness population, they cannot fully represent all of the major dimensions of chronic illness that are critically important in shaping what life is like. For

example, both represent chronic illnesses in which lengthy periods of relative stability may make people more accessible to researchers. As Conrad (1990) pointed out, much of the available research into chronic illness experience seems to have been done on populations accessed through ambulatory outpatient clinics. This may suggest that convenience rather than theoretical or demographic interests play a role in determining the samples that are most commonly represented in the research literature.

Another observation that can be made on the basis of this body of work is that diseases that influence verbal communication, such as stroke, amyotrophic lateral sclerosis, or Parkinson's disease, make disproportionately unpopular research topics. This suggests to us that, besides the convenience factor, qualitative researchers may reveal a preference for conducting studies with adults who are easily articulate (Paterson et al, 2001). With the exception of studies that explicitly study a particular ethnic or social grouping's distinct experience with chronic illness, the sample populations of many studies are heavily weighted in the direction of white, educated, middle-class women, regardless of the extent to which that subgroup is representative of the total demographic picture of any particular chronic condition. Thus it might be argued that the subjective experiential knowledge that we have compiled may be rather strongly influenced by dominant values, beliefs, and assumptions common to that particular group and, because of this, much of the diversity inherent in chronic illness experience may have been rendered invisible within our research literature.

In addition to the general issues associated with what has been studied and what has not, a review of the body of work reveals some additional sampling issues that may influence our

ability to extract general knowledge from the research-based literature. Among these is the frequency with which small samples are used in qualitative inquiries. While the depth and richness that a qualitative researcher typically seeks is more accessible when the sample size is constrained, most researchers would agree that there is a considerable trade-off with regard to the degree to which the findings are understood as generalizable, or relevant beyond the immediate study population. However, many researchers appear to lose sight of the size and nature of their samples in their enthusiasm to convey their confidence that their conceptualizations of the phenomena have far-reaching implications (Thorne, 2001). Thus, far too many research reports articulate implications applicable to populations that grossly exceed those for which they have theoretically sampled and can justifiably draw conclusions. They may ignore the possibility that there are relevant variations between urban and rural populations, between face-to-face interview data and data obtained by other methods, or between samples tapped on a single occasion as opposed to those followed over time. They may not recognize that there are numerous gaps in our knowledge base with regard to the impact of such discrete variables as age, gender, economic advantage, or ethnicity, as well as less explicit variables such as outlook on life, geographic or social location, and health system context.

Finally, another complicating factor within this body of research is the unfortunate tendency among some researchers to publish multiple reports on what appear to be the same data set without explicitly articulating common samples (such as would be the case in secondary analysis) (Paterson et al., 2001). By examining the demographics reported in what otherwise appear to be presented as discrete studies (that is, they claim distinct research questions, theoretical frameworks, analytic strategies and findings), one often suspects that researchers have

simply split different kinds of conclusions from a single study into multiple research reports. Because publishers may be less enthusiastic about accepting manuscripts that claim to be partial findings, the culture of the research industry may have inadvertently contributed to this problem. Further, because the acceptable length of journal article research reports has been reduced in recent years due to economic pressures on publishers, investigators may not feel that a single journal article is sufficient to capture the depth and detail required for an effective and scholarly qualitative research account. Thus, while multiple publication is understandable, the failure of many researchers to acknowledge openly the interrelations between their data sets and findings creates a difficulty for those who are trying to make cumulative sense of entire bodies of literature. If the multiple research report represents constructions by the same researchers (instruments) on the same sample, the weight of conclusions from multiple publications should not rely more heavily in our interpretation than would those from a single written report, although sheer volume of writing sometimes affords an unwarranted impression of credibility. From our consideration of this large body of research, therefore, we believe that matters of sampling may be critically important to our shared understanding of any particular phenomenon.

Conclusions

Thus, our adventures in meta-study have afforded us an opportunity to reflect on the various ways in which historical context, discipline, theoretical orientation, and method shape individual qualitative research studies. We have become convinced that the research frame, or the angle of vision from which the researcher approaches a particular study, is critically important to understanding why a piece of research becomes what it does and what sense we might make of its contribution to the field of knowledge. It seems clear that, in closely examining each study in relation to each of these dimensions, we can learn a great deal about the researcher and,

hopefully, something meaningful about the phenomenon about which the researcher is trying to generate new knowledge.

Clearly the theoretical and disciplinary direction of qualitative research in general is dynamic and evolving. The knowledge that we think we can extract from the products of such research is fluid and slippery, changing in both form and nature even as we re-examine it from yet another angle. As we continue to feel the pressure to account for the foundational knowledge that qualitative research offers to health care and health science, we would be well advised to steer clear of tight meta-syntheses and grand generalizations. Qualitative research does offer a different window on the world from that of its quantitative counterparts. But, despite an explosion of enthusiasm for qualitative inquiry into matters of health and illness, what it is that we actually 'see' when we look through this window will not be uncomplicated or consensual.

References

- Altheide, D. L. & Johnson, J. M. (1994). Criteria for assessing validity in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 485-499). Thousand Oaks, CA: Sage.
- Bland, M. (1999). On living with chronic leg ulcers. In I. Madjar & J. A. Walton (Eds.), *Nursing and the experience of illness: Phenomenology in practice* (pp. 36-56). St. Leonards, NSW: Allen & Unwin.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168-195.
- Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (1998). Beyond body image: The experience of breast cancer. *Oncology Nursing Forum*, 25, 835-841.
- Conrad, P. (1990). Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science & Medicine*, 30, 1257-1263.

- Coward, D. D. (1990). The lived experience of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly*, 3 (4), 162-169.
- Frankel, R. M. (1999). Standards of qualitative research. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (2nd ed.) (pp. 333-346). Thousand Oaks, CA: Sage.
- Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story. *Social Science & Medicine*, 30, 1149-1159.
- Hilton, B. A. (1988). The phenomenon of uncertainty in women with breast cancer. *Issues in Mental Health Nursing*, 9, 217-238.
- Kvale, S. (1995). The social construction of validity. *Qualitative Inquiry*, 1, 19-40.
- Lincoln, Y. S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, 3, 275-289.
- Miller, W. L., & Crabtree, B. F. (1999). Clinical research: A multimethod typology and qualitative roadmap. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (2nd ed.) (pp. 3-30). Thousand Oaks, CA: Sage.
- Nelson, J. P. (1996). Struggling to gain meaning: living with the uncertainty of breast cancer. *Advances in Nursing Science*, 18 (3), 59-76.
- Paterson, B. L. (2001). The Shifting Perspectives Model of chronic illness. *Image: Journal of Nursing Scholarship*, 33 (1), 21-26.
- Paterson, B., Canam, C., Joachim, G., & Thorne, S. (in review). Qualitative researchers' conceptualizations of fatigue in chronic illness.
- Paterson, B., Thorne, S. & Dewis, M. (1998) Adapting to and managing diabetes. *Image: Journal for Nursing Scholarship*, 30 (1), 57-62.
- Paterson, B. L., Thorne, S. E., Canam, C. & Jillings, C. (2001). Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis. Thousand Oaks, CA: Sage.
- Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum*, 24, 1343-1353.
- Ritzer, G. (1992). Metatheorizing in sociology: Explaining the coming of age. In G. Ritzer (Ed.), *Metatheorizing* (pp. 7-26). Newbury Park, CA: Sage.
- Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in Nursing & Health*, 16, 213-218.

- Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, 8, 26-43.
- Schneider, J. W., & Conrad, P. (1983). *Having epilepsy: The experience of control and illness*. Philadelphia: Temple University Press.
- Schwandt, T. A. (1997). *Qualitative inquiry: A dictionary of terms*. Thousand Oaks, CA: Sage.
- Smith, J. K. (1990). Alternative research paradigms and the problem of criteria. In E. G. Guba (Ed.), *The paradigm dialog* (pp. 167-187). Newbury Park, CA: Sage.
- Strauss, A. L. (1975). *Chronic illness and the quality of life* (1st ed.). St. Louis, MO: Mosby.
- Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: Analysis of the issues. *Qualitative Health Research*, 1, 178-199.
- Thorne, S. E. (2001). The implications of disciplinary agenda on quality criteria for qualitative research. In J. M. Morse, J. Swanson, & A. Kuzel (Eds.), *The nature of qualitative evidence* (pp. 141-159). Thousand Oaks, CA: Sage.
- Thorne, S., Reimer Kirkham, S. & MacDonald-Emes, J. (1997). Interpretive description: A non-categorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 2, 169-177.
- Thorne, S. E. & Murray, C. (2000). Social constructions of breast cancer. *Health Care for Women International*, 21, 141-159.
- Thorne, S. & Paterson, B. (1998). Shifting images of chronic illness. *Image: The Journal of Nursing Scholarship*, 30, 173-8.
- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G. & Jillings, C. (in press). Chronic illness experience: Insights from a qualitative meta-study. *Qualitative Health Research*.
- Wellard, S. (1998). Constructions of chronic illness. *International Journal of Nursing Studies*, 35, 49-55.
- Zhao, S. (1991). Metatheory, metamethod, meta-data-analysis: What, why and how? *Sociological Perspectives*, 34, 377-390.

Appendix 1: Chronic Illness Meta-Study Primary Sources (N=292)

[Qualitative studies of adult chronic illness experience published 1980-1996. Additional detail of inclusion criteria published in: Paterson, B., Thorne, S., Canam, C., & Jillings, C. (2001). *Meta-study of Qualitative Research: A Practical Guide to Meta-analysis and Meta-Synthesis*. Thousand Oaks, CA: Sage Publications.]

Ablon, J. (1996). Gender response to neurofibromatosis. *Social Science and Medicine*, 42, 99-109.

Ailinger, R. L., & Schweitzer, E. (1993). Patients' explanations of rheumatoid arthritis. *Western Journal of Nursing Research*, 15, 340-351.

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41, 303-315.

Anderson, J. M. (1991). Immigrant women speak of chronic illness: The social construction of the devalued self. *Journal of Advanced Nursing*, 16, 710-717.

Anderson, J. M., Blue, C., Holbrook, A., & Ng, M. (1993). On chronic illness: Immigrant women in Canada's work force-A feminist perspective. *Canadian Journal of Nursing Research*, 25, 7-22.

Anderson, J. M., Blue, C., & Lau, A. (1991). Women's perspectives on chronic illness: Ethnicity, ideology and restructuring of life. *Social Science and Medicine*, 33, 101-113.

Anderson, R. (1988). The quality of life of stroke patients and their carers. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 14-42). Boston: Unwin Hyman.

Anderson, R. M., Barr, P. A., Edwards, G. J., Funnell, M. M., Fitzgerald, J. T., & Wisdom, K. (1996). Using focus groups to identify psychosocial issues of urban black individuals with diabetes. *The Diabetes Educator*, 22 (1), 28-33.

Arluke, A. (1980). Judging drugs: Patients' conceptions of therapeutic efficacy in the treatment of arthritis. *Human Organization*, 39 (1), 84-88.

Armstrong, V. N. (1990). Perceptions of adults with insulin-requiring diabetes of factors influencing their self-management. Unpublished doctoral dissertation, University of Georgia, Athens.

Arruda, E. N., Larson, P. J., & Meleis, A. I. (1992). Comfort: Immigrant Hispanic cancer patients' views. *Cancer Nursing*, 15, 387-394.

Bach, C. A., & McDaniel, R. W. (1993). Quality of life in quadriplegic adults: A focus group study. *Rehabilitation Nursing*, 18, 364-367.

- Bailey, B. J., & Kahn, A. (1993). Apportioning illness management authority: How diabetic individuals evaluate and respond to spousal help. *Qualitative Health Research*, 3, 55-73.
- Baker, C., & Stern, P. N. (1994). Finding meaning in chronic illness as the key to self-care. *Canadian Journal of Nursing Research*, 25, 23-36.
- Baldock, J., & Ungerson, C. (1994). A consumer view of the 'New Community Care': The homecare experiences of a sample of stroke survivors and their carers. *Care in Place*, 1, 175-187.
- Barrett, J. (1995). Multiple sclerosis: The experience of a disease. *Women's Studies International Forum*, 18, 159-171.
- Barroso, J. (1995). Self-care activities of long-term survivors of acquired immunodeficiency syndrome. *Holistic Nursing Practice*, 10, 44-53.
- Barroso, J. (1996). Focusing on living: Attitudinal approaches of long-term survivors of AIDS. *Issues in Mental Health Nursing*, 17, 395-407.
- Barton, J. A., Magilvy, J. K., & Quinn, A. A. (1994). Maintaining the fighting spirit: Veterans living with multiple sclerosis. *Rehabilitation Nursing Research*, 3, 86-96.
- Bates, M. S., & Rankin-Hill, L. (1994). Control, culture and chronic pain. *Social Sciences and Medicine*, 39, 629-645.
- Beaudoin, P. (1993). *Living with AIDS*. Unpublished doctoral dissertation, University of Toronto, Toronto.
- Bechtel, G. A. (1994). Purpose in life among gay men with HIV disease. *NursingConnections*, 7 (4), 5-11.
- Becker, G., Janson-Bjerklie, S., Benner, P., Slobin, K., & Ferketich, S. (1993). The dilemma of seeking urgent care: Asthma episodes and emergency service use. *Social Science & Medicine*, 37, 305-313.
- Becker, G., & Kaufman, S. R. (1995). Managing an uncertain illness trajectory in old age: Patients' and physicians' views of stroke. *Medical Anthropology Quarterly*, 9, 165-187.
- Beisecker, A. E., Kuckelman Cobb, A., & Ziegler, D. K. (1988). Patient's perspectives of the role of care providers in amyotrophic lateral sclerosis. *Archives of Neurology*, 45, 553-556.
- Benner, P., Janson-Bjerklie, S., Ferketich, S., & Becker, G. (1994). Moral dimensions of living with a chronic illness: Autonomy, responsibility, and the limits of control. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring and ethics in health and illness* (pp. 225-254). Thousand Oaks, CA: Sage.

- Berg, J. (1996). Quality of life in COPD patients using transtracheal oxygen. *MEDSURG Nursing*, 5 (1), 36-40.
- Berry, D. L. (1994). Detection and diagnosis experiences of employed persons with urologic cancer. *Urologic Nursing*, 14, 52-56.
- Bertero, C., & El, A. C. (1993). Quality of life of adults with acute leukaemia. *Journal of Advanced Nursing*, 18, 1346-1353.
- Blake, K. (1995). The social isolation of young men with quadriplegia. *Rehabilitation Nursing*, 20, 17-21.
- Bonwich, E. (1985). Sex role attitudes and role reorganization in spinal cord injured women. In M. J. Deegan & N. A. Brooks (Eds.), *Women and disability: The double handicap* (pp. 56-67). New Brunswick, NJ: Transaction Books.
- Bowman, J. M. (1991). The meaning of chronic low back pain. *AAOHN Journal*, 39, 381-384.
- Bowman, J. M. (1994). Experiencing the chronic pain phenomenon: A study. *Rehabilitation Nursing*, 19, 91-95.
- Bozzacco, V. (1993). Long-term psychosocial effects of spinal cord injury. *Rehabilitation Nursing*, 18 (2), 82-87.
- Bredenberg, P. A. (1991). *Who cares? Social support and women with breast cancer*. Unpublished doctoral dissertation, Syracuse University, Syracuse.
- Bridge, M. J. (1986). *A phenomenological study of being a homosexual male who has been diagnosed with AIDS*. Unpublished doctoral dissertation, California School of Professional Psychology, Fresno.
- Brodsky, M. S. (1995). Testicular cancer survivors' impression of the impact of the disease on their lives. *Qualitative Health Research*, 5, 78-96.
- Brodwin, P. E. (1992). Symptoms and social performances: The case of Diane Reden. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 77-99). Berkeley, CA: University of California.
- Brooks, N. A., & Matson, R. R. (1987). Managing multiple sclerosis. *Research in the Sociology of Health Care*, 6, 73-106.
- Brown, S., & Williams, A. (1995). Women's experiences of rheumatoid arthritis. *Journal of Advanced Nursing*, 21, 695-701.

- Burnette, J. D. (1991). *The management of chronic illness by older people living alone: A multi-method investigation*. Unpublished doctoral dissertation, University of California, Berkeley.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 167-182.
- Bury, M. (1988). Meanings at risk: The experience of arthritis. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 89-116). Boston: Unwin Hyman.
- Callaghan, D., & Williams, D. (1994). Living with diabetes: Issues for nursing practice. *Journal of Advanced Nursing*, 20, 132-139.
- Carpenter, C. (1994). The experience of spinal cord injury: The individual's perspective--implications for rehabilitation practice. *Physical Therapy*, 74, 614-629.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168-195.
- Charmaz, K. (1991). *Good days, bad days: The self in control, illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1995). Identity dilemmas for chronically ill men. In D. Sabo & D. F. Gordon (Eds.), *Men's health and illness: Gender, power and the body* (pp. 266-291). Thousand Oaks, CA: Sage.
- Chaturvedi, S. K. (1991). What's important for quality of life to Indians—in relation to cancer. *Social Science & Medicine*, 33 (1), 91-94.
- Cigoli, V., Binda, W., & Martas, E. (1994). Marital relationships and type II diabetes. *Family Systems Medicine*, 12, 295-314.
- Coates, V. E., & Boore, J. R. P. (1995). Self-management of chronic illness: Implications for nursing. *International Journal of Nursing Studies*, 32, 628-640.
- Cobb, A. K., & Hamera, E. (1986). Illness experience in a chronic disease -- ALS. *Social Science & Medicine*, 7, 641-650.
- Corbin, J. M., & Strauss, A. L. (1984). Collaboration: Couples working together to manage chronic illness. *Image: The Journal of Nursing Scholarship*, 16, 109-115.
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8, 224-247.
- Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco, CA: Jossey-Bass.

- Coward, D. D. (1990). The lived experience of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly*, 3, 162-169.
- Coward, D. D., & Lewis, F. M. (1993). The lived experience of self-transcendence in gay men with AIDS. *Oncology Nursing Forum*, 20, 1363-1368.
- Coyler, H. (1996). Women's experience of living with cancer. *Journal of Advanced Nursing*, 23, 496-501.
- Cull-Wilby, B. L. (1993). *Living with asthma: A phenomenological search for meaning*. Unpublished doctoral dissertation, University of Rochester, Rochester.
- Cury, S. E., Ferraz, M. B., Dos Santos, J. Q., Miranda, C., Redko, C., Vilar, M. J. P., & Atra, E. (1995). The use of focus group interview in the evaluation of patients with ankylosing spondylitis. *British Journal of Rheumatology*, 34, 150-155.
- David, J. (1995). Patients' views on rehabilitation. *Journal of Cancer Care*, 4, 57-60.
- DelVecchio-Good, M. J. (1992). Work as a haven from pain. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 49-75). Berkeley, CA: University of California Press.
- Demas, P., Schoenbaum, E. E., Wills, T. A., Doll, L. S., & Klein, R. S. (1995). Stress, coping, and attitudes toward HIV treatment in injecting drug users: A qualitative study. *AIDS Education and Prevention*, 7, 429-442.
- Derenowski-Fleury, J. (1991). Empowering potential: A theory of wellness motivation. *Nursing Research*, 40, 286-291.
- DeVito, A. J. (1990). Dyspnea during hospitalization for acute phase of illness as recalled by patients with chronic obstructive pulmonary disease. *Heart & Lung*, 19, 186-191.
- Dewar, A. L., & Morse, J. M. (1995). Unbearable incidents: failure to endure the experience of illness. *Journal of Advanced Nursing*, 22, 957-964.
- Dietrich, U. C. (1996). Factors influencing the attitudes held by women with type II diabetes: A qualitative study. *Patient Education and Counselling*, 29, 13-23.
- Dildy, S. M. P. (1992). A naturalistic study of the nature, meaning and impact of suffering in people with rheumatoid arthritis. Unpublished doctoral dissertation, The University of Texas at Austin, Austin.
- Dildy, S. M. P. (1996). Suffering in people with rheumatoid arthritis. *Applied Nursing Research*, 9, 177-183.

- Doktorchik, M. (1991). Adaptation to diabetes. *Beta Release*, 15, 49-54.
- Doolittle, N. D. (1991). Clinical ethnography of lacunar stroke: Implications for acute care. *Journal of Neuroscience Nursing*, 23, 235-240.
- Doolittle, N. D. (1992). The experience of recovery following lacunar stroke. *Rehabilitation Nursing*, 17, 122-125.
- Doyle, D. L., & Stern, P. N. (1992). Negotiating self-care in rehabilitation nursing. *Rehabilitation Nursing*, 17, 319-321, 326.
- Dunaway, F. W., Hueston, W. J., & Clevinger, L. (1995). An exploratory study of the experiences of rural women with breast cancer. *KMA Journal*, 93, 241-245.
- Duval, M. L. (1984). Psychosocial metaphors of physical distress among MS patients. *Social Science & Medicine*, 19, 635-638.
- Dyck, I. (1995). Hidden geographies: The changing lifeworlds of women with multiple sclerosis. *Social Science & Medicine*, 40, 307-320.
- Eberhardt, E. I. (1983). *Experiencing cancer: A phenomenological study*. Unpublished doctoral dissertation, California School of Professional Psychology, Fresno.
- Erdmann, B. R. (1988). *Living with chronic pain*. Unpublished doctoral dissertation, The University of Tennessee, Memphis.
- Fenwick, B. (1988). *The meaning of illness in men after myocardial infarction*. Unpublished master's thesis, University of Washington, Seattle.
- Ferrans, C. E. (1994). Quality of life throughout the eyes of survivors of breast cancer. *Oncology Nursing Forum*, 21, 1645-1651.
- Ferrell, B. R., Taylor, E. J., Grant, M., Fowler, M., & Corbisiero, R. M. (1993). Pain management at home: Struggle, comfort, and mission. *Cancer Nursing*, 16, 169-178.
- Fife, B. L. (1994). The conceptualization of meaning in illness. *Social Science & Medicine*, 38, 309-316.
- Finfgeld, D. L. (1992). Courage in the chronically-ill elderly: A grounded theory study. Unpublished doctoral dissertation, The University of Texas, Austin.
- Finfgeld, D. L. (1995). Becoming and being courageous in the chronically ill elderly. *Issues in Mental Health Nursing*, 16, 1-11.

- Fisher, B., & Galler, R. (1985). Friendship and fairness: How disability affects friendship between women. In M. Fine & A. Ash (Eds.), *Women with disabilities* (pp. 172-194). Philadelphia: Temple University Press.
- Folden, S. L. (1994). Managing the effects of a stroke. *Rehabilitation Nursing Research*, 3, 79-85.
- Ford, J. S. (1987). *Living with a history of a heart attack: A human science investigation*. Unpublished doctoral dissertation, University of Alberta, Edmonton.
- Ford, J. S. (1989). Living with a history of a heart attack: A human science investigation. *Journal of Advanced Nursing*, 14, 173-179.
- Foulds, J. S. (1985). *Inflammatory bowel disease as a cultural artifact: An ethnography of the politics of suffering*. Unpublished doctoral dissertation, University of British Columbia, Vancouver.
- Francis, G. M., & Munjas, B. A. (1992). Research with HIV positive persons: Problems. *Virginia Nurse*, 60 (1), 21-23
- Francke, A. L. & Theeuwien, I. (1994). Inhibition in expressing pain: A qualitative study among Dutch surgical breast cancer patients. *Cancer Nursing*, 17, 193-199.
- Freedman, T. G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing*, 17, 334-341.
- Fuller, A. (1991). *Diabetic diet management: A native Indian perspective*. Unpublished masters thesis, University of British Columbia, Vancouver.
- Garro, L. C. (1992). Chronic illness and the construction of narrative. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 100-137). Berkeley, CA: University of California Press.
- Garro, L. C. (1995). Individual or social responsibility?: Explanations of diabetes in an Anishinaabe (Ojibway) community. *Social Science & Medicine*, 40 (1), 37-46.
- Gatter, P. N. (1995). Anthropology, HIV and contingent identities. *Social Science & Medicine*, 41, 1523-1533.
- Gerhardt, U. (1990). Patient careers in end-stage renal failure. *Social Science & Medicine*, 30, 1211-1224.
- Glaus, A., Crow, R., & Hammond, S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. *Supportive Care in Cancer*, 4, 82-96.

- Gloersen, B., Kendall, J., Gray, P., McConnell, S., Turner, J., & Lewkowicz, J. W. (1993). The phenomena of doing well in people with AIDS. *Western Journal of Nursing Research*, 15 (1), 44-58.
- Good, B. J. (1992). A body in pain: The making of a world of chronic pain. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 29-47). Berkeley, CA: University of California Press.
- Good, B. J. & Del Vecchio Good, M. J. (1994). In the subjunctive mode: Epilepsy narratives in Turkey. *Social Science & Medicine*, 38, 835-842.
- Gramling, L., Boyle, J. S., McCain, N., Ferrell, J., Hodnicki, D., & Muller, R. (1996). Reconstructing a woman's experiences with AIDS. *Family and Community Health*, 19 (3), 49-56.
- Gregory, D. (1994). The myth of control: Suffering in palliative care. *Journal of Palliative Care*, 10 (2), 18-22.
- Gulick, E. E., Yam, M., & Touw, M. M. (1989). Work performance by persons with multiple sclerosis: Conditions that impede or enable the performance of work. *International Journal of Nursing Studies*, 26, 301-311.
- Gullickson, C. (1993). My death nearing its future: A Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness. *Journal of Advanced Nursing*, 18, 1386-1392.
- Gurowka, K. J., & Lightman, E. S. (1995). Supportive and unsupportive interactions as perceived by cancer patients. *Social Work in Health Care*, 21 (4), 71-88.
- Haase, J. E. (1987). Components of courage in chronically ill adolescents: A phenomenological study. *Advances in Nursing Science*, 9 (2), 64-80.
- Hack, T. F., Degner, L. F., & Dyck, D. G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science & Medicine*, 39, 279-289.
- Hagstrom, T., Axelsson, K., & Norberg, A. (1994). The experience of living with stroke sequelae illuminated by means of stories and metaphors. *Qualitative Health Research*, 4, 321-337.
- Hainsworth, M. A. (1994). Living with multiple sclerosis: The experience of chronic sorrow. *Journal of Neuroscience Nursing*, 26, 237-240.
- Hainsworth, M. A., Eakes, G. G., & Burke, M. L. (1994). Coping with chronic sorrow. *Issues in Mental Health Nursing*, 15, 59-66.

- Haisfield, M. E., McGuire, D. B., Krumm, S., Shore, A. D., Zabora, J., & Rubin, H. R. (1994). Patients' and healthcare providers' opinions regarding advance directives. *Oncology Nursing Forum*, 21, 1179-1187.
- Halldorsdottir, S., & Hamrin, E. (1996). Experiencing existential changes: The lived experience of having cancer. *Cancer Nursing*, 19, 29-36.
- Hall, B. A. (1994). Ways of maintaining hope in HIV disease. *Research in Nursing & Health*, 17, 283-293.
- Handron, D. S., & Leggett-Frazier, N. K. (1994). Utilizing content analysis of counseling sessions to identify psychosocial stressors among patients with Type II diabetes. *The Diabetes Educator*, 20, 515-520.
- Hanna, K. M., & Jacobs, P. (1993). The use of photography to explore the meaning of health among adolescents with cancer. *Issues in Comprehensive Pediatric Nursing*, 16, 155-164.
- Henriksson, C. M. (1995). Living with continuous muscular pain - Patient perspectives. Part I: Encounters and consequences. *Scandinavian Journal of Caring Sciences*, 9, 67-76.
- Henriksson, C. M. (1995). Living with continuous muscular pain - Patient perspectives. Part II: Strategies for daily life. *Scandinavian Journal of Caring Sciences*, 9, 77-86.
- Hernandez, C. A. (1991). *The lived experience of Type 1 diabetes: Implications for diabetes education*. Unpublished doctoral dissertation, The University of Toronto, Toronto.
- Hernandez, C. A. (1995). The experience of living with insulin-dependent diabetes: Lessons for the diabetes educator. *The Diabetes Educator*, 21, 33-37.
- Hernandez, C. A. (1996). Integration: The experience of living with insulin dependent (Type I) diabetes mellitus. *Canadian Journal of Nursing Research*, 28, 37-56.
- Hildingh, C., Fridlund, B., & Segesten, K. (1995). Social support in self-help groups, as experienced by persons having coronary heart disease and their next of kin. *International Journal of Nursing Studies*, 32, 224-232.
- Hilton, B. A. (1986). *Coping with the uncertainties of breast cancer: Appraisal and coping strategies*. Unpublished doctoral dissertation, University of Texas, Austin.
- Howell, S. L. (1994). Natural/alternative health care practices used by women with chronic pain: Findings from a grounded theory research study. *Nurse Practitioner Forum*, 5, 98-105.
- Hughey, D. R. (1991). *A phenomenological-psychological study of the experience of chronic fatigue syndrome*. Unpublished doctoral dissertation, Saybrook Institute, San Francisco.

- Iphofen, R. (1990). Coping with a 'perforated life': A case study in managing the stigma of petit mal epilepsy. *Sociology*, 24, 447-463.
- Jackson, J. E. (1992). "After a while no one believes you": Real and unreal pain. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 138-168). Berkeley, CA: University of California Press.
- Jayne, R. L. (1993). *Self-regulation: Negotiating treatment regimens in insulin-dependent diabetes*. Unpublished doctoral dissertation, University of California, San Francisco.
- Jillings, C. R. (1992). Back in circulation, or dancing around the circle? Participatory action research in the context of cardiac rehabilitation. Unpublished doctoral dissertation, Union Institute, Cincinnati.
- Johnson, J. L. (1988). *The process of adjustment following myocardial infarction*. Unpublished master's thesis, University of Alberta, Edmonton.
- Johnson, J. L., & Morse, J. M. (1990). Regaining control: The process of adjustment after myocardial infarction. *Heart & Lung*, 19, 126-135.
- Johnston, D., Smith, K., & Stall, R. (1994). A comparison of public health care utilization by gay men and intravenous drug users with AIDS in San Francisco. *AIDS CARE*, 6, 303-316.
- Jones, R. V. H., & Greenwood, B. (1994). Breast cancer: Causes of patients' distress identified by qualitative analysis. *British Journal of General Practice*, 44, 370-371.
- Jubala, J. A. (1989). Right hemisphere cerebrovascular accident: A phenomenological study of living through the first three months. Unpublished doctoral dissertation, Duquesne University, Pittsburgh.
- Kagawa-Singer, M. (1993). Redefining health: Living with cancer. *Social Science & Medicine*, 37, 295-304.
- Kaprowy, J. A. (1991). A descriptive study to investigate end stage renal disease patients' desire for information and preferences about roles in treatment decision making. Unpublished master's thesis, University of Manitoba, Winnipeg.
- Kasper, A. S. (1994). A feminist, qualitative methodology: A study of women with breast cancer. *Qualitative Sociology*, 17, 263-281.
- Katz, A. (1995). Gaining a new perspective on life as a consequence of uncertainty in HIV infection. Unpublished master's thesis, University of Manitoba, Winnipeg.
- Kaufman, S. R. (1988). Toward a phenomenology of boundaries in medicine: Chronic illness experience in the case of stroke. *Medical Anthropology Quarterly*, 2, 339-354.

- Kaufman, S.R. (1992). Illness, biography, and the interpretation of self following a stroke. In J. F. Gubrium & K. Charmaz (Eds.), *Aging, self and community: A collection of readings* (pp. 71-81). Greenwich, CT: JAI Press.
- Kelleher, D. (1988). Coming to terms with diabetes: Coping strategies and non-compliance. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 137-155). Boston: Unwin Hyman.
- Kelly, M. P. (1991). Coping with an ileostomy. *Social Science & Medicine*, 33, 115-125.
- Kendall, J. (1991). *Human association and wellness in homosexual men with HIV infection: A grounded theory*. Unpublished doctoral dissertation, Georgia State University, Atlanta.
- Kirk, K. (1990). *Chronically ill patient's perceptions of nursing care*. Unpublished master's thesis, University of Saskatchewan, Saskatoon.
- Kirk, K. (1993). Chronically ill patients' perceptions of nursing care. *Rehabilitation Nursing*, 18 (2), 99-104.
- Kleinman, A. (1992). Pain and resistance: The delegitimation and relegitimation of local worlds. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as a human experience: An anthropological perspective* (pp. 169-197). Berkeley, CA: University of California Press.
- Kodiath, M. F., & Kodiath, A. (1995). A comparative study of patients who experience chronic malignant pain in India and the United States. *Cancer Nursing*, 18, 189-196.
- Krefting, L. (1990). Double bind and disability: The case of traumatic head injury. *Social Science & Medicine*, 30, 839-865.
- Kutner, N. G., & Gray, H. L. (1985). Women and renal failure: Some neglected issues. In M. J. Deegan & N. A. Brooks (Eds.), *Women and disability: The double handicap* (pp. 105-116). New Brunswick, NJ: Transaction Books.
- Laryea, M., & Gien, L. (1993). The impact of HIV-positive diagnosis on the individual. *Clinical Nursing Research*, 2, 245-266.
- Laskiwski, S. M. A. (1989). *An ethnography of the spinal cord injury unit*. Unpublished master's thesis, University of Alberta, Edmonton.
- Laskiwski, S. (1990). An ethnography of the spinal cord injury unit. *AARN*, 46, 14-15.
- Laskiwski, S., & Morse, J. M. (1993). The patient with spinal cord injury: The modification of hope and expressions of despair. *Canadian Journal of Rehabilitation*, 6 (3), 143-153.

- le Gallez, P. (1993). Rheumatoid arthritis: Effects on the family. *Nursing Standard*, 7 (39), 30-34.
- Leidy, N., & Haase, J. E. (1996). Functional performance in people with chronic obstructive pulmonary disease: A qualitative analysis. *Advances in Nursing Science*, 18, 77-89.
- LeMone, P. (1991). Transforming: Patterns of sexual function in adults with insulin-dependent diabetes mellitus. Unpublished doctoral dissertation, University of Alabama, Birmingham.
- LeMone, P. (1993). Human sexuality in adults with insulin-dependent diabetes mellitus. *IMAGE: Journal of Nursing Scholarship*, 25, 101-105.
- LeMone, P. (1995). Assessing psychosexual concerns in adults with diabetes: Pilot project using Roy's modes of adaptation. *Issues in Mental Health Nursing*, 16, 67-78.
- Lennon, M. C. (1989). The stigma of chronic facial pain and its impact on social relationships. *Social Problems*, 36, 117-134.
- Lev, E. L. (1992). Patients' strategies for adapting to cancer treatment. *Western Journal of Nursing Research*, 14, 595-617.
- Levy, S. M. (1981). Experience of undergoing a heart attack. *Journal of Phenomenological Psychology*, 12, 153-72.
- Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: A study of the married couple's experience with breast cancer recurrence. *Oncology Nursing Forum*, 22, 943-953.
- Lewis, M. C. (1988). Attribution and illness. *Journal of Psychosocial Nursing*, 26, 15-21.
- Lindsey, A. E. (1993). *Health within illness: Experiences of the chronically ill disabled*. Unpublished doctoral dissertation, University of Victoria, Victoria.
- Locker, D. (1983). *Disability and disadvantage*. London: Tavistock Publications.
- Locker, D., & Kaufert, J. (1988). The breath of life: Medical technology and the careers of people with post-respiratory poliomyelitis. *Sociology of Health and Illness*, 10, 23-40.
- Loomis, M. E., & Conco, D. (1991). Patients' perceptions of health, chronic illness, and nursing diagnosis. *Nursing Diagnosis*, 2, 162-170.
- Lough, M. A. (1996). Ongoing work of older adults at home after hospitalization. *Journal of Advanced Nursing*, 23, 804-809.
- Loveys, B. J., & Klaich, K. (1991). Breast cancer: Demands of illness. *Oncology Nursing Forum*, 18 (1), 75-80.

- Luker, K. A., Beaver, K., Leinster, S. J., & Owens, R. G. (1996). Meaning of illness for women with breast cancer. *Journal of Advanced Nursing*, 23, 1194-1201.
- Lundman, B., & Norberg, A. (1993). Coping strategies in people with insulin-dependent diabetes mellitus. *The Diabetes Educator*, 19, 198-204.
- Luyas, G. T. (1991). An explanatory model of diabetes. *Western Journal of Nursing Research*, 13, 681-697.
- Macdonald, L. (1988). The experience of stigma: Living with rectal cancer. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 177-202). Boston: Unwin Hyman.
- Maclean, H. M. (1991). Patterns of diet related self-care in diabetes. *Social Science & Medicine*, 32, 689-696.
- Maclean, H., & Oram, B. (1988). *Living with diabetes*. Toronto, Canada: University of Toronto Press.
- Madsen, W. C. (1992). Problematic treatment: Interaction of patient, spouse, and physician beliefs in medical noncompliance. *Family Systems Medicine*, 10, 365-383.
- Mahon, S. D. (1991). *Psychosocial adjustment to recurrent cancer*. Unpublished doctoral dissertation, Rush University, Chicago.
- Maillet, N. A., Melkus, G. D., & Spollett, G. (1996). Using focus groups to characterize the health beliefs and practices of black women with non-insulin-dependent diabetes. *The Diabetes Educator*, 22 (1), 39-46.
- Maines, D. R. (1991). The storied nature of health and diabetic self-help groups. *Advances in Medical Sociology*, 2, 185-202.
- Marr, J. A. (1988). *The experience of living with Parkinson's Disease*. Unpublished master's thesis, University of Toronto, Toronto.
- Marr, J. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing*, 23, 325-329.
- Mathews, J. F., Lannin, D. R., & Mitchell, J. P. (1994). Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. *Social Science & Medicine*, 38, 789-800.
- McBride, S. (1993). Perceived control in patients with chronic obstructive pulmonary disease. *Western Journal of Nursing Research*, 15, 456-464.

- McBride, S. (1994). Patients with chronic obstructive pulmonary disease: Their beliefs about measures that increase activity tolerance. *Rehabilitation Nursing, 19* (1), 37-41.
- McCord, E. C. & Brandenburg, C. (1995). Beliefs and attitudes of persons with diabetes. *Family Medicine, 27*, 267-271.
- McLaughlin, J., & Zeeberg, I. (1993). Self-care and multiple sclerosis: A view from two cultures. *Social Science & Medicine, 37*, 315-329.
- McSweeney, J. C. (1993). Making behavior changes after a myocardial infarction. *Western Journal of Nursing Research, 15*, 441-455.
- McWilliam, C. L., Stewart, M., Brown, J. B., Desai, K., & Coderre, P. (1996). Creating health with chronic illness. *Advances in Nursing Science, 18*, 1-15.
- Miles-Tapping, C., & MacDonald, L. J. (1994). Lifestyle implications of power mobility. *Physical & Occupational Therapy in Geriatrics, 12*, 31-49.
- Milliken, P. J., & Northcott, H. C. (1996). Seeking validation: Hypothyroidism and the chronic illness trajectory. *Qualitative Health Research, 6*, 202-223.
- Moch, S. D. (1990). Health within the experience of breast cancer. *Journal of Advanced Nursing, 15*, 1426-1435.
- Molzahn, A. (1991). The reported quality of life of selected home hemodialysis patients. *ANNA Journal, 18*, 173-181.
- Monks, J. (1995). Life stories and sickness experience: A performance perspective. *Culture, Medicine and Psychiatry, 19*, 453-478.
- Montbriand, M. J. (1995). Alternative therapies as control behaviours used by cancer patients. *Journal of Advanced Nursing, 22*, 646-654.
- Morales, E. (1994). Meaning of touch to hospitalized Puerto Ricans with cancer. *Cancer Nursing, 17*, 464-469.
- Morgan, J. (1988). Living with renal failure on home haemodialysis. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 203-224). Boston: Unwin Hyman.
- Morse, J. M., & Johnson, J. L. (Eds.). (1991). *The illness experience*. Newbury Park, CA: Sage.
- Mumma, C. M. (1986). Perceived losses following stroke. *Rehabilitation Nursing, 11*, 19-21.
- Naess, M. H. & Malterud, K. (1995). Patients' stories: Science, clinical facts, or fairy tales? *Scandinavian Journal of Primary Health Care, 13*, 59-64.

- Nelson, J. P. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science*, 18, 59-76.
- Newman, M. A., & Moch, S. D. (1991). Life patterns of persons with coronary heart disease. *Nursing Science Quarterly*, 4, 161-167.
- Nyhlin, K. T. (1990). A contribution of qualitative research to a better understanding of diabetic patients. *Journal of Advanced Nursing*, 15, 796-803.
- Nyhlin, K. T. (1990). Diabetic patients facing long-term complications: Coping with uncertainty. *Journal of Advanced Nursing*, 15, 1021-1029.
- Nyhlin, K. T. (1990). *Patient's experiences in the self-management of diabetes mellitus*. Unpublished doctoral dissertation, University of Umea, Umea.
- Nyhlin, K. T., Lithner, F., & Norberg, A. (1987). The experience of being diabetic. *Scandinavian Journal of Caring Sciences*, 1, 59-67.
- Nokes, K. M., & Carver, K. (1991). The meaning of living with AIDS: A study using Parse's theory of man-living-health. *Nursing Science Quarterly*, 4, 175-179.
- Nosek, M. A. (1996). Wellness among women with physical disabilities. *Sexuality and Disability*, 14, 165-181.
- O'Brien, M. O. (1993). *The courage to survive: The life career of the chronic dialysis patient*. New York: Grune and Stratton.
- Oram, B. (1992). The personal meaning of chronic illness within the context of everyday life: A case study of the experiences of people with insulin-dependent diabetes. Unpublished doctoral dissertation, University of Toronto, Toronto.
- Padilla, G. V., Ferrell, B., Grant, M. M., & Rhiner, M. (1990). Defining the content domain of quality of life for cancer patients with pain. *Cancer Nursing*, 13, 108-115.
- Pakenham, K. I., Dadds, M. R., & Terry, D. J. (1996). Adaptive demands along the HIV disease continuum. *Social Science & Medicine*, 42, 245-256.
- Parker, J. G. (1994). The lived experience of native americans with diabetes within a transcultural nursing perspective. *Journal of Transcultural Nursing*, 6, 5-11.
- Paterson, B. L., & Sloan, J. (1994). A phenomenological study of the decision-making experience of individuals with long-standing diabetes. *Canadian Journal of Diabetes Care*, 18, 10-19.
- Paul, L. R. (1994). *The first recurrence of cancer: Rebuilding the hopeful veneer*. Unpublished master's thesis, University of Alberta, Edmonton.

- Peyrot, M., McMurry, Jr., J. F., & Hedges, R. (1988). Marital adjustment to adult diabetes: Interpersonal congruence and spouse satisfaction. *Journal of Marriage and the Family*, 50, 363-376.
- Phillips, M. J. (1985). Disability and ethnicity in conflict: A study in transformation. In M. Fine & A. Ash (Eds.), *Women with disabilities* (pp. 195-225). Philadelphia: Temple University Press.
- Phillips, M. J. (1992). "Try harder": The experience of disability and the dilemma of normalization. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 213-227). New York: Teachers College Press.
- Pierce, P. F. (1996). When the patient chooses: Describing unaided decisions in health care. *Human Factors*, 38, 278-287.
- Pinder, R. (1988). Striking balances: Living with Parkinson's disease. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 67-88). Boston: Unwin Hyman.
- Pinder, R. (1995). Bringing back the body without the blame?: The experience of ill and disabled people at work. *Sociology of Health and Illness*, 17, 605-631.
- Pobl, C. M. (1992). The meaning of disability in a caring environment. *Journal of Nursing Administration*, 22, 29-35.
- Powell-Cope, G. M. (1995). The experiences of gay couples affected by HIV infection. *Qualitative Health Research*, 5, 36-62.
- Powell-Cope, G. M. (1996). HIV disease symptom management in the context of committed relationships. *Journal of the Association of Nurses in AIDS Care*, 7 (3), 19-28.
- Predeger, E. (1996). Womanspirit: A journey into healing through art in breast cancer. *Advances in Nursing Science*, 18, 48-58.
- Price, M. J. (1988). Perceived uncertainty associated with the management trajectory of a chronic illness - diabetes mellitus. Unpublished doctoral dissertation, University of California, San Francisco.
- Price, M. (1989). Qualitative analysis of the patient-provider interactions: The patient's perspective. *The Diabetes Educator*, 15, 144-148.
- Price, M. (1993). Exploration of body listening: Health and physical self-awareness in chronic illness. *Advances in Nursing Science*, 15, 37-52.
- Price, M. (1993). An experiential model of learning diabetes self-management. *Qualitative Health Research*, 3, 29-54.

- Price-Lackey, P., & Cashman, J. (1996). Jenny's story: Reinventing oneself through occupation and narrative configuration. *The American Journal of Occupational Therapy*, 50, 306-314.
- Primomo, J. (1989). Patterns of chronic illness management, psychosocial development, family and social environment and adaptation among diabetic women. Unpublished doctoral dissertation, University of Washington, Seattle.
- Quinn, A. A., Barton, J. A., & Maglivi, J. K. (1995). Weathering the storm: Metaphors and stories of living with multiple sclerosis. *Rehabilitation Nursing Research*, 4, 19-27.
- Radley, A., & Green, R. (1986). Bearing illness: Study of couples where the husband awaits coronary graft surgery. *Social Science & Medicine*, 23, 577-585.
- Ragsdale, D., Kotarba, J. A., & Morrow Jr., J. R. (1992). Quality of life of hospitalized person with AIDS. *IMAGE: Journal of Nursing Scholarship*, 24, 259-265.
- Ragsdale, D., Kotarba, J. A., & Morrow Jr., J. R. (1994). How HIV+ persons manage everyday life in the hospital and at home. *Qualitative Health Research*, 4, 431-443.
- Raleigh, E. D. H. (1992). Sources of hope in chronic illness. *Oncology Nursing Forum*, 19, 443-448.
- Rauyajin, O., Kamthornwachara, B., & Yablo, P. (1995). Socio-cultural and behavioural aspects of mosquito-borne lymphatic filariasis in Thailand: A qualitative analysis. *Social Science & Medicine*, 41, 1705-1713.
- Rawnsley, M. M. (1994). Recurrence of cancer: A crisis of courage. *Cancer Nursing*, 17, 342-347.
- Remien, R. H., Carballo-Diequez, A., & Wagner, G. (1995). Intimacy and sexual risk behaviour in serodiscordant male couples. *AIDS CARE*, 7, 429-438.
- Riessman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine*, 30, 1195-1200.
- Rintala, D. H., Young, M. E., Spencer, J. C., & Bates, P. S. (1996). Family relationships and adaptation to spinal cord injury: A qualitative study. *Rehabilitation Nursing*, 21 (2), 67-74, 90.
- Rittman, M., Northsea, C., Hausauser, N. Green, C., & Swanson, L. (1993). Living with renal failure. *ANNA Journal*, 20, 327-331.
- Roberson, M. H. B. (1992). The meaning of compliance: Patient perspectives. *Qualitative Health Research*, 2, 7-26.

- Robinson, I. (1988). Reconstructing lives: Negotiating the meaning of multiple sclerosis. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 43-66). Boston: Unwin Hyman.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, 30, 1173-1186.
- Sandelowski, M., & Pollock, C. (1986). Women's experiences of infertility. *IMAGE: Journal of Nursing Scholarship*, 18 (4), 140-144.
- Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, 8, 26-43.
- Scambler, G., & Hopkins, A. (1990). Generating a model of epileptic stigma: The role of qualitative analysis. *Social Science & Medicine*, 30, 1187-1194.
- Schaefer, K. M. (1995). Women living in paradox: Loss and discovery in chronic illness. *Holistic Nursing Practice*, 9, 63-74.
- Scherer, M. J. (1988). Assistive device utilization and quality-of-life in adults with spinal cord injuries or cerebral palsy. *Journal of Applied Rehabilitation Counseling*, 19 (2), 21-30.
- Schneider, J. W., & Conrad, P. (1980). In the closet with illness: Epilepsy, stigma potential and information control. *Social Problems*, 28, 32-44.
- Schneider, J. W., & Conrad, P. (1983). *Having epilepsy: The experience of control and illness*. Philadelphia: Temple University Press.
- Seals, B. F., Sowell, R. L., Demi, A. S., Moneyham, L., Cohen, L., & Guillory, J. (1995). Falling through the cracks: Social service concerns of women infected with HIV. *Qualitative Health Research*, 5, 496-515.
- Sebring, D. L., & Moglia, P. (1987). Amyotrophic Lateral Sclerosis: Psychosocial interventions for patients and their families. *Health and Social Work, Spring*, 113-120.
- Shah, H. S. (1989). Psychosocial adjustment, self-concept, and sexual satisfaction of women with diabetes. Unpublished doctoral dissertation, Boston University, Boston.
- Shaul, M. P. (1995). From early twinges to mastery: The process of adjustment in living with rheumatoid arthritis. *Arthritis Care and Research*, 8, 290-297.
- Shaul, M. P. (1995). Quality of life among older women with rheumatoid arthritis. *Journal of Women & Aging*, 7, 101-116.

- Shaul, S., Dowling, P. J., & Laden, B. F. (1985). Like other women: Perspectives of mothers with physical disabilities. In M. J. Deegan & N. A. Brooks (Eds.), *Women and disability: The double handicap* (pp. 133-142). New Brunswick, NJ: Transaction Books.
- Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior*, 32, 17-32.
- Simon, B. L. (1985). Never-married old women and disability: A majority experience. In M. Fine & A. Ash (Eds.), *Women with disabilities* (pp. 215-225). Philadelphia: Temple University Press.
- Sloan, R. S. (1996). A hermeneutical study of the medical treatment decision for end stage renal disease patients and their families. Unpublished doctoral dissertation, University of Kentucky, Lexington.
- Smeltzer, S. C. (1994). The concerns of pregnant women with multiple sclerosis. *Qualitative Health Research*, 4, 480-502.
- Stein, H. F. (1992). The many-voiced cultural story line of a case of diabetes mellitus. *The Journal of Family Practice*, 35, 529-533.
- Stewart, D. C., & Sullivan, T. J. (1982). Illness behavior and the sick role in chronic disease: The case of multiple sclerosis. *Social Science & Medicine*, 16, 1397-1404.
- Stuifbergen, A. K., Becker, H. A., Ingalsbe, K., & Sands, D. (1990). Perceptions of health among adults with disabilities. *Health Values*, 14, 18-26.
- Swanson, J. M., & Chenitz, W. C. (1993). Regaining a valued self: The process of adaptation to living with genital herpes. *Qualitative Health Research*, 3, 270-297.
- Tewksbury, R. (1995). Sexual adaptations among gay men with HIV. In D. Sabo & D. F. Gordon (Eds.), *Men's health and illness: Gender, power and the body* (pp. 222-245). Thousand Oaks, CA: Sage.
- Thoman-Touet, S. K. (1992). *A qualitative study of the effect of chronic illness on marital quality*. Unpublished doctoral dissertation, Iowa State University, Ames.
- Thomas, C., & Parry, A. (1996). Research on users' views about stroke services: Towards an empowerment research paradigm or more of the same? *Physiotherapy*, 82 (1), 6-12.
- Thompson, D. R., Ersser, S. J., & Webster, R. A. (1995). The experiences of patients and their partners 1 month after a heart attack. *Journal of Advanced Nursing*, 22, 707-714.
- Thorne, S. E. (1990). Constructive noncompliance in chronic illness. *Holistic Nursing Practice*, 5, 62-69.

- Thorne, S. E. (1990). *Navigating troubled waters: Chronic illness experience in a health care crisis*. Unpublished doctoral dissertation, Union Institute, Cincinnati.
- Thorne, S. E. & Robinson, C. A. (1988). Health care relationships: The chronic illness perspective. *Research in Nursing and Health*, 11, 293-300.
- Valentine, L., Bigner, J. J., Cook, A. S., & Guest, R. E. (1992). Assessment of the interpersonal themes in therapy of a person with AIDS. *Journal of Family Psychotherapy*, 3 (2), 71-86.
- Ventimiglia, J. (1986). Helping couples with neurological disabilities: A job description for clinical sociologists. *Clinical Sociology Review*, 4, 123-139.
- Viney, L. L., & Bousfield, L. (1991). Narrative analysis: A method of psychosocial research for AIDS-affected people. *Social Science & Medicine*, 32, 757-765.
- Wagenaar, H. (1995). An exploratory descriptive study of fatigue in women with systemic lupus erythematosus. Unpublished master's thesis, Dalhousie University, Halifax.
- Walshe, C. (1995). Living with a venous leg ulcer: A descriptive study of patients' experiences. *Journal of Advanced Nursing*, 22, 1092-1100.
- Webber, K. S. (1985). *Patient perceptions after a myocardial infarction: Interpreting the message*. Unpublished master's thesis, Dalhousie University, Halifax.
- Whipple, B., Richards, E., Tepper, M., & Komisaruk, B. R. (1996). Sexual response in women with complete spinal cord injury. *Sexuality and Disability*, 14, 191-201.
- Wikblad, K. F. (1991). Patient perspectives of diabetes care and education. *Journal of Advanced Nursing*, 16, 837-844.
- Wikblad, K. F. & Montin, K. R. (1992). Coping with a chronic disease. *Diabetes Educator*, 18, 316-320.
- Willer, B., Allen, K., Durnan, M., & Ferry, A. (1990). Problems and coping strategies of mothers, siblings and young adult males with traumatic brain injury. *Canadian Journal of Rehabilitation*, 3, 167-173.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness*, 6, 175-200.
- Wright, L. M., Bell, J. M., & Rock, B. L. (1989). Smoking behaviour and spouses: A case report. *Family Systems Medicine*, 7, 158-171.
- Wyatt, G., Kurtz, M. E., & Liken, M. (1993). Breast cancer survivors: An exploration of quality of life issues. *Cancer Nursing*, 16, 440-448.

- Yoshida, K. K. (1991). *Life reconstruction among individuals with spinal cord injuries: A sociological analysis*. Unpublished doctoral dissertation, University of Toronto, Toronto.
- Yoshida, K. K. (1993). Reshaping of self: A pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health and Illness*, 15, 217-245.
- Young, C. (1993). Spirituality and the chronically ill Christian elderly. *Geriatric Nursing*, 14, 298-303.
- Zola, I. K. (1992). "Any distinguishing features?": The portrayal of disability in the crime-mystery genre. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 213-227). New York: Teachers College Press.

Appendix 2: Fatigue Meta-Study Primary Sources (N=33)

[Inclusion Criteria: qualitative interpretive research published 1980 through Jan 1999 in which the experience of fatigue was studied from the perspective of individuals with a chronic illness and there was sufficient methodological and demographic detail for indepth review]

- Barton, J. A., Magilvy, J. K., & Quinn, A. A. (1994). Maintaining the fighting spirit: Veterans living with multiple sclerosis. *Rehabilitation Nursing Research*, 3 (3), 86-96.
- Berman, A. J. (1993). *Sailing a course through chemotherapy: The experience of women with breast cancer*. Unpublished doctoral dissertation, University of California, San Francisco.
- Clements, A., Sharpe, M., Simkin, S., Borrill, J., & Hawton, K. (1997). Chronic fatigue syndrome: A qualitative investigation of patients' beliefs about the illness. *Journal of Psychosomatic Research*, 42, 615-624.
- Deatrick, J. A., Brennan, D., & Cameron, M. A. (1998). Mothers with multiple sclerosis and their children: Effects of fatigue and exacerbations on maternal support. *Nursing Research*, 47, 205-210
- Dzurec, L. C. (1997). Experiences of fatigue and depression before and after low-dose 1-thyroxine supplementation in essentially euthyroid individuals. *Research in Nursing & Health*, 20, 389-398.
- Erixon, G., Jerlock, M., & Dahlberg, K. (1997). Upplevelser av att leva med karlkamp. [Experiences of living with angina pectoris] [Swedish] *Vard i Norden [Nursing Science & Research in the Nordic Countries]*, 17 (2), 34-38.
- Ferrell, B. R., Grant, M., Dean, G. E., Funk, B., & Ly, J. (1996). "Bone tired": The experience of fatigue and its impact on quality of life. *Oncology Nursing Forum*, 23, 1539-1547.
- Glaus, A., Crow, R., & Hammond, S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. *European Journal of Cancer Care*, 5 (2 suppl), 8-23.
- Henriksson, C. M. (1995). Living with continuous muscular pain—Patient perspectives. Part II: Strategies for daily life. *Scandinavian Journal of Caring Sciences*, 9, 77-86.
- Hughey, D. R. (1991). *A phenomenological-psychological study of the experience of chronic fatigue syndrome*. Unpublished doctoral dissertation, Saybrook Institute, San Francisco.
- Jamar, S. (1989). Fatigue in women receiving chemotherapy for ovarian cancer. In S. Funk, E. Tornquist, M. Champagne, L. Copp, & R. Weise, R. (Eds.). *Key Aspects of Comfort Management of Pain, Fatigue and Nausea*. New York: Springer.

- Krishnasamy, M. (1997). Exploring the nature and impact of fatigue in advanced cancer. *International Journal of Palliative Care Nursing*, 3 (3), 126-131.
- LaCharity, L. A. (1997). The experiences of postmenopausal women with coronary artery disease. *Western Journal of Nursing Research*, 19, 583-602.
- Leidy, N. K., & Haase, J. E. (1996). Functional performance in people with chronic obstructive pulmonary disease: A qualitative analysis. *Advances in Nursing Science*, 18 (3), 77-89.
- Lerdal, A. (1998). A concept analysis of energy. Its meaning in the lives of three individuals with chronic illness. *Scandinavian Journal of Caring Sciences*, 12, 3-10.
- Libbus, M. K. (1996). Women's beliefs regarding persistent fatigue. *Issues in Mental Health Nursing*, 17, 589-600.
- Messias, D. K., Yeager, K. A., Dibble, S. L., & Dodd, M. J. (1997). Patients' perspective of fatigue while undergoing chemotherapy. *Oncology Nursing Forum*, 24 (1), 43-48.
- Pearce, S. & Richardson, A. (1996). Fatigue in cancer: a phenomenological perspective. *European Journal of Cancer Care*, 5, 111-115.
- Price, M. (1993). Exploration of body listening: Health and physical self-awareness in chronic illness. *Advances in Nursing Science*, 15 (4), 37-52.
- Ream, E. & Richardson, A. (1997). Fatigue in patients with cancer and chronic obstructive airways disease: a phenomenological enquiry. *International Journal of Nursing Studies*, 34 (1), 44-53.
- Rhodes, V. A., Watson, P. M., & Hanson, B. M. (1988). Patients' descriptions of the influence of tiredness and weakness on self-care abilities. *Cancer Nursing*, 11 (3), 186-194.
- Richardson, A. & Ream, E. (1996). The experience of fatigue and other symptoms in patients receiving chemotherapy. *European Journal of Cancer Care*, 5 (Suppl. 2), 24-30.
- Rose, L., Pugh, L. C., Lears, K., & Gordon, D. L. (1998). The fatigue experience: persons with HIV infection. *Journal of Advanced Nursing*, 28, 295-304.
- Schaefer, K. M. (1995). Struggling to maintain balance: a study of women living with fibromyalgia. *Journal of Advanced Nursing*, 21, 95-102.
- Schaefer, K. M. (1997). Health patterns of women with fibromyalgia. *Journal of Advanced Nursing*, 26, 565-571.
- Schweitzer, R., Kelly, B., Foran, A., Terry, D., & Whiting, J. (1995). Quality of life in chronic fatigue syndrome. *Social Science & Medicine*, 41, 1367-1372.

- Srivastava, R. H. (1989). Fatigue in end-stage renal disease patients. In S. Funk, E. Tornquist, M. Champagne, L. Copp, & R. Weise (Eds.). *Key Aspects of Comfort Management of Pain, Fatigue and Nausea*. New York: Springer.
- Stuifbergen, A. K., & Rogers, S. (1997). The experience of fatigue and strategies of self-care among persons with multiple sclerosis. *Applied Nursing Research*, 10 (1), 2-10.
- Tack, B. B. (1990). Fatigue in rheumatoid arthritis: Conditions, strategies, and consequences. *Arthritis Care and Research*, 3 (2), 65-70.
- Tierney, A. J., Taylor, J., & Closs, S. J. (1992). Knowledge, expectations, and experiences of patients receiving chemotherapy for breast cancer. *Scandinavian Journal of Caring Sciences*, 6 (2), 75-80.
- Tuck, I., & Human, N. (1998). The experience of living with chronic fatigue syndrome. *Journal of Psychosocial Nursing*, 36 (2), 15-19.
- van Servellen, G., Sarna, L., Jablonski, K. J. (1998). Women with HIV: Living with symptoms. *Western Journal of Nursing Research*, 20, 448-464.
- Wagenaar, H. (1995). An exploratory descriptive study of fatigue in women with systemic lupus erythematosus. Unpublished master's thesis, Dalhousie University, Halifax.