

# Subjective Experience of Symptoms in Schizophrenia

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On a procédé à une étude qualitative en utilisant la méthode d'interactionisme interprétatif afin d'examiner les expériences intérieures des personnes atteintes de schizophrénie, expériences qui encerclent, mobilisent et façonnent leur conscience des symptômes de leur maladie et leurs réactions à ceux-ci. On a recueilli les données biographiques d'un échantillon intentionnel de quinze personnes atteintes de cette maladie. Leurs récits montraient que la douleur psychique dominait leur vie; ce thème était mêlé à ceux du manque de maîtrise, d'échec et de perte. La douleur psychique représentait pour les répondants le facteur essentiel dans le développement de la prise de conscience des fluctuations dans la progression de leur maladie. Les résultats indiquent que les infirmières pourraient faciliter la maîtrise des symptômes chez les schizophrènes en s'occupant de la détresse émotionnelle qui pénètre chaque aspect de leur existence et en les aidant à procéder à leur introspection afin d'augmenter leur conscience des composantes précises de la détresse psychique.

A qualitative study using the interpretive interactionism method was conducted to investigate the inner experiences of individuals with schizophrenia that surround, mobilize, and shape their awareness of, and responses to, the symptoms of their illness. Biographical data were collected from a purposive sample of 15 respondents suffering from this illness. Their narratives indicated that psychic pain dominated their lives; this theme was intertwined with the themes of lack of control, failure, and loss. Psychic pain was the key factor in informants' developing recognition of fluctuations in the course of their illness. The findings suggest that nurses may facilitate symptom monitoring in individuals who have schizophrenia, by attending to the emotional distress permeating every facet of their existence and by helping them look inward, to heighten their consciousness of specific components of psychic distress.

For many years nurses have been teaching individuals with chronic physical illnesses, such as diabetes and hypertension, the specific self-care skill of symptom monitoring. The clinical approaches they use, however, are not readily transferable to schizophrenia. No instruments are available to detect the presence or severity of this long-term mental illness whose symptoms may exacerbate and remit for many years. The only potential indices are objective and subjective observations of feelings, thought processes, and behaviours. In order to identify fluctuations in symptoms, the person with schizophrenia must develop an awareness of subjective indicators of the illness. He or she must, therefore, manage the illness by using those very cognitive processes being

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affected by its symptoms. Yet studies have found that about half of individuals with schizophrenia develop an ability to detect signs of impending decompensation. Many are able to use this knowledge to abort a full-blown relapse by seeking early medical intervention (Heinrichs, Cohen, & Carpenter, 1985; Herz & Melville, 1980; McCandless-Glimcher, McKnight, Hamera, Smith, & Plumlee, 1986).

A qualitative study was conducted to determine how this self-care knowledge is acquired. The processes involved in the evolution of the ability to detect signs of relapse have been presented elsewhere (Baker, 1995). This paper will describe the inner experiences that surround, mobilize, and drive informants' evolving symptom awareness and symptom monitoring.

### **Background Literature**

Bleuler (1950) considered unawareness of symptoms to be a part of the schizophrenic disorder. This opinion was supported by the World Health Organization's (1973) International Pilot Study of Schizophrenia, which found that 97% of a sample of 811 recent-onset cases lacked insight. Similarly, Wilson, Ban, and Guy (1986) reported that 89% of a multinational sample of 768 individuals with schizophrenia denied having symptoms of a mental illness. Despite these findings, there is considerable evidence that a post hoc awareness of psychosis is common once symptoms begin to subside (Amador, Strauss, Yale, & Gorman, 1991; McEvoy et al., 1989; Wing, Monck, Brown, & Carstairs, 1964). Furthermore, social scientists have found that denial of illness may be a strategy to protect one's self-concept from being stigmatized (Estroff, Lachicotte, Illingworth, & Johnston, 1991; Lally, 1989). Lally (1984), for instance, collected psychiatric patients' theories of their illness and identified a number of techniques that respondents used to keep a sense of self-competence, such as choosing a less stigmatizing label for their illness and distancing themselves from their symptoms.

Studies have also shown that many individuals with schizophrenia recognize early indicators of decompensation. In Chapman's 1966 landmark phenomenological study of the decompensation process, patients described feelings of over-stimulation and of trying to maintain self-control before perceptual impairment began. Subsequent studies identified a predictable sequence of intensifying feelings and confusion during relapse (Docherty, Van Kammen, Siris, & Marder, 1978; Donlon & Blacker, 1973), which led to an interest in determining whether individuals with schizophrenia recognize and respond to the onset of a

relapse. Herz and Melville (1980) found that 70% of a sample of patients were able to describe prodromal symptoms preceding a recent psychosis; Heinrichs et al. (1985) reported that 63% of patients being followed at an outpatient clinic detected the prodromal phase of a psychotic episode; and McCandless-Glimcher et al. (1986) found that 59% of their sample of clinic patients identified indicators of relapse. Evidence suggests that individuals with schizophrenia not only recognize illness symptoms but also take actions to mitigate their effect. When symptoms increased among a sample of 20 chronic mental patients during a two-year study, report Breir and Strauss (1983), 17 tried to control them by talking themselves out of them, decreasing their involvement in activity, or increasing their involvement in activity. Similarly, Harris (1990), guided by Orem's self-care model, identified actions that inpatients with schizophrenia initiated on their own to meet the self-care requisite of maintaining a balance between solitude and social interaction. Following rules, looking away, and watching television alone were some of the methods they used to meet solitude needs; joking, participating in groups, and talking sensibly are examples of the self-care actions these patients took to meet their need for social interaction. A study by Falloon and Talbot (1981) identified frequently used strategies to cope with persistent hallucination among a sample of outpatients with schizophrenia. These included changes in activity, interpersonal contact, manipulation of physiological arousal, and attentional control.

### **Purpose**

Previous studies, then, demonstrate that individuals with schizophrenia have fluctuating and differing levels of awareness of their symptoms, and also that they interact actively with their symptoms in order to alleviate them. However, little attention has been paid to the subjective web of meanings and emotions in which this recognition and management of symptoms is grounded and shaped. Furthermore, the inner experience of schizophrenic symptoms is alien to the observer and thus difficult to grasp. A greater understanding of this dimension would be useful for nurses in helping clients understand and monitor their symptoms.

### **Method**

Interpretive interactionism as developed by Norman Denzin (1989) is the methodology guiding this study. This qualitative, nonpositivist

method of inquiry is intended to provide genuine understanding of phenomena through thick description of the everyday lives of people. Developed for the investigation of personal problems that are also public issues, interpretive interactionism is based on the premise that public programs are more effective if they take into account the perspectives of those they are designed to serve. In the present study, symptom exacerbation in schizophrenia was viewed as a personal trouble that often provokes a collective, societal response and is a public issue.

The subject matter of an interpretive interactionist study is existentially relevant biographical experience. The investigator seeks narratives about the experiences of individuals living the personal trouble being studied. In particular, the investigator looks for personal stories that describe significant experiential moments that mark a person's life. Denzin argues that these epiphanies have the potential to transform people. Epiphanies sought out by the investigator may be (a) major, in which a sudden shattering experience alters a person's life irrevocably, (b) minor, in which underlying elements of a situation are illuminated for the person, (c) relived, in which the transformational moment connected to an experience occurs at a later period, or (d) cumulative, in which the epiphany is the result of an accumulation of events in a person's life (Denzin, 1989, p. 17).

At the outset, the investigator clearly states her or his value position on the phenomenon under study. Thus the following personal values of the investigator were identified prior to data collection: individuals with chronic mental illness benefit from understanding their illness, and self-management of the course of the illness is helpful to individuals with long-term mental illness. An interpretive interactionist study has five steps. They are deconstruction, capture, bracketing, construction, and contextualization (Denzin, 1989, p. 27).

### *Deconstruction*

Deconstruction is carried out before the data are collected. Its purpose is to provide a critical interpretation of previous work so that underlying biases are identified. A deconstructive reading of the literature indicated that published studies focusing on symptom monitoring treat it as a cognitive skill detached from the experience of the symptoms. Work on the subjective experience of schizophrenia has primarily been concerned with the negative impact of the diagnostic label, rather than the symptoms, on the sense of self.

*Capture: Sample*

Capture involves going to the social worlds in which the personal trouble being investigated occurs, to collect narratives about the phenomenon (Denzin, 1989, p. 127). In this study, therefore, 15 respondents with schizophrenia, forming a non-probabilistic, purposive sample, were recruited through three psychiatric institutions located in Moncton, N.B.: the Moncton Mental Health Clinic, the Moncton City Hospital Psychiatric Unit, and the Dr. Georges L. Dumont Psychiatric Day Unit. Criteria for inclusion were that respondents had been hospitalized at least once for schizophrenia, that their acute psychotic symptoms had remitted, and that they were being followed on an outpatient basis. In addition, they were purposively selected so that the sample would include individuals of both sexes, various age groups, varying ability to recognize signs of relapse, and different lengths of time since diagnosis (Table 1).

Table 1			
Sample Characteristics			
Gender		Education	
Male	10	Less than grade 12	3
Female	5	Grade 12	2
Age		Some technical	1
		Some university	2
18 years	1	Technical diploma	6
20-29	2	University degree	1
30-39	6	Employment	
40-49	4		
50-59	1	Unemployed	9
70	1	Employed part-time	2
Marriage		Sheltered workshop	3
		Retired	1
Single	11		
Common-law	1		
Divorced	3		
N = 15			

Each in-depth interview with respondents took approximately two hours. All but one was audiotaped; one informant asked that the interviewer take notes instead because the tape recorder made him feel paranoid. The interviews were flexible and involved working from a general list of questions about the respondents' experience of their

illness history, family history, social history, and residential history. For instance, respondents were asked the following two questions: (a) Most people's mental health goes up and down. Can you tell me about a period in your life when your mental health was at its best? (b) Can you tell me about a period in your life when your mental health was poor? A short semistructured questionnaire was also administered in order to collect socio-demographic and treatment data.

### *Bracketing*

*Bracketing* is a term borrowed by Denzin from Husserlian phenomenology. In interpretive interactionism it refers to the dissection of informants' narratives in order to isolate and list the essential recurring elements of the phenomenon being studied (Denzin, 1989, p. 55). In this step, preconceptions about the phenomenon are put aside; epiphanies are identified in the informants' narratives, which are divided into key experiential units; phrases and statements within these units that relate to the phenomenon are located; the meaning of these phrases is interpreted; these meanings are inspected for recurring features that speak to the phenomenon.

### *Construction*

Construction builds on bracketing. Bracketed elements are reassembled into a coherent whole by identifying how they occur within the experience being investigated. In this study, construction yielded a sequence of processes in the evolution of the ability to detect signs of relapse, which, as noted earlier, have been described elsewhere.

### *Contextualization*

In the last step, contextualization, the investigator relocates the constructed processes in the informants' biographies. Narratives that either embody the processes or illustrate variations in their stages are identified. The aim is to discover how specific lived experiences shape the phenomenon being studied. It is this personal, subjective context surrounding the evolution of the ability to detect signs of relapse that will be described in this paper.

### *Controls in the Research Procedure*

Several measures were taken to enhance the trustworthiness of qualitative studies (Lincoln & Guba, 1985; Sandelowksi, 1986). Four respon-



dents were ask to validate the processes involved in detecting relapse and the contextual themes shaping these processes. They stated that these findings reflected their personal lived experience. An extensive audit trail included a reflexive journal, all data reduction products, data interpretations, and data reconstruction products. This trail was audited by a doctoral nursing student, who was able to trace the emerging analysis and found an appropriate fit between the illustrating experiences and the interpretive categories. However, from the postmodern, interpretive interactionist perspective, findings of any study are interpretations and as such are always provisional and incomplete (Denzin, 1989, p. 64). Furthermore, Sandelowski (1993) points out the contradictions inherent in using consensual and corroboratory procedures to establish reliability in studies based on a paradigm that assumes reality to be multiple and constructed.

### *Ethical Considerations*

The human subjects committee of the University of Texas at Austin approved the study proposal. The facilities where informants had been treated also approved it. Respondents signed a consent form; confidentiality was maintained at all times; and a prime concern during the interviews was the well-being of the respondents. Names used here are fictitious.

### **Findings**

Psychic pain dominated informants' biographies. It appeared to be a central feature of their existence and was the inner context driving the evolution of self-monitoring for signs of relapse. On the one hand, this pain seemed to be an *integral part* of the symptoms of schizophrenia; it increased when symptoms worsened and was the personal trouble that drove informants into the public arena in search of relief. On the other hand, pain appeared to be a *consequence* of the symptoms of the illness; it resulted from incidents involving a lack of self-control, failure, and loss when symptom exacerbation wrought havoc on informants' lives. Pain, control, failure, and loss were, therefore, the problematic experiences underlying the epiphanies that shaped informants' interpretations of their symptoms and the course of their illness (Table 2). Each of these contextual themes will be discussed in turn. Informants will be quoted liberally to provide thick descriptions of these disturbing inner experiences.

**Table 2**  
*Contextual Themes*

<b>Pain</b>	<b>Failure</b>
Accompanying symptoms	Letting oneself down
Resulting from symptoms	Letting others down
<b>Control</b>	<b>Loss</b>
Losing control of self	Losing a normal life
Controlled by others	Losing roles and relationships

### *Pain*

The psychic pain that permeated informants' narratives ranged in intensity from instances of chronic, subacute discomfort to periods of terrible anguish. As noted, a part of their distress seemed to be a constituent of their symptoms, and many respondents specifically used the term "pain" to describe this emotional distress.

Informants depicted the onset of schizophrenia as their introduction to a life of persistent emotional discomfort. Often their distress was low level. Alex said, "You can't ever feel comfortable." Brian said of it, "I'm always nervous and tense with people." Jim observed, "I always have a little edge," and both Marjelaine and Dan said they were "always a little paranoid." Marjelaine described herself as constantly feeling "a little anxious." Guy said he had a persistent feeling that "something is holding me back, like putting your foot forward and something's in your way and you can't..." Luc described a feeling of worry and insecurity that never left him, and Doug commented that he continually feared that people would hurt him.

Informants illustrated these subacute feelings of distress by contrasting them with how they felt before the onset of the symptoms of schizophrenia. For instance, Jason said of this earlier period of his life: "You're not even conscious that there's something wrong – you're just seeing what's going on." Similarly, Doug said, "When my mental health is at its best, I don't realize that I have a problem. This is what I use as a reference point but I've never really come back to that point since I got into a serious nervous-breakdown situation."

Low-level discomfort periodically intensifies. Informants used very strong adjectives to describe this phenomenon. They spoke of a living



hell, of torment, terror, rage, despair, and wanting to kill themselves to escape the anguish. Jim said, for instance, "I feel like suicide. I feel like taking a knife and putting it right through my chest." Doug described an acute fear that completely overwhelmed him. Even thinking of periods when this happened, he said, brought "a feeling of terror rippling over me."

High levels of psychic pain seemed to stem from what several respondents referred to explicitly as "being out of touch with reality." Although informants' visions, voices, and strange thoughts were not always negative, they tended to become increasingly distressful, eventually taking over their lives for stretches of time. Mike and John spoke of periods when they had been "tormented by voices" that wouldn't leave them alone. John explained that voices had become "so intense I couldn't sleep – they were just at me constantly." Jane, a 50-year-old informant whose dead mother "keeps coming back," said these apparitions were initially occasional and comforting. However, they soon became persistent and frightening. She said of them: "The death is there. It's scary, it's cool. They don't act the same way.... I was scared she'd be getting it in her mind to take me with her, and that's what scared me." And sometimes being out of touch with reality was more than tormenting or frightening; it was terrifying. Guy, a young man, described it as being "like a nightmare...I was really scared and I started seeing, like, people coming out of the woodwork. It's just thoughts that were going through my mind. It's just, like, right there, there they are, and all of a sudden, in another five minutes, there's another one over there."

The pain that informants experienced as a consequence rather than a component of symptom exacerbation appeared to be a diffuse and fairly continuous aspect of their lives. Their experiences of lack of control, failure, and loss will be described to highlight the sources of this pain.

### *Control*

Problematic experiences with control resulted from fluctuations in the intensity of symptoms and were painful for informants. These experiences involved what they referred to as losing control and being controlled by others.

*Losing control.* Informants were often overcome by unpredictable and uncontrollable feelings that determined what they did and how they behaved. Frequently, this loss of control was minimal and affected

only their ability to manage day-to-day activities. At other times, it was a major epiphany that drastically disordered their lives and had serious consequences for their future.

Minor threats to informants' sense of self-control included unpredictable daily fluctuations of energy, anxiety, and what many referred to as paranoia. For instance, Annette, a 33-year-old woman, described her life as a constant battle with an unreliable amount of energy. She believed firmly in the importance of being active but her determination was often overwhelmed and she couldn't even bring herself to get out of bed. Similarly, spurts of agitation often interfered with informants' daily lives. Alex explained: "Sometimes with this disease you have panic situations where you're panicking, like, quite severe, and then good days when you don't have that type of thing." He considered this to be "crippling...it affects your lifestyle and your being able to take care of your own response and life situations." Sudden surges of paranoia also put enormous restrictions on several informants' ability to do what they wanted. Annette described an incident earlier in the day when such feelings had emerged suddenly and disrupted her daily walk with a group of friends. During the outing, she began to feel that the people in the cars driving by were laughing at her and talking about her, so she surprised her friends by insisting that the group alter their route and led them way off course to a street where there were no cars.

Besides facing minor ongoing threats to their sense of self-control, informants had experienced dramatic incidents during which their behaviour had become completely disruptive. Many had tried to hurt themselves during one of these episodes. John described a terrible incident where losing control of himself seriously endangered his life:

Everything was so distorted that I felt that everyone was out to get me. And I got to my home and then I tried to impale myself on a stake. I was just terrified. It was terror. And then when I got home I slashed my wrist and that didn't work fast enough so I cut off my hand.

Fortunately, a friend was at John's home within seconds of this and he was in the operating room in less than half an hour. His life and his hand were saved, although his wrist is encircled by a large scar and his hand is puffy, discoloured, and difficult to use.

*Being controlled by others.* Frequently, the upshot of losing control of oneself was that others took over and imposed controls on informants, which was another element that contributed to their inner distress. Important sources for this included involuntary hospitalizations and the experience of having to depend on others.

Many informants had been brought to hospital against their will, by friends, relatives, employers, and police. Although the resulting hospitalization was often perceived as a refuge from the turmoil that had overwhelmed them, it could also be lived as a terrible loss of control. Doug explained why one of his hospitalizations had been this type of experience:

I was put on various drugs. I don't know if I can remember them all. I think one of the main ones was stelazine. There was a whole host of drugs I was taking there. It was as if they were trying to find a cure for I don't know what. Then I was told that I wasn't allowed to leave the hospital unless I agreed to six months of injections outside the hospital. I was never all right there. At one time I refused to eat. I was just fed up with this and so I quit eating and this doctor, he says, "If you don't eat we're giving you shock treatment," just like that. So I was totally devastated. This is terrorism to me – when I'm forced to take drugs, when I'm secluded, I'm watched everywhere I go. It disrupted my life and terrorized me.

Being dependent on others, especially on family members, to meet basic survival needs was common for informants, and this also contributed to their sense of being controlled by others. Jim, a 36-year-old who resented his lack of autonomy, described how family control works.

My parents say that if you want to come to the cottage this summer you got to come back after two nights and you've got to take the train in Truro. They say you have to do this and you have to do that. You have to get your beard trimmed, you have to get your hair cut before you go. I'll give you the money but you got to do it before we leave and you've got to talk to your doctor and you're not going until I talk to your doctor, until you see your doctor and get your needle.

The problem, Jim explained, in resisting this control was that visits to his parents' cottage provided a welcome break from the Salvation Army hostel where he lived. As a result he agreed to comply with his parents' demands.

### *Failure*

Losing control had disruptive repercussions in all areas of informants' lives, bringing devastating failures in its wake. Thus an overriding sense of failure was another element of the psychic pain that resulted from symptom exacerbation. Informants perceived that they had let themselves down and had failed to meet others' expectations of them.

*Letting oneself down.* Although informants struggled to overcome the consequences of their symptoms, they felt that they had let themselves down because they had experienced persistent difficulties in becoming the type of person they wanted to be. They had made plans to realize personal goals, taken steps to put their plans into action, and failed – multiple times. Jim spoke at length about this, because the night before the interview he had let himself down by taking gravel, which he said gives one a “cheap high,” like “doing acid or something.” He felt his repeated failures to reach the goals he set for himself was the reason for taking this gravel and described the following minor epiphany: “It hit me last night, I can’t handle a job, I can’t keep a girlfriend, I don’t have a house.”

Brian, a 35-year-old with a university degree in mathematics and physics, was living with his parents because he had been unable to establish an independent life for himself. He desperately wanted to have a permanent full-time job, but had discovered that “whenever I am put under a stressful situation,... I always seem to fall through.” Brian contrasted this reality with his aspirations for himself: “It’s important to feel that you can work regularly and steady like anyone else and do something to help the rest of the world.”

*Letting others down.* For many informants, losing control of oneself and losing touch with reality had culminated in situations in which others had made it clear to them that they had failed to meet their expectations. A recurring phrase in respondents’ narratives that captures this experience succinctly is “kicked out.” Here are several examples.

Following his first psychotic episode John was removed from his job, but he persuaded his employers to give him another chance. He eventually regained their confidence and was sent by his company to a community college to study industrial mechanics. However, “I got psychotic again” and “I missed too much time and they kicked me out of school and I’ve been off work ever since.”

Guy also described himself as having been “kicked out.” In his case, it was from the army, where he was a corporal. He had been in the military for five years and loved it, but had to leave because he was charged too many times with being unreliable.

Brian, whose life was, more than any other informants, dominated by a sense of failing to meet others’ expectations, believed he had been unsatisfactory at just about everything he had tried since leaving university. He was transferred from his first job, as a draughtsman, because

he made "enormous mistakes." He tried being a teacher's aide at a high school but wasn't rehired because, he was told, his mannerisms were a problem. He then enrolled in a teacher's training program but failed the student teaching component. Next he tried working in a grocery store, but once again was unsuccessful, because he would give the groceries to the wrong customer. He then got a job working as a janitor at McDonald's but after eight shifts was fired. Brian's efforts to establish relationships with women had met with the same lack of success. In summing up the cumulative epiphany that resulted from the last incident of being fired, he said, "It doesn't matter which way I interpret things, it means I'm a failure."

### *Loss*

A third painful theme pervading informants' narratives was losing what mattered to them. This included both a general expectation of living a normal life and actual valued relationships or social roles. Again, these losses were often sustained as a result of episodes in which the informants lost control of themselves, and they contributed significantly to the chronic distress that informants experienced.

*Losing a normal life.* Informants' symptoms had seriously compromised their ability to live the kind of life they had grown up expecting for themselves. Before the onset of schizophrenia, they had not anticipated developing a mental illness. Indeed, they described themselves as having had the same negative attitudes about the mentally ill that were prevalent in their communities. They contrasted their circumstances with those of their brothers and sisters, who had the kinds of lives they believed would have been theirs had they not developed a mental illness. Even respondents who had begun to have serious problems with their mental health as teenagers expressed an acute sense of a normal life having eluded them. For example, Annette, whose symptoms first appeared when she was 17, felt enormous regret that her illness had prevented her from marrying and having children, which is what she said she had always wanted most in life. Jim also expressed feelings of loss: "My dreams are shattered. I wish I had a car, a job, a girlfriend, and everything, but I've been starting at the bottom for 10 years now and I'm not going anywhere, and that's the way I'm going to be for the rest of my life."

*Losing roles and relationships.* Respondents who had been able to establish relationships that mattered to them, find jobs that they liked, and gain material possessions that they cared about had been unable to hold on to them. Jeanine's most terrible loss was having to give up her



youngest son for adoption because she got "too sick to take care of him." She said, "He meant more to me than my other children because I had seven good years with him when I was really well." Dan, whose wife had divorced him six years earlier, still felt the grief: "I have no life. I still love my wife and I love my boy. I understand my wife – she's remarried, I accept that, you know, she's got her life – but I still love her." Losing what matters was most dramatic for Alex, who had been diagnosed as having schizophrenia only a year before being interviewed. A significant series of losses culminated in a major epiphany, a tumultuous turning point in his life when his illness became evident. He was fired from the job he had held for some 12 years and his wife divorced him and was awarded their house and custody of their two children. "Schizophrenia is a debilitating disease," said Alex, "it affects your lifestyle, and your being able to take care of your own, and your ability to deal with life situations. You're not able as you once were, as I once was."

## Discussion

The evolution of self-monitoring for early signs of an imminent relapse was an introspective and solitary journey driven by the subjective experience of psychic pain. Elevations in the intensity of the distress that accompany symptoms of schizophrenia initiated this journey. At the beginning of the illness course informants sought relief from diverse sources, including illegal drugs, whenever their pain escalated. Sooner or later each informant's efforts to escape elevated distress resulted in a pattern in which he or she looked to the health-care system when symptoms worsened, and they found some temporary help in reducing distress in this way. The interaction between trying to diminish the pain felt when symptoms worsened and meeting with some success in doing so resulted in cumulative epiphanies in which informants began to consciously discriminate between a tolerable and an intolerable level of distress. Initially, then, their identification of signs of relapse represented an unspecific differentiation between heightened distress and low-level emotional discomfort. It resulted from a non-reflective reaction to intensifying pain. As problematic experiences with control, failure, and loss accumulated, a fear of relapsing crystallized in epiphanies in which informants began to anticipate that these painful sequelae would result from symptom exacerbation. Once this fear took hold, informants began to watch for increasingly subtle evidence of intensifying distress. They became conscious of minor increases in emotional discomfort brought on by everyday stressors. Moving in and out of these distressful situations refined their perceptions of symptomatic pain. As their



experience with fluctuations in distress accumulated, their ability to detect the component feelings and thoughts of increasing psychic pain became sharper. Thus, a fear of the painful consequences of relapse associated with a lack of control, failure, and loss generated self-surveillance for signs of deterioration.

This data suggest, then, that self-monitoring for symptom exacerbation was not the result of cognitive learning about the disease process; it was embedded in the illness experience of suffering. For informants, the overriding element in decompensation was increasing emotional distress, and the significant outcome of relapse was the pain associated with a lack of control, failure, and loss. As a result, a response to immediate suffering evolved into a response to anticipated suffering, and a general awareness of heightened distress evolved into an awareness of increasingly subtle components of distress.

Qualitative studies are idiographic and, therefore, inherently non-generalizable. Nonetheless, these findings could have implications for nurses helping clients avoid relapse by detecting early signs of decompensation. The data analysis suggests that self-monitoring for indicators of relapse involves skills that need to be uncovered by the person with schizophrenia rather than taught to them by others. By directing the person's subjective attention to the internal experience of increasing and decreasing distress, nurses may be able to promote this process by helping clients increase their existing level of awareness of signs of deterioration. As self-monitoring abilities appear to evolve over time, nurses should begin by assessing the degree of specificity of their clients' current level of distress awareness and the extent to which increasing distress is anticipated rather than simply reacted to. Using such an assessment as a starting point, they can foster development of self-monitoring abilities by encouraging clients to examine and identify fluctuations in subjective psychic discomfort at a somewhat greater degree of specificity.

In summary, although the public issue surrounding the symptoms of schizophrenia tends to be the inappropriate social behaviour that they entail, the personal trouble for people with the illness is the pain that accompanies the symptoms and results from them. It is important, therefore, that nursing interventions regarding self-management of the symptoms of schizophrenia be guided by an empathy for the alien, invisible, and disturbing distress that permeates the lived experience of this very difficult illness.

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