Exploration of the Perspectives of Persons With Schizophrenia Regarding Quality of Life

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Objective. This study is the first phase of a two-phase study aimed at exploring the perspectives of consumers with schizophrenia regarding quality of life and developing a quality-of-life assessment that addresses factors experienced as important by consumers.

Method. Focus groups were used to explore the perspectives of 35 persons with schizophrenia regarding the meaning of quality of life and factors important to quality of life.

Results. Seven major factors that had an impact on quality of life resulted from inductive analysis, including activity, social interaction, time, disclosure, "being normal," finances, and management of illness. These factors relate to three overall themes: managing time, connecting and belonging, and making choices and maintaining control.

Conclusions. Although the findings confirm the importance of factors included in existing quality-of-life assessments, they also highlight the need to look at new dimensions of commonly included factors and to include other factors. The findings support beliefs regarding occupation that are central to occupational therapy and the use of occupation as means and ends of therapy.

and evaluation efforts to go beyond traditional measures of clinical status, such as symptom severity or readmission rate, and attend to multidimensional variables, such as functional ability and quality of life (Atkinson, Coia, Gilmour, & Harper, 1996; Atkinson, Zibin, & Chuang, 1997; Sainfort, Becker, & Diamond, 1996). Baker and Intagliata (1982) and Simmons (1994) highlighted several other reasons for focusing on quality of life in the planning and evaluation of services for persons with mental illness. These reasons include the importance of maintaining and enhancing quality of life in situations in which illnesses cannot be cured and the rise of consumerism with a concomitant demand for services that significantly affect consumers’ lives.

Quality of life is an outcome that has long been of concern to occupational therapists. The link between occupation and quality of life is one of the basic beliefs guiding the practice of occupational therapy (Wilcock, 1993; Yerxa, 1994). Indeed, numerous authors describe the central objective of occupational therapy as promoting health and quality of life through enabling occupation (CAOT, 1994; Polatajko, 1994; Yerxa, 1994). The importance of quality of life was emphasized by Yerxa et al. (1990), who stated that “medicine is concerned with preserving life; occupational therapy is concerned with the quality of life preserved” (p. 8). With specific reference to clients with chronic mental illnesses, Hachey and Mercier (1993) described the role of occupational therapy in community psychiatry as that of working with a multidisciplinary team to offer clients the necessary conditions for quality of life.

Even though the term quality of life first appeared in research literature in the 1930s and is prominent in recent literature, the questions of what quality of life is, how it can be enhanced, and how it can be measured cannot be easily answered because there are many competing perspectives (Raphael, 1997; Till, 1994). Although much of the work in the area of quality of life and mental illness has focused on clients with schizophrenia (Awad, 1992, 1995; Lehman, 1983, 1988), there is no consensus regarding how to best conceptualize or measure quality of life with this specific population (Atkinson & Zibin, 1996). A frequently noted weakness of existing assessments for clients with schizophrenia is that these assessments lack a guiding conceptual framework of quality of life (Simmons, 1994). However, despite the lack of consensus regarding conceptualization, measures developed for persons with mental illness—such as the Quality of Life Interview (Lehman, 1983, 1988), the Quality of Life Questionnaire and Interview (Bigelow, Gareau, & Young, 1990), Bigelow, McFarland, & Olson, 1991), and the Quality of Life Profile (Oliver, 1992)—often tap similar domains. These domains include health status, psychiatric symptoms, finances, living situation, social relations, leisure, productivity, education, and general well-being (Atkinson & Zibin, 1996; Simmons, 1994).

Another common limitation within this area of mental health research is that the definition of quality of life and its domains has largely been based on researchers’ perspectives, and there has been little input from clients (Simmons, 1994). Little is known about clients’ values and preferences regarding what domains or factors are important for quality of life and how these factors are experienced as affecting quality of life. The ways in which researchers and clinicians define quality of life and the factors they perceive to be important contributors may be different from clients’ perspectives (Clark, Scott, & Krupa, 1993; Lord, 1989). With specific reference to quality of life and clients with severe mental illnesses, Sainfort et al. (1996) described two potential types of discordance between clinicians’ and clients’ views. First, clinicians and clients may disagree on the importance of specific domains, such as work or education, in terms of their contribution to quality of life. Second, clinicians and clients may have different reference systems in judging satisfaction and performance within such domains. In a study conducted with 37 clients with schizophrenia and their primary clinicians, Sainfort et al. found that although clients and clinicians provided similar ratings of satisfaction with respect to symptoms and function, there was little agreement in terms of social relations and occupational aspects of quality of life.

Due to the potential discrepancies among the perspectives of researchers, clinicians, and clients, exploring clients’ perspectives is increasingly being recognized as an important research endeavor, both as a way to further the understanding of issues important to clients and as an initial step in the development of assessments (Bauman & Adair, 1992; Clark, et al., 1993). There is an emerging consensus that clients’ values and preferences need to be addressed in treatment planning and evaluation to ensure that services are not biased toward the perspective of service providers and are optimally relevant to clients’ lives (Atkinson & Zibin, 1996; Nelson & Niederberger, 1990). Thus, the use of existing quality-of-life assessments that have not incorporated the perspective of clients may mean that treatment and outcome evaluations become focused on factors that clients neither experience nor define as key to their quality of life (Sainfort et al., 1996).

A client-centered approach can be defined as “an approach to occupational therapy which embraces a philosophy of, respect for, and partnership with, people receiving services” (Law, Baptiste, & Mills, 1995, p. 253). To most effectively use this approach in occupational therapy, practitioners need to understand how clients perceive their lives and need to develop assessments that capture the realities experienced by clients. This article describes the first phase of a two-phase research project aimed at developing a quality-of-life assessment that is based on the perspectives of clients with schizophrenia. In this first phase, focus groups were used to explore the perspectives of 35 persons with schizophrenia regarding the meaning of quality of life and factors important to their quality of life. The informa-
tion gathered has implications for quality-of-life assessment, the occupational therapy knowledge base, and the planning of occupational therapy services.

Method

Research Design

Qualitative research techniques are designed to facilitate exploration of the meaning that informants attach to phenomena (Marshall & Rossman, 1989; Strauss & Corbin, 1990); therefore, we used a qualitative research approach involving semistructured focus group discussions. In conducting qualitative research, it is important to attend to the issue of trustworthiness, which is the extent to which the findings of a study can be viewed as worthy of confidence (Krefting, 1991). Lincoln and Guba (1985) based trustworthiness on the criteria of credibility, transferability, dependability, and confirmability. The issue of credibility was addressed in this study through the use of open-ended questions designed to prompt informants to openly discuss their perspectives. Additionally, a process of peer examination of the analysis process and findings was used to maximize credibility, dependability, and confirmability. Descriptive information regarding informants allows for the reader’s evaluation of transferability.

Informants

Informants were obtained using convenience sampling from persons receiving outpatient services at two urban mental health facilities. Screening interviews were conducted with 52 potential informants to collect descriptive data and determine fit with inclusion criteria, which were (a) meeting DSM-IV (Diagnostic and Statistical Manual of Mental Disorders [4th ed.]; American Psychiatric Association, 1994) diagnostic criteria for diagnosis of schizophrenia, (b) being between the ages of 18 and 65 years, (c) having the ability to provide informed consent, (d) currently residing in the community, and (e) having sufficient English language skills to participate in a group discussion. Forty-seven of the 52 persons screened met all inclusion criteria and were invited to participate in the study. Of these 47 potential informants invited to participate in the study, 35 both agreed to participate and attended a focus group. Three of the 47 potential informants declined to participate, and 9 who agreed to participate did not attend a focus group. Written consent was obtained from all informants.

The principle of maximum variation suggests that a range of descriptive characteristics is desirable to maximize the transferability of findings (Lincoln & Guba, 1985). Of the 35 informants, 25 were men (71.4%), and 10 were women (28.6%). The ages of the informants ranged from 22 to 63 years ($M = 40.3$ years). Twenty-six informants were single (74.3%), 5 were in a marital or common-law relationship (14.3%), and 4 were separated or divorced (11.4%). Educational levels ranged from completion of some elementary school to completion of university, with 77.1% ($n = 27$) of the sample having at least a high school degree. Employment status included part-time worker ($n = 5$), full-time student ($n = 2$), part-time student ($n = 3$), retired ($n = 4$), and unemployed ($n = 21$). Living arrangements included living with others in a private place ($n = 17$), alone in a private place ($n = 8$), supportive housing ($n = 9$), and hostel or emergency housing ($n = 1$). Self-ratings of current health varied from fair to excellent, with fair health being the most commonly selected rating (48.6%).

Information Gathering

All information, except demographic data, was collected in focus groups. On the basis of the methodological suggestions of several authors (Krueger, 1994; Merton, 1990; Patton, 1990), each focus group consisted of at least 8 informants and no more than 12 informants. Specifically, the 35 informants attended one of four focus groups, each consisting of 8 to 11 informants. A consumer facilitator and a nonconsumer facilitator, both of whom had previous experience leading focus groups, conducted the groups, each of which lasted for approximately 2 hr. Notes were taken by a co-investigator, and all focus groups were audio-taped and transcribed verbatim.

The study investigators developed a semistructured interview guide for the focus groups that consisted of open-ended questions. Main topics included the following:

- What are the things that make life good for you?
- What are the things that make life not so good for you?
- What does quality of life mean to you?
- Do you think that quality of life should be looked at differently for people who have been diagnosed with schizophrenia than for other people?

Questions addressing these main topics were used to frame the focus group discussions and were presented in the same order in each group conducted.

Analysis of the Information

Focus group transcripts were analyzed using the constant comparative method to identify themes relating to quality of life (Strauss & Corbin, 1990). In this analysis process, the transcribed text is broken down into units of information that are then combined into categories. The categories, in turn, are grouped together to highlight major factors and issues (Lincoln & Guba, 1985). The results of this analysis process were then combined into larger themes through a process of theorizing, which involved examining the relationships between factors (Morse & Field, 1995).

Analysis was completed by two of the investigators who engaged in a circular process involving several readings of all transcripts. One of the investigators completed a line-
by-line analysis of the transcripts aimed at identifying units of information. After these units of information were reviewed by the second investigator, the two investigators worked together to combine the units into categories, factors, and larger themes. This process involved analyzing the units of information separately and then coming together to discuss hypotheses and ideas for categories, factors, and larger themes.

Informants’ Perspectives

In addition to understandings regarding how informants defined quality of life, seven major factors pertinent to quality of life emerged. These major factors included activity, social interaction, time, “being normal,” disclosure, finances, and management of illness. Examination of the relationships among these factors resulted in three major themes: managing time, connecting and belonging, and making choices and maintaining control. The following interpretative analysis is illustrated by quotations from the informants, each of whom has been assigned an identification number. Ellipsis points are used to indicate when part of a quote has been removed.

Definition of Quality of Life

Varied responses were received to the question, “What does quality of life mean to you?” Informant 10 replied, “Freedom of being alive; saying hello to people; having a girlfriend or getting married in the future…it is an ongoing thing.” Informant 3 stated:

To have people that give you respect and dignity, recognize you have a disability, that you are not useless, you can still contribute whatever you can to society…people survive with friends…have a job, have a family or just have a nice place.

Informant 5 described quality of life as being able to “find joy in simple things, like nature or like appreciate things, like you watch a program you appreciate it, you understand it to your fullest ability.” Another informant asserted: “For me, it’s to have a quality of life that’s good enough to keep the stress and the weight off the illness…and to eventually someday to support myself, not have to rely on FBA [family benefits allowance].” Overall, informants’ definitions tended to include both subjective aspects (i.e., feelings of freedom) and objective aspects (i.e., having a job).

Managing Time

A common concern expressed by informants was related to the issue of using time well. As Informant 25 stated, “Because we have lots of time on our hands, and the thing is that you want to develop and use that time wisely and not foolishly and squander it…the thing is you want to make use of it as best as you can.” Being able to manage time, in terms of both the present and the future, appeared to be a challenge for informants, and, in turn, dealing with this challenge appeared important to quality of life.

Activity emerged as the major means used by informants to manage time. Informants discussed the importance of structuring their time, with many suggesting that a lack of activity with which to structure their days had negative consequences. For example, Informant 8 commented:

When I get up in the morning, sometimes I panic because I do not know what I am going to do that day. I wake up and the whole world is waiting. I start to panic because there is no structure in my life. I am not working enough, I am not coming here enough. Things are in limbo. I panic because I don’t know what I’m going to do.

When asked about what things make life not so good, Informant 28 responded with “idleness,” indicating that this had a negative impact because “you don’t have a structure.”

The positive outcomes that could be derived from the strategy of using activity to structure and fill in time included increased motivation, diversion from present problems, and avoidance of negative moods. With respect to motivation, Informant 20 stated, “I keep myself busy during the day, occupying myself. I play the races, the horse racing. I am interested in sports and stuff like that. That keeps me …just getting up in the morning and feeling good and healthy.” When asked about what makes life good, Informant 1 remarked:

Just having something to do in general because some days when I do not have to do something, I’ll sleep in extra long, you know that sort of thing, just something to do besides sit there in front of the TV.

In terms of diversion, Informant 23 stated, “The actual work, whatever it is, is good for the mind and soul. Like, you forget yourself. You forget your own problems when you are working.” With respect to mood, Informant 33 pointed out that

In the morning I have to do something. Some job or something I should do. Otherwise, I become bored and then become depressed because I don’t have anything to do…I start doing…and I don’t feel sad or anything, [but] when I have nothing to do, I become sad and unhappy and become very depressed, and I don’t know what to do. It is very difficult.

A second coping strategy for dealing with time was to parcel the time into manageable chunks, such as days. This strategy seemed to have the potential benefit of decreasing feelings of being overwhelmed. For example, Informant 11 stated, “I do more day-to-day, rather than looking really far into the future. Taking 1 day at a time, as they say,” whereas Informant 4 remarked, “If you take 1 day at a time, it is better that way because if you rush too fast, you cannot concentrate.”

Although informants discussed managing “day by day,” it was also apparent that many were concerned about the future. Informants discussed various types of fears they had regarding the future. Informant 11, for example, discussed her fears regarding having children: “I think that if I had children, the chance of them having the illness is greater.” Others, such as Informant 29, expressed concern
regarding future financial status: “Sometimes I would think, ‘What would happen when I’m 65? I haven’t got Canada Pension, et cetera, I just have the senior citizens pension.’” Others, such as Informant 2, appeared to have a general fear about the potential consequences of their decisions:

The thing that confuses me is, every time when I am making new decisions now…have to think about it a lot because I made a very big, big mistake before. So now, if I have a choice, it is very difficult to decide which way I should go.

Dealing with fears regarding the future and achieving the belief that one was working toward a positive time in the future appeared to be important to quality of life. For example, Informant 26 indicated that “knowing what you want and being able to follow through with it and feeling good about what you are doing and feeling good about your goals, your aspirations and just sort of being able to focus on making it operative” was important for quality of life. At the same time, it was apparent that achieving the feeling that they were working toward a positive future was a challenge to those informants who were coping with symptoms of schizophrenia. Informant 3 reported that “I got sick around my second year in university, and I felt hopeless,” whereas Informant 25 stated, “A lot of us sometimes lower our aspirations like, in other words, instead of aiming too high, we lower them so we are not disappointed as much.”

Activity was the major tool used by informants who were attempting to work toward a positive future. Informant 2 explained the importance of school for her and its connection to goals relating to her sense of identity: “I think if I stick to my goals and if I try to…I would one day reach my goal and will be the person I used to be.” In a similar manner, Informant 26 stated, “I know, for me, I go to university and I focus on that and look forward to that because I know that in the end it is going to work out for my benefit.” Overall, it was apparent that activity could be used both to provide a sense of purpose in the present and to work toward goals for the future.

**Connecting and Belonging**

Connecting with others and achieving a sense of belonging emerged as key to quality of life. As Informant 4 stated, “You need friends to be happy…you need affection, you need to be loved by people, or else you would never get ahead in life. You will always be miserable and unhappy.” Informants highlighted several important functions of social interaction in their lives and discussed the challenges they faced in attempting to connect and belong. Informants indicated that a major barrier to achieving a sense of belonging was that they were not perceived by others—and often did not perceive themselves—as “normal.” In addition to being the major means used to manage time, activity emerged as a key means to work toward “being normal” and to connect with others.

Three important functions of social interaction emerged from the informants’ comments, including source of support, source of belonging, and source of feeling loved. When discussing the importance of having friends, Informant 28 highlighted the support that friends can provide, stating, “Every night I get together with friends for about half an hour. It is amazing how much they have helped me, just by having ordinary conversation.” Likewise, Informant 32 remarked, “I think just talking with people is therapeutic in itself. Like a release.” Informant 19 defined quality of life as being specifically related to a sense of belonging: “Quality of life for me is like being with my family and being with friends, like sharing what you have and what they have, like being in a community.” Although a sense of belonging was described as important, the size of the desired social group varied. Some wanted to achieve a feeling of belonging to a larger community, but others, such as Informant 25, expressed a need to connect with a much more narrowly defined group:

Well, in order to have a good quality of life, I like to feel detached from society. I feel I like to be away from people and to be with my four cats and dog, and I like to be with my wife.

Informants also highlighted the importance of having a significant other. Informant 32 linked the importance of a significant other to “having a good sexual relationship with someone,” realizing life goals such as having children and the fact that “you grow together, you learn together, you go through things together, phases.” Informant 23 clarified that “it is not just good enough to be a sex mate, it has to be a life mate.”

At the same time informants discussed the importance of connecting and belonging, they discussed the difficulties they encountered, often due to their illness. For example, Informant 32 stated, “It is hard to find a good friend. I feel lonely at times.” When talking about persons who were able to provide support, Informant 4 indicated that “parents don’t understand the illness. They don’t understand us. They can’t help us. That’s the problem.” With respect to belonging, Informant 11 discussed how it was difficult for her to feel she belonged to social groups outside of the hospital: “Say my brother has a party and I go to the party, I feel like I don’t belong, trying to interact with people. I feel more a sense of belonging when I come to the [hospital facility].” Informants also spoke about the challenges posed by their illnesses when attempting to find and maintain a relationship with a significant other. Informant 32 reported,

If I were to meet someone now that I am separated—I would like to have someone in [my] life. I’m lonely in terms of having a companion, a female…what happens if I told them what I had in the past, about my illness…would they really understand, would they understand that I am [on] social assistance now? Would they still accept me as an individual?

Informant 25 added, “If you want a relationship with the opposite sex and they find out you’re mentally ill…that will ruin everything.”
Overall, opportunities to connect with others were intimately tied to activity. For example, Informant 1 liked “keeping in touch with friends, the odd night out,” whereas Informant 32 liked “going out and listening to music at a bar and dancing and meeting people.” Others suggested that they sometimes engaged in activities because they offered the chance to interact with others. When asked what she liked about volunteering at an old age home, Informant 11 indicated, “Listening about their experiences, and I just like to interact with them.”

When discussing the importance and challenge of connecting and belonging, informants often described what they considered to be a “normal” person and expressed that they neither felt normal nor believed that they were perceived as normal. When defining what they considered to be a normal person, informants emphasized what normal people do. Informant 21 stated, “The perfect person. Okay. Up every morning. Work the whole day. Come home, have dinner, watch a little TV, then goes to bed.” Regardless of the definition, most informants expressed a need to both feel and be perceived as normal. For example, Informant 2 remarked, “The thing is that I want to be a normal person and achieve something in my life,” and Informant 25 stated, “I’d like to be treated as equal in society.”

Informants spoke about not feeling like other persons and implied that this set them apart. As Informant 16 stated, I don’t want to be mentally ill, I wanna be normal so I can study normally, go to school normally, get married, this and that. Since I was 17, I have wondered what kind of life I’m going to get, so I have to first get myself all cured and get out.

Informant 4 commented, “I just feel a sense of inadequacy,” and Informant 14 stated, “I feel different...like a different species.”

It was apparent that the effects of not being perceived as normal by others influenced social interactions and quality of life. Informant 12 stated that “once you are told you are schizophrenic, any conflict or difficulty you have can be written off to that illness.” A consequence of others’ perception described by Informant 2 was the withdrawal of persons with schizophrenia from society.

Working toward being perceived as normal and engaging in social activities that were perceived as typical of “normal” people were discussed as ways to improve quality of life. In particular, the pursuit of vocational and educational activities seemed to be a way to work toward both feeling and being perceived as normal. This appeared to be true for Informant 3, who remarked,

I have a part-time job, and I come here a lot and I keep myself busy, and I just want to show to other people, my family and everyone, [that] I am not as useless as they think. I try to do the best I can. Sometimes maybe too much—that makes me sick—but I am not just going to give up.

Informant 7 stated,

At this point, it seems important to be in some kind of professional program [because] I got a degree and I don’t have a job. So, there’s professional programs like, well, there’s teaching and there’s investment counseling...but to be in some socially recognized program...to get back into mainstream.

Making Choices and Maintaining Control

A common thread throughout the focus groups was the issue of control, which was closely related to opportunities to make choices. It appears that quality of life was associated with feeling that one was able to make choices and could maintain control. Major topics discussed in relation to choice and control included disclosure, finances, and illness management.

Informants struggled with controlling and disclosing information about their illness and situations such as work and being on social assistance. Whereas Informant 31 indicated, “I don’t just go and say I’m mentally ill. I don’t say it to anybody,” other informants grappled with the issue of disclosure regarding their illness, suspecting that it could be discovered by other people. When one informant asked the group why they would consider telling others about their illness, Informant 2 answered, “I just kinda think they will find out.” Others spoke about factors to consider when choosing when and to whom to disclose their illness. Informant 28 pointed out that “you have got to be careful what you disclose to some people. You have to choose the people.” With respect to when to disclose, Informant 2 stated, “Before you get to know each other, [you] can’t tell that person that you [have an] illness. Until he knows you, she knows you. Then you probably tell them.” Sometimes decisions related to disclosing or not disclosing information were not directly about one’s illness, but pertained to other areas associated with being ill. Informant 3, who did not have a current job, stated, “My mom and my parents told me, if somebody asks you where you are working, tell them I’m working in an accounting firm.”

Although informants may sometimes feel control over when and to whom they disclose, the outcome of the disclosure was often described as out of their control. Informant 4 explained, “I had friends, and I find that all my friends have deserted me,” adding that “they treat you as if you are an animal.” As well, on the job, Informant 28 cautioned: “If you tell them that you are a consumer, they are not interested in you.”

Informants discussed how factors such as a lack of money and the structure of government programs limited the choices they could make about things such as their living and work situations. In turn, this restriction on choices negatively affected quality of life. For example, when describing her living arrangements, Informant 1 reported “It is a shoebox. It’s the smallest bachelor [apartment] I have ever seen. I have a mouse problem. I have a cockroach problem...So I want to move out.” With respect to government financial assistance and work, Informant 3 stated, “I think that [would be] a problem, like, if I get off FBA.
Comparison With Existing Quality-of-Life Assessments

The factors and themes that emerged in this study overlap, elaborate on, and add to factors commonly included in quality-of-life assessments developed for persons with mental illness. Factors that clearly overlap include finances, activity, and social interaction. At the same time, the ways in which informants discussed the connection between quality of life and both activity and social interaction does not necessarily reflect how these factors are typically addressed in existing quality-of-life assessments. Although existing measures may ask clients to report the frequency of their participation in and satisfaction with different types of activities (Atkinson & Zibin, 1996), informants in this study did not emphasize the type of activity. Informants did discuss their work and educational activities; however, they emphasized the various benefits received from engaging in activity in general. This result suggests that quality-of-life assessments need to tap not only what persons do and their overall satisfaction with their activities, but also the extent to which they are able to use activity to manage time, connect with others, achieve a sense of belonging, and achieve a sense of control. With respect to social interaction, it was not just the frequency of interaction or the type of people that were important to informants, but also the quality of the interaction in terms of the extent to which it enhanced feelings of being connected, belonging, and being normal.

Factors that emerged that are not commonly included as explicit factors in existing quality-of-life assessments for persons with mental illness include time, “being normal,” disclosure, opportunities for choice, and feelings of control. Although factors such as productivity and education are commonly included in quality-of-life measures and indirectly address the use of time (Simmons, 1994), informants spoke about aspects of time other than overall time use, including structuring time, attempting to manage the future, and balancing short-term and long-term perspectives. Although authors have stressed the potential negative impact of social stigma on the lives of persons with mental illness (Estroff, 1989; Rebeiro, 1998), many existing quality-of-life measures do not explicitly ask about the experience of stigma. Informants’ comments related to the issues of being normal and the impact of disclosure regarding their illness—as well as the challenges they discussed in attempting to connect and belong—suggest that societal beliefs and attitudes regarding mental illness do effect how persons with mental illness perceive themselves, how they act in the social world, and how they evaluate their quality of life. The informants’ comments suggest that quality-of-life assessment needs to attend to the issue of stigma, including feelings of belonging or lack of belonging, and barriers experienced in attempting to socially connect with others. In contrast to the growing awareness of the importance of personal empowerment and feelings of control in the mental health literature (Kirsh, 1996; Lord &

Discussion

This study explored the perspectives of persons with schizophrenia regarding the meaning of quality of life, factors important to quality of life, and the ways in which various factors affect quality of life. Seven major factors important to quality of life emerged: activity, social interaction, time, disclosure, “being normal,” finances, and management of illness. The three themes of managing time, connecting and belonging, and making choices and maintaining control describe the varied ways in which these factors relate to quality of life. The findings both confirm the importance of many factors included in existing quality-of-life assessments and highlight issues that have not been frequently addressed by such assessments. The findings also have implications for the occupational therapy knowledge base and for occupational therapy services aimed at enhancing the quality of life of persons with schizophrenia. In addition, these new understandings will be used by the study investigators to develop a quality-of-life assessment.
Hutchison, 1993), few existing quality-of-life measures for this population directly address issues of choice and control. The findings of the current study clearly indicate a need to examine opportunities for choice and feelings of control when assessing quality of life.

Existing quality-of-life measures vary in the extent to which they focus on persons’ subjective perceptions, such as feelings of satisfaction in various areas of life, or more objective phenomena, such as amount of income (Raphael, 1997). Some authors have concluded that the quality of life of a person with mental illness can only be meaningfully evaluated by the person (Simmons, 1994). Others have cautioned against reliance on self-ratings when assessing the quality of life of a person with schizophrenia, arguing that more reliable and valid data will be obtained by focusing on observable phenomena (Atkinson et al., 1997). The findings of this study support an approach to measurement that goes beyond objective aspects and includes subjective perception. For example, when informants discussed their symptoms, they did not stress the specific types and frequency of symptoms. Instead, the extent to which informants felt able to control their symptoms and their experiences of the impact of their symptoms on their social life seemed more essential to the relationship between symptomatology and quality of life.

Understanding How Factors Can Affect Quality of Life

Overall, the findings of the current study suggest that interventions related to time management, social belonging, and choice and control have the potential to influence the quality of life of persons with schizophrenia. In addition, it is apparent that interventions that use activity have the potential to effectively address these three issues.

Numerous studies examining the quality of life of persons with mental illness have found that measures related to time use and social belonging have major relationships to quality of life (Koivumaa-Honkanen et al., 1996; Lehman, Reed, & Possidente, 1982). Additionally, a number of authors have concluded that managing time and maintaining social relations are challenges for persons with schizophrenia (Davidson & Stayner, 1997; Lysaker, Bell, Bryson, & Kaplan, 1998). For example, in a study conducted with 152 former psychiatric patients who had either schizophrenia or major affective disorder, Hachey and Mercier (1993) found that time use and close relationships were among the four most problematic domains for former clients living in the community and that both domains had strong correlations with how participants felt about their lives as a whole. In a qualitative study conducted with 10 persons with schizophrenia, Suto and Frank (1994) found that participants who appeared to have a greater perspective of future time were engaged in more goal-directed actions and had more realistic goals than those participants who preferred only to make plans and goals in the present. Thus, the current study adds to the body of evidence supporting the need to address issues of time management and social belonging when working with persons with schizophrenia.

In comparison to evidence related to time management and social belonging, there appears to be relatively little work examining the relationship for persons with schizophrenia between quality of life and opportunities for choice and feelings of control. Part of this neglect may stem from the use of quality-of-life measures that do not address these domains. At the same time, theoretical literature in both the mental health field and occupational therapy (CAOT, 1997; National Institute of Mental Health, 1987) combined with a rise in consumerism (Simmons, 1994) have led to an increasing emphasis on the importance of a sense of control to effective functioning and well-being. The current study suggests several issues that may be important to address when working with clients to enhance feelings of control, including disclosure, symptoms, medications, and activity. The findings also suggest that interventions to address issues of choice and control need to attend to how programs and services, such as financial assistance programs, are structured. Further research examining the relationships among choice, control, and quality of life is required to understand the complex interactions among these variables.

The ways in which informants used activity to address all three themes that emerged in the study is of particular relevance to occupational therapy because beliefs regarding the value of participation in activity, or occupation, are core to its knowledge base and practice (Moll & Cook, 1997; Yerxa, 1994). The results of the current study provide empirical support for some of the basic beliefs regarding occupation that underlie occupational therapy and support the use of occupation as ends and means in occupational therapy practice.

Although numerous potential benefits of occupation have been described in the occupational therapy literature, there is a need for research to substantiate many of these benefits (American Occupational Therapy Association, 1995; Christiansen, 1990). At the most general level, the current study supports the assumption that occupation can positively influence health and quality of life. Informants repeatedly referred to the ability to be involved in activities as an important factor for quality of life. Indeed, focus groups began with the question, “What are the things that make life good for you?” and informants often initially responded by referring to activities. More specifically, findings regarding the ways in which occupation can exert a positive influence on quality of life—including providing a means to manage time, connect, and achieve a sense of control—support benefits of occupation proposed in the occupational therapy literature (Kielhofner, 1985; Rudman, Cook, & Polatajko, 1997; Wilcock, 1993).

Literature addressing the use of occupation has suggested both that occupation should be the goal of the ther-
apeutic process and that occupation should be the means of practice, with the emphasis on occupation as ends or occupation as means shifting over historical time (Moll & Cook, 1997; Rebeiro, 1998). The findings of the current study highlight the potential implications of using occupation both as ends and as means. The value of occupation as the goal of intervention is supported by findings that highlight the benefits informants derived from participation in occupation, such as experiencing a sense of being normal and achieving a sense of purpose for the future. With respect to occupation as means, the findings suggest that the use of occupation as a therapeutic medium could be aimed at several goals, such as increasing connections with others and establishing a daily structure.

The findings also highlight the need for occupational therapists to attend to not only the barriers to occupation identified within a person, but also the impact of external environments on occupation and quality of life. In agreement with several authors (Anthony & Liberman, 1986; Rebeiro, 1998; Suto & Frank, 1994), the findings of this study suggest that social and institutional environments can create handicaps for persons with mental illness. There is a potential advocacy role for occupational therapists to work with consumers to provide education aimed at changing attitudes regarding mental illness and to inform policy development relevant to those with mental illnesses.

Limitations

The major limitations of this study relate to characteristics of the sample. Informants varied with respect to age, educational background, marital status, housing, and employment; however, they all resided in one major metropolitan center. Thus, the findings may reflect factors important in an urban context and may not adequately address factors important in a rural context or smaller city. Additionally, the results largely reflect the perspectives of men. Although the findings may not address all of the factors that contribute to the quality of life of persons with schizophrenia, the results identify several factors that likely play an important role in the lives of many persons with schizophrenia.

Future Research

The second phase of the study is currently under way. Eighty-two assessment items that address the factors highlighted by informants have been developed for a new quality-of-life assessment. To assess content validity and the clarity of items, the items are being reviewed by a sample of 50 clinicians, consumer representatives, and researchers with expertise in the mental health field or quality of life research. Additionally, informants who participated in the original focus groups are participating in a second series of focus groups in which they are rating the relevance and clarity of the items. All participants are also providing their opinions regarding the most appropriate type of rating scale and administration method. It is anticipated that findings of the content validity phase will assist the research team in reducing the number of items and in finalizing the format of the assessment. Once the assessment is finalized, it will be completed by a larger sample of persons who have schizophrenia in order to assess construct validity and test–retest reliability.

Conclusion

Overall, this study demonstrates the value of a qualitative approach to research that focuses on obtaining clients’ perspectives. In addition to confirming aspects of existing quality-of-life measures and occupational therapy beliefs regarding occupation, the findings suggest the need to address additional issues when assessing quality of life. Moreover, the findings indicate areas to address in intervention aimed at optimizing the quality of life of persons with schizophrenia. Further examination of the perspectives of persons with schizophrenia is required to expand on these findings and achieve a more comprehensive understanding of quality of life. Another potential related area for research is the examination of the effectiveness of clinical strategies aimed at enabling occupation and optimizing quality of life. 

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