USE OF THE DELPHI TECHNIQUE AND QUALITATIVE METHOD TO COMPARE THE WAY IN WHICH MENTAL HEALTH CONSUMERS AND PROVIDERS UNDERSTAND THE MEANING OF QUALITY OF LIFE

by

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ABSTRACT

In spite of the widespread interest in quality of life there is no common understanding or definition of quality of life among providers and consumers of mental health services.

Purpose: The study compared consumers' and providers' perceptions of the meaning of quality of life and explored whether a modified delphi technique and the qualitative ethnoscience method would facilitate such a comparison.

Sample: Purposive sampling was used to select 14 consumers receiving services in the community, each of whom had a minimum lifetime accumulation of 6 months as a psychiatric inpatient, was articulate and interested in discussing issues that affected their lives. Purposive sampling was used to select ten experienced multidisciplinary mental health providers.

Method: Open ended questions about the meaning of quality of life were asked using a modified delphi of three parallel rounds of face-to-face interviews with consumers and providers. In each round, interviews with consumers and providers were audiotaped, transcribed verbatim and analysed separately. In round I, the beginning categories of quality of life were generated. In rounds II and III these categories were clarified and amplified. Round II participants were also asked which categories were most and least important.

Results: Consumers generated eight final quality of life categories: "basic needs," "good mental health," "relationships," "belief & spirituality," "freedom &

independence," "daily routine," "self-care & recreation," and "giving to others." Providers generated six categories: "resources for living," "meaningful daily activities," "connected to the community," "social & professional support," "physical & mental health," and "optimum living." Neither consumer nor provider participants were able to reach consensus on the most and least important categories

<u>Conclusions</u>: The delphi technique and ethnoscience methodology were useful in comparing similarities and differences between the views of consumers and providers. While there was general consistency between consumers and providers on the content of some categories, differences were noted in the degree of importance attached to some categories. Consumers placed a greater value on "belief and spirituality," the role of pets as companions, and the idea of "giving to others." There were no direct consumer counterparts to the providers categories of "optimum living," and "connected to the community."

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CHAPTER 1: INTRODUCTION

In 1977, quality of life became a "key word" by which journal articles could be retrieved by the U.S. National Library of Medicine ("MEDLINE") computer search program (Jenkins, 1992). By the end of 1990, the number of retrievable documents that mentioned quality of life or health status in their titles, had them as an index-term, or made sufficient reference to them to be detected as an appropriate search was about 10,000 (Joyce, 1994). According to Joyce , additional publications of such topics were growing at the rate of about 1,000 per year for each concept. The interest and proliferation of quality of life studies was further evidenced by the new multidisciplinary journal "Quality of Life Research" devoted to quality of life aspects of "Treatment", "Care" and "Rehabilitation" (Abstracts & Programme, 1995). More recently, Health Canada published a report on "Quality of Life Measurement Among Persons With Chronic Mental Illness (Atkinson & Zibin, 1996) and Van Nieuwenhuizen, Schene, Boevink and Wolf, (1997) and Lehman (1996a) also summarised the relevant literature as it applied to persons with mental illness.

Purpose of the study

In spite of the widespread interest in quality of life, there is no consensus definition of quality of life for any population or group. Moreover, the literature also suggests that there is no common understanding or definition of quality of life among providers and consumers at the service delivery level.

Although quality of life is important to many populations affected by illness, the issues facing men and women with serious and persistent mental illness are far reaching and pervasive. In addition to the impact of the illness itself, persons with mental illness are often bereft of social supports, subject to poverty, live in inadequate housing, constitute about a third of the homeless population, end up in prisons, are often unemployed or under employed, and receive inadequate and fragmented services (Cohen & Tsmberis, 1991; Gottleib & Coppard, 1987; Lafave, de Souza, Prince, Atchison & Gerber, 1995; Polak & Warner, 1996).

This study focused on whether or not the delphi technique and the ethnoscience qualitative method yields information that would allow a comparison of similarities and differences between the perceptions of providers and consumers about quality of life. The present study also explored the meaning of quality of life of persons with serious mental illness from the perspective of the consumer of mental health services and the provider of mental health services.

Outline of the thesis

Including this chapter, the thesis consists of 6 chapters. Chapter 2 provides a review and discussion of the literature on quality of life, and articulates the research questions. Chapter 3 describes the methodology and discusses the ethnoscience qualitative method, and the use of the delphi technique. This chapter also describes the sampling process, study design and procedure, and method of analysis. An overview of the three interview rounds for consumers and providers is also provided in this chapter. Chapter 4 reports on the analysis and results of the interviews with consumers and providers for each of the three rounds. A detailed description is provided for each quality of life category. Chapter 5 discusses the results in relation to the two research questions and the broader literature on quality of life. This chapter also addresses the utility of the ethnoscience and the delphi technique used in this study, implications for practice and research, limitations of the study, and personal reflections on the findings of the study. Chapter 6 consists of a summary and conclusions of the thesis.

CHAPTER 2: LITERATURE REVIEW

The problem of the meaning of quality of life

Rodgers (1993) argues that "a concept is not merely the word or expression but the mental cluster that lies behind the word" (p.74). Moreover a concept becomes significant and achieves usefulness and clarity through the cycle of frequent use, emphasis and study (Rodgers, 1993). Although quality of life as a concept is frequently used, emphasized and widely studied, consensus on a definition or paradigm of quality of life has not yet been achieved (Atkinson & Zibin, 1996; Bowling 1991; O'Boyle et al. 1993; Schalock, Keith, Hoffman & Karan, 1989).

The World Health Organization defines quality of life as "an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Orley, Saxena & Herrman, 1998, p. 291). Cella and Tulsky (1990), also emphasized the gap between perceptions and expectations and define the concept as "patient's" appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal" (p. 30).

In contrast, Lehman (1983), focuses on present living conditions and defines quality of life in terms "a sense of global well-being" and satisfaction (p. 369) Schipper, Clinch and Powell (1990), in a book offering guidance to researchers in academic, government and pharmaceutical settings, define quality of life in the context of the outcome of the interaction of disease and treatment. According to Schipper, Clinch and Powell, quality of life is defined as "the functional effects of an illness and its consequent therapy upon a patient as perceived by the patient. Four broad domains contribute to the overall effect: physical and occupational function; psychologic state; social integration and somatic sensation" (p. 16).

Rodgers (1993) in her work on concept analysis, notes that the attributes of a concept are not fixed and may change over time in response to the need to maintain utility. The dynamic nature of the evolution of the concept of quality of life is illustrated by the varied definitions above by different researchers for different circumstances. Within the field of quality of life research, several authors have noted the challenge of deriving specific meaning from the concept. According to Felce and Perry (1995), "quality of life is an elusive concept approachable at varying levels of generality from the assessment of societal or community wellbeing to the specific evaluation of the situations of individuals or groups" (p. 51). Similarly, O'Boyle, McGee, and Joyce(1994) point out that complexity of the nature of quality of life has resulted in an array of measurement techniques that underscores the lack of agreement and definition. Stedman (1996) likens the concept of quality of life to the every day utility of the abstract concept of "the economy" where the term is used to convey a variety of meanings such as economic growth, employment, inflation and has spawned such offspring as "healthy" versus "unhealthy" economy.

Definitional difficulties notwithstanding, what has emerged is a surfeit of similar closely related variables or categories widely discussed and studied. Schalock, Keith, Hoffman and Karan (1989) identify three components typically described in the literature, namely, social indicators, psychological indicators and goodness-of-fit/social policy. Social indicators are external variables (health, social welfare, friendship, standard of living, education, public safety, housing, neighbourhood, and leisure) suitable for measuring the collective quality of community life. Psychological indicators capture the person's subjective reactions to life experiences. The belief is that the greater one's satisfaction with his/her resources, the greater will be the feelings of life satisfaction and well-being.

The goodness-of-fit/social policy perspective argues that quality of life is a crucial criteria for the formulation and analysis of social policies and should therefore be used to identify unmet needs in the population. This information should then be used to differentially weigh the importance of need areas; and in turn be used to influence resource allocation.

Similarly, Pearlman and Jonsen (1990) argue for three types of conceptual meanings of quality of life, namely, subjective, objective and societal. Subjective quality of life takes the individual's perspective of his/her physical, mental and social situation while the objective meaning is derived from the perspective of an outside observer. The societal meaning is taken from those collective attributes valued by society as contributing to the good life.

Felce and Perry (1995) suggest that quality of life involves overall well-being as a function of the interplay of objective life condition, subjective feelings of well-being, personal values and aspirations, and external influences. Jones (1995) describes quality of life as the gap between the desired and the achievable, and argues in favour of measuring the direct impact of disease on daily life and well-being. This approach, however, implies a unidirectional relationship between illness and well-being, and overlooks the converse relationship, namely, the impact of life issues on increased risk for disease. This element is captured by Shin and Johnson (cited in Bowling, 1991, p. 9) who emphasized the importance of "possession of resources" as a crucial requirement in order to address the satisfaction of needs, participation in activities and the achievement of self-actualization.

Other components of quality of life include "the individual's achievement of a satisfactory social situation within the limits of perceived physical capacity" (Mendola & Pelligrini, cited in Bowling, 1991, p. 9), general health, performance status, general comfort, emotional status, and economic status (Patterson, 1975).

One of the more interesting and integrative approaches is that of Spilker (1990) who organizes quality of life according to three hierarchical levels diagrammatically illustrated with a pyramid. At the apex of the pyramid is an overall assessment of the individual's satisfaction with life, and sense of personal well-being. The middle level consists of assessments of specific domains similar to Patterson (1975) - physical status and functional abilities, psychological status and well-being, economic status and related factors and social interactions. The base level includes all aspects of each domain that are specifically assessed by quality of life scales and tests.

Health related quality of life

Health related quality of life is a branch of the quality of life literature that typically refers to specific measures of functioning likely to be affected by health problems and/or general or global measures of health (Bowling, 1991; Guillemin, Bombardier & Beaton, 1993; Spilker, 1990). Some of the general areas affected by health include, physical functioning, physical health, mental health, cognitive functioning, social functioning, sexual functioning and productivity. For example, Morris and Perez (1998), define health related quality of life as a multidimensional construct with core domains of psychological functioning, social functioning, physical status and disease and treatment-related symptoms.

In health related quality of life, specific measures are designed to address selected changes that are unique to an identified illness or population. For example, there are measures of quality of life specific to cardiovascular disorders (Wenger & Furberg 1990), neurological illness (Wilson & Goetz, 1990), inflammatory bowel disease (Garett, Drossman & Patrick, 1990) and severe mental illness in the community (Lehman & Burns, 1990). Brooks et al. (1995) developed health related quality of life measures specific to the evaluation of prostate cancer rehabilitation evaluation. Health related quality of life outcomes can also be used to develop a shared view of disease and treatment outcome between health professionals and patients (Patrick, 1992), and an understanding of how persons perceive their own health in relation to predictions of loss of function, morbidity and mortality (Segovia, Barlett & Edwards, 1989). For example, physicians (in the case of prostate cancer), have tended to minimize the impact of surgery or radiation therapy on quality of life and have focused on attempting to maximize longevity (Brooks et al., 1995).

Another example, of the application of health related quality of life, is in the area of disability. Fifteen percent of Americans have a restriction in activity and up to 7% are unable to perform major activities because of disease, injury, and impairment (Patrick, 1992). Moreover, one in seven Americans has a disabling health condition that interferes with his/her daily life activities. In this context, quality of life assessment of persons with disabilities in clinical practice requires both generic health status measures as well as specific measures and methodologies that are tailored to the concerns of people with disability.

Health related quality of life has a different focus than general quality of life. Nevertheless, this distinction is not always made in the literature. For example, Gill and Feinstein (1994) in their review of 75 articles on quality of life revealed that none of the reports distinguished the overall quality of life from quality of life affected by health or illness. Consistent with the rest of the quality of life literature it is also noteworthy that health-related quality of life "... is rarely well-defined" (Stedman, 1996, p. 734).

Health related quality of life has it's roots more in the field of health than in quality of life. According to Guyatt, Feeny, and Patrick (1993), health related quality of life is a measure of health that takes into consideration the broader issues of income, freedom and the quality of the environment that may influence health outcome. Similarly, Stedman (1996), suggests that health related quality of life is to be contrasted with "traditional measures of health interventions" (p. 734) that focuses on physiological outcomes, symptoms and side effects.

The concepts of health related quality of life and quality of life are not mutually exclusive. The two concepts and approaches are related to the extent that quality of life can include a component of health-related quality of life (Guyatt et al., 1993). That is, questions rooted in the impact of illness or attempts to ascertain the impact of intervention on particular symptoms.

This study focused on the broader concept of quality of life since the concept of health-related quality of life was too narrow and too specialized. This approach did not exclude the possibility that participants could identify categories that might be illness specific. The fact is that the concept of health-related quality of life seems to be still underdeveloped in the area of mental health. For example, it is noteworthy, that Stedman (1996) in his review of the literature on quality of life related to mental illness states that "no disease specific health-related quality of life measure suitable for mental illness has been developed." (p. 736).

The role of the individual in determining quality of life

There are a number of well known and widely used quality of life and health related quality of life scales such as the Nottingham Health Profile, the McMaster Health Index Questionnaire, the Sickness Impact Profile (Bowling, 1991), and Quality of Life Interview (Lehman, 1988). Scales and the methods of rating and analysing them have been derived by assessing the quality of life of groups of individuals in order to produce normative tests. However, it is not unusual for tests to be used with individuals in circumstances dissimilar from those groups on which they were standardized.

According to Hickey et al. (1996), although such tests offer good reliability, they " ... may not be relevant to an individual's present life situation," (p.29). In other words, the value of aggregate data notwithstanding, such measures and techniques can not provide a measure of quality of life for a specific person at a particular point in time. Moreover, although some authors have highlighted the importance of self-report both on economic grounds and as a way of reflecting the importance of the consumer's perspective (Russo et al.,1997), these self-reports are often based on a forced choice scenario (Hickey et al., 1996; O'Boyle et al., 1993).

In response, O'Boyle and colleagues (O'Boyle et al., 1993;) over the past several years have developed the SEIQoL (Schedule for evaluation of individual quality of life) and more recently the weighted version, the SEIQoL-DW (Schedule for evaluation of individual quality of life - direct weighting). This measurement uses the method of "judgement analysis" to maximize the consumer's participation. Essentially, the consumer generates his/her own quality of life categories and then proceeds to assign differing levels of importance by using bar graph-visual analogues. Conceptually, this process is very consumer sensitive, but the process is actually quite demanding since it presupposes an ability to think abstractly and make judgements based on information presented in diagrammatic form. Recognizing the latter, the SEIQoL-DW is an attempt to achieve the same end with a less complex process by using a system of rotating disks that the individual manipulates until he/she is satisfied with the proportion of the pie chart suitable to the five self-selected quality of life variables. Although this process may indeed be more user-friendly to some, it nevertheless remains complex, or at least conveys the impression of being complex with considerable demand characteristics attached. Nevertheless, work such as the latter underscores a fundamental principle of acknowledging and respecting the importance of asking the consumers themselves about their quality of life.

There seems to be widespread agreement in the literature that the individual must be at centre stage with respect to the interpretation of the meaning and value of life; or the quality of life measures are flawed. According to Bowling (1991) " ... what matters in the 20th century is how the patient feels, rather than how doctors think they ought to feel on the basis of clinical measurement" (p.1). Similarly, O'Boyle, McGee and Joyce (1994) state that quality of life should be defined as "no more and no less than what she considers it to be" (p. 161). As a health-care outcome, quality of life, according to Ware (1995), "...has come to mean the extent to which the results of treatment meet a patient's needs or expectation," (p. 328).

The importance of placing the individual's interpretation of the value and meaning of life at the centre is illustrated by the example of patient cited by Lipman (1995). The patient was a 72 year old woman diagnosed with cancer of the pancreas likely to die within a year, and the different values and perceptions of the physician and the patient. The oncologist assigned to the case recommended aggressive chemotherapy, but since the outcome was likely to be the same with or without treatment (death in a year) the primary care physician advised the patient to spare herself the unwanted side effects of chemotherapy and to focus instead on spending her remaining time enjoying life. Although the primary care physician was able to predict changes in health status, on the basis of clinical knowledge, he was not able to predict how the patient would feel about those changes. In fact the decision not to accept chemotherapy resulted in the patient feeling more discouraged because she had given up without a fight.

Another illustration of the need to, not only consider quality of life, but quality of life from the patient's perspective comes from the work of Pearlman and Jonsen (1990). They studied the use of quality of life as a variable in deciding whether or not to use mechanical ventilation to sustain life. In their study, 37% of the 205 physicians presented with the same case scenario, made their decision based in part on quality of life variables. However, the most interesting finding was that of those who decided to use mechanical ventilation, 29% considered quality of life in reaching their decision; and of those who decided not to use the mechanical ventilation, 49% considered quality of life as a determining factor. In other words, physicians used quality of life judgements as a basis to support clinical opinions on opposite ends of the continuum.

Clearly, patient preferences for treatment outcomes should be central to treatment decisions. Including patients in the difficult decisions about choosing one course of treatment that will result in improvement in one area and cause harm in another area (Patrick, 1992) needs to become part of common practice. However, this is clearly not currently the case in practice as revealed by Gill and Feinstein (1994), who found that only 13 (17 %) of 75 articles on measurement of quality of life invited patients to offer a separate global rating for quality of life.

Importance of a consensus understanding of quality of life

For many, quality of life has emerged as the research "... issue of the 90's" (Schalock, Keith, Hoffman & Karan, 1989). It is precisely because of the extensive and pervasive use of the term and related measures that consensus is necessary. Quality of life measures are used as: 1) a mechanism for consumers and family members to participate in treatment and program planning (Atkinson & Zibin, 1996); 2) an outcome measure for health care policy makers who are required to demonstrate economic efficiency and treatment effectiveness of programs (Atkinson & Zibin, 1996; Atkinson, Zibin & Chuang, 1997); 3) a means of monitoring the quality of life of persons with disabilities living in the community, particularly those who have previously had a lengthy tenure in an institution (Schalock et al., 1989; Schalock & Keith, 1993); 4) a way of demonstrating that social environments have considerable impact on an individual's way of life; 5) one of many outcome measures in complex multidimensional program evaluation (Baker & Intagliata, 1982); 6) a natural expression of the re-emergence of the holistic health perspective; 7) an attempt to estimate and report on "comfort rather than cure" in those instances where cure is not seen as a possible outcome of treatment such as in some forms of cancer and mental illness (Baker & Intagliata, 1982); and 8) as a way of determining assignment of case mix (Russo et al., 1997).

Despite being a contemporary priority agenda item (Schalock et al., 1989) in clinical work (Browne, et al., 1996; Greenly, Greenberg, & Brown, 1997; Payne, et al., 1997), program evaluation, and policy development (Atkinson & Zibin, 1996), quality of life as a concept or model remains undefined or ill defined. According to Schipper, Clinch and Powell (1990) "... to conduct valid quality of life studies, a clear definition of quality of life broadly accepted and understood by those doing the quality of life research, is essential. At the present time most so-called quality of life studies utilize this terminology without definition" (p. 11) In more dramatic terms, Gill and Feinstein (1994) after reviewing the literature concluded that "... most measurements of quality of life in the medical literature seem to aim at the wrong target. Quality of life can be suitably measured only by determining the opinions of patients and by supplementing (or replacing) the instruments developed by experts"(p. 619).

Quality of life and the mentally ill

Although there seems to be general support for the contention that the perception of the individual is paramount in the assessment of quality of life, both clinical and research practice consistently exclude the individual (Gill & Feinstein, 1994). Studies of quality of life have not only emphasized the need to consult with patients on their care, but point out the different perceptions between staff and patients on quality of life issues (Cella & Tulsky, 1990; Sainfort, Becker & Diamond, 1996; Thapa & Rowland, 1989). These issues are particularly important because of the continuing shift of persons with mental illness from institutions to community and the accompanying concern and debate about the resulting impact on both the mentally ill and the communities in which they reside.

The negative image of the early deinstitutionalization phenomenon continues to engender a suspicious attitude about efforts at community based programming and has given rise to a number of concerns where quality of life is seen as the barometer for judging change (Van Nieuwenhuizen, Schene, Boevink, & Wolf, 1997). For example, several authors have noted issues of poverty and lack of employment of those living in the community (Brill, 1978; Brill, Weinstein, & Garrat, 1969; Bruce, Takeuchi & Leaf, 1991; Lamb, 1982; Lurigio, & Lewis, 1989; Polak & Warner, 1996).

Another issue begging the question of quality of life is homelessness and substandard housing for most persons with psychiatric disabilities (Wasow, 1986). For example, Torrey (1990) estimates that 30% of the homeless population in the U.S. have a serious mental illnesses. Moreover, although the premise of community treatment and rehabilitation is to transform the "patient" to "person" living in an integrated way in his/her community participating in work, recreation, learning, and social relationships; much of the latter still seems contrary to the conventional wisdom not to hospitalize and offer "asylum," "protection," and "control" (Mosher, 1983; Torrey, 1990; Wasow, 1986).

Quality of life, therefore, has been used as an outcome measure to tailor services and discover gaps in services; as a measure of client satisfaction, and as a measure of adequacy of standard of living. For example, Lehman, Possidente and Hawker (1986) compared four groups of psychiatric patients living in either state hospitals or community residences and used overall satisfaction scores to conclude that boarding homes in the community provided a reasonable alternative to hospitalization. Similarly, Lafave, de Souza & Gerber(1996), used quality of life as one of four outcome measurements in a comparison of hospital and community treatment programs for persons with severe mental illness and found that those living in community settings reported better quality of life than those in hospital based programs.

Research questions to be addressed

The present study involved respondents from two groups, namely, professionals who provide mental health services(providers) and persons with severe mental illness who receive mental health services (consumers) and addressed the following questions: 1) Will the delphi technique and ethnoscience qualitative method yield information that will allow a comparison of similarities and differences between the perceptions of providers and consumers about quality of life? and 2) What is the meaning of quality of life of persons with serious mental illness, living in the community, from the perspective of the consumer of mental health services and the provider of mental health services?

CHAPTER 3: METHODOLOGY

The role of qualitative methodology

There is clearly a need to begin to ascertain the meaning of quality of life for individuals with serious mental illness; and since perceptions between professionals and consumers differ, both groups need to identify their perspective for effective partnership in clinical relationships. One strategy for beginning to address the dilemma of ascertaining actual quality of life of individuals, while at the same time satisfying the need for normative or group data for professional or program use, is to adopt a qualitative approach for defining (and periodically redefining) the meaning of quality of life as it relates to a particular group of consumers receiving services from a particular program. Leininger (1985a), contrasted qualitative and quantitative methodologies along sixteen domains including the domain of "general research focus." In contrast to the quantitative focus on "measurement of controlled or manipulated variables by experimental, quasi-experimental, and other controlled methods," (p.14 Table 1) the qualitative approach favours "description, documentation, and analysis of patterns, values, essences, world view, meanings, beliefs and attitudes" (Leininger, 1985a, p. 14 Table 1). In other words, when the researcher is interested in the insiders perspective on a particular issue, qualitative methodology is the preferred approach.

Using a qualitative method to ascertain the consumer's voice has also been advocated recently by Avis (1997), who highlights the merits of qualitative approaches as the ability to garner information from less structured and more detailed interview and observation, based more on a naturalistic approach to inquiry, rather than on controlling and measuring variables. Similarly, Pope and Mays (1995) capture the essence of the qualitative method by titling their article in the British Medical Journal as "reaching the parts other methods cannot reach ... (p. 42) and note the poor fit between the culture of day to day clinical practice and the application of "randomised controlled trials," (p. 42).

In order to derive helpful and useful information for clinical and program design purposes it is important to determine what "quality of life" means for the particular population served by a particular program, both from the perspective of the consumers and the professionals providing the service. The method for determining this should be practical, easy to implement and part of a process that can be updated regularly.

One such method is ethnoscience with its motivation to study how people conceive and think about the things and events that make up their world and construct prevailing semantic categories (Field & Morse, 1985, chap. 2; Morse, 1992, part V; Polit & Hungler, 1997). Field and Morse (1985), note that an element of the ethnoscience interview is that the data takes its significance from the insider's perspective, rather than from the outsider's perspective. Similarly, Leininger (1985b) describes ethnoscience as a systematic study of people from their perspective (the emic view) in order to gain an accurate appreciation of how people internalize and categorize the world around them. According to Leininger (1985b), the client-derived data of ethnoscience allows for a more accurate reading of clients' needs and concerns. This is due to the fact that the ethnoscience method of data collection overcomes or at least can counter balance the natural tendency for professionals to impose their values and beliefs upon clients or families.

The ability of the ethnoscience method to yield "... meanings, attributes, and characteristics of a particular domain of inquiry" (Leininger, 1995b, p. 241) suggests that it might be a best-fit methodology for studying and deriving meanings about quality of life issues from the perspective of both the provider and the consumer.

The ethnoscience method utilizes a variety of data gathering techniques such as fieldwork, participant observation, and interviews (Morse, 1994). The typical data collection strategy used with ethnoscience is the "card sort" (Field and Morse 1985, p. 107). However, one of the limitations of the card sort, is the element of forced choice and demand characteristics that it places on the participant. The delphi technique, with its emphasis on determining or collating group opinion, is an excellent alternative strategy to deploy with an ethnoscience methodology.

The delphi technique

The delphi technique, devised in the early 1950's is a multi-stage process that requires the collection and synthesis of judgements from a panel of experts from within a field of study to reach a consensus of opinions. The delphi was originally developed as a forecasting technique and was used to collect data that would be useful in determining group opinion. (Jeffery, Hache & Lehr, 1995;

Moore, 1987). The delphi technique uses a series of questionnaires to aggregate the knowledge, judgement, or opinions of experts, who are usually anonymous. Individual contributions are shared with the whole group by using the results from each questionnaire to construct the next questionnaire and so on (Delbecq, Vande Ven & Gustafson, 1975).

According to Delbecq et al. (1975), it is a tool and should be modified to suit the needs of the study. The typical delphi involves seeking a set of opinions, usually from individual experts on problems that are difficult to quantify. The process involves surveying the participants (referred to as a panel), summarizing their responses; and sending out the summary to start the next round of inquiry. Each participant is given time for thought and an equal opportunity to contribute. A panel member may change his/her estimate in the direction of an emerging consensus. Alternatively he/she may leave his/her original estimate intact and provide information justifying it. Instead of discarding an item of information which disagrees with other items, it is used to gather more detailed information. The amount of consensus typically increases with each round. The process stops when consensus is sufficiently achieved, that is, no new information is forthcoming (Delbecq, Vande Ven & Gustafson,1975; Jeffery, Hache & Lehr, 1995).

Relevance of the delphi technique

The delphi technique lends itself well to the contemporary realization of the "consumer" as expert. In other words, rather than depend on a panel of professional or academic experts, consumers can also serve as respondents. For example, Kurth-Schai (1988) used a delphi approach with child panelists in a study of their (children's) perceptions of the future. This study provided evidence that the technique of involving those who participate in the process, also had value as an educational tool. Her results indicate that delphi, in addition to providing data, furnished a means of empowering participants. Participants experienced it as an enjoyable and educational activity, one that enhanced self-concept.

The delphi technique is not only a way of producing consensus on a topic, but also allows for the emergence of diverging or opposite perspectives thereby broadening understanding of the topic of study (Gallagher, Hares, Spencer, Bradshaw & Webb, 1992; Linstone and Turoff, 1975).

As noted above the delphi technique is typically executed via mail-out, however, the present study used individual face-to-face interviews. Individual interviews overcome some of the disadvantages of the delphi method. For example, Delbecq et al. (1975) point out that the delphi technique should not be used when time is limited. However, personal interviews reduce the time related to repeated mailing of questionnaires. They also argue that it might not be suitable for participants who have difficulty reading or in expressing themselves in written communication. The latter is overcome by audiotaping personal interviews. Finally, personal interviews eliminate the criticism that mail-outs result in a lack of social and emotional stimulation and disconnection from the problem solving process (Delbecq, Vande Ven & Gustafson,1975; Moore, 1987).

The present study used the delphi technique and qualitative analysis to compare the meaning of quality of life as defined by persons with serious mental illness (consumers) and the meaning as defined by professionals (providers) working with a similar consumer group. The delphi technique was modified by conducting face-to-face interviews to survey the participants in each panel group.

Sampling

Participants. Purposive sampling (Patton, 1990) was used to select all participants. According to Miles and Huberman (1994), qualitative research typically relies on purposive sampling because of the emphasis on in-depth study of small samples where the context and the social process is important. There were two participant groups, consumers and providers.

Consumers were men and women of various ages who experienced serious mental illness and were receiving mental health services in the community. Serious mental illness was operationally defined as having at least a minimum lifetime accumulation of 6 months as an inpatient in a psychiatric hospital setting. Consumer-participants were recruited, on behalf of the researcher, by providers on the basis of being articulate and interested in discussing issues that affect their lives.

Using the established criteria, 14 consumers were selected from community programs. Nine of the participants were women. Data on diagnosis was not requested, but based on unsolicited comments by consumers, diagnoses included, depression, schizophrenia, obsessive compulsive disorder, eating disorder, manic depressive disorder and personality disorder. Actual history of hospitalization was not requested, however, it was clear from comments made by consumers and the criteria of the treatment program (Assertive Community Treatment Team) that most of the consumers had histories of extensive hospitalization in the range of several years. It is also noteworthy that many of these consumers, with the assistance of the Assertive Community Treatment Team, had been able to break the cycle of long-term hospitalization and had been living in the community for a number of years.

Providers were experienced multidisciplinary staff who worked with persons identified as seriously mentally ill as defined above. Experience was operationally defined as a minimum of one year working with persons with severe mental illness. On the basis of purposive sampling representatives from the disciplines of nursing, vocational counselling, recreation, personal support worker, and social work were selected. Ten providers were recruited on a volunteer basis from out-patient programs of the Brockville Psychiatric Hospital, namely, the Assertive Community Treatment Teams. One of the teams was located in Brockville and the other team was located in Ottawa. The mandate of these programs is to provide services to persons with serious mental illness and thus staff of these programs easily met the criteria described above. Among the 10 participants, there were three registered nurses, one personal support worker, three social workers, two vocational workers and one recreation therapist.

Selection process, and protection of confidentiality and participants' rights. The proposal was approved by Queen's University Health Sciences Research Ethics Board. A memo asking for assistance in recruiting consumers to participate in the study (see Appendix A) and a detailed information sheet describing the study (see Appendix B) were sent through hospital mail to mental health providers working in outpatient programs of the Brockville Psychiatric Hospital. Based on the study criteria, providers approached potential consumer participants, reviewed the information letter with them and if they agreed to participate in the study, their names and phone numbers were given to the researcher.

The researcher contacted the potential consumer participants, and arranged to meet with them at a location of their choice, and at a time convenient to them. During the first meeting, the researcher reviewed the information sheet and the consent form (see Appendix C) with the consumer and confirmed his/her understanding of the content. Prior to beginning the first interview, the consumer signed two copies of the consent form. One copy along with the information sheet remained with the consumer and the other copy was filed, by the researcher, in a locked cabinet. The interview was audiotaped, but the consumer's name was not used on the tape.

A similar process was followed for provider participants. A memo and an accompanying information letter outlining the purpose of the project and the selection criteria for provider participants was mailed to program team leaders asking them to circulate it to potential candidates (see Appendix D and Appendix E, respectively). Interested staff, who met the criteria, contacted the researcher to set up interviews. Prior to the first interview, the researcher reviewed the information letter with the provider, confirmed his/her understanding of the content and requested his/her signed consent (see Appendix F for copy of provider consent form). The provider signed two copies of the consent form. One copy, along with the information letter, was given to the provider and the other copy was filed by the researcher in a locked cabinet.

Sample size. In qualitative studies, sample size is based on informational rather than statistical considerations. In other words, data selection to the point of redundancy is the criterion rather than establishing an "n" that will be statistically representative of a given population (Lincoln & Guba, 1985). An adequate sample, therefore relies on the amount of data collected, rather than on the number of subjects in the study. Adequacy is attained when sufficient data have been collected that saturation occurs and variation is both accounted for and understood. Morse (1994) recommends 30-50 interviews when the research strategy is ethnoscience. This study involved 24 participants, resulting in 70 interviews.

Study design and procedure

There were three parallel rounds of face-to-face interviews for each study group (consumer and provider) and these are illustrated in Figure 1. In the first round, questions were asked of all participants in each study group. The responses were audiotaped, transcribed verbatim, analysed and quality of life categories were separately formulated for each study group. Based on the

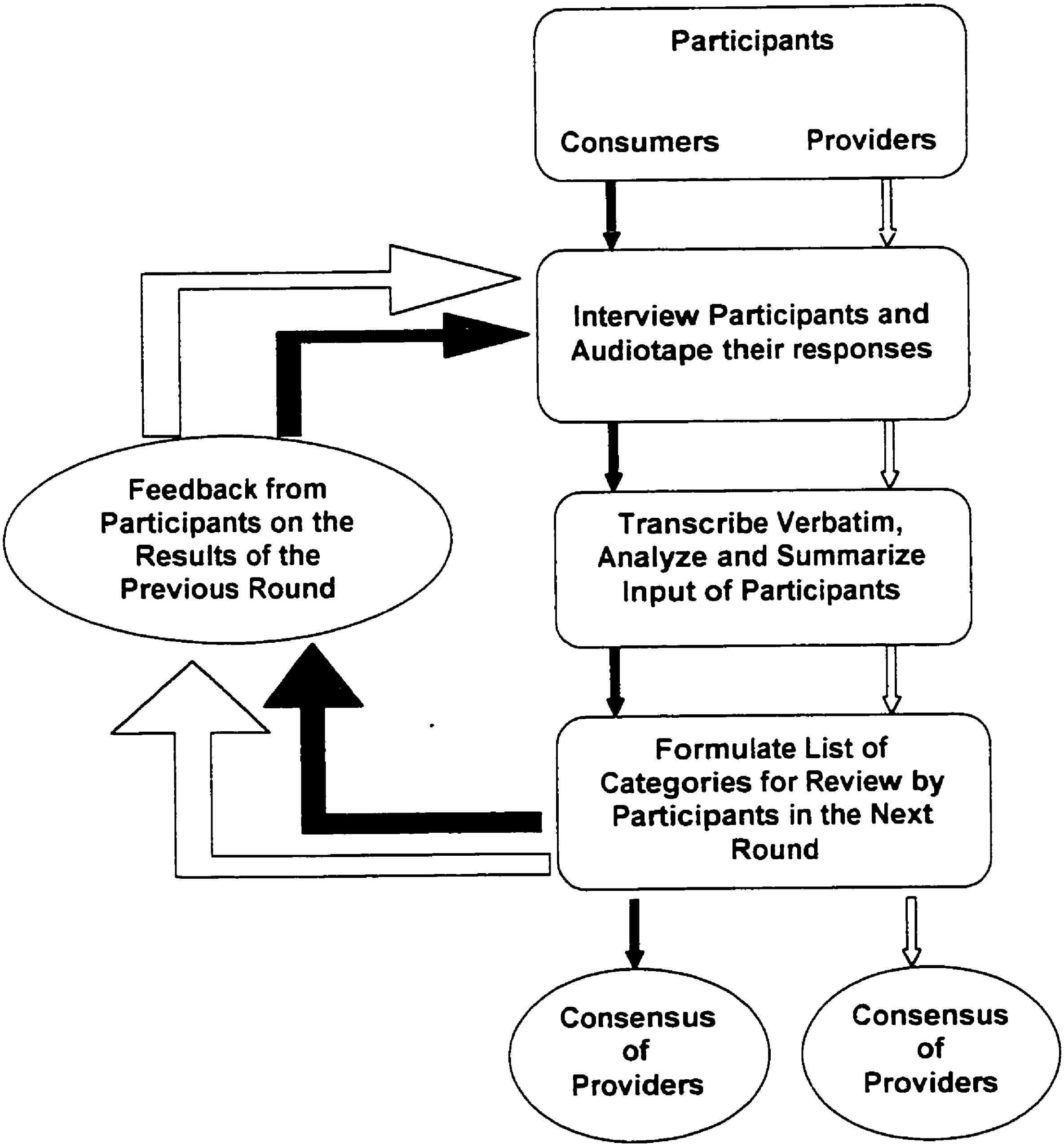

Figure 1. The delphi process for consumers and providers followed in this study.

findings of the first round, questions were formulated for the second round. The second-round interviews were also audiotaped, transcribed and analysed. A similar process was followed for the third round. The role of the researcher was to design questions for each round, interview the participants, and analyse and summarize the verbatim responses of all participants.

Ideally the delphi process should be repeated and concluded only when no new information is forthcoming from interviews with participants. However, asking for consent to an open-ended number of interviews is unreasonable. Consequently, the delphi was designed to conclude after three rounds with the option of a fourth round if this was needed.

As anticipated, saturation occurred by the third round, that is, no new information was being generated at the third round. Individual first round interviews concluded after about 20-30 minutes. Second round interviews ranged from a few minutes to about 20 minutes. The final round of interviews ranged from a few minutes to about 15 minutes. Since several of the provider participants were recruited from the same multidisciplinary mental health team, they were asked not to discuss their responses between interviews in order to ensure the greatest diversity of responses possible.

Consumers and providers were offered post study debriefing sessions to address any concerns, issues, or questions related to the study. However, there were no requests for debriefing sessions from either consumer or provider participants.

The location of the interviews was governed by the preference of consumers and providers. Three consumers were interviewed at an office at Brockville Psychiatric Hospital. All others were interviewed at their residence. All providers were interviewed at offices of the Brockville Psychiatric Hospital. Five were interviewed at the Brockville campus and the other five were interviewed at an off-site office located in Ottawa.

Round I. The goal of the questions in round I was to generate the participants' perspectives and therefore the questions in round I of the delphi were simple, open ended, non-leading and without forced choices. In other words, the questions were designed to avoid leading the participants in formulating any particular objective or subjective categories of quality of life. The preamble for consumers and providers and the interview guides for round I are presented in Appendix G. The key questions in round I were as follows: a) What does quality of life mean to you?; b) What are the things that contribute to good quality of life?; c) What are the things that contribute to poor quality of life?

Round II. The goal of the questions in round II was to elicit consensus and divergence on categories generated in round I. In this round, participants were also invited to comment on categories they considered to be critical or essential to an understanding of quality of life. However, participants were not actually asked to rank the categories in order of preference. The preamble for consumers and providers and interview guides are presented in Appendix H The key questions in round II were as follows: 1) Are there any categories missing?; 2) Are there categories that you would group together ... in other words are there some categories that are saying the same thing?; 3) Which of the categories would you say are the critical ones, the essential ingredients for good quality of life?; 4) Which categories would you say are the least important ... if you had to are there any categories that you would take out?; 5) Anything you want to add about quality of life? Prior to taping of responses in round II, participants were provided with a summary of the categories from round I along with the supporting comments in the form of actual quotes and given sufficient time to review it. Typically participants needed about 10 to15 minutes.

Round III. The goal of the questions in round III was to elicit consensus and divergence on categories generated in round II. The preamble for consumers and providers and interview guides are presented in Appendix I. The key questions in round III were as follows: 1) Are there any categories missing?; 2) Are there categories that can be combined?; 3) Are there categories that should be separated?; 4) Do the category names make sense? Prior to taping of responses in round III, participants were provided with a summary of the categories from round II along with the supporting comments in the form of actual quotes and given sufficient time to review it. Typically participants needed about 10 to15 minutes.

Method of analysis

Consistent with the methodology outlined by Miles & Huberman (1994), the analysis of the data consisted of data reduction, data display, conclusion drawing, checking with participants for accuracy of interpretation; and displaying findings.

Data reduction involved a process of sorting and categorizing patterns and themes and reducing data to small manageable units to begin with, then using these units to build the analysis. Data display involved organizing the information in a form so that conclusions could logically be made.

Wordperfect searches and Ethnograph were used to assist in the analysis of the data. The verbatim transcription of each interview was prepared in Wordperfect and separately read and categorized using Wordperfect searches of key words and phrases. The transcriptions of all the consumer interviews for a particular round were combined and analyzed using Ethnograph. Ethnograph automatically numbered each line of text and allowed for easy coding and referencing.

Beginning with the transcript of the first interview, the text was read and coded using the actual terms of the respondent. The key terms used by the first respondent were then used to search the rest of the document. Attached to each term was the corresponding verbatim comments or explanation of that particular term. Similarly, the transcript of the second participant was read and the key terms used by this respondent were used to search the rest of the combined document. This process was continued until there were no more categories. The provider transcripts were analysed separately using the same process.

After each round the categories and the supporting comments were displayed in a chart format with the categories in one column and the supporting comments in another in order to compare and cross-reference categories of information and to establish a picture of a range of categories (Fetterman, 1989;

Miles & Huberman, 1994).

Data sources. The primary data sources were verbatim transcripts of audiotapes, and interview observations. Observations included extraneous comments by participants before, during, and after the interview (Henderson, 1995).

Strategies to ensure trustworthiness. In qualitative studies, establishing confidence in the findings is embodied in the concept of trustworthiness, analogous to the concepts of validity, reliability and objectivity (Lincoln & Guba, 1985). Trustworthiness was achieved in this study through several mechanisms.

Given that the methodology involved checking with participants themselves after each round the issue of reliability becomes moot. In each round, the researcher also asked any pertinent follow-up questions to further clarify and amplify understanding of the categories of quality of life that emerged during the rounds.

The researcher used a respected framework for analysis described by Miles and Huberman (1994). Moreover the use of a clearly outlined interview and study protocol allowed for auditing and replication of the study.

Conclusion drawing and checking for verification of the data was achieved by virtue of repeatedly checking with participants for consistency of the data and sustainability of categories and variables. This process of "member checks," according to Lincoln and Guba (1985) is "the most crucial technique for establishing credibility" (p. 314). The very nature of the delphi process, therefore, constituted a powerful mechanism of trustworthiness. For example, the results of the preceding round were used to build consensus by allowing participants (the source of the data) the opportunity to clarify interpretation, make corrections and otherwise verify or make additions to the data.

In addition to achieving member checks, the latter process also offered a measure of triangulation. According to Lincoln and Guba (1985), multiple interviews with different sources constitutes one of the methods of establishing triangulation.

Trustworthiness of the data was also maintained by audiotaping interviews, transcribing verbatim, using open-ended questions, and using participants actual words and expressions to label categories.

Another component of trustworthiness involved the use of "self" with reference to the researcher. Lincoln and Guba refer to the latter as "the human as instrument" (p. 192). In contrast to quantitative studies, where the researcher tries to be as invisible as possible, the researcher in qualitative studies tries to be transparent and use his tacit knowledge and experiences to facilitate the interactive process.

Since the methodology involved repeated contacts with each participant, the researcher used his experience with the participants to facilitate engagement of the participants and facilitate an atmosphere whereby participants could feel at ease with the process. The researcher, for example, listened to information and discussion about issues not directly related to the study, before and after the interview sessions, such as issues with landlords, or application for benefits or information about services that might be available. In fact for some participants the researcher allotted more time in advance of the actual interview process, and at the end of the process. In a couple of instances the researcher provided transportation, for the consumer, to the local grocery store in order to accommodate scheduling. The latter communicated respect for the participants' time and also provided opportunities for continued engagement. Moreover, every effort was made to communicate that the information provided by the participant was valued. For example, the researcher regularly reminded participants that they were the "experts" on the information being sought and that their unqualified responses were important.

CHAPTER 4: RESULTS

Seventy interviews were completed (13 consumer participants interviewed three times, one consumer interviewed once and 10 provider participants interviewed three times). Consumers perceptions of the meaning of quality of life were analysed and categorized for each of the successive three rounds of interviews. In round I, consumers generated 12 categories. In the second round, 11 categories were identified and in the third round, 8 categories emerged.

Similarly, providers perceptions of the meaning of quality of life were analysed and categorized for each of the successive three rounds of interviews. In round I, providers generated 27 categories. In the second round, providers collapsed the number of categories to 6. In the third round, providers refined the 6 categories that emerged from the second round.

Analysis of interviews

Consumer interviews

Round I consumer categories.

Twelve general categories were identified by consumers. These categories were not necessarily mutually exclusive, but were sufficiently different to warrant being separated (see Table 1). Not all consumers contributed to all categories and this improved the richness of the data for round II questions. It was also noteworthy that some categories depended on other categories for interpretation and meaning. These relationships are described below. The following categories are not presented in any order of preference.

Table 1

The categories identified by consumers in Round I

- Basic needs
- Money (beyond the ability to purchase essentials)
- Housing
- Mental & physical health
- Happiness & enjoyment
- State of mind
- Relationships
- Belief & spirituality
- Freedom & independence
- Work & education
- Self-care & recreation
- Giving to others

(1) Basic needs. Basic needs included a number of essentials such as access to resources, transportation, food, meals, medication to control symptoms, and professional help to get through tough times. "They (professionals) try and make sure that I am eating and that everything is going smooth and that I'm taking my medication."

This category of basic needs also overlapped with other categories such as independence, relationships, physical health and mental health. For example, transportation facilitated the experience of a sense of independence. Similarly, medication was seen as key to maintaining good mental health.

(2) Money (beyond the ability to purchase essentials). Money was identified as important. However, participants readily differentiated between money to meet basic needs and money to pursue higher level needs, such as recreation, leisure and purchase of "treats." "You can't afford to do fun things ... you have to cut back .. you might want to treat yourself, but you can just (afford to) get the basics." Lacking money was even seen as a barrier to sustaining relationships. For example, going out and socializing requires money. "I don't have friends because I can't spend money."

(3) Housing. Housing not only meant a place to live, and living conditions, but also symbolized independence, choice, privacy, and establishing a home. The essence of housing can best be described by the statement "... a place of your own that looks good; instead of just a room - you don't feel like it's your home, you're just staying there."

(4) Mental & physical health. Good mental and physical health was seen as a condition for having good quality of life. "If I'm not feeling well and I'm depressed that means I can't go out and I can't do the things I enjoy so I'm not enjoying life and the quality of life is less." Quality of life for some was directly linked to "getting over mental illness" or "not having a mental illness." One participant described quality of life as "having ambition and not having to push yourself to do the things that you feel good about."

(5) Happiness & enjoyment. "Quality of life means to me that I am able to enjoy doing what I want to do." Moreover, quality of life was seen as a function of happiness. For example, "If you're not happy, everything suffers."

"Happiness and enjoyment were also closely linked to "having a normal life," or living "a normal daily life." "To me quality of life means to go about daily tasks week in, week out, every month, every year, being as natural and productive as possible to work with people that will give you self-esteem, just means being able to function and being happy in the community."

(6) State of mind. State of mind expressed the individual's perception and outlook on life. It related outlook to an interpretation of one's surroundings and corresponding feelings. "I think being friendly and happy in many situations, rather than being negative, you have a happier life." It also included ideas of "self esteem", "positive thinking", and "thinking things out" to effect a more desirable outcome.

The idea also included taking personal responsibility for one's happiness. "You can't always be looking for someone else to make you happy, you've gotta feel good about yourself first." State of mind highlighted the interplay between resources, feelings and cognition. "It's not just your living conditions it's your mind and other things; when certain areas are improved your overall outlook starts to change slightly." "Be grateful for what you have got," "I think being friendly and happy in many situations, rather than being negative, you then have a happier life."

It also encompassed mental strategies or cognitive gymnastics to enhance coping such as: "you can think things out rather than jump to conclusions or be impulsive."

(7) Relationships. Relationships involved friends, family, and pets and was a large category in terms of the magnitude of comments. Relationship was seen as a source of love. "It is important that you have people that love you." Trust was another element. "Trusting and relying on that person, feeling comfortable with them."

Family was a component of relationship. "I like to have my children around, that's important to me ... it makes a lot of difference when you have contact with your kids." Neighbours were a particularly important source of relationship for one of the participants. "I'm (living in a senior citizen building) with older people which is good because I relate well to them."

Relationships brought companionship. "Good companion, I have a friend who is very helpful, understanding and kind." Another consumer described companionship this way, "... so that when you need a sounding board and constant companionship is a big change in quality of life; companionship gives you better quality of life; if you are married that's a good thing." Others saw companionship as, "... someone to understand you and someone to talk to and be there when you need them;" or as someone to live with, "friend that lives here with me, having people around helps, companionship."

Relationships provide the context to receive a sense of caring. "Getting a rose once in a while, that made me feel good that somebody cared." "My son went out and bought me a valentine's present." Social interaction occurred in the context of relationships, for example, "... having friends, doing things with friends, being together, having the same interest being yourself."

Those consumers who had pets very strongly endorsed the relationship qualities of their pets. Pets provided an opportunity to care for "someone" without the complexities of human relationship dynamics which are often dependent on conditional love and approval. This was illustrated by a number of comments. "The cat needs me and I need my cat." "I love my old cat, she's my baby, I mean she doesn't talk back to me but I can talk to her, all a pet wants is unconditional love, they don't care if you are feeling lousy, I mean I have hugged her and cried sometimes when I am feeling down, but she doesn't care she still loves me." Pets also provided an outward focus. "It is someone else to focus your attention on and think about." As with human relationships, pets also provided companionship. "I appreciate my cat. He keeps me company, looks after me when I'm not feeling well"

(8) Belief & spirituality. Spiritual beliefs included comfort derived from communication with God and knowing that God is in control. For example, "God in your life contributes to quality of life if you're lonely, sad or whatever the case may be." "Jesus Christ is the only one that can give you peace, really true peace and happiness and that means a lot to me."

Belief was also connected to good self-esteem in the sense that the individual was valuable to God. "I have good self-esteem, I feel good about myself and I always have the feeling that oh well you don't have to worry, God doesn't make junk."

Belief also captured the practical support and fellowship aspect of involvement in religious meetings. For example, "I also go to ... fellowship bible study group that I attend on Thursday evening."

(9) Freedom & independence. Freedom and independence were not obviously distinguishable, however both seem to be dependent on the outcome of other components of quality of life such as transportation. "It's freedom having your own source of transportation." Housing was another commodity that provided freedom. "It was hard in the beginning, living on my own, but I'm glad now that I do and it's real; I have more freedom, like to go outside and I can go outside if I want to go outside and I can get up in the morning when I want to..." Freedom was also experienced through the latitude of choices by virtue of being out of hospital. "You can do whatever you want to do; I can go to bed whenever I want without having somebody around."

Some examples of the context in which independence was featured included: "I would like to live on my own, being able to cook, finances... a sense of independence ... independence having a sense of security, not being afraid ... I've tried to live on my own; it hasn't worked; so I had to learn to walk by myself instead of always leaning on somebody."

(10) Work & education. Work was described as important for a number of reasons: a) as a means to earn money to buy things, b) as a way of accomplishing a daily task or activity and feeling "productive." "You feel good when you can do it... you feel like you have done something all day and you just feel good," c) as a balance to other activities and d) as a way of staying busy. Some participants also lamented not having a job and not being able to work. One participant stated "I can't get a job because I can't take my medicine on

time."

Volunteering was described as a way of keeping busy and having an outward focus. "Volunteering I think is ideal because it allows one to not think of all the problems they have been through." Similarly another consumer talking about volunteering noted, "I think it is good to get out and think of other people."

Education was mentioned as important by a few participants, but this was not elaborated upon in this round.

(11) Self-care & recreation. Self-care included a range of protective and coping activities designed to sooth and relax such as, "a nice hot bath and read a book or watch tv or put on your favourite music ... nurturing yourself." In contrast, recreation referred to more sports like activities such as "motorcycling," "snowmobiling," "bike riding," and "walking."

(12) Giving to others. Giving to others offered an opportunity to focus one's attention outward and this was seen as favourably affecting quality of life. "I don't know if this is because I am a positive person, but I find that every time we do something good, it opens all our hearts to humanity." Similar comments were, "... I think it is good to ... think of other people;" and "It allows one not to think of all the problems they have been through."

Sometimes the giving to others was formalized. For example, "I give some of my pension to "Feed the Children." Similarly, "it does give me a lot of satisfaction to help preserve the wildlife." It also meant personal services to friends and housemates. "I gave (money) to mom last year to get her tooth filled." "Even the way I help here (at the group home) ... I might wash the dishes for one of the guys and I'll peel potatoes for the meal."

Round II consumer categories.

The above 12 categories were taken to the consumer study group for review and comment. The preamble and interview guides for round II are shown in Appendix H. In particular, round II focussed on testing the trustworthiness and comprehensiveness of the above categories, while at the same time seeking to understand and reduce overlapping concepts. For example, in round II consumers were asked to comment on categories that might be missing and categories that might be saying the same thing. In addition, participants were asked to identify which categories they felt held the greatest importance to quality of life. Conversely, they were also asked which ones were least important. The purpose of these two latter questions was not to produce a rank ordering, but rather to understand if there were particular categories that immediately evoked an image of quality of life. Study participants were also invited to offer comments about quality of life in general.

The results of this round are summarized in Table 2. This round yielded 11 categories: basic needs, ("money," and "housing" were grouped as "basic needs"), good mental and physical health ("mental & physical health," "happiness and enjoyment," and "state of mind," were categorized as "good mental and physical health"), "relationship with friends and family," "relationship with treatment team," and "romantic relationships" ("relationships" was subdivided into three separate categories of relationships), "belief and spirituality," "freedom," and "independence" ("freedom and independence" was subdivided into two separate

Table 2

The relationship between consumer categories identified in rounds I and II

Round	Consumer categories							
ROUND I	•Basic needs •Money •Housing	•Mental & physical health •Happiness & enjoyment •State of mind	•Relationships	•Belief & spirituality	•Freedom & independence	•Work & education	•Self-care & recreation	•Giving to others
ROUND II	•Basic needs	•Good mental & physical health	•Relationship with friends & family •Relationship with treatment team •Romantic relationships	• Belief & spirituality	•Freedom •Independence	•Daily routine	•Self-care & recreation	•Giving to others

categories), "daily routine" ("work and education" was combined with other themes to create the category of "daily routine"). The two remaining categories of "self-care and recreation," and "giving to others" remained unchanged.

(1) Basic needs. The concept of basic needs was foundational to other aspects of quality of life described above. "Obviously, for quality of life, you have to start with your very basics, I mean, if you don't have food or shelter you're out in the cold - so those are probably very important, you know, for the basics."

Basic needs not only included familiar necessities, but also items specific to this particular population such as "medications" and "professional resources." Money was an essential element of basic needs, "money to purchase essentials - this is really essential to the quality of life, to make sure that you have what you need."

As mentioned above, it was noteworthy that professional help was seen as a basic need. For example, "without the help of professionals or resources I wouldn't be able perhaps to cope ... I realize I need the help from professionals in order to keep myself ... well."

Similarly, access to mental health resources, as a way of addressing needs, was also seen as a basic need, "I don't utilize the hospital a lot to see professionals, but I do utilize it, to get my bus pass, get my pin money ... those programs, I think, are essential and will need to be in place ... because without my bus pass, how can I get around and do all my stuff, volunteer work that I do, so it's important." Added to the list of basic needs was "reasonably priced" housing.

(2) Good mental and physical health. The feedback on happiness, state of mind, and good mental and physical health suggested that these categories should be combined. "Good mental health usually means that you are happy hopefully." "Your

state of mind is your mental health and what most people achieve ... quality of life is happiness so I think they are all kind of related under a topic of, I don't know, mental health. It is just that I think they should all be together instead of separate ... I would call it mental health, like personal mental health, your perception of it, but mental health generally, that it encompasses all of it."

An analogous comment was,"... I think state of mind would categorize with good mental health and good physical health. Well, being that, the way I look at it - state of mind - I would group it with that (good physical and mental health) because I would want good mental health and good physical health and that would be good state of mind for me."

One comment suggested that, "... good mental health includes happiness." On the other hand, someone else saw happiness as the product of good mental health and state of mind. "I sort of feel, from my own experience, that if you are healthy, physically, you stand a better chance of being healthy mentally; good mental health means you are understanding things clearly and etc... and I sort of think good mental health and state of mind go together, but happiness ... comes from the other two."

(3) Relationship with friends, family. Consumers confirmed that this was an important category and that it should include friends, family and pets. "Relationships, friends, family and pets - relationships are very important to me; I feel they are very important to quality of life." One comment was that, "..friends are important to me because you can get support from friends, you can spend time with friends, and that is really important to the quality of life." Another consumer put it this way, "... just the idea of being able to speak to friends over the phone and if you have friends, you have relationships." Family was also heralded as "important, although once you get away for awhile, it makes you appreciate family more when you do see them". As before, relationships were also seen as the arena for "... socialization and recreation. "

(4) Relationship with treatment team. Consumers suggested that a category describing relationship to "treatment" or to the "treatment team" needed to be added because of trust and reliance accumulated over a long term relationship with a core group of professionals. "Our relationships with our treatment, I mean, it says professional resources, but it's not really mentioned as a category as such you know, ... treatment. So I think, for people like us, that should be included as a topic." This was further elaborated on in the following way: "Well, I mean it is a big part of our lives, we talk to them (team members), and see doctors who give medication, it's part of our life .... professional ... and medication doesn't normally come under treatment relationship with doctor, with the ACT team, with other people, you know, I think that should be a separate category."

(5) Romantic relationships. One consumer argued that romantic relationship was not covered under the category of relationship. She reasoned that "relationships, like something more that friends, sort of like, in my case would be like a boyfriend," needed to be included as a separate category.

(6) Belief and spirituality. This included formal religion, belief, and spirituality. As with other concepts, belief and spirituality were closely interrelated with good mental health as this next comment illustrates. "Well, good mental health and belief and spirituality could go together because they have to be a unit, with me. I actually have beliefs in God and Jesus Christ and the angels, and that is what causes good mental health with me. " Similarly, "I'm a Christian. I feel that this is important - if my spiritual life is intact, then the rest of my life will follow suit. I feel that religion should be basic."

Another consumer, while acknowledging it's importance in his life was less specific about how belief contributed to quality of life. "I sort of renewed my faith, so I'd say belief and spirituality are important to me. You know, I can't define precisely what they do for my quality of life, but, to me, they are a very good and helpful thing."

(7) Freedom. In round I, the concepts of freedom and independence were combined in the same category because of their considerable overlap in meaning as described by participants. However, some consumers, in round II, attempted to articulate their differences.

"They (freedom and independence) are two different things. For instance, "I was living with my parents, so I was under their house and under their roof, and

I had to follow their rules. Then if you are living on your own, you're independent, you can have some freedom, and sort of more taking care of your own issues."

Another perspective yielded this explanation, "I feel like I have a lot of freedom, basically. I feel like I can do anything I want, but in myself, I don't feel very independent. I feel like I rely on a lot of others, like I don't feel very strong within myself. I know I am more independent than I use to be so I see a difference between freedom. Freedom is something almost that you are given, where you live, where your circumstance, and independence is almost something internal - how you are." Freedom seemed to be linked more to liberty in expression and action. For example, "freedom is being able to express yourself the way you would like to, to conduct a lifestyle that didn't have restraint from anything you would do or say."

(8) Independence. In contrast, independence seemed to have more to do with control and the degree of reliance on others. "Independence is like leading life and making sure you are in control of everything that happens. That's what I would see." In this light one consumer argued that he would link housing "with freedom and independence – housing, because I see it connected because it is a sense of being independent, now that I am commenting on the housing, it's being a sense that you are in your own home, you are secure. Like me, for instance, setting my home up with furniture I like and people coming and going, and decorating my apartment and just basically to come and go as you please."

(9) Daily routine. This category was created to better capture the themes of work, volunteering, school, social outings, scheduled recreation, and

meeting friends, as activities that were important by virtue of giving routine to life. "I guess for some people, doing work for payment is important, but helping others ... like your volunteer work, that's very important too. And if you do quite a bit of volunteer work, it relates to good mental health, as far as I'm concerned."

(10) Self-care and recreation. Self-care and recreation were seen by consumers as ways of looking after themselves according to their own choosing and timing in a way that was tailored to their personal needs. For example, "self-care and recreation - these are like things that are very essential to quality of life, so that you can keep on track." Self-care involves, "taking care of yourself, doing things to help feel better." Examples of self-care include, "going out and getting your hair cut," or "being able to take care of yourself."

Recreation was also highly valued, "yes, one needs recreation very badly in life, too." Recreation included more than exercise and overlapped with social leisure to the extent that it also seemed to be a way of interacting with the environment. The following comment illustrates this overlap: "last year I just lived downtown, every night I'd eat supper and head to Hardy Park. Just sit there for a few hours. It was nice. I liked it. There were a few people who go down there all the time and you get to know them. But it's nice to do things. Right now, I'm more or less housebound. You don't go out as much during the winter. Although I do a lot of activities at the Y for recreation. "

(11) Giving to others. This involved contributing to a cause and helping others with the benefit, to the consumer, of focussing outward and away from one's self. This category was validated in round II. "Giving to others or to a

cause, helping others because that would help give you a good state of mind." However, one consumer suggested that this category was already captured under the category of relationships. "I think that relationships, friends and family and things like that would go in together with the idea of giving to others or to helping others."

Most and least important categories.

In round II of the delphi, consumers were asked to indicate which categories they considered the most and least important. This question did not add clarification to the categories. There was no consensus on "most" or "least" important categories by consumers. Across the sample of consumers, all the separate categories were endorsed as the "most important" by at least one consumer. Consumers had difficulty choosing and eliminating categories on the basis of importance to the meaning of quality of life.

Round III consumer categories.

In round III, the above categories from round II were taken to the consumer panel for review and comment. The preamble and interview guides for round III appear in Appendix I. As with round II, round III focussed on testing the trustworthiness and comprehensiveness of the above 11 categories, while at the same time looking to understand and reduce or clarify overlapping concepts. In round III, consumers were asked to comment on categories that might be missing and categories that might be saying the same thing. Study participants were also invited to offer general comments about quality of life.

As illustrated in Table 3, round III yielded eight categories. The category of "basic needs" remained unchanged. The category of "good mental and physical health" was consolidated as "good mental health." The three separate relationship categories were combined. Essentially, participants agreed that "relationship with friends and family," "relationship with treatment team," and "romantic relationships," could be described by the term "relationships." Similarly, "freedom," and "independence" were recombined as a one category labelled "freedom and independence." The categories of "daily routine," "self-care &recreation," and "giving to others" remained unchanged. The details of the categories are described below:

(1) Basic needs. The category of basic needs remained central and included the fundamental resources of food, housing, transportation, medications, professional resources and money.

(2) Good mental health. There was agreement in round III that good mental health was a descriptor for the experiences of state of mind, happiness, good physical health, normal life and good self-esteem. In essence, the general impression was that these, often described as separate concepts, were too interdependent to stand alone. For example, does good state of mind lead to happiness? or does feeling happy improve ones state of mind?

(3) Relationships. Relationships included romantic relationship, having a pet as a companion, maintaining connections with family and friends and knowing and relying on the consistency of members of a treatment team. Although romantic relationships were seen as important it did not apply across the

Table 3

The relationship between consumer categories identified in rounds I, II, and III

Rounds	Consumer Categories							
ROUND I	•Basic needs •Money •Housing	•Mental & physical health •Happiness & enjoyment •State of mind	•Relationships	•Belief & spirituality	•Freedom & independence	•Work & education	•Self-care & recreation	•Giving to others
ROUND II	•Basic needs	•Good mental & physical health	•Relationship with friends & family •Relationship with treatment team •Romantic relationships	• Belief & spirituality	•Freedom •Independence	•Daily routine	•Self-care & recreation	•Giving to others
ROUND III	•Basic needs	Good mental health	•Relationships	• Belief & spirituality	•Freedom & independence	•Daily routine	Self-care & recreation	Giving to others

board. In other words, "it just doesn't apply to everyone." Romantic relationships presented specific challenges such as overcoming the stigma of mental illness. This is best illustrated by these comments from a consumer who described her first hand experience with dating. "Like romantic relationship, you practically have to be within the consumer type of person (consumer peer group) - like somebody else who suffers from a depression. I don't think that anyone who suffers from a depression could get into a relationship with anyone else but someone who had suffered from a depression."

As in round II, consumers in round III confirmed the importance of pets as relationship companions. For example, "I also believe that pets are very important in relationships. My cat helped me keep out of hospital a number of times, because at times I was to be hospitalized, I thought I have no one to look after him." Round III also settled the issue of whether or not relationship to the treatment team belonged as a separate category or part of the general relationship group. The consensus was that it belonged with the general category of "relationships."

(4) Belief/spirituality. In contrast to the compound category of "good mental health," spirituality was seen as a separate category. "I think it (belief and spirituality) should be categorized in itself; I don't think it should be put with happiness, state of mind, freedom, normal life." Nevertheless, belief and spirituality did contribute to general well being; "I find that when I pray, and things like that, then I find I feel better."

(5) Freedom & independence. Responses in round III facilitated the re-combining of freedom and independence in the same category. This occurred largely because the responses continued to suggest a compound or interdependent meaning for each term. Sometimes the meanings varied, as noted before, and at other times they were used interchangeably. As one consumer put it, "Independence and freedom, they're sort of different, but they're a bit alike, but it's difficult to draw the line between the two of them." Others were more explicit about stating that "freedom is separate from independence." Independence to them meant, "when you're feeling better you can be more self-productive, strong." On a practical level, freedom can mean "you've got your own house, your own key; same with a room, you've got your own key - so that would be freedom for them." Freedom can also mean freedom from the challenges of mental illness, "your illness never lets you go free, unless they can find a cure for it, of course, and I just shut mine off some days, this last pill, only 200mg per day - it really does help."

The interrelationship of freedom and independence was further highlighted by the following quote: "Freedom and independence go hand in hand, freedom is something you're naturally given, living in Canada. Independence is something you develop after you have been sick and hospitalized. When you are discharged at first you're very dependent on people from the hospital. Slowly as you get better you become more independent, able to do things on your own, not so dependent on other people." A contrasting perspective was that, "freedom is not something you are given, it is something you have to work for;" and independence involved "... relying on oneself, getting by and being able to cope with very little help."

(6) Daily routine. In round III, daily routine continued to include the activities of work, volunteering, education and social outing. Daily routine was seen as varying according to the individual, his/her capabilities and interests. It can be, "just getting up and going downtown and having a cup of coffee, because that's their level, so that's their basic routine; doing something and getting out." Daily routine can also mean, "keeping your place of residence clean and tidy; making nourishing meals; having friends drop by."

(7) Self-care and recreation. There was general agreement that self-care includes recreation and that the combination of the two deserved to be a separate category.

(8) Giving to others. Giving to others was confirmed as similar to contributing to a cause and connecting to the community. In other words, it is "ability to be a person inside the community and to help others."

Summary of consumer rounds.

Round I yielded 12 categories which were revised to 11 categories in round II and finally 8 categories in round III. The final category of "basic needs" included the elements of money and housing and the concept of basis needs itself identified in round I. "Good mental health" resulted from "mental and physical health," "happiness and enjoyment," and "state of mind," identified in round I. In round II this category was called "good mental and physical health," but was reduced to "good mental health," because mental health is already dependant on physical health. "Relationships" began as "relationships," but was subdivided in round II to delineate the separate components of "relationship with friends and family," relationship with treatment team," and "romantic relationships." "Belief and spirituality" remained unchanged as a category over the three rounds, as did "self-care and recreation," and "giving to others." "Freedom and independence" emerged in round II as separate categories, "freedom," and "independence," before being combined again in the final round. "Daily routine," was the reconceptualization of the round I category of "work and education." The other component of round II was the question of the most and least important categories. This question did not add additional information to the study since participants saw all categories that they generated, as important.

Provider interviews

Round I provider categories.

In round I, 27 general categories were identified by providers. These categories were not necessarily mutually exclusive, but were sufficiently different or the meaning was sufficiently unclear to warrant being in different groups. Not all providers contributed to all categories and this improved the richness of the data in round II interviews. It was also noteworthy that some categories depended on other categories for interpretation and meaning. Table 4, provides a list of the categories. The content of each category is described below.

Table 4

Categories identified by providers in Round I

- Money
- Food, clothing, transportation, sleep, basic needs
- Having own place
- Medication
- Universal standards
- Maintaining standards of living
- Meaningful daily activities
- Recreation
- Work, volunteering, something with a purpose to do
- Knowledge & education
- Spirituality
- Challenges (someone to push you)
- Opposite of isolation (integration?)
- Participating, belonging in community
- Friends, relationships, family, community connections, support system
- Professional services
- Protective, structured social opportunities (professionally driven)
- Social support (professionally driven)
- Physical health
- Emotionally healthy; mental health stability
- Happy, contentment
- Reason to live
- Optimum living
- Equalization with normal life
- Respect
- Growth
- Choices, independence, control, freedom, do things on own

(1) Money. Money was a variable that cut across several other categories such as housing, social interactions and basic needs of food and clothing. The comments on money demonstrated the overlap or underlying relationship with other aspects of life. "Money is probably one of the bigger ones, I would say, because your proper housing and stuff depends on how much you have;" "having enough money so that you can meet your physical needs." Money

was related to food, for example, "having enough money to buy a coffee, being able to purchase relatively nutritious food." Social and recreational activities were contingent on money. "A lot of people say they can't do anything, they can't get out and enjoy a movie because they have no money."

The limited income of consumers was a concern. In particular, the contrast between having enough money to adequately meet the broader needs of consumers and having to make do. "For very many, it just even involves having a bit of money, more money than they have now than meets their basic needs ... that they have sufficient amount of money ... rather than making do."

Another illustration is "quality of life sometimes is, I can buy a new outfit in the store, I don't have to go to the thrift shop all the time." In general, the issue of poverty was seen to impact on quality of life for consumers, "often they are living well below the poverty line on government assistance, dependent on that $112 a week, if they are in a boarding home, that is all they have to buy their cigarettes; and so you know, financially they are not able to get what they want, to buy what they want, buy what they need."

(2) Food, clothing, transportation, sleep, basic needs. Most providers identified the idea of basic needs as a core component of quality of life. This can be seen from statements such as "quality of life is to have the proper food," and "having enough money to buy a coffee, being able to purchase relatively nutritious food," or " you have meals; lots of sleep ... having a sound nutritional intake."

Similarly, other basic needs were noted such as having clothes, "we have people that, the only clothes they get are the clothes that are second-hand, hand-me-downs from the Salvation Army, from our own centre here that distributes clothes. It's nice to be able to go and buy a nice outfit."

Transportation was also described as a fundamental need, "I think not being able to do things just because of money and distance sometimes is a problem ... transportation (is a problem)." Some providers suggested a wider definition of basic needs that ranged from recreational activities to social interaction to dental care: "entertainment, leisure, sports; proper nutrition and care of themselves, like clothing and dentistry and things like that, " and "getting up in the morning and keeping themselves clean, being fed, and having an interaction with the world in a social way."

(3) Having own place. Housing was characterized as both a place to live as well as a symbol of choice and independence: "people feel better about themselves because they have their own places of ownership;" "their own apartment, their own room." Housing involved different scenarios such as, "some people are able to live in an apartment .... some people live with their families," "having one (an apartment) that's close to things e.g. the YMCA, the shopping areas, and having an apartment that's set up - be it a couch, a tv if they wish, goes back to choices there again."

Affordability was germane to the issue of housing. "Lots of times your dwelling is based on income, if it's not a high income, and the living situations aren't the nicest. People sometimes are in situations they don't want to be in."

(4) Medication. Providers saw medication as important to the consumer in achieving good quality of life because it improved their functioning. "Medication is a big thing because that helps them be stabilized."

(5) Universal standards. Similar to the above, it was also suggested that there were universal standards related to quality of life, a kind of package of essential ingredients. "There are universal things that I think we all tend to agree on, and the universal ones would be ... health, social, financial, spiritual, and yeh I think those would be the main ones."

(6) Maintaining standards of living. One provider argued that any discussion of quality of life must include some acknowledgement of maintaining a certain standard of living below which the consensus is that quality of life is poor. "From a provider's point of view, I feel also that there should be certain standards that if our clientele are not able to do it on their own that they should have the support ... because some of our clients they ... fall down a lot, they are just not able to keep their environment clean and tidy or even themselves and they really do need the assistance for this."

(7) Meaningful daily activity. Quality of life means "having something meaningful to do with their day; having a purpose to get out of bed in the morning, if it's just even to go for a.walk or something, they need a purpose for the day." The value of a diversionary program was seen as contributing to having a purpose for the day. For example, one provider shared her experience with a client during a time when the sheltered workshop was not available: "... right now, the workshop is out of work and a lot of our clients who are very

customized to going in there every day, they don't have that to do and they are having a hard time filling their day, and you know ... can you not find me something else?" or "I need something else to do. I really miss that. I miss the comradeship."

(8) Recreation. Some providers identified "doing recreational activities in the community" as a component of quality of life. Examples of activities included, "music, being able to watch tv, read, join groups, go out to concerts, that kind of stuff." There was some obvious similarity with the above category (meaningful daily activity) to the extent that recreation was also defined as "having something to do." For example, "a lot of times, people that are having a hard time coping, I think it's because they don't have things to do, and they don't have people to be with, and to have friends I think is a big part of it."

(9) Work, volunteering, something with a purpose to do. Work and volunteering were seen by providers as part of satisfying the consumer's need for a purpose in life, for example, "I also think that consumers need to have a purpose in life and they want to be contributing so they very much like to have a job or (be) a volunteer or be important to somebody else, ... and that society also rewards them with having sufficient money and sufficient standard of living ... that experience with me increases the quality of life."

(10) Knowledge and education. Knowledge and education were suggested as possibly important to making choices that might enhance quality of life. For example, "maybe, knowledge and education to some degree, like if they don't know about nutrition or proper cooking then they're not going to achieve that

without assistance."

(11) Spirituality. Providers saw "spirituality" as part of "... having a balanced quality of life." Spirituality was also considered as part of the consumer's participation in the community to the extent that he/she belonged to a church or organization. In other words, providers underscored the structural or institutional benefits accompanying spirituality.

(12) Challenges (someone to push you). Similar to the idea of professional support and professionally driven protective structure was the idea of having someone in your life to push you or challenge you when needed. An illustration of this is as follow: " I saw her yesterday; she thanked me immensely for being behind her and really pushing her to attend work. She said 'I hated to get out of bed', but I reinforced how important work was and this type of thing, and she wanted me to make sure that I gave her thanks to the team for supporting her. We're starting to see her three times a week, and she said 'You got me through it'. They were her choices whether she got out of bed to come to work, but yet, with us telling her that she was needed so much, it sort of gave her that purpose to come in, and she said that's what got her through it."

(13) Opposite of isolated (Integration?). Some providers identified "isolation" as one of the conditions that limits quality of life. The likely assumption was that the opposite of "isolation" would contribute to quality of life. Consequently, in preparation for round II, this category was left with the label of 'opposite of isolation,' with the question of does this therefore mean that the affirmative concept is 'integration?'

Isolation was described as, "... being alone and not wanting to be I think, or spending too much time alone to the point where you just lose your social skills and you lose your ability to interact in a comfortable way with other people;" An example of an isolated person was therefore, "... the person who is not connected and is always staying in bed." A dynamic of isolation is stigma. "One of the problems for people with chronic mental illness and schizophrenia is isolation. There is the stigma society has about them, that many people don't understand the illness or they are afraid of interacting with them when they are stable because of the possibility of them being violent which is a myth that is perpetuated in our culture and we all know about that. And, if they don't look normal or they have mannerisms or habits that cause people to be a little bit uncomfortable then they won't interact with them."

Other examples of isolation included: "... housing isolation and if you don't feel comfortable or don't fit in to where you are living then you are isolated;" "having no friends you are isolated because you feel like you can't go anywhere;" "not having the education or feeling that you don't have the education to go out into the world and do anything - that is an isolation;" "in order to socialize, if you don't have those skills you are also isolated there because people don't understand your behaviour."

(14) Participating, belonging in community. The idea of connectedness to the community in some fashion was seen by some participants as important to quality of life. At this first stage it was not known whether or not this would remain a concept separate from issues such as isolation or integration.

Providers identified the issue of loneliness as a limiting factor in quality of life, for example, "loneliness.. a lot of our clients complain about loneliness... we really struggle, I think with getting them, not only in the community, but to be a participant in the community, so that they are actually part of the community they are living in." Another provider put it this way, "living somewhere where you don't feel part of the community, you don't feel you are accepted by other people, it could be the stigma that is attached to that, not having access to friends and maybe not having people phone or drop in, maybe you wouldn't even have a phone."

(15) Friends relationships, family, community connections, support system, nonjudgmental person to talk to. This was one of the larger categories with considerable overlap and/or shades of meaning of the same concept. Providers identified the basic elements of friendships, relationships and support.

"Friends is very important. I find with a lot of people, that to have success is to have relationships and friends." Friends and family were seen as ways of establishing "some connection with the community." Friends and family provided support "things like family, positive family supports...and or friends, relationships... a support system to a person when they're not feeling well." Friends were also seen as a way of ameliorating isolation, fostering acceptance and building trust. "Without friends, you don't have someone you can trust, anyone you can rely on, you feel isolated because you can't call or you can't talk to someone. There is no one to do anything with, no one to accept you the way you are." Another provider accented the idea of unconditional positive regard and framed it this way, "I think a lot has to do with having people to talk to that you know aren't going to judge you, that are just going to be, not basically a sympathetic ear, but an ear, just so you know there's not going to be any judgment at the end of it."

Reliability and availability were valued components of a support system as the following comment illustrates: "... a very good support system that they can count on and they know the people and they feel very comfortable with. And that is going to be there whenever they need it, even if they never need it."

The relationship aspect of having a pet was not explicitly mentioned, but the opportunity to make the choice about having a pet was highlighted as follows: "... actually, it could be pets too. I never thought of that, maybe live in a place where you could actually have a pet and that might not be a choice that people could make."

Sharing experiences and doing things together are other elements of friendship. "Well, if you have friends, people you can share experiences with, you can do things with, might be people to encourage you to get out and enjoy life, someone you can share your thoughts with, your problems, someone there to support you during the difficult times." Similar comments were also echoed by other participants: "People to have fun with," "getting out with other people to have coffee."

Intimate relationships were also described by providers as important to quality of life, "close friendships could develop ... romantic friendships ... family unit ... marriage. I know a lot of people who want to have children." Similarly one provider noted that, "... probably an intimate relationship is part of quality of life."

(16) Professional services. Some providers identified professional services as a contributor to quality of life. "A lot of people do need ACTT (Assertive

Community Treatment Team) support and we can give them (that support) and with that support they can have a good life." "We're there to help them to show them and guide them along as far as maybe possibly making better choices."

(17) Protective, structured social opportunities (professionally driven). In contrast to the category of integration (as an opposite of isolation), it was also noted that some consumers may well prefer and thus experience better quality of life from reduced interaction. For example, "my quality of life would not be the same as one of my clients who is quite happy not interacting with people for several days at a time. For him or her that may be quite fine, for me I wouldn't be happy doing that at all." However, one provider took the idea of preferred isolation further by suggesting that professionals, in recognition of the latter, may actually wish to structure isolation or offer some sort of protective structure to the consumer to enhance his/her quality of life. Put another way, "a lot of people can't tolerate too many people so they will avoid group situations, they will avoid crowds, they will avoid going out into the mall or the city or places where they can meet other people so often the attraction has to be structured and created for them in order for them to feel safe and comfortable"

(18) Social support (professionally provided). Social support can be derived from family and natural relationships and from persons who are paid to be supportive. At stage one of the interview process, these categories were

separated with a view to hearing feedback from providers during round II. This comment summarized the perspective of professional support:: "... social supports I think are very important and that is why I think the work we do is key because we are able to connect with people who may not be connecting with family, have very few friends and the only people they see in their lives are nurses, or doctors, or staff at a home ... so having a very limited social system affects their quality of life."

(19) Physical health. Physical health was conceptualized as both coping with specific health problems as well as generally feeling healthy. "Often there is physical health problems that they are living with on a day-to-day basis; So, for most people health would be the first thing that they would say, well if I'm healthy then my quality of life is good because I am able to do what I want to do, I have the energy, I have the stamina, and you know and that feels good, so for people with mental illness often they don't feel good." Physical wellness was seen as a prerequisite to a more active life and community integration for example, "if you are physically healthy, you are able to participate in more stuff, you are able to do things independently; you are able to be an active member of the community and look after yourself."

(20) Emotionally healthy, mental health stability. The concept of emotional health or mental stability was another component of quality of life identified by providers. At times it also included the concept of physical health identified above, that is, "... being healthy, reasonably healthy, mentally and physically ... depression, you know, not having that drive, or not being well

enough mentally or physically, that you know you're not going to be able to get up and do what you want, or just inner turmoil." Similarly, being "... emotionally healthy" was considered to be "... feeling stable both physically and mentally." However, for this first round, emotional health and mental stability was separated from physical health.

Mental stability was associated with discernment of need and being able to communicate this assertively: "... some kind of stability in the mental health aspect; their ability to be assertive over their needs, or even, back to their mental health capacity, that they're stable enough to know what they want or can assert themselves." Judgement was seen as a byproduct of stability. "If someone's psychotic or if someone's manic, they don't have the same judgement as someone who is mentally stable would display. When somebody's mentally stable, they're more capable of being up for whatever happens."

Mental stability was seen as influencing one's housing or living environmental choices for example, "their mental health stability that they have to be able to live in different settings, like if a boarding home is appropriate, then if they're not able to handle living with other people, then they're not going to be able to live there."

Mental stability was also associated with ability to participate in daily activities as illustrated by this comment: "they tend to sit in their homes and smoke and they don't get out, and they don't have the energy to do anything."

Medication was a feature of mental stability and the complexity of this was illustrated by this comment: "... a lot of them complain about the side effects of their medication, not wanting to be seen in public because their hands shake or because they're stiff when they walk, or because it's very noticeable."

(21) Happy, contentment. Happiness and contentment was seen as a component of quality of life, if not the meaning of quality of life itself. "It is really what makes the client happy, what makes the client content - either in their living situation, social, or recreational, or what have you, but what makes them content with themselves."

(22) Reason to live. 'Reason to live' addressed the reality of being faced with the question, perhaps routinely for some consumers, about the need to continue living. The following comment by one of the providers suitably summarises this concept: "... yeh, it would be the sort of feeling that you can't do what you want to do and feeling a general malaise and frustration with life, you know, chronic depression or not wanting to live, not feeling any value in your life, feeling I'd rather be dead, I'd rather be dead than have the life of internal pain, no more people to struggle with and that is the reality for many of our clients that they struggle on a daily basis to find a reason to be alive."

(23) Optimum living. Providers saw quality of life as a measure of the extent to which consumers were able to "live to their optimum," where optimum meant that they were able to "do things to their highest potential, whatever that may be." Another description highlighted independence and a minimum of limitations as the key components of optimum living. For example, "to live to their optimum, have independence ... to be able to go through your daily life and do what you like to do with as few limitations as possible, basically that is

quality of life."

(24) Equalization with normal life. Quality of life was seen as achieving equalization with those who experience no limitations related to having a mental illness. For example, "quality of life for them (consumers), to my mind, would be to have equalization with what people who haven't had their experiences have, so that their daily routine could come as close as possible (to) what so called normal people with everyday stressors and realities have to deal with."

(25) Respect. One provider saw quality of life as meaning "being respected and accepted" and having people see the consumer in a "non-judgmental way."

(26) Growth. Personal growth over time in response to changes and overcoming "... stumbling blocks" was seen as integral to quality of life. For example, "if a person keeps on growing that is really the key to a quality of life."

(27) Choices, independence, control, freedom, do things on own. Choice and independence were considered important components of quality of life. For example, "being in the community people feel better about themselves because they have their own places of ownership, they have independence, they are able to make choices". Similarly control was an associated feature, as illustrated by this statement, "a lot of consumers will answer that I have my own place, I can make up my own mind, I can decide what to eat, I can decide when to go to bed ... they are in control." Providers also talked about the relationship between their role and the consumer's choice, " yea, I think that's really important

to our clients. Like we can try to influence, but ultimately it is their choice and the thing with med (medication) compliance and everything like it comes down to them." A further elaboration of choice is captured in this statement; "I mean we may think that quitting this or starting that might improve their quality of life, but if they don't see it that way you know, they're an individual and that's their right ..."

Round II provider categories.

The above 27 categories were taken to the provider study group for review and comment. The preamble and interview guides for round II are shown in Appendix H. In particular, round II focussed on testing the trustworthiness and comprehensiveness of the above categories, while at the same time seeking to understand and reduce overlapping concepts. For example, in round II providers were asked to comment on categories that might be missing and categories that might be saying the same thing. In addition, providers were asked to identify which categories they felt held the greatest importance to quality of life. Conversely, they were also asked which ones were least important. The purpose of these last two questions was not to produce a rank ordering, but rather to understand if there were particular categories that immediately evoked an image of quality of life. Study participants were also invited to offer comments about quality of life in general. Six categories resulted from this round and these are listed in Table 5 and described below.

In round II of the delphi, providers were asked to indicate which categories they considered the most and least important. This will be reported on at the end of this section.

Table 5

The relationship between provider categories identified in rounds I and II

Round I provider categories					
•Money •Food, clothing, transportation, sleep, basic needs •Having own place •Medication •Universal standards •Maintaining standards of living	•Recreation •Work, volunteering, something with a purpose to do •Knowledge & education •Spirituality •Challenges	•Opposite of isolation •Participating, belonging in community •Friends, relationships, family, community connections, support system •Spirituality	•Professional services •Protective, structured social opportunities (professionally driven) •Social support (professionally driven) •Challenges	•Physical health •Emotionally healthy, mental health stability •Happy, contentment •Reason to live	•Optimum living •Equalization with normal life •Respect •Growth •Choices, independence, control, freedom, do things on own •Spirituality
Round II provider categories					
Resources for living	Meaningful daily activities	Connected to the community	Social & professional support	Physical & mental health	Optimum living

Note: Overlapping categories are underlined.

(1) Resources for living. Resources for living included, "... food, clothing, transportation, ... basic needs, having own place, money, finances." Put another way, "In order of priority, I think you would group having own place, money, finances, clothing, sleep, basic needs as the most important." The necessary resources also included access to medication, "... the new medications right now - quite often we can't give them to the people, because they ... cost $5.00 a pill and people can't afford it.."

(2) Meaningful daily activities. Providers collapsed a number of categories, from round I, to constitute the category of meaningful daily activities. Meaningful daily activities included recreation, volunteering, knowledge and education, and work. One perspective suggested that meaningful daily activity included, "recreational/vocational, even getting up in the morning and doing your own personal hygiene ..." and even encompassed, "getting out of bed at a regular time each day." Other perspectives added "volunteering" and "knowledge and education" to the range. The thinking behind meaningful daily activity was the idea of "having something purposeful to do." Some providers even connected it to the idea of having a "reason to live." The latter is illustrated by this provider's comments: "... um... the recreation and the work/volunteering and the day activities and giving them a reason to live - basically those things. That's the category that's important - you need something to look forward to, something to do, something to keep you moving."

The concept of challenges and having a challenge in one's life appeared in this context as well as in the category of social support. The difference seemed to be related to whether or not the discussion was about facing challenges or needing to have challenges on a daily basis; or whether the focus was on having someone in your life to challenge you to be more active or grow. The former is captured by this statement, " I guess depending on the person and what kind of challenges we're talking about, some people may need some challenges, but to me that would be more the meaningful daily activity and participating and belonging in the community." In contrast, another provider stated explicitly that "... challenges really has to do with growth." Spirituality, was included as a feature of this category and will be addressed separately later in this section.

(3) Connected to the community. Connected to the community addressed the issue of community integration. One provider described it this way: "... so you don't feel isolated; you're probably integrated into your environment; you're participating in your community." Another comment was that 'connected to the community' also included, "... friends, relationships, family community connections." This is the second category that also included "spirituality." The latter will be reported on separately later in this section.

(4) Social and professional support. The concept of support was central to quality of life. However, the sources of support varied and there were some differences of opinions about whether or not support from professionals should be a separate category or combined with other sources of support. This provider's statement favoured the idea of all support as forming a network of support. "I would say the professional services, friends/relationships, social support ... are more of a network; a support network - be it professional - be it

friends - be it family, whatever." In contrast, another provider noted the difference between professional and natural support, "I guess there's a distinction between professional supports and sort of more natural, normal supports in a community. So, it could be separate, I guess it depends on how many categories you want to have here. Professional supports, though, could help somebody with their emotional health, and their feeling of belonging and participating, but that's not the natural support system." A provider with a perspective that showed the interrelationship between the two had this to say, "Well, it's a bit of both, really, because in one way professional support really helps the individual with having their own personal support, their own social support themselves. (The) professional is mostly there for the guidance and to help the person grow to become more independent." One of the differences appeared to be the element of structure that professionals brought to the concept of support as described in the following commentary: "The other one would be the professional service, with the social/professional support service to be structured and the challenges and medication; that would all be in one, because the provider would be helping you structure all of your activities and giving you the positive feedback and the challenges to get you out there, get you going." As noted above, in the "meaningful daily activities" category, the concept of challenge overlapped with the idea of support; "... because they're talking about challenges as being somebody involved in their life, and pushing them."

(5) Physical and mental health. Physical and mental health also combined to include such concepts as happiness and contentment and having a

reason to live. For example, "physically healthy, emotionally healthy, mental health stability, and mental and physical health - I think they could all be grouped together." Additionally, "... happiness and contentment, to me - emotional health and often physical, emotional, mental health piece is connected, but it can give people a reason to live." Similarly, "(if) they are physically happy, they're emotionally and mentally happy."

(6) Optimum living. This embodied such concepts as "restoration" (of health and skills etc.), psychological "growth," needing to be respected and feeling respected and accepted. " "Optimum living, functioning with as few limitations as possible, may be, could be linked with growth and also equalization with and normal life; and to me being respected and being able to feel and receive respect would go with optimum living." Similarly, "I think the optimum living, restoration and respected acceptance - they could be grouped together ...they're all very similar, what they're saying." One provider, saw optimum living as the result of stability. "Optimum living - I mean it's part of being mentally stable if you're happy and content." This is the third category that included "spirituality" and this will be reported on separately, later in this section.

Themes not included as a separate categories.

(a) Spirituality. The concept of spirituality although it was not seen in round II as a separate category generated diverse opinions. For example, it was suggested that it belonged in the 'meaningful daily activities' category above. "Spirituality, I would put maybe in part of the work/volunteering and the recreation, cause it's all part of giving you something to do, giving you a reason to live." On the other hand it was seen as part of the support category. "... It is a social network if you're thinking of a church, or something." A similar suggestion asserted that: "... spirituality could be, in my opinion, ... grouped in with the friendships/ friends/relationships/ community connections." Another view was that "growth and spirituality can go together," which would mean that it belonged in the optimum living category. Yet another view was that, "... it may be connected with emotional health." In preparation for round III, spirituality was included in several of the above categories, namely, 'meaningful daily activities,' 'optimum living,' and 'connected to the community.' This offered providers the spectrum of views to comment on it in round III.

(b) Challenges. There were differing perspectives on the idea of 'challenges.' One perspective says that 'challenges' was, "... probably part of the support network." "That's what your support network does, I would think. I mean, if you're in your room, and you're in there for five days, someone's going to come along and say what's going on? Now this also probably is a professional thing we see people that have a personality disorder, or um, let's say, an agoraphobia or some kind of phobia, maybe someone will give them a little push, or one step at a time, but that can be anybody in your support network, I would think". Another perspective, included 'challenges' as part of 'meaningful daily activities. "... Some people may need some challenges, but to me that would be more the meaningful daily activity and participating and belonging in the community."

Most and least important categories.

In round II of the delphi, providers were asked to indicate which categories they considered the most and least important. This question did not add clarification to the categories. There was no consensus on most or least important categories by providers. Across the sample of providers, all the separate categories were endorsed as "the most important" by at least one provider. Providers had difficulty choosing and eliminating categories on the basis of importance to the meaning of quality of life.

Round III provider categories.

The above six categories were taken to the provider group for review and comment. The preamble and interview guides for round III are shown in Appendix I. Round III focussed on testing the trustworthiness and comprehensiveness of the above categories, while at the same time seeking to understand and reduce overlapping concepts. As in round II, providers were asked to comment on categories that might be missing and categories that might be saying the same thing. In round III, the categories remained the same, but the content of some of the categories was modified (see Table 6). The details of the various categories are presented below.

(1) Resources for living. Money, food, clothing, housing, transportation, and medication was seen as the basic resources forming the foundation of quality of life. Some providers included the idea of access to professional assistance as a basic component of these fundamental resources. However, there was no agreement that there was a "universal standard of living."

Table 6

The relationship between provider categories identified in rounds I, II, III

Round II provider categories					
•Money •Food, clothing, transportation, sleep, basic needs •Having own place •Medication Eliminated •Universal standards •Maintaining standards of	•Recreation •Work, volunteering, something with a purpose to do •Knowledge & education Moved to other category •Spirituality •Challenges	•Opposite of isolation •Participating, belonging in community •Friends, relationships, family, community connections Moved to other category •Spirituality	•Professional services •Protective, structured social opportunities (professionally driven) •Social support (professionally driven) •Challenges	•Physical health •Emotionally Healthy, Mental health stability •Happy, content •Reason to live	•Optimum living •Equalization with normal life •Respect •Growth •Choices, independence, freedom, do things on own •Spirituality
Round III					
Resources for living	**Meaningful daily activities**	**Connected to the community**	**Social & professional support**	**Physical & mental health**	**Optimum living**

Note: "Universal standards" and "maintaining standards of living" were eliminated. "Spirituality" was moved to "optimum living." "Challenges" was moved to "social and professional support."

<u>(2) Meaningful daily activities.</u> There was general agreement that this category involved such things as day to day activities ranging from getting up in the morning and taking care of personal hygiene to volunteering, work, education, recreation and going out with a friend. The underlying meaning was that of maintaining status quo on one end of the continuum to having a purpose in life and facing challenges at the other end of the continuum. Engaging in meaningful daily activities was seen as dependent on finances and consequently also on the other "resources for living." Prior to this round, "challenges" and "spirituality," were components of this category. However, these were removed by the consensus of this round.

<u>(3) Connected to the community</u>. The thinking behind this category was that quality of life was improved by experiencing a sense of integration in the community. This was in contrast to the often cited issue of social isolation. Connected to the community also included connections to family, friends and other social supports. Participation in the community seemed to be another measure of connectedness to the community. Work and volunteering were recognized ways of experiencing community connectedness. Prior to clarification in this round, "spirituality" was also included as a component of this category.

<u>(4) Social and professional support</u>. Support in general was seen as a key building block of quality of life and the context for the interaction of other variables such as "physical and mental health", "connected to the community" and "meaningful daily activities". Although there was some acknowledgement that

there was a difference

between professional support and natural supports, most providers throughout all rounds agreed that they should be combined in the same category. Professional support was sometimes connected with phrases such as "protective structure" or "structured social opportunities." Some providers also emphasised the deliberate "non-judgmental" or "listening posture" or "accepting attitude" conveyed by professionals as key elements of professional support. It is also noteworthy that the idea of "challenges" was maintained in this category and moved from the category of "meaningful daily activities."

(5) Physical and mental health. There seemed to be agreement, although one or two providers expressed second thoughts, that 'physical' and 'mental health' belonged together in the same category because of their high level of interdependence. Mental health was translated as stability and seen as the prerequisite to contentment and happiness. Meaningful daily activity was seen as foundational to maintaining good physical and mental health.

(6) Optimum living. Optimum living was almost synonymous with quality of life itself since it seemed to encompass all the other categories or at least seemed to be the culmination of the achievements in the other categories. Consistent with latter, and since it was not seen as significant enough to be a separate category, "spirituality" was maintained as a component of "optimum living."

Summary of provider rounds

In round I, providers introduced 27 categories, some of which seemed similar. However, the researcher elected to defer collapsing too many categories until receiving feedback from round II. Consequently, this strategy accounted for the larger number of categories in round I. However, clarification in round II reduced the categories to six, with some overlap in the content of the categories because of the interrelationship of categories or the personal meanings that categories had for individuals. The most noteworthy overlap occurred with "spirituality" and "challenges." In round II, "spirituality" was seen by some as a component of three different categories, namely, "meaningful daily activities," "connected to the community, " and "optimum living." Similarly, "challenges" was included as a component of "meaningful daily activities," and "social and professional support." The question of most and least important categories was posed in round II, but as with consumers, providers saw all of the categories selected as important to quality of life. In round III, two categories were eliminated on the basis of consensus. These were, "universal standards for living," and "maintaining standards of living." The variable of "challenges" moved from the category of "meaningful daily activities" to the final category of "social and professional support." Similarly, the variable of "spirituality" was moved from the categories of "meaningful daily activities" and "connected to the community" but remained in the "optimum living" category.

CHAPTER 5: DISCUSSION

The purpose of this study was two fold. Firstly, to examine the similarities and differences between the perceptions of consumers and providers regarding the meaning of quality of life. Secondly, to examine whether the delphi techniques and the ethnoscience qualitative method would yield information that would allow a comparison of similarities and differences between the perceptions of consumers and providers, of mental health services, about quality of life. The study achieved both objectives.

Similarity and differences between consumers and providers

The first research question asked by this study was: 1) What is the meaning of quality of life for persons with serious mental illness from the perspective of the consumer of mental health services and the provider of mental health services? In response, this study's methodology demonstrated that there were obvious similarities and differences between the perceptions of consumers and providers regarding the meaning of quality of life.

The final round of the three round modified delphi resulted in eight consumer categories of quality of life and six provider categories. This general finding of some similarities and differences between consumers and providers is consistent with the limited amount of literature available on this topic. For example, Thapa and Rowland (1989) concluded that staff and patients show "significant divergences" as well as "some similarities" regarding quality of life variables. Similar outcomes were reported by Zissi, Barry and Cochrane (1998) and Becker (1998). Sainfort et al. (1996) found that consumers and providers judgements are more likely to coincide on clinical aspects of quality of life than on social aspects.

The next two sections discuss some of the similarities and differences found in this study. However, given the complex nature of the meaning of quality of life, the division of the discussion separately into "similarities" and "differences" does not eliminate the need for overlap in the discussion.

Similarities

There were apparent similarities between four of the consumer and provider categories. The consumer category of "basic needs" was similar to the provider category of "resources for living". Both categories involved variables of necessities such as, food, housing, money, transportation, professional resources and medications. In both instances, there was agreement between consumers and providers that these basic commodities were foundational to achieving quality of life. Over the course of the interviews, it was noted by consumers and providers that basic resources were taken for granted or should be taken for granted in an Ontario setting. In other words, some would argue that even if the theme of "basic resources" was not mentioned that it was implied; and that supplying the resources and addressing the underlying consumer needs (since they were so basic) should be guaranteed by the government.

These respective categories of " basic needs" and "resources for living" were supported by the finding in the literature of "possession of resources" as a crucial component to addressing satisfaction of needs, participation in activities and ultimately self-actualization (Shin & Johnson, cited in Bowling, 1991, p. 9). In fact the work of Skantze et al. (1992) concluded, in more trenchant terms, that as long as basic needs were met, standard of living and income were independent of perceived quality of life.

An interesting finding was that consumers included medications as a basic resource. This is important given the sometimes contentious debate in mental health circles regarding issues of medication compliance and the prevailing view that the acceptance of the value of medications is more of a provider driven issue, than an issue that would receive favourable review by consumers (Van Dongen, 1996). Some studies (Collins, Hogan & Desai, 1991; Mulaik, 1992) have reported that consumers do not favour taking psychotropic medications. However, consistent with the finding of the present study, Diamond (1985) and Van Dongen (1996) reported a more favourable attitude towards medications by consumers. In fact, in Van Dongen's study, 83% of 92 consumers "expressed a very positive attitude towards their medications," (p. 541).

The consumer category of "good mental health" was similar to the provider category of "physical and mental health." Both of these categories emphasized those aspects of quality of life related to psychological needs, such as state of mind, happiness and contentment, experiencing a normal life (free of symptoms of mental illness), self-esteem, and emotional and mental health stability.

The third area of similarity was in the categories of "daily routine," as labelled by consumers, and "meaningful daily activities," as labelled by providers. In contrast to the above psychological categories where the focus was on abstract qualities, albeit dependant on more tangible resources for their realization, these categories involved "activities." They included the activities of work, volunteering, pursuing education and knowledge, social outings, engaging in something with purpose, and recreation.

Consistent with the findings of Van Dongen (1996), consumers in this study viewed work not only as a means to earn money, but as a way of accomplishing a daily task and feeling "productive;" "you feel good when you can do it." Similarly, Bebout and Harris (1995) conceptualize work as "... less about finding something to do and more about recovering or discovering something to be" (p. 401). This is in tune with the belief in the field of psychiatric rehabilitation that work positively effect other areas of functioning of those with mental illness (Mueser et al. 1997). However, this is contrasted with the majority of studies that, in fact suggest, that employment does not directly lead to generalized improvement in subjective quality of life (Mueser et al. 1997).

One of the differences between consumers and providers, in this category, was that consumers did not include the idea of "knowledge and education" as an important daily activity.

The fourth area of similarity occurred in the respective categories of "relationships," and "social and professional support." They included maintaining connections with family and friends, knowing and relying on the consistency of members of a treatment team, realizing community connections, involvement in a support system, and having a nonjudgmental person to talk to.

In the first round, there was some question about whether or not professional relationships should be included in the same general category of "relationships." However, both consumers and professionals subsequently confirmed that they belonged in the same category. Moreover, consumers noted the importance of professionals in their lives in the areas of support, expertise, and being available to "give them a push" when this was needed.

These consumers were part of the Assertive Community Treatment team program that maintains a long-term continuous commitment to consumers (Stein & Santos, 1998), consequently the consumers in the study would have known their providers for several years; some for as long as ten years, the length of time the program has been in operation. With this in mind, it should not be surprising that consumers considered professionals an integral part of their social and relational support system.

One of the differences in this category between consumers and providers was that consumers highlighted the value of pets as part of their relationship, and support network. Indeed, those consumers with pets spoke poignantly about the unconditional positive regard they received from their pets. They found comfort in the fact that they could talk to their pets without being judged, and that they could share personal details without worry of betrayal. The security of this relationship also meant that consumers could safely vent angry feelings with their pets without fear of retribution or criticism.

Caring for pets also provided consumers opportunities to focus attention away from self and refocus on taking care of "someone" and having "someone" depend on them. One consumer stated that she was able to stay out of hospital on a number of occasions because of her pet cat. She recognized that if she "allowed herself to be admitted" to hospital that there would be no one to take care of her pet. This focus-on-the-other, gave her the strength to persist and sustain her tenure in the community with the help of her treatment team.

The literature has documented a variety of benefits of having pets as companions. In the psychosocial arena, the noted benefits of having a pet include, enhanced self-esteem, better motivation, experiencing a greater measure of responsibility and respect, and unconditional positive regard and companionship (Kongable, Buckwalter, & Strolly, 1989). In fact, pet companionship seems to offer benefits even in the clinical area of mental illness. For example, Barker and Dawson (1998), found that animal-assisted therapy produced significant reductions in anxiety for patients with psychotic disorders, mood disorders, and "other disorders."

Although one of the providers, in the present study, mentioned pets, her focus was more on the rights of consumers, as tenants, to have pets rather than on the relationship aspect. For example, she focused on whether on not the consumer could find housing where pets would be allowed.

The other difference in this category was that consumers specifically identified the need for romantic relationships, and commented on the challenges that this brings. For example, one consumer concluded that she could only date within the mentally ill peer group because of the stigma associated with her label, as someone with a mental illness. Providers mentioned having a partner as part of relationships, but did not single it out for emphasis, or comment on the challenges of romantic relationships outside the consumer peer-group.

It was also noteworthy that apart from this reference to stigma in dating relationships, the concept of stigma was not identified by consumers as a limiting factor in achieving quality of life. This sharply contrasts with the summary of a workshop on quality of life, where Holley (1998) noted that "social stigma was identified as the single most important factor undermining the quality of life of both consumers/survivors and their family members ..." (p. 13). Moreover, Holley (1998) lamented the finding that stigma "has not been considered a key component of quality of life and is not represented in any quality of life instrument for use with people with mental illness" (p. 13). Similarly, Carne (1998), a consumer and consumer-advocate, stated that "quality of life is a life free of the stigma of mental illness," (p. 26).

There is no clear explanation for the discrepancy between the findings of this study and the findings in the literature. It may be that the individuals in the present study did not experience stigma, or that stigma was subsumed under other issues, such as the underlying reason for wanting to have "good mental health" and a "normal life." In other words, it is reasonable to conclude that "good mental health," and a "normal life" precludes the experience of stigma.

An alternative explanation could be that for the consumers in this study, the effects of stigma might have been somewhat muted by the nature of the environment or community in which they lived. This explanation is rooted in the fact that the relatively small local community of Brockville is home to a large provincial psychiatric hospital, with a sizeable number of consumers living in the community, thereby giving rise to frequent interactions between consumers and the general public. Thus, this environment may serve to reduce stigma through multiple positive contacts.

The literature regarding proximity of a psychiatric hospital and/or the existence of community based psychiatric services, and tolerance towards the mentally ill is inconclusive. For example, a study by Brockington, Hall, Levings & Murphy (1993), using a questionnaire methodology, concluded that residents of a town served by a psychiatric hospital were more tolerant toward the mentally ill than residents of a town served by a community based service. On the other hand, when a methodology of face to face interviews using case vignettes of a mentally ill person was used, in the same town, the results were reversed (Hall, Brockington, Levings & Murphy, 1993).

Differences

In general, it should be noted that the range of themes and variables identified by both study groups were similar. Sometimes the "differences" between consumer and provider categories represented the differential degree of importance and emphasis, respectively placed on specific categories and variables that comprised those categories. For example, both consumers and providers acknowledged the element of "spirituality," nevertheless for consumers it was important enough to be a category by itself. Providers saw it as "just" a component of something else.

There were no distinct counterparts in the provider categories for four of the consumer categories. Consumers identified "freedom and independence," "belief and spirituality," "self-care and recreation," and "giving to others," as separate categories. Conversely, for one of the provider categories, there was no distinct counterpart in the consumer categories. Providers identified "optimum living" as a category for which there was no explicit consumer counterpart.

Consumer specific categories. Although the distinction between the two concepts was not always clear, consumers saw freedom and independence as important to their quality of life. In the first round, the category was given the compound label of "freedom and independence." In the second round, some consumers argued that there was sufficient distinction to justify separate categories of "freedom," and "independence." However, by the third round, the consensus was that the compound label of "freedom and independence" was more appropriate.

For some, freedom meant the rights that he/she is granted as a citizen of a free society, and the liberty to do whatever he/she wants within the rules of society. In general it meant the absence of constraints on choices. Independence meant being able to make choices on one's own and achieving a measure of self-sufficiency. It also had to do with control over ones life and the degree of reliance on others. However, the terms were also used interchangeably. For example, freedom meant simply being out of hospital (i.e. living independent of the constraints of an institution). Even having access to transportation provided a measure of freedom. On the other hand, both freedom and independence were also used to express the idea that consumers had "their own place."

These findings are similar to those of Davidson, Hoge, Merrill, Rakfeldt and Griffith (1995), who studied the experiences of long-stay psychiatric inpatients returning to the community. According to Davidson et al. (1995), the issue of freedom was prominent in their interviews with patients. They contrasted their freedom in the community with the restrictions and loss of control experienced in hospital with respect to basic issues such as making "simple decisions about where to go, what to do, and when to sleep, wake up, or eat ..." (p. 126). Indeed one of the striking finding of Davidson et al. (1995), was that consumers valued freedom and control over his/her life, even in the face of poor community living conditions and inactivity. Davidson and colleagues did not identify the issue of "independence" in their work, although their descriptions of "freedom" are the same as those described in this study under the compound title of "freedom and independence." Providers identified the concepts of freedom, and independence, but included them as part of the category they called "optimum living."

The second category without specific provider counterpart was "belief and spirituality." Consumers highly valued ideas and practices related to belief and spirituality. Belief and spirituality had literal and explicit meaning to consumers. It meant, belief in God, church participation, praying, worship and fellowship, and communion with God. A relationship with God offered meaning to life as well as comfort and support.

Providers mentioned spirituality, but saw it more as an elective psychological and abstract quality, applicable after basic needs had been met; not as part of a day to day coping and survival mechanism. For example, providers included spirituality in their category of "optimum living" along with themes of "equalization with normal life," "respect," "growth," "freedom," and "independence." This is an important difference because it raises the concern that providers may not be attending to spiritual issues in their work with consumers.

The latter is underscored by Fallot (1998a) and Koenig, Larson and Weaver (1998), who suggested that one of the factors in the relative neglect of religious and spiritual dimensions of consumers' lives may be the so-called religiosity gap between mental health professionals and the general public. According to Fallot (1998a), organized religion and certain traditional religious beliefs apparently play a smaller role in the lives of mental health professionals. However, there is evidence that the religious beliefs and practices of consumers are similar to those of the general public (Fallot, 1998a; Kroll & Sheehan, 1989), where religious beliefs and practices play an important role. A similar explanation was offered by Atkinson and Zibin (1996), who noted that the "omission" of spirituality from quality of life measures may be the result of "scepticism" about the role of spirituality in the lives of consumers (p. 5).

The third category without specific provider counterpart was self-care and recreation. Consumers chose to combine these into one category, albeit, in round I they articulated different functions for each; and to some extent this persisted to the third round.

In round I, self-care was seen as activities that consumers engaged in specifically as a way of coping. It involved self-soothing activities such as, relaxation, reading a book, having a bath, or watching television. It should be noted that labelling the category as "self-care," and not as "self-soothing" was the choice of the consumers. The former is consistent with prescriptions in many mental health self-help books.

On the other hand, recreation involved more sports related activities such as biking and walking. However, clarification in round II resulted in a blurring of these distinctions, such that self-care and recreation were both seen as ways of "taking care of yourself," " staying on track," and even as a way of interacting with the environment.

Providers did not specifically identify the theme of self-care, but identified recreation. However, providers saw recreation as part of the category of "meaningful daily activities," along with work and volunteering. It is also noteworthy that in the study by Thapa and Rowland (1989), there were differences between consumers and providers in the area of leisure such that consumers rated the contribution of leisure to quality of life significantly higher than providers.

The fourth category without specific provider counterpart was "giving to others." The theme of this category was of contributing to directly assist others or a cause (such as to endangered animals). The other component of this theme was the benefit derived from "giving" or focussing on other than self. Aanes and Rootes (1992), in their work on self-help groups, noted that through the act of helping others, the helper creates change in themselves, not just in the other person. The theme of "giving to others" was not addressed as a part of any of the provider categories.

Provider specific categories. The provider-categories without specific consumer counterpart were: "connected to the community" and "optimum living." "Connected to the community," was formulated in round I as the opposite to "social isolation," identified by providers as one of the significant barriers, faced by consumers, to achieving quality of life. This category addressed issues of community integration through participation in the community with the assistance of friends, family and other relationships. It was distinguishable from the category of "social and professional support," where family and friends were viewed as part of a "support system" beyond a vehicle of community participation.

Optimum living, to some extent could be taken as a proxy for quality of life itself. It reflected concepts of restoration to "normal life," "respect," "growth," "choices," "freedom," "independence," and "spirituality." The concept probably has its origin in the rehabilitation field, where the goal of rehabilitation is conceptualized as assisting consumers to achieve their optimal level of functioning (Saraceno, 1997).

Comparison of most important and least important categories

The delphi technique not only facilitate consensus building in a subject area, but also allows for the emergence of divergent or opposite perspectives (Jeffrey, Hache and Lehr, 1995). In order to explore the latter, in round II of the delphi, both consumers and providers were asked to indicate which categories they considered the most and least important. This question unfortunately did not add much clarification to the understanding of quality of life. There was no consensus on most or least important categories by consumers. Across the sample of consumers all the separate categories were endorsed as "the most important" by at least one consumer. The result was similar for providers. Both consumers and providers had difficulty choosing and eliminating categories on the basis of importance to the meaning of quality of life.

The most likely explanation for this finding is that the question, of "most and least importance," was redundant to the delphi process of refining categories at each round. Along these lines, providers in round II eliminated the categories of "universal standards," and "maintaining standards of living," as ways of understanding the meaning of quality of life. This confirmed that consumers and providers were, in effect, already selecting the "most important categories" by eliminating some, and clarifying and modifying others at each round. This conclusion is further supported by the fact that many consumers and providers when asked to make choices offered the comment that all the categories were important. Another possible explanation could be related to the fact that both consumers and providers were selected on the basis of purposive sampling. Although demographic data was not collected, it would not be unreasonable to speculate that the respective samples were somewhat homogeneous thereby favouring opinions that converge rather than diverge. Finally, it should be noted that one of the criticisms of the delphi technique is that the use of multiple rounds of inquiry, by definition, favours convergence of opinions and may minimize dissenting perspectives (Goodman, 1987). This is an unlikely explanation with respect to the consumer sample, since their responses remained relatively consistent across the three rounds. However, this explanation may have some merit with respect to the provider sample, where the twenty-seven categories in round I were reduced to only 6 categories by the end of round II.

Comparison with widely accepted categories of quality of life in the literature

Although there is no gold standard for measuring quality of life of persons with severe mental illness, "the best known and most widely used" (Greenly, Greenberg & Brown, 1997, p. 245; Goodman, Hull, Terkelsen, Smith & Anthony, 1997) quality of life instrument is the Quality of Life Interview (QOLI) developed by Lehman (Lehman, Ward & Linn,1982; Lehman,1988). In this regard, there is merit in comparing the categories derived from the present study with the domains or categories of the QOLI. This structured interview instrument assesses both subjective and objective quality of life across eight domains of life. The instrument also provides a measure of overall well-being. For purposes of comparison the core version (153 items) of the QOLI (Lehman, 1996b) was used.

In order to further broaden the comparison with the literature, the results of this study were compared to the work of Felce and Perry (1995). Felce and Perry (1995), lamenting the lack of definition of quality of life reviewed fifteen "key literature sources," that described models of quality of life, and constructed "an overall model" of quality of life. They based their model on the five general domains distilled from the literature. These domains are "physical well-being," "material well-being," "social well-being," "developmental activity," and "emotional well-being."

To the extent that the QOLI and the work of Felce and Perry (1995) represent the broader tenor of the literature, the consumer and provider categories in this study compare favourably with categories identified in the literature. For example, there appeared to be comparable categories in the QOLI and the work of Felce and Perry (1995) in the areas of, "basic needs," and "resources for living;" "good mental health," and "physical and mental health;" "daily routine," and "meaningful daily activities;" "recreation; and "relationships," and "social and professional supports." Some of the elements of "connected to the community" were also covered.

There were, however, some notable differences. In particular, neither the QOLI nor the work of Felce and Perry (1995) included professional resources and medications as an element of basic need; and neither identified the aspect of relationship to professionals or "a treatment team," and relationship with pets as an important aspect of "relationships." Providers in this study included the rehabilitation concept of "restoration to normal life," as part of the broader category of "optimum living," but there was no apparent counterpart in the QOLI or the work of Felce and Perry. Although the category of recreation was covered, the idea of "self-care" was not addressed in either of the latter works. Similarly, "transportation," as a variable, was not identified in the QOLI. This is a crucial omission given that consumers in this study live in a largely rural area. Transportation was identified by Felce and Perry. "Freedom and independence", and "giving to others" were also not covered in QOLI. Some of these elements were addressed by Felce and Perry.

The consumer category of "belief and spirituality" is not covered in the core (153 items) version of the QOLI (Lehman, 1996b, p. 117-119). However, according to Lehman (1988), "a ninth domain, religion, was added on the basis of open-ended responses from patients," (p.53) and appears in some versions of the QOLI. Felce and Perry subsume faith and belief under the category of "emotional well-being."

In contrast, the QOLI category of "legal and safety issues" did not emerge in the present study by either consumers or providers. This category was also not addressed by Felce and Perry.

In general there seems to be consistency in the identification of a core set of categories when compared with the literature and these are contrasted with important differences. These observations are consistent with the conclusions of a review of quality of life instruments by Van Nieuwenhuizen, Schene, Boevink and Wolf (1997) that there is a core set of variables covered in "nearly all instruments" (p. 39). These include health, work, leisure, living situation, friends/social relations, and family relations. Van Nieuwenhuizen, Schene, Boevink and Wolf (1997), also noted that some categories consistently receive little or no attention in assessment instruments designed for use with the mentally ill. These include, "independence", "sense of purpose," "intimate relationship", "spirituality," and "self-care."

One of the most important observations arising from the comparison of consumer and provider categories and categories identified in the literature is that the content or properties of categories can not always be judged by the label of the category. In fact a range of labels is used to describe similar variables. For example, the QOLI uses the category of "health" (with a sub-label of "medical outcome study questionnaire) to address both physical health and emotional or psychological health (questions about "feelings" and mood). Felce and Perry, on the other hand use the label of "physical well-being" to address "health," "fitness," "mobility," and "physical safety;" but use "emotional well-being," to cover the issue of "positive affect," and "self-esteem."

These findings are also consistent with the present study where variables such as "family" and "friends" overlap the categories of "connected to the community" and "social and professional support." In the former category, family, and friends are seen as the instrumental vehicle for community connectedness; and in the latter category family and friends are seen as an important component of the emotional support system.

The danger of judging a quality of life category by its label is further amplified by the work of Goodman, Hull, Terkelsen, Smith and Anthony (1997). These authors performed a factor analysis on the eight subjective categories of the QOLI and generated two primary factors, namely, "instrumental" (housing, health services, and family situation), and "affiliative" (quality of interpersonal relationships and leisure activities). Based on their analysis, Goodman et al. (1997) concluded that "there are several inconsistencies with the labeling of factors and findings" (p. 479). For example the QOLI subjective category of family relations was within the "instrumental" factor rather than the expected "affiliative" factor. Similarly, the category of "finance" emerged as an "affiliative" factor, rather than an "instrumental" factor. Finally, it was most noteworthy, that the "global satisfaction" rating of the QOLI was not "found to be the sum of individual subjective domains" (p. 479) as proposed by the author of the QOLI (Lehman, 1983; 1988).

Utility of the ethnoscience methodology and the delphi technique

The second research question asked in this study was: will the delphi technique and ethnoscience qualitative method yield information that will allow a comparison of similarities and differences between the perceptions of providers and consumers about the meaning of quality of life? In response, the methodology of this study offered a number of advantages, both as a single methodology; and as a methodology that could easily complement other program methodologies in understanding the meaning of quality of life from the dual perspective of consumer and provider. The dual perspective is particularly important when both consumer and provider are affiliated with the same mental health program.

According to Leininger (1985b), the client-derived data of ethnoscience allows for a more accurate reading of clients' needs and concerns. The ability of the ethnoscience method to yield "... meanings, attributes, and characteristics of a particular domain of inquiry" (Leininger, 1995b, p. 241) makes it an excellent methodology for studying and deriving meanings about quality of life issues from the perspective of both the provider and the consumer.

Participants seemed comfortable with the methodology. For example, consumers and providers commented that they felt at ease during interviews. This methodology allowed participants opportunities to focus on the issues without the constraints of forced choices often accompanying other methods. Consumers in particular seemed to appreciate being asked to share their thoughts about quality of life in an open-ended way. It is also noteworthy that there were no drop-outs among consumer or provider participants. One consumer did not participate in the second and third round of interviews because of a problem with his voice. The study results compared well with the findings from reports in the literature while at the same time remaining specific to the themes identified by this local group of consumers and providers.

This is consistent with the work of others such as Nikkonen (1996) who noted that use of the qualitative method in quality of life studies with deinstitutionalized consumers, albeit only a few such studies exist, creates opportunity for enhanced self-expression and in so doing gives voice to the participants. Similarly, Davidson, Hoge, Merrill, Rakfeldt and Griffith (1995) also use a qualitative method in order to include the consumers' "voice" in their study.

The delphi technique proved to be a useful way of clarifying meaning across individuals; and procedurally had a built in high trustworthiness factor. The first round seemed to be the most empowering for consumers, as it was totally open-ended. The second and third rounds, although still open ended, may have placed a measure of constraint on responses since consumers were being asked to comment and clarify their thoughts as it related to aggregate finding that included responses from other consumers. For example, on a few occasions in the second and third rounds, consumers asked if they were giving the "correct answers" and needed to be reassured that there were no right or wrong answers. Nevertheless, it is significant that consumers remained relatively consistent in their responses from the first to the third round.

Providers, on the other hand, seemed to flourish, in the second and third rounds of the delphi. In the first round, providers generated twenty seven categories, albeit with considerable overlap. However, providers had no trouble reducing these to six categories. The latter might be related to the fact that providers are accustomed to dealing with classifications, and categories and so were well practised with the cognitive set required for rounds II and III. Additional research is needed to determine if in fact there is a difference in cognitive styles between consumers and providers and the implications of this for communications between both parties.

Implications for practice and research

Practice implications.

The results of this study suggested that there are general differences between providers and consumers in their understanding of the importance of categories and variables related to quality of life; and that this methodology can be used by mental health programs to periodically determine or clarify the meaning of quality of life of those served by the program, and contrast this with the meanings held by providers. The method, therefore, offers the prospect of periodically reorienting providers to ensure that their service delivery is consistent with the individual and collective needs of the persons they serve. This is particularly important because quality of life issues change overtime (Stedman, 1996), and may be specific to specific locales and cultures. For example, consumers in rural areas may have different preferences and values and experience different barriers than consumers in urban areas. Transportation, and by extension access to services is known, for instance, to be more of a problem for those in rural than in urban areas.

The methodology allowed the researcher to highlight differences between consumers and providers and this information can be used in a continuing education format to sensitize and enlighten providers on topical issues relevant to the specific consumer group they serve. In the case of this particular study, one of the obvious areas for professional development is in the area of spirituality. Providers should be as familiar with the ranges of opportunities for addressing spiritual needs as they are with the range of resources for addressing psychological and housing needs. They should be familiar with the role of spirituality in the lives of consumers as it relates to increasing self-understanding and identity, facilitating recovery, enhancing psychological well-being, and as a way of adding cultural sensitivity to the delivery of services (Fallot, 1998c). Providers should also become familiar and comfortable understanding "religious talk" (Fallot, 1998b). Other professional development areas should include sensitizing providers to the role of pets as companions to consumers; and the function in the lives of consumers to finding ways to "give to others."

Related to the above, this methodology is applicable to any culture or subgroup. According to Guillemin, Bombardier and Beaton (1993), there is a need for culturally appropriate quality of life measures among immigrant populations, since cultural groups vary in how they interpret and express the symptoms of disease. The ethnoscience method and the delphi techniques can easily be used as a tool to reduce this gap in understanding between consumers and providers. This would be particularly important in instances where the consumers and the providers are from different cultures. The open ended interview and clarifying style of the delphi, and the fact that it also offers participants a voice, suitably lends itself as a tool for engaging new consumers.

The findings of this study, conveyed that quality of life issues are central to the personhood of the individual and his/her place in the community. Consequently, one suggestion might be for mental health teams to engage consumers in quality-of-life-planning instead of the traditional "treatment planning." This study showed that components of the latter are already encompassed in quality of life categories. For example, issues of support, medications, work, recreation, spirituality, mental health, relationships and so on were readily identified as important to consumers as part of their quality of life.

The fact that there are differences between providers and consumers on quality of life means that individual consumers may have different priorities than providers. Clarifying these and tailoring services to identified needs and priorities may increase efficacy, and efficiency of service delivery and enhance service outcomes.

Research implications

There continues to be debate about the value of qualitative methodologies in contrast to quantitative methods. Ideally, both methods should be applied to most studies involving quality of life issues. The former is often used to capture subjective meaning and expression, and the latter is often relied on for objective assessments. Nevertheless, it would be instructive to compare the methodology of this study with the use of a standardized quality of life instrument with the same consumers. Such a study would assist in answering the question, to what extent does endorsement of items on forced choice standardized instruments questions, actually reflect the consumer's views about quality of life issues. As Field and Morse (1985) point out, the use of questionnaires and corresponding statistical analysis offers no interpretation of the meaning of the data.

In order to ensure that the study was manageable, it was decided not to collect demographic data about consumers. Nevertheless, future studies, through purposeful sampling, should give consideration to selecting according to particular age groups. Studies on age and gender with the mentally ill generally show that gender has no influence on subjective perception of quality of life (Mercier et al., 1998). Albeit a study by Lehman, Slaughter and Myers (1992) found an interaction of age and gender such that women between the ages of 36 and 45 expressed less satisfaction than men at this stage in life. More typically the findings have been that older individuals express higher levels of life satisfaction than younger individuals (Mercier et al., 1998). Rather than focus on measuring quality of life for various age groups, it would be important to understand if the meaning of quality of life varies with age. This sentiment has been echoed by Awad (1999) who noted that "unfortunately, the field has been preoccupied more with how to measure QOL (quality of life) than with what QOL means or what enters into such an equation," (p. 140).

Limitations of the study

It has been suggested in this study, based on comments by consumers and providers, that they liked the process and found it helpful in thinking through issues related to quality of life. Given that one of the goals of the study was to assess the utility of the methodology itself, the study would have been enhanced by formally surveying participants about their impressions of the method with a view to refining it.

The present study appropriately modified the delphi technique from a mail-out process to a face-to-face interview process. However, prior to rounds II and III participants were required to briefly review the results of the previous round before the interview formally commenced. Although none of the participants expressed any concern about feeling rushed by having only a few minutes to review the material, the richness of the data may have improved if the summary of the previous round was given to participants well in advance of scheduling interviews.

Finally, consumer participants who were known to be articulate and comfortable discussing issues were preselected and as such this study can only conclude that the methodology has application to consumers with these characteristics.

Personal reflections

The researcher was impressed with the extent to which consumer participants seem to appreciate the opportunity to voice their perspective on quality of life issues and with the consistency between and within consumers. The most instructive feature of the study was the finding that categories (or domains as it is often referred to in the literature) of quality of life can not be compared based on their labels. For example, when reading the literature, it can not be taken for granted that when several researchers refer to a particular category, such as "psychological well being," that they are referring to the same content.

CHAPTER 6: SUMMARY AND CONCLUSIONS

This study utilized a highly participant centered method to understand the meaning of quality of life from the perspective of consumers and providers. The approach was consistent with the strong suggestion in the literature that the bias in assessing and understanding quality of life should favour consumer input and choice. Quality of life information is used for a variety of purposes including as a measure of program success, and consumer success in terms of goal attainment and satisfaction with life. Consequently, it is important that providers (and programs), and consumers have a common understanding of the meaning of quality of life. At least, each should be familiar with the level of understanding of the other. While it is important to continue to work on defining the core elements of quality of life, it is more important to have a consumer centered method to regularly assess quality of life at the service delivery level to realistically achieve consumer responsive outcomes.

The methodology for the latter, must be easy to implement, sensitive to a variety of settings and cultures, and able to detect change in both the clients served and those providing service. The method should also focus more on meaning than on measurement (Awad, 1999). For example it is possible to get a low quality of life measurement score on a standardized tool, but still experience good quality of life, if the measured items have little or no relevance to the individual's values and life circumstances. The converse is also true.

There was considerable consistency between consumers and providers on the meaning of quality of life. On the broader level there was also concordance with quality of life categories cited in the literature. However, the latter comparison remains a superficial one, given that it is difficult to tell what categories reported on in the literature really mean. As this study illustrated, even when providers and consumers used the same terminology (such as spirituality) they meant very different things.

There were, however, important differences between the perceptions of consumers and providers. These are best illustrated by the examples of differing perspectives on spirituality, and relationships. These differences were not ones of lack of recognition of the issue or topic, but more importantly one of recognition of the value, scope, and importance of the issue. In the case of spirituality, providers recognized it as a component of quality of life and a consumer need, but not to the same degree and extent as consumers saw it. Providers saw it as part of a larger component of rounding-off life, and consumers saw it as fundamental to day to day coping, support, encouragement, and hope for the future. Similarly, in the case of relationships, those consumers with pets, placed a high premium on the companionship value. in contrast to the perspective of providers. It is noteworthy, that an overall score of "well-being" on a standardized scale would have also missed these important differences.

Recommendations on quality of life need to address two needs in the literature. The first is service oriented, where the focus should be on finding ways of ascertaining the quality of life needs of consumers and responsively addressing these.

On the service delivery level, teams and professionals should routinely engage in quality of life planning sessions with consumers to ensure mutual understanding of the quality of life issues germane to particular individuals. Similarly, at the aggregate level, because of the potential differences between them, consumers and providers should periodically engage in a review of their respective perceptions of quality of life. This is important because the categories and their importance may change over time. Because of changes in the consumer caseload and changes in staff, sessions on values clarification may be warranted in order to maintain a quality of life responsive service delivery system.

On the clinical front providers should explore the role of spirituality with consumers and ways of addressing these needs. Providers may also want to look at professional development in this area. As Fallot (1998b) put it, providers should become comfortable with the "content of religious talk" (p. 13). In this regard Fallot (1998b) also offers a "community connections spiritual assessment" (p. 21) model. Similarly, providers may want to explore other differences in perceptions between themselves and consumers such as the consumers' need to "give to others," and the role of pets in their lives.

The second need is research oriented. The idea of a universal definition seems highly unlikely given the personal nature of the meaning of quality of life. However, additional research that extends the understanding of what constitutes the core elements of quality of life is nevertheless required. Having a common understanding is seen as necessary for generalization and comparisons across programs and even across countries.

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APPENDICES

Appendix A

Memo asking staff for assistance in recruiting consumers

Date: November 10, 1998

To: Staff of BPH community programs

From: Henry de Souza

Re: Request for assistance in recruiting consumers to participate in a study on quality of life

I am writing to ask for your assistance in recruiting 10 consumers to participate in a study using a qualitative research method to determine how consumers and providers understand and define the meaning of quality of life.

The study involves interviewing the 10 participants (men and women) who live in the community and use mental health services. There are many forms of mental illnesses and various degrees of experiences. This study is interested in persons of various ages who are articulate, comfortable discussing issues that affect their lives such as quality of life, and have experience being in a psychiatric hospital setting for an accumulation of at least 6 months over their life time.

The attached information letter will provide additional information. If you have questions please contact me at extension 2402.

Sincerely,

____

Henry de Souza

Appendix B

Information sheet describing the study to consumers

TO RECRUIT CONSUMERS OF MENTAL HEALTH TO PARTICIPATE IN A STUDY COMPARING THE WAY IN WHICH MENTAL HEALTH CONSUMERS AND PROVIDERS UNDERSTAND THE MEANING OF QUALITY OF LIFE

1) Introduction

I am writing to invite you to participate in a study comparing the way in which consumers and providers understand the meaning of quality of life. The title of the study is: "Use of the delphi technique and qualitative analysis to compare the way in which mental health consumers and providers understand the meaning of quality of life". The research project will be conducted by Henry de Souza, M.S.W.

2) Overview of the Study

The study involves separate interviews with you and nine other participants who life in the community and receive mental health services. This study is interested in men and women of various ages who are comfortable discussing issues that affect their lives such as quality of life, and have experience being in a psychiatric hospital setting for an accumulation of at least 6 months over their life time. A program staff will review this information sheet and consent form with you, and answer any questions that you may have.

3) Interview Process

You will be interviewed a maximum of 4 times, although I am anticipating that 3 interviews will be sufficient. During the first round of interviews three discussion questions about quality of life will be asked. Your responses will be taped, transcribed, analysed and a preliminary definition or collection of key ideas about quality of life will be put together. The first interview is expected to last about 30 minutes.

During the second round of interview the preliminary definition or key ideas will be discussed separately with you and the other participants. You and other participants will then have the opportunity to indicate agreement, disagreement, add additional information or raise questions. Your responses will taped and the definition or key ideas about quality of life will be refined. The second interview is expected to last about 15 minutes. The third interview will follow the same process and is expected to last about 15 minutes. I am hoping that only 3 interviews will be required, but I may request a 4th interview if this is needed.

The interviews will be transcribed onto paper either by the researcher or a typist. Apart from these two persons, my supervisor at Queen's University, Dr. M. Jamieson, is the only other person who may listed to the tapes. The audio tapes will not be used for any purpose other than to do this study, and will not be played for any reason other than to do this study. These tapes will be destroyed at the completion of the study. The written transcripts will not contain your name or any identifying information and will not be used for any reason other than to do this study and to transmit study findings through publications and presentations. Interviews will be held at either a program office of Brockville Psychiatric Hospital, or your home whichever you find more suitable. All interviews will be scheduled at a time that is convenient for you.

4) Risks and benefits

There are no apparent risks to participating in this research study. It is possible that some discussions about stressful situations related to quality of life may produce anxious feelings. If at any time you begin to feel uncomfortable you should tell the researcher you want to stop the interview or move onto a different topic. You may also choose to have a staff or other person present during the interviews, as long as that person does not participate in the discussion. Your participation or withdrawal from participation will not in any way affect the services you currently receive from the mental health-program you are enrolled in.

While the study may not be of immediate benefit to you, some people find it helpful to have the opportunity to talk about their experiences. Moreover, the results of the study may add to our understanding of quality of life.

5) Voluntary participation and confidentiality

Participation in this study is entirely voluntary. You may decide to withdraw from the study any time, for whatever reason, without any impact on the treatment you are receiving from the hospital. All information obtained during this study will be kept confidential. Your anonymity will be protected by assigning you a different name. This will be the name heard on the tape and the name that will be in the transcript of the tape. Only the researcher will know your true identity. The researcher's faculty advisor at Queen's University and the person making a written copy of the tape will have access to the tapes. All tapes will be stored in a locked drawer and your real name will not appear in the written copy of the tapes. You will not be identified in any publications or presentations arising from this study.

6) Contacts to address problems or concerts

If you have any questions or concerns, please fell free to contact

Henry de Souza at Brockville Psychiatric Hospital (613) 345-1461 extension 2402

Dr. M. Jamieson at the School of Rehabilitation Therapy, Queen's University at (613) 545-6088

Dr. S. Olney, Director of the School of Rehabilitation Therapy, Queen's University at (613) 545-6102

Appendix C

Consumer consent form

CONSUMER-CONSENT TO PARTICIPATE IN A STUDY USING A QUALITATIVE METHODOLOGY TO DETERMINE HOW CONSUMERS AND PROVIDERS UNDERSTAND AND DEFINE THE MEANING OF QUALITY OF LIFE

Researcher: Henry de Souza, M.S.W

I ...., hereby consent to participate in the study determining the way in which consumers (those receiving mental health services) and providers (those providing mental health services) understand and define the meaning of quality of life. My participation will involve up to four interviews with the researcher each ranging from about 15 to 30 minutes.

I understand that I will be interviewed as an individual and that the interviews will be audiotaped, but that my name or any obvious identifying information will not be used in the study. The information I provide will be confidential and will not be shared with anyone other than the researcher, and his supervisor, Dr. M. Jamieson. However, the information that I collect will be grouped with the information from other participants and a summary of the findings will be shared. The results of the study may also be published.

I understand that my participation is voluntary, that I may refuse to answer any question and that I can withdraw from the study at any time, for any reason, without any impact on the treatment I am receiving from the hospital.

I understand that there will be no direct service benefit to me from participation in this study and that my participation will in to way affect the services I may be receiving.

Additional interviews may be scheduled at my request to clarify any concerns or questions that I may have about the study. I will be given a copy of this signed information/consent form for my records.

Name Participant (print) Signature Date

I have explained the nature of the study to the participant and I believe that she/he understands the study.

Researcher (print) Signature Date

Appendix D

Information sheet describing the study to providers

Date: November 10, 1998

To: Staff of BPH community programs

From: Henry de Souza

Re: Request for providers to participate in a study on quality of life

I am writing to invite you to participate in a study using a particular qualitative research method to determine how consumers and provides understand and define the meaning of quality of life.

The attached information letter will provide the information you require. If you have questions please contact me at extension 2402.

Sincerely,

____

Henry de Souza

Appendix E

Memo to staff inviting them to participate in the study

TO RECRUIT PROVIDERS OF MENTAL HEALTH TO PARTICIPATE IN A STUDY USING A QUALITATIVE METHODOLOGY TO DETERMINE HOW CONSUMERS AND PROVIDERS UNDERSTAND AND DEFINE THE MEANING OF QUALITY OF LIFE

1) INTRODUCTION

The purpose of this letter is to introduce the study to you, invite you to participate and ask you to contact me to discuss your participation.

2) OVERVIEW OF THE STUDY

In spite of the widespread interest in quality of life, there is no common definition of quality of life for any population or group. You are invited to participate in a research project using a qualitative methodology to determine how mental health consumers and providers understand and define the meaning of quality of life. This research project will be conducted by Henry de Souza, M.S.W. I am a part-time student in the Masters Program at Queen's University School of Rehabilitation and also a member of the staff at Brockville Psychiatric Hospital. This study is part of my thesis requirement for the Master of Science degree in Rehabilitation at Queen's University. The title of the study is: "Use of the delphi technique and qualitative analysis to compare the way in which mental health consumers and providers understand the meaning of quality of life".

3) DETAILS OF THE STUDY

a) Participants

The study will involve two categories of participants: Consumer-participants and provider-participants.

Providers: The study involves interviewing you and nine other providers from the disciplines of nursing, occupational therapy, vocational counselling, psychiatry, recreation and social work. To qualify as a provider-participant you must have at least one year's experience in a program serving persons with mental health needs.

Consumers: Ten men and women who life in the community and use mental health services will be interviewed. There are many forms of mental illnesses and various degrees of experiences. This study is interested in persons of various ages who are articulate, comfortable discussing issues that affect their lives such as quality of life, and have experience being in a psychiatric hospital setting for an accumulation of at least 6 months over their life time.

b) Interview Process

Provider-participant Interviews: You will be interviewed a maximum of 4 times, although I am anticipating that 3 interviews will be sufficient. During the first round of interviews you will be asked three discussion questions about quality of life. Your responses will be taped, transcribed, analysed and a preliminary definition or collection of key ideas about quality of life will be formulated. This first interview is expected to last about 30 minutes.

During the second round of interview the preliminary definition or key ideas will be discussed with you. You will then have the opportunity to indicate agreement, disagreement, add additional information or raise questions. Your responses will taped and the definition or key ideas about quality of life will be refined. The second interview is expected to last about 15 minutes.

During the third and final round of interviews the refined definition or key ideas about quality of life will be discussed with you. You will again have the opportunity to indicate agreement, disagreement, add additional information or raise questions. The third interview is expected to last no more than 15 minutes. As I mentioned above, I am anticipating that only 3 interviews will be required, but I may request a 4th interview if this is needed.

Consumer-participant Interviews: The process will be the same for consumer-participants as for provider-participants.

c) Taping interviews

All interviews will be audiotape recorded. The first interview will take about 30 minutes and the second and third interviews will each take about 15 minutes. The interviews will be transcribed onto paper by either the researcher or a typist. Apart from these two persons, the researcher's supervisor at Queen's, Dr. M. Jamieson, is the only other person wh may listen to the tapes. The audiotapes will not be used for any purpose other than to do this study, and will not be played for any reason other than to do this study. These tapes will be destroyed at the completion of the thesis requirements and will not be used for any reason other than to do this study and to transmit study findings through publications and presentation.

d) Location of interviews

With the permission of the Administrator of the Brockville Psychiatric Hospital, interviews will be held at a program office at Brockville Psychiatric Hospital. All interviews will be scheduled at a time that is convenient for you.

4) RISKS AND BENEFITS

There are no apparent risks for providers who participate in this research study. However, some staff may worry that their opinions will be relayed to their supervisor and affect their performance rating in some way. Please be reassured that the information you provide is confidential and that you may stop the interview at any time and withdraw from the study without penalty.

While the study may not be of immediate benefit to you, some providers may find it helpful to have the opportunity to express their opinions about issues of quality of life. Moreover, the results of the study may add to the understanding of quality of life ane methods for determining quality of life.

5) VOLUNTARY PARTICIPATION

Your participation in this study is entirely voluntary. You may decide to withdraw from the study any time, for whatever reason, without penalty.

6) CONFIDENTIALITY

All information obtained during this study will be kept confidential. Your anonymity will be protected through the used of a pseudonym. I am the only one that will have access to the pseudonym coding system. My faculty advisor at Queen's University and the transcriber will have access to the tapes, but no to the coding system. All tapes will be stored in a locked drawer. You will not be identified in any publications arising from this study. The written transcripts will not contain your name or any identifying information and will not be used for any reason other than to do this study.

7) PERMISSION TO PARTICIPATE

The attached letter from the Administrator of the Brockville Psychiatric Hospital gives authorization for you to participate in the study, with the understanding that the results of the study will be presented at a continuing education seminar at Brockville Psychiatric Hospital.

8) CONTACTS TO ADDRESS PROBLEMS OR CONCERNS

If you have any questions, problems or concerns, please feel free to contact

Henry de Souza at Brockville Psychiatric Hospital (613) 345-1461 extension 2402

Dr. M. Jamieson at the School of Rehabilitation Therapy, Queen's University at (613) 545-6088

Dr. S. Olney, Director of the School of Rehabilitation Therapy, Queen's University at (613) 545-6102

I have read the information sheet and I am interested in participating in the study.

Name of Staff ____________________

Signature of Staff ___________________________ Date _________________

Interested staff are asked to contact me (613-345-1461 extension 2402) to raise any questions and/or to set up interviews. Prior to the interview I will review the information letter and seek signed consent using the attached consent form.

____

Henry de Souza

Appendix F

Provider consent form

PROVIDER-CONSENT TO PARTICIPATE IN A STUDY USING A QUALITATIVE METHODOLOGY TO DETERMINE HOW CONSUMERS AND PROVIDERS UNDERSTAND AND DEFINE THE MEANING OF QUALITY OF LIFE

Researcher: Henry de Souza, M.S.W

I ...., hereby consent to participate in the study determining the way in which consumers (those receiving mental health services) and providers (those providing mental health services) understand and define the meaning of quality of life. This study is part of the thesis requirement for the Master of Science degree in Rehabilitation at Queen's University. My participation will involve up to four interviews with the researcher each ranging from about 15 to 30 minutes.

I understand that the interviews will be audiotaped, but that my name or any obvious identifying information will not be used in the study. The information I provide will be confidential and will not be shared with anyone other than the researcher, and his supervisor, Dr. M. Jamieson. However, the information that I collect will be grouped with the information from other participants and a summary of the findings will be shared. The results of the study may also be published.

I understand that my participation is voluntary, that I may refuse to answer any question and that I can withdraw from the study at any time, for any reason, without penalty.

I understand that there will be no direct service benefit to me from participation in this study and that my participation will in to way affect my employment.

Additional interviews may be scheduled at my request to clarify any concerns or questions that I may have about the study.

Name Participant (print)	Signature	Date

I have explained the nature of the study to the participant and I believe that she/he understands the study.

Researcher (print)	Signature	Date

Appendix G

Preamble and interview guides for consumer and provider round I

Preamble for round I

Many people have different ideas about quality of life. I am trying to understand and describe the meaning of quality of life for those individuals who have experienced hospitalization and are now living in the community.

Interview Guides round I interview

a) What does quality of life mean to you?

b) What are the things that contribute to good quality of life?

c) What are the things that contribute to poor quality of life?

Appendix H

Preamble and interview guides for consumer and provider round II

Preamble for round II

Here is a list of the categories that I came up with from reviewing the 12 consumer interviews. I need your help in understanding if these categories fit for you? ... are there categories of quality of life missing? Are some of the categories really saying the same thing? Are there some categories you would take out? Etc.

Interview Guides round II interview

1 Are there any categories missing?

2 Are there categories that you would group together ... in other words are there some categories that are saying the same thing?

3 Which of the categories would you say are the least important ... if you had to are there any categories that you would take out?

4 Anything you want to add about quality of life?

Appendix I

Preamble and interview guides for consumer and provider round III

Preamble for round III

Here is the revised list of the categories that I came up with from reviewing the responses in Round II. I need your help in understanding if there are categories of quality of life missing? Are there some of the categories that can be combined? Are there some categories that should be separated? And do the category names make sense.

Interview Guides round III interview

1 Are there any categories missing?

2 Are there categories that can be combined?

3 Are there categories that should be separated?

4 Do the category names make sense?