

Des stratégies pour distancer la maladie : les cas de la schizophrénie précoce et des maladies chroniques du rein

Heather Beanlands, Elizabeth McCay et Janet Landeen

Même si les recherches indiquent que la perte d'identité est un thème universel qui concerne l'ensemble des maladies chroniques, peu d'études jusqu'ici ont abordé cette question en comparant la maladie mentale et la maladie physique. C'est ce qui amené les auteures à comparer ce phénomène chez des sujets souffrant de maladie mentale (schizophrénie précoce) et des sujets atteints d'une maladie physique (maladies chroniques du rein) dans le cadre d'une analyse secondaire. Elles ont étudié des données provenant de deux groupes échantillons afin de relever les points communs et divergents des thèmes émergents. Un but commun se dégage chez les sujets des deux groupes, soit de chercher à *développer le meilleur de soi-même et à reprendre sa vie en main*, mais les stratégies pour y parvenir diffèrent. Pour trouver un équilibre entre les exigences imposées par la maladie et les autres aspects de leur vie, les sujets ont rapporté s'investir dans des activités pour *apprivoiser la maladie, s'adapter et se retrouver*. Le désir de *développer le meilleur de soi-même* comportait des points communs dans les deux groupes, ce qui laisse croire que le désir de préserver l'intégrité du soi au-delà de la maladie ne découlerait pas du fait même d'être malade. Les résultats préliminaires de l'étude indiquent que la construction d'une identité positive est un facteur clé du processus d'adaptation à la maladie. Il reste donc beaucoup à apprendre sur l'éventail de stratégies mises en œuvre par les principaux intéressés pour distancer la maladie.

Mots clés : Maladies chroniques du rein, schizophrénie précoce, perte d'identité, groupes échantillons

Strategies for Moving Beyond the Illness in Early Schizophrenia and in Chronic Kidney Disease

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Although the literature suggests that loss of self is a universal concern across chronic illnesses in general, little consideration has been given to loss of self across physical and mental illnesses. The authors compare loss of self in individuals with a mental illness (early schizophrenia) and in those with a physical illness (chronic kidney disease). In this secondary analysis, focus group data from 2 samples are examined for similarities and differences in the emergent themes. While *striving to be my best self: getting on with life* was an overarching goal for both groups, the strategies for achieving it differed. The participants engaged in activities related to *approaching the illness, accommodating, and connecting* in order to strike a balance between the demands of the illness and non-illness aspects of their lives. The commonalities in the wish to *be my best self* that were found in both groups indicate that the wish to preserve a sense of self beyond the illness may not be illness-specific. The preliminary results of this secondary analysis suggest that building a positive sense of self in the face of illness is a critical part of illness adjustment and that there are opportunities for nurses and researchers to learn about the spectrum of strategies employed by individuals as they strive to move beyond the illness.

Keywords: Chronic kidney disease, early schizophrenia, loss of self, engulfment, focus groups, qualitative research

Introduction

Chronic illness is frequently accompanied by a host of social, economic, and personal issues, including social isolation, financial pressures, family stressors, emotional upheaval, social role constriction, and stigmatization (Charmaz, 1991; Devins, 1994; Strauss et al., 1984). In conjunction with this vast array of issues, chronic illness and its treatment challenge an individual's sense of identity (Charmaz, 1983, 1991). In some instances the effect is so pervasive that the person experiences a *loss of self*, whereby conceptions of the self are eroded (Charmaz, 1983; Corbin & Strauss, 1987). Some individuals living with chronic illness are never free of the influence of their illness on their self-concept (Curbow, Somerfield, Legro, & Sonnega, 1990) and this illness identity leads to decreased self-

esteem, depression, and decreased satisfaction with life (Baker et al., 1994; Foltz, 1987).

While loss of self has been identified in a number of conditions, it is not known whether it is a universal concern across chronic illnesses in general. Charmaz (1983) eloquently describes the profound impact of serious chronic physical illness on the self. Based on in-depth interviewing of persons with various forms of medical illness, she observes that people with chronic illness suffer “from a loss of self in which their former images of self disappear without the development of equally valued new ones” (p. 68). Similarly, loss of self is described in the psychiatric literature as an often undeniable process in severe mental illness (Davidson & Strauss, 1992; Estroff, 1989; Lally, 1989). Despite similar descriptions of loss of self in mental and physical conditions, there is virtually no literature describing either the commonalities or the differences in the effects of mental and physical illness on an individual’s sense of self.

As researchers working in the realm of chronic illness, we have observed that individuals living with either physical or mental illness may experience loss of self that transcends the physiologic nature of the disease. We have tested a theoretical model of *engulfment* in chronic illness that provides a means of understanding loss of self in mental and physical illness. Specifically, this model has guided research in schizophrenia and chronic kidney disease (CKD), since both of these illnesses challenge the sense of self and quality of life. Although it is readily apparent that the experience of the disorder and its treatment is very different for the two illnesses, research findings suggest that the impact of the illness experience on the sense of self is comparable (Beanlands, 2001; McCay, 1994; McCay & Seeman, 1998). Separate preliminary qualitative studies undertaken to explore the experience of living with early schizophrenia (ES) and CKD suggest that loss of self is a central and common concern for both disorders, which led the authors to raise the question of how these experiences compared. Thus the aim of this secondary analysis was to examine the experiences of loss of self in individuals with a mental illness (ES) and in those with a physical illness (CKD). Specifically, we sought to compare and contrast the experience of loss of self between these groups and the strategies employed by each to address issues related to loss of self.

Literature Review

Loss of Self and Early Schizophrenia

For individuals coping with ES, their sense of self is called into question as soon as they realize that they have an illness they have already identi-

fied as highly stigmatizing (Holmes & River, 1998; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). This orientation towards self-stigmatization frequently results in feelings of powerlessness and uncertainty about the future. Specifically, many believe that previously held goals, as well as a positive future, are beyond their reach (McCay & Ryan, 2002). Efforts to move forward and cope with the illness become arduous, as young people recovering from ES may experience profound difficulty motivating themselves to follow through with self-set goals (McCay, Landeen, & Vishnevsky, 2005), reinforcing their negative perceptions of themselves. In conjunction with the numerous challenges associated with maintaining a healthy sense of self, these individuals frequently experience social withdrawal — specifically, the loss of social roles and relationships over time (Birchwood, Todd, & Jackson, 1998; Estroff, 1989; McGorry, 1992).

Despite the challenges inherent in living with schizophrenia, several studies have found that it is possible for individuals to acquire a positive sense of self, and this has been identified as a critical element in recovery (Czuchta & Johnson, 1998; Davidson & Strauss, 1992). Based on 15 life-history interviews with individuals living with schizophrenia, Williams and Collins (1999) propose a subjective theory of illness and recovery that identifies enhanced self-image and social connection as critical elements in moving beyond the illness. From this perspective the person's sense of self can be viewed as the agency of change. Similarly, McCann and Clarke (2004), using grounded theory, found that increased self-determination in recovery was related to increased well-being and self-control in young adults with schizophrenia. The results of these qualitative studies point to the central role of self in understanding the experience of illness and recovery, an approach that is consistent with the conceptualization of engulfment described below.

Loss of Self and Chronic Kidney Disease

Individuals living with CKD requiring dialysis face a number of physical, social, and psychological challenges that can profoundly influence how they view themselves. Researchers have consistently identified major life changes and restrictions experienced by individuals on dialysis, including alterations in body function and appearance, loss of roles, social isolation, and dependence on family, technology, and the health-care team (Eichel, 1986; Gurklis & Menke, 1995; King, 1994; Lindqvist, Carlsson, & Sjoden, 2000; Nagle, 1998; Welch & Austin, 1999; White & Greyner, 1999). Inherent in these challenges is a sense of limitation and loss that can profoundly influence persons' thoughts and feelings about themselves.

A growing body of empirical evidence indicates that these experiences with CKD can threaten an individual's conceptions of self (Devins,

Beanlands, Mandin, & Paul, 1997; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Kutner, 1987; Nagle, 1998). For example, Gregory et al. uncovered *redefinition of self* as a major construct in their grounded theory study with individuals on dialysis. Similarly, participants in Nagle's phenomenological inquiry identified a loss of personhood and wholeness resulting from dialysis and described *a struggle to be the same while being different*. For some, the process of self-redefinition in response to CKD and dialysis may offer a "new lease on life" and consequently boost sense of self (Gregory et al.). In other instances, however, the illness-related changes associated with CKD are so pervasive that thoughts and feelings about the illness come to dominate the self-concept and individuals begin to view themselves solely terms of the disease (Devins et al.; Kutner; Nagle; O'Brien, 1983). In other words, the physical and psychosocial challenges experienced by those living with CKD place them at risk for engulfment. Persons being treated with continuous ambulatory peritoneal dialysis (CAPD) may be particularly vulnerable to engulfment, as this therapy is performed at home, several times a day, and requires a high degree of vigilance in order to avoid treatment complications.

Theoretical Perspective

The engulfment construct offers one perspective for examining the impact of chronic illness on an individual's self-concept. Adapted from the role engulfment perspective (Lally, 1989), engulfment is manifested by alterations in self-concept and the adoption of patient and illness roles. Engulfment occurs through a loss of normal roles, acceptance of the illness label, a sense of having been changed by the illness, comparing oneself unfavourably to others, loss of self-esteem, and viewing the change in self as permanent (Lally; McCay & Seeman, 1998). Unable to reconstruct a valued non-illness self-concept, the person defines himself or herself in terms of the disease, and activities become illness-centred (Nerenz & Leventhal, 1983); in other words, engulfment results.

Empirical evidence supports the theory that, in both mental and physical illness, engulfment is closely associated with low self-esteem, hopelessness, decreased self-efficacy, and poor social adjustment. In schizophrenia, engulfment, as measured using the Modified Engulfment Scale (MES), has been found to be associated with hopelessness, depression, low self-esteem, decreased self-efficacy, and poor social adjustment (McCay & Seeman, 1998). Similarly, research in CKD, also using the MES, has found increased engulfment to be associated with a range of psychological sequelae, including depression and dissatisfaction with life (Beanlands, 2001). These quantitative findings suggest that engulfment has

implications for psychosocial well-being in both illness populations. However, it is not clear whether the subjective experiences of loss of self in these diverse populations will also be comparable. In order to address this issue, a secondary analysis of qualitative focus group data was undertaken to compare the experiences of loss of self in individuals with a mental illness (ES) and in individuals with a physical condition (CKD).

Design and Methods

Design

A secondary analysis of data from two preliminary descriptive qualitative studies was undertaken. The first project was designed to address unique challenges for individuals living with ES and the second addressed issues for individuals living with CKD. The two studies used focus group methodologies and employed similar approaches to data collection and analysis.

Data Collection

For both projects, semi-structured interview schedules were developed to guide focus group discussions. Each session was conducted by two members of the research team with expertise in focus group facilitation. All focus groups were held in private meeting rooms in the clinical setting where the participants were receiving care. They were attended by a research assistant, who took written notes, and were audiotaped.

For the participants with ES, the focus group questions were designed to invite discussion regarding issues of motivation and self-concept for young adults in the earliest phases of schizophrenia. Participants were asked if they had experienced problems becoming motivated as well as about barriers to motivation. They were also asked whether feelings about themselves affected their ability to be motivated and about strategies that might enhance their motivation and sense of life satisfaction.

For the participants with CKD, separate focus groups were held with individuals on CAPD and with health-care providers, in order to elucidate the challenges and stressors associated with the predialysis period. In this paper, only the results of the client focus group are considered. Questions in the CAPD sample centred on the participants' sense of self, experiences in learning about and preparing for dialysis, and strategies used to manage their illness and treatment. Participants were asked to discuss how dialysis affected their view of themselves and to describe the strategies that helped them manage their illness and treatment.

Participants

For the ES groups, participants had received a diagnosis of schizophrenia, schizoaffective disorder, or schizophreniform disorder within the preceding 2 years, could speak and comprehend English, and were deemed able to participate in a focus group by their clinician. Exclusion criteria were drug-related psychosis, significant medical illness, and organic brain syndrome. A total of eight individuals (six men and two women) participated in two focus groups. The mean age of participants was 30 years and the age at onset of the illness ranged from 16 to 34 years. Four participants lived independently, three lived with family, and one lived in a supportive setting.

Individuals on CAPD were invited to take part in the study if they had been on dialysis for more than 3 months, could speak English, and were willing to share their thoughts and ideas in a group setting. Individuals were excluded if they could not speak English or were deemed medically unstable by their clinician. A total of four participants (three men and one woman) took part in the CKD focus group. They ranged in age from 37 to 57 years ($M = 46.2$). Two of the four participants were married. One participant was employed.

The demographic characteristics of the two samples are compared in Table 1. The samples were similar with respect to sex and level of education, both comprising mostly males with 14 years of schooling. On average, the ES sample was younger than the CKD sample and comprised more single individuals; this is consistent with the course of ES, which tends to present in young adults, whereas the dialysis population generally consists of middle-aged or elderly adults.

Table 1 Demographic Characteristics of Participants		
	Early Schizophrenia (2 focus groups, n = 8)	Chronic Kidney Disease (1 focus group, n = 4)
Sex		
Male	6	3
Female	2	1
Age		
Mean years	30.0	46.2
Education		
Mean years	14.6	14.2
Marital Status		
Single	7	2
Married/ living common law	1	2

Human Subjects Considerations

Ethics approval was obtained from the institutional review boards at the respective universities and participating institutions. All participants gave their written informed consent and agreed to maintain confidentiality of the information shared within the group. The research team ensured the participants' anonymity by removing any names or identifying information when transcribing the data and by assigning each participant an identification number. Audiotapes were stored in a locked cabinet accessible only to members of the research team and were destroyed upon completion of analysis. Prior to beginning each focus group, the investigators made provisions for support and referral in the event that a participant became upset during the session; however, no participant experienced distress or required referral.

Data Analysis

Original focus group studies. The primary approaches to data analysis were similar for the two samples. Audiotapes were transcribed verbatim and the transcripts from each sample were analyzed separately using an approach outlined by Miles and Huberman (1994). This approach involves a sequential process. First, the principal investigators from each project read the transcripts to identify initial reflections that emerged from the focus group discussions. The investigators then reviewed the transcripts in depth to develop a coding scheme reflecting salient categories emerging from the focus group discussions. The transcripts were coded, using this coding scheme, by the investigators and the research assistant, who assigned the appropriate category labels to sections of the text. The investigators then sifted through the coded data to identify patterns, themes, and differences within and between categories.

The result of the primary analysis in both groups was a comprehensive list of categories and themes emerging from the data. In the ES focus group, themes included the experience of motivation, motivation in the context of illness, making a difference, and envisioning the future. Although the themes focused on the experience of motivation, issues related to the impact of the illness on the self, the need to push oneself to feel well, and the importance of supportive relationships were clearly described. In the CKD focus group, similarly, the themes included preserving the self and negotiating patient-caregiver relationships, as well as themes related to stressors and supports associated with the predialysis period. In both instances, loss of self and strategies used to enhance the self emerged as relevant, which led the authors to raise the question of how these experiences compared.

Secondary analysis. The approach to secondary analysis was guided by the first stages of the synthesis process for qualitative data. In this approach, findings from different studies are translated into metaphors, which facilitates comparison across studies (Evans & Pearson, 2001; Noblit & Hare, 1988; Sandelowski, Docherty, & Emden, 1997). In order to compare loss of self in the two samples, the authors first read and reread the original focus group transcripts and the themes generated by the primary analysis for each sample separately. Particular attention was paid to themes related to loss of self and to uncovering key metaphors that described these themes. Separate metaphors were generated for the ES data and the CKD data.

Two authors (HB and EM) then engaged in an iterative process of dialogue and discussion in order to identify similarities and differences in the metaphors identified for each group. The third author (JL) then invited the others to participate in a “peer debriefing” process (Lincoln & Guba, 1985). In this process, HB and EM described the steps of the secondary analysis to JL, with a focus on the rationale for the choice of metaphors. Furthermore, JL contrasted the findings to those of previous qualitative research she had conducted with individuals with long-standing schizophrenia (Kirkpatrick, Landeen, Woodside, & Byrne, 2001; Landeen, 2000). According to Loiselle, Profetto-McGrath, Polit, and Beck (2004), this process is “a means of strengthening the trustworthiness of the data” (p. 479). Finally, overarching metaphors, which captured the themes that intersected the two groups, were identified and the inter-relationships between them were explored.

Findings

The key overarching metaphor arising from the two groups was *striving to be my best self: getting on with life*. Getting on with life meant moving beyond the illness in ways that allowed the individual to address both the immediate demands of the illness and the non-illness aspects of life — that is, striving to be *my best self*. While the overarching goal of getting on with life and being *my best self* was common to the two groups, the strategies for achieving it differed, particularly with regard to strategies for *approaching the illness*, *accommodating*, and *connecting*.

Approaching the Illness: Moderating versus Managing the Illness

Both groups described approaching life with the illness in such a way as to prevent the illness from taking over. The young adults with ES did this by *moderating the illness*, by accepting it so that they could resume their normal lives. Those with CKD, on the other hand, emphasized the importance of *managing the illness* by taking charge and being in control

of their own care. The young adults with ES described moderating illness as involving both understanding and accepting it in order to move forward with their lives. One respondent said:

You learn. You understand what you went through, and you can accept it. When you can accept things, it's much...easier to go forward.

Understanding and accepting enabled participants with ES to go forward and get on with their lives, because it put illness in perspective and made it less frightening. Similarly, maintaining a positive attitude was a strategy for reframing the perception of illness to help individuals with ES moderate the effects of their illness. One respondent with ES explained:

You have to think positive. That's a good thing about having the illness: you learn to think positively. ...you have to or else you're not going to make it.

For others in the ES group, moderating the illness meant taking time away from it so that illness was not the focus of daily activities:

I try to make time for enjoyment...going out with my friends...or being with my family or my dogs or whatever. To have time off my schooling...

Taking "time off" allowed some respondents with ES to keep illness in the background in order to moderate its effects on everyday life. In contrast, those with CKD, in one respondent's words, "experience this whole thing day in day out, 24 out of 24, 7 days out of 7 days." Thus in order to prevent the illness from taking over, those with CKD became illness managers. By managing the illness, they took control and became time managers. One respondent explained that this required planning:

You have to manage your time as far as [dialysis] exchanges are concerned. And then you have to plan. If I'm getting up early tomorrow morning, I have to go to bed X hours, and so forth.

Individuals with CKD not only were time managers but also saw themselves as being actively involved in managing all aspects of their illness. As one respondent put it, "You're in charge of your medical well-being; you have to be on top of things." Being knowledgeable was seen as the best way of being on top of things, and information enabled those with CKD to "stick up for" themselves. One participant with CKD explained:

I think you have to be an informed patient... I mean, I think you have to stick up for yourself, because no one in the end is going to do it for you.

For both groups of respondents, approaching the illness through either moderating it or managing it allowed them to live with their illness without having it “take over.” However, this approach was balanced with that of accommodating the unique challenges of their particular disease.

Accommodating: Pushing Myself versus Pacing Myself

In order to be their best selves and to get on with life, both the ES and the CKD participants highlighted the importance of *accommodating*, or tailoring their actions and activities to the illness in order to minimize its negative consequences. Young adults with ES described *pushing myself* to meet challenges related to motivation and reintegration into social settings that often accompany the illness. In contrast, those with CKD described *pacing myself* in order to conserve energy for valued activities and interests. For those with ES, *pushing myself* represented an acknowledgement of the need to stay motivated and active in order to “get well”:

I'm pushing myself more. ...I'm motivating myself to get well. I feel I got really ill very quickly...and I said, "I'm not going to take that long to get well," so I've been pushing myself to get really well quickly — medication and everything.

For these individuals, “getting well” was a central concern; *pushing myself* reflected an awareness of the need to do what was necessary to get on with life:

Even when I was...very ill...I would do whatever I could do...not necessarily the level that I'm working at right now, but...I would try to keep going, I would try to not let my mind stall, I would sort of continue with my life.

While for those with ES getting well required an effort to be involved and to “continue with life,” individuals with CKD were conscious of the need to pace themselves in order to conserve energy for important activities. Like *pushing myself*, *pacing myself* was a conscious effort to get on with life, which required both planning and balancing:

Everything that I have managed to do is basically accomplished by planning and an effort of will.

Pacing myself and conserving energy were necessary not only for activities and interests, but also for interpersonal interactions. Respondents with CKD acknowledged that a lack of energy could affect their relationships by causing them to be “abrupt” or, as one man put it, “snarky”:

I tend to just measure myself out in terms of how to use my energy, because I'd rather be my good self for 4 hours a day than act as a son of a bitch for 18... So there's just pacing yourself...

Thus, *pacing myself* allowed individuals with CKD to be their best selves by conserving their resources for activities, interests, and personal interactions. For both the ES and the CKD participants, establishing and maintaining personal relationships was crucial to moving beyond the illness. Hence, *connecting* was a common strategy identified in both groups.

Connecting: Making Connections beyond the Illness versus Making Illness-Centred Connections

Connecting was a strategy used to develop or maintain relationships. It helped respondents either to mitigate the negative consequences of their illness, in the case of the ES sample, or to manage their illness, in the case of the CKD sample. *Connecting* was seen as an active, purposeful approach to establishing or maintaining relationships. Participants with ES described the importance of *making connections beyond the illness*, while those with CKD highlighted the need to make *illness-centred connections*. For those with ES, having a support network outside their illness was central in helping them to accept their illness. Reconnecting with friends was a pivotal means of gaining support:

...the sharing that you have in a friendship...you can discuss anything with a friend, and you can talk to them about everything...and the good advice that they give if you respect their opinion...

For the ES participants, friendships not only provided opportunities for sharing and being respected, but were also sources of tangible support. One respondent explained that talking with friends could be motivating:

...well, these days anyways, I'm having more success...supportive friends as well, I would say...they talk a lot of sense. It helps. That keeps me going...

Clearly, for those with ES, supportive friends were essential in order for them to “keep going” and to move beyond the illness. Respondents actively sought out opportunities to reconnect with their friends, even if this required them to push themselves.

While making connections beyond the illness was the predominant strategy described within the ES group, these participants made little if any reference to relationships with members of the health-care team. In contrast, participants in the CKD group stressed the need to establish

relationships with members of the health-care team. It should be noted that CKD participants also described non-illness relationships (with family and friends) as crucial to their moving beyond the illness. However, the focus of their discussion of connections requiring active, purposeful interactions was the health-care team. Thus, *making illness-centred connections* was the predominant strategy described by this group. The need to be active in establishing these relationships is exemplified by a comment made within the CKD group: “I was prepared to wrestle it out with the doctor in the beginning, to get some understanding.”

While not all respondents felt the need to “wrestle it out” with their health-care team, the importance of establishing relationships with members of the team was an identifiable thread. The sheer number of health professionals with whom participants interacted necessitated vigilance in both making connections and balancing information and guidance received from various sources. Several participants with CKD felt that they alone had a perspective on their overall health:

Part of the problem is...I've got, like, five or six doctors...Dr Lipids, Dr. Heart, Dr. Kidney... So I've got these guys all lined up...they all own their little piece of me...but nobody seems to own me...

Participants established connections that enabled them to play a part in decision-making about their own care because of the absence of ownership by any one member of the health-care team. One participant in the CKD group had worked with his doctor to establish the best approach to his care:

I was able to be part of the team that made decisions about my treatment...we were a couple of good minds working on a problem is the way I'd see it.

Participants did not view all interactions with the health-care team as collaborative, and making successful illness-centred connections often took considerable effort. However, being a part of the treatment team was viewed as essential, and in many instances making illness-centred connections not only provided opportunities for gaining information and understanding but also allowed participants with CKD to take greater control of their illness and to get on with life.

Striving to Be My Best Self: Getting on with Life

The strategies of approaching the illness, accommodating, and connecting employed by individuals with ES and CKD enabled them to strike a balance between addressing the demands of the illness and enjoying non-illness aspects of their lives. Underlying this balance was a need to preserve a fundamental sense of the person that existed before the illness

in order to move on. *Striving to be my best self* involved both an acknowledgement of the illness having changed the individual and an awareness of the persistence of an essential self. One participant in the ES group reflected on coming to this realization:

I didn't used to act this way, and when I started taking my medication... I noticed that I was coming back to my original self.

This sense of an original self that persisted even in the face of illness-related changes was echoed by a participant in the CKD group:

Of course the same things bring me joy as before...you are essentially the same person.

One way that respondents got on with life and minimized the engulfing effects of their illness was by continuing to find joy in valued activities, interests, and relationships. Some participants described finding new “activities that I enjoy doing,” whereas others made plans or set goals. A will to move beyond the illness and get on with life was common to the two samples. A respondent with ES stated:

You have to move on. You have to get on with your life... You can't stay in the past forever, wondering what happened. ...I have to get up every morning and get going and do the things I do. So there's a place in my past for what happened.

Finding a place for the illness was essential in order for the participants to move beyond the illness, because, as summed up eloquently by a member of the CKD group, “being sick does not make you immune to life.”

Discussion

Relatively little consideration has been given to examining similarities and differences in the experiences of individuals living with physical and mental illnesses. The results of this analysis suggest that moving beyond the illness is a goal common to individuals with early schizophrenia and those with chronic kidney disease. Consistent with the engulfment construct, the participants described a range of strategies used to preserve a positive sense of self in order to mitigate the engulfing effects of illness. The findings also suggest some illness-specific differences in the strategies used in this pursuit. In general, participants with ES described strategies for keeping the illness in check (*moderating it*) while at the same time employing strategies for connecting with healthier aspects of themselves (*pushing myself* and making connections beyond the illness). In contrast, participants with CKD described strategies for minimizing the impact of

the illness on their activities and interests (*managing it* and *pacing myself*) and for establishing relationships that enabled them to participate in decisions related to their care (making illness-centred connections). Such differences may be explained in part by the characteristics of the participants (e.g., age and marital status) and the distinct nature of their illness experiences.

The onset of schizophrenia often occurs in late adolescence or early adulthood when individuals are typically facing developmental transitions related to establishing independence and preparing for their future. For example, Williams and Collins (1999) report that people in their sample with a first episode of schizophrenia were cognizant of the paradox of being young yet having no sense of the future. Peer groups also play a central role at this developmental stage as young people make the transition to adulthood (Coleman, 1980). In our study the participants with ES identified the importance of having supportive friends. The focus on making connections beyond the illness, as described by the participants with ES, may therefore be reflective of a developmental need to remain connected to peers in order to get on with life. The importance of peer-group interactions at this developmental stage may have resulted in a group discussion centred on peers and social relationships, to the exclusion of health-care providers, and may not necessarily be indicative of the importance, to individuals with ES, of relationships with health professionals.

The unique developmental needs of young people with ES are challenged by the highly stigmatizing nature of schizophrenia (Schulze & Angermeyer, 2002; Skinner, Berry, Griffith, & Byers, 1995) and the symptoms of the underlying disease (e.g., amotivation, social withdrawal), which can greatly inhibit social interaction. Thus, the strategies of moderating it, *pushing myself*, and making connections beyond the illness may have been the participants' way of responding to the unique social concerns posed by such a stigmatized illness. Similar findings are reported in the literature. For example, in a phenomenological study with 10 adults with schizophrenia, Walton (2000) found that participants made an effort to stay engaged with others despite the challenges they encountered in "living with others."

The course and treatment of chronic kidney disease are very different from those of schizophrenia. Whereas the symptoms associated with schizophrenia may be considered somewhat manageable or episodic, persons with CKD must deal with their illness and treatment 24 hours a day, 7 days a week. CKD requiring dialysis is "not just another chronic illness" (Sensky, 1993). The daily demands of dialysis treatment, the physical symptoms of CKD, and the complex medication and diet regimens demand that individuals on dialysis be illness managers. The

CKD participants in our study expressed a need to be vigilant in their interactions with the health-care team and to take charge of their own well-being. They identified the importance of being on top of things and “sticking up” for themselves. Other authors similarly report that the strategies used by individuals with CKD to manage their illness often involve managing relationships with the health-care team and managing the health-care system; they describe such strategies as “vigilant oversight of care,” “active self-advocacy” (Braun Curtin & Mapes, 2001), and “trying to maintain control” (Eichel, 1986).

Despite the fundamental differences in the nature of their illnesses, both groups of participants described a will to move beyond their illness. While their strategies were necessarily illness-specific, in both cases the purpose of the strategies was to allow the person to strike a balance between addressing the demands of the illness and enjoying non-illness aspects of his or her life. This finding is consistent with Paterson’s (2001) observation that individuals with chronic illness must learn to manage their illness in order to participate in valued non-illness activities: “the illness requires attention in order not to have to pay attention to it” (p. 24). While Paterson is reporting on results of studies in chronic physical illness, our findings suggest that this paradox may also apply to individuals with mental illness.

Further, the commonalities in the wish to *be my best self* revealed in both samples suggest that the self is central to illness adjustment and that maintaining a sense of self beyond the illness is not disease-specific. Other authors have described the centrality of the self to adjustment in chronic illness. For example, in a phenomenological study with eight people with various chronic conditions, Lindsey (1996) discovered the phenomenon of being healthy while living with a chronic illness. Health within illness as described by Lindsey’s participants includes the themes “honouring the self” and “seeking and connecting with others.” Consistent with our findings, Lindsey’s participants described the importance of celebrating life by living it to the fullest. Lindsey’s sample was focused in nature, yet this conceptualization is consistent with all of our participants’ descriptions of the importance of moving beyond the illness, thus demonstrating the significance of this aspiration for those living with either physical or mental illness.

Our analysis concerns two specific illnesses, schizophrenia and chronic kidney disease, and represents a first step in identifying strategies used to maintain a healthy sense of self in two populations. While the results highlight the strategies employed by two specific groups of individuals, they indicate that it may be important to attend to the person’s sense of self regardless of the health condition. Future research on the impact of chronic physical or mental illness on the sense of self, specifi-

cally engulfment, could examine whether the themes of approaching illness, accommodating, and connecting identified in this analysis are meaningful for persons with other chronic conditions. Work in this area could eventually provide direction for the development of interventions to reinforce an individual's sense of self. Further, the observation that participants with ES did not discuss their interactions with health-care providers suggests the need for studies that explicitly examine these relationships. Such research is critically important, since it is well known that engagement of this young, vulnerable population in treatment is most challenging. Research to address the formation of therapeutic relationships may provide direction for nursing practice with this population.

Nurses are in a unique position to support individuals' strategies aimed at moving beyond their illness. Preliminary findings suggest that there may be opportunities for nurses to learn about the spectrum of strategies employed by people as they strive to cope with their illness. This knowledge may provide perspective for nurses in understanding the impact of living with chronic illness on individuals' self-definition and to support their efforts to move beyond their illness.

Limitations

The results of this analysis should be considered in the context of limitations underlying the methodologies used in the original studies. Focus group methodologies, while offering possibilities for rich dialogue, can be limited by the manner in which participants respond to each other; since no two groups are the same, the generalizability of the findings is necessarily restricted (Carey, 1995). Both samples included a relatively small number of participants who were willing to share their perspectives in a group setting; their views may not reflect the experiences of others with the same illness. Finally, the metaphors described in this paper are only those that intersected; they therefore do not necessarily reflect all of the themes identified in the two samples.

Conclusions

Above all else, chronic illness and its treatment challenge an individual's sense of who he or she is (Charmaz, 1983, 1991). Ultimately, an individual with a chronic illness requires a redefinition of the self (Biordi, 1995), one that incorporates and accommodates the illness in a positive and realistic light and avoids the risk of engulfment. It may be that an ability to redefine the self in a way that accommodates the illness while preserving the original self based on meaningful traits or values will allow persons with a chronic physical or mental illness to avoid the engulfing effects of the illness and to rebuild their lives. We encourage researchers

in the field of chronic illness to broaden their scope of study to include participants across the full range of chronic illnesses and disabilities. Researchers and clinicians may then begin to address the stigma that is endured by individuals living with mental illness, with the understanding that the will to move beyond illness and disability is truly a human phenomenon.

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