Perceptions and Needs of Parents during a Young Adult’s First Psychiatric Hospitalization: “We’re All on This Little Island and We’re Going to Drown Real Soon”

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A young person’s first psychiatric hospitalization can present a crisis for the family. This initial contact with the mental health care system and health care providers, whether positive or negative, has the potential to set the foundation for all future interactions. The purpose of this study was to examine the impact of a young person’s first hospitalization on his or her parents and to determine the parents’ perspectives on their own emotional and practical support needs. Ten parents (nine mothers and one father) of a young person aged 18 to 25 were recruited through local support groups and by snowball sampling. Based on Aguilera and Messick’s (1986) crisis theory, participants were asked about their perception of the event, coping methods they used, and support systems they engaged while their adult child was hospitalized. Six themes were identified: feeling relief about receiving a diagnosis; shock and disbelief associated with the diagnosis of a mental illness; isolation associated with the stigma of mental illness; feeling excluded during the discharge process; and grieving for the loss associated with an altered future. The results revealed that participants received their support from family, friends, and support groups and did not find mental health care providers to be helpful or supportive. The participants provided recommendations for those who work with families experiencing the crisis of a first psychiatric hospitalization.

The first time a young person is hospitalized for a mental illness can be a time of crisis for the individual and the family. Not only is the individual acutely ill, but the stark realization develops in the family that they may be facing a future with a potentially chronic mental illness. This initial contact with the mental health care system and mental health care providers has the potential to set the foundation for all future interactions. The first hospitalization can be an opportunity for health care providers to engage with the family, within privacy allowances, and collaborate for the individual’s recovery. If the family perceives mental health care providers to be approachable and supportive, a much more positive atmosphere is created than if the health care professionals are perceived to be unapproachable or adversarial. The purpose of this study was to examine the impact of a young person’s first hospitalization for mental illness on their parents and to determine the parents’ perspectives on their own emotional and practical support needs.

BACKGROUND

Although the impact of caring for a family member with mental illness and the place the family might have in facilitating recovery has been well described (e.g., Huong & Slevin, 1999; Karp & Tanarugsachock, 2000; Sin, Moone, & Harris, 2008; Szmukler, Burgess, Herrman, Benson, Colusa, & Block, 1996; Yamashita, 1998), few researchers have examined the experiences of parents at the time of the initial psychiatric diagnosis and hospitalization. Even though the first hospitalization has been reported to have a tremendous impact on families and is acknowledged by health care providers to be very stressful, it has been rarely studied for exactly that reason—the event is considered to be too stressful for the family to participate in research at the time (Levine & Leginza, 2002; Rose, 1983, 1998). Scharer (2000) studied the reactions of parents to the admission process in general and strongly argued that this initial contact point could set the stage for the relationship between the family members and health care providers. Initial contact can provide an opportunity to explore the expectations of the family, clarify roles, and ultimately contribute to a more positive relationship. Furthermore, parents’ expectations and prior experiences with psychiatric treatment have been identified as important factors influencing the nurse-parent relationship. Scharer’s study sample included first time parents as well as those who had been through the admission process many times. Several differences

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were noted in the expectations of the first timers. First time parents often based their expectations on preconceived stereotypes or media examples of health care professionals and the hospital mental health setting. Those individuals who expressed the strongest negative experience with the admission process had no previous experience with health care and their perceived expectations were not met.

In the literature, a strong theme is families’ assertion that there is a need for more support from health care providers (Letvak, 2002). To illustrate this point, Cradock, Young, and Forquer (2002) asked family members to identify and rate what they would like to see as outcomes of a mental health program. The main outcomes included “a supportive and understanding clinician” (p. 259) as well as “an excellent relationship with family” (p. 259). This has not always been realized, however, as Solomon and Marcenko (1992) reported “high levels of dissatisfaction with the hospital in terms of teaching them about medication, teaching them to motivate their relative, providing practical advice on how to cope with their situation, providing assistance in crisis, and giving them emotional support” (para, 32). Similarly, Ferriter and Huband (2003), in a study examining how families rated health care professionals when providing support to the family, found that health care providers were perceived as being the least helpful while support groups and other family members were perceived as being the most helpful. Doornbos (2002) further found that 34% of caregivers in her sample found nothing at all supportive about the mental health care system.

Research suggests, that while health care providers are not perceived to be particularly supportive, they are in an advantageous position to assess the needs, coping mechanisms, and supports used by family members and to offer interventions (Ferriter & Huband, 2003). Saunders (1999) recommended that “since families in crisis are disorganized and frequently unable to restore stability to the family system, nurses must learn to objectively assess a multitude of family processes such as coping, psychological distress, patient behavioral problems, and family social support” (p. 108). Hill, Shepherd, and Hardy (1998) also identified the need for coping strategies and concluded that caregivers caring for people with bipolar affective disorder wanted to know more about personal coping strategies. As a consequence, in this study, we chose to examine the crisis of initial hospital admission and how health care providers might be better positioned to assist parents and, by extension, the entire family.

Theoretical Framework

RESEARCH DESIGN

Since little is known about the needs of family members at the time individuals are first admitted for a mental illness, a descriptive, exploratory study was designed within a qualitative paradigm. Crisis theory was chosen as the theoretical framework because it maintains the focus on the limited time of hospitalization and because a first hospital admission has the potential to become a crisis event.

Crisis theory maintains that a crisis event can be viewed as either an opportunity or a threat. Aquilera and Messick (1986) explain that the main danger of a crisis event is that the family and/or the individual in question may be affected negatively in terms of mental health. On the other hand, the crisis event may present the opportunity for families to grow and learn in a personal sense so they can be more amenable to other available therapeutic interventions leading to recovery. In either case, a state of disequilibrium can occur after the event when the individual and family must either adapt to the event and resolve subsequent problems, or adjust to a non-solution. Ultimately a new state of equilibrium must somehow be established.

This theoretical framework is sufficiently generic to serve a variety of different situations. It begins with stressors that threaten the equilibrium of the individual and family. When the stressors produce a state of disequilibrium, equilibrium must be restored. Balancing factors are identified as those areas that have an influence on the ability of an individual to re-establish equilibrium and include the perception of the event, situational supports, and coping mechanisms. These factors may be distorted or inadequate, however, ultimately influencing the family’s ability to establish a new equilibrium. If a new equilibrium is not established, the crisis continues.

PARTICIPANTS

The first participants were recruited in the winter of 2004 from a local support group for families of young people with psychotic illnesses. A snowball sample was further obtained from these individuals. Nine mothers and one father of young adults with psychiatric diagnoses ranging from psychotic illness to major depression were recruited into the study. Half of the parents were between 50 and 59 and the other half were between 40 and 49 years of age. They were well educated with seven of the ten having university degrees. Seven were working full time and seven were married. All parents had close contact with their child with the mental illness and most of them had their child living with them. Interviews were focused on three areas: perception of the hospitalization; situational supports used during the hospitalization; and coping mechanisms used during the hospitalization. The perception of the hospitalization was simply defined as how the parents appraised and reported their feelings and experiences within the context of the hospitalization. The one- to two-hour interviews were semi-structured.

ANALYSIS

Interviews were transcribed verbatim and analysis was completed using Morse and Field’s (1995) four processes: comprehending; synthesizing; theorizing; and recontextualizing. The data collection and analysis occurred concurrently so that, as the similarities emerged, they could be further explored in subsequent interviews. The transcripts were then read and reread
while listening to the interview tapes until the interview data was understood and the next level of examination could begin (comprehending). Colour highlighters were then used to code similarities and the transcripts were read to ensure that the meaning of the interview data was appropriately identified (synthesizing). Similarities were identified as themes which were combined or renamed (theorizing). Finally, the data were analyzed for patterns and relationships between categories and for the extent to which the data fit with the conceptual framework (recontextualizing). This involved many discussions with a key informant and a secondary discussion with eight of the participants.

**RESULTS**

**Perception of the Event**

Six themes were identified: feeling relief upon receiving a diagnosis; shock and disbelief associated with the diagnosis of a mental illness; isolation associated with the stigma of mental illness; feeling excluded during discharge; and grieving the losses associated with an altered future. Most of the informants also provided remarkably consistent recommendations for mental health care providers regarding interactions with family members during the individual’s first hospitalization.

**Feeling Relief**

Relief was the first emotion that the participants identified at the time of the hospital admission. The family members provided lengthy, detailed, and often emotionally overwhelming stories about the behaviours and events that led up to the hospitalization. They often described days, weeks, even months of bizarre behaviour and of knowing that something was wrong with their son or daughter but being unsure about how to deal with it. One parent described her son’s first suicide attempt as the event that led to the hospitalization. Another parent described weeks of sleeping on the floor of her agitated and paranoid son’s room prior to bringing him to emergency.

Once the parent was able to bring his or her son or daughter to the hospital, acknowledging that something was indeed wrong, they felt a sense of relief with the hope that things were going to be fixed or that, at least, help was available. One parent said:

> Oh, God! Did I want to leave him there? Yes, in some ways ... it’s like you know he’s not safe at home. And something had to be done

**Disbelief and Shock**

Relief did not last long before disbelief and shock set in. The sense of disbelief and shock was described by family members who had not been aware of their son’s or daughter’s diagnosis before the admission. Informants described themselves as being in a “fog,” where their lives were a blur interspersed with moments of crystal clarity. One parent said: “And we went to walk out the door and I’ll never forget the sound of that door shutting. Very gentle touch and this little click indicating he’s locked, he’s locked in. My baby!”

During this time parents often expressed their concern that their child did not “belong” on a psychiatric unit. In most situations, the hospital setting was a locked unit where patients of various ages and in diverse mental states appeared to be wandering around. Parents who were experiencing this type of environment for the first time were clearly uncomfortable with it. Their expectations may have been based either on television or movie portrayals, their imaginations, or the situation seen in other general areas of the hospital. One mother described her experience of leaving her son behind in a locked unit: “... it’s ... it’s like, this is not happening. This is NOT happening. You open the door and you get out of the elevator and you get into that locked unit...”

**Feeling Alone and Stigmatized**

A “feeling of being alone” was a theme clearly identified by every participant. At some point in the hospitalization they felt that no one had ever experienced this type of situation before and that hope was lost. The fact that inpatient staff seldom, if ever, acknowledged their presence on the unit when visiting their child further exacerbated their feelings of invisibility and guilt.

Contributing to this sense of isolation was the stigma of mental illness. The parents often felt they could not share what was happening to their son or daughter with their friends or co-workers because of a fear of being judged, appearing to be awkward, or because the topic seemed to be unacceptable. Some parents commented:

> Do you read stuff about this in the paper? No, it’s almost like oh, hush, hush, don’t talk about this.”

> “And most of our friends didn’t understand it. Lord knows we didn’t, so it was hard for them. They stayed away because they didn’t know what to say. Yeah, so it’s like, OK, here we are on this little island and we’re all floating and we’re going to drown real soon.”

Some parents described a need to hide the experience from other family members or to keep their son or daughter’s mental illness a secret. One parent was asked to keep the secret from his other siblings at the request of her hospitalized son.

For my son, there was so much stigma attached to [the hospital] and being in [the hospital], when we took him there, that first night, and he said, I do not want you to tell anyone that I am here.

**Feeling Excluded During the Discharge**

Every interviewed parent told a discharge story that expressed the feeling of being excluded from the process in many ways. They felt excluded even when they had been invited to the discharge meetings. Parents wanted to be heard when they expressed their concerns or asked questions about discharge and wanted to know what and what not to do to do next. Receiving an invitation to a discharge meeting on the day of discharge did
not allow sufficient time for the family to adjust to the idea of discharge or to prepare for the care of their family member that might be required once they were home. Parents reported that discharge meetings were intimidating and that they did not feel they were heard nor that their input was deemed to be of any significance:

It felt more like, this is our [the health care team’s] plan. Our plan is to discharge him and, you know, like it wasn’t, it wasn’t a joint decision. It was like, he’s going to get discharged. What do we need to talk about before it happens? Like it was a place to air concerns but it wasn’t a place that decisions were going to be changed or anything you know. I was, at that point I was relatively happy to have him in the hospital . . . relatively concerned about him coming home.”

Grieving for the Loss of Expectations and an Altered Future

Loss and grief was the last theme identified from the interviews. Often this part of the interview was the most emotional. Coming to the realization of and understanding the reality of the diagnosis was similar to a grief reaction for the parents as it represented the loss of expectations and dreams for their child. One of the participants tried to explain the intricacies of the process during the interview:

You’ve lost the person, the expectations, the athletic guy, the pretty good marks, you know, he’s got a future . . . You’re losing your dreams of where he will be, of having a normal life and having a family and of grandchildren . . . and you’re grieving for yourself but also grieving for them because you know that they realize, or they will realize that, that they, that their lives will be different.

Environmental Supports

Environmental supports were identified by the family members based on what they received and what they wanted. Parents identified their own family or friends as their main source of support but also mentioned different support groups or places such as local self-help organizations, where information was readily available. Interestingly, the families clearly did not perceive the hospital staff as being supportive. Participants stated they were seldom, if ever, acknowledged when they visited their child and were infrequently and inconsistently included in any discussions prior to discharge. When asked outright if they found the health care providers to be supportive, they answered resoundingly, “No.”

Coping

The final part of the interview included questions about coping where participants were simply asked “What did you do to cope with the experience of the first hospitalization?” Parents reported using a variety of coping mechanisms, which worked to varying degrees. According to Lazarus and Folkman (1984), conceptualized coping functions can be either emotion-focused or problem-focused. Emotion-focused methods are used when the perception is that nothing can be done to change or control the situation. Problem-focused coping occurs when the situation is appraised as being changeable and problem-solving techniques are used to address the situation.

Problem-focused methods of coping that were identified by parents included seeking information or learning about the illness, becoming physically active (e.g., aerobics or walking), and going to work where no one knew about their son’s or daughter’s situation so they could feel “normal” for a short time. Emotion-focused methods of coping included escaping, substance use, and expressing emotions. The most frequently mentioned method described was expressing emotions by crying. For example, one parent said, “After visiting him in the hospital, I’d drive up to the cottage, go for a walk on the beach, and just cry.”

Surprisingly, the parents readily volunteered information about their use of alcohol, cigarettes, and prescription medications to cope with their situation.

Towards the end of the interview, the participants were asked if they had any suggestions for health care providers that would have helped them cope with the crisis of the diagnosis and hospitalization. They had many, which included:

- **Acknowledge the family and make a connection**: The family is entering into an unknown experience that is not “just another routine admission” for them. Hospitalization is a last resort and the parents have already played a huge role in the story leading up to the hospital admission. This needs to be validated as does their contribution. Simply say “Hello” and ask “How are you?”
- **Offer coping mechanisms**: By discussing effective coping mechanisms with the family, the staff could demonstrate understanding of their situation and can offer some support. Trustworthy and accurate, evidence-based information is necessary to decrease family members’ anxiety, assist with problem-focused coping, and decrease the feelings of helplessness. Recommend a support group. These groups are essential so that parents can pool resources and address their feelings of isolation.
- **Provide comprehensive involvement at discharge**: The reality is that most families take their children home from the hospital and become their caregivers. Families need to be a part of the overall plan for continuity and consistency of care and ultimately, an important part of the clients’ recovery.
- **Instil hope**: Hope in a time of crisis depends on others. However, health care providers need to consider the ambiguity of mental illness and their own beliefs about recovery when discussing prognosis with the family.

It is important to note however, that none of these recommendations is of any use if health care providers do not interact with the family. Several parents stated that the health care providers
would not or could not interact with them because their son or daughter had not consented to having information shared with the family. Some parents went so far as to suggest that the hospital staff were hiding behind the Personal Health Information Act. In any case, the lack of consent for sharing of personal health information does not prohibit health care providers from intervening with any of the aforementioned suggestions. The privacy rights of the client can be maintained while still attending to the emotional and informational needs of the family.

DISCUSSION

The diagnosis of mental illness in a young adult child was indeed a crisis event in the lives of the families who participated in this study. In their perceptions of the event, they related experiencing emotions ranging from relief to shock to grief. Accordingly, in this study, the family members wanted validation that their experiences were difficult and devastating. They also wanted recognition that their efforts to help their child in the time leading up to the hospitalization weren’t in vain and they wanted to know that they were not deemed to be failures as parents. This recognition was generally not forthcoming from the mental health care professionals they encountered in the inpatient system. As a result, they felt that they were expected to relinquish their roles as parents while their child was hospitalized. Milliken and Northcott (2003) described similar experiences at a stage where parents became disenfranchised as they realized the situation they were in was one where their experience and expertise as parents was marginalized. Although parents believe they know their child better than anyone else, psychiatrists and other professionals seldom consulted or even listened to them. Yet, paradoxically, the young person was often discharged to the parents’ home and care. The majority of these parents discovered that “their ability to take responsibility for their child was effectively blocked by the law, by mental health professionals, and often by their own children” (p. 104).

Parents described these feelings of isolation and marginalization progressing throughout the hospitalization through to discharge. Chambers, Ryan, and Connor (2001) recommended “a need for a systematic discharge strategy” so that carers do not feel they have to take the initiative to seek professional help” (p. 104). Although their study was not specific to mental health, their conclusions and research findings were surprisingly similar to those presented here. They also recommended that health care professionals be more aware of the experiences of caregivers, provide referrals to support groups, and address the need for coping strategies to include “problem solving, as well as [institute] treatment aimed at emotional catharsis” (Chambers et al., 2001, p. 104).

In the current study, the participants did not identify hope as being present in great abundance. They did, however, identify helplessness, which is inversely linked with hope. As long as people believe that the situation is hopeless and describe themselves as being alone, they see little chance of hope. Therefore it is largely dependent on others to take the early initiative. To quote Miller (2000): “When significant others believe in the possibility of a positive outcome and convey a willingness to share the crisis, hope is enlivened” (p. 524). This is where health care professionals and support groups can make a difference and facilitate positive coping mechanisms.

The coping method that was most often described by parents in the current study was crying, a type of emotion-focused coping, suggesting that family members may have viewed their situation as one over which they had little or no control. The family members also identified a need to learn more coping skills (Hill, Shepherd, & Hardy, 1998). Some researchers have specifically focused their research on coping. Huong and Slevin (1999) identified many methods of coping used by caregivers of individuals with schizophrenia, many of which were also identified by the participants in the current study. The methods of coping were categorized into psychological coping, physical coping, and social coping and included such activities such as keeping busy, seeking information, using alcohol or smoking, and getting physical exercise.

By recognizing this and discussing these aspects with family members and informing them about what they might expect to experience during this difficult time, health care workers can aid them in coping with the situation. Offers of support to the family, and the recognition of the reality of the situation can be beneficial. Health care professionals can be helpful by suggesting family members avoid more problematic coping techniques that would be of little overall benefit, such as increased alcohol consumption or drug use. At the very least, health care professionals should ask family members about what they have done in the past to cope with stressful situations. This discussion may prompt families to use coping mechanisms that were successful in the past.

However, in this study, since support was not forthcoming from mental health care professionals, parents needed to look elsewhere for knowledgeable, credible support, and information. Family members not only identified the need to have access to information about support groups but also recognized the benefits of support groups. Mannion, Meisel, Drainie, and Drainie (1996) compared family members who attended a support group with those who did not and concluded “that participation in a support group positively affects key variables in the participant’s adaptation to mental illness in a relative . . . members report more extensive adaptive coping and less subjective burden than do non-members” (para. 30).

LIMITATIONS

The sample size (N = 10) was small, although all of the city’s inpatient mental health care sites were equally represented. A replica study that accessed a larger group of individuals would strengthen the conclusions.

The current sample included nine mothers and only one father. As has been noted by other authors in mental health
research (e.g., Nystrom & Svensson, 2004) recruiting male participants is typically a difficult task. Since several of the female participants in the current study suggested the needs and experiences of fathers were different than their own as mothers, exploration and comparison of the experiences of fathers is needed. It was interesting to note, however, the striking similarities between the findings in this study and Nystrom and Svensson’s (2004) work with the experiences of fathers in caregiving roles.

In the current study, a variety of mental illnesses were represented. Little is known about how the needs of parents might be different for a son or daughter who may suffer with depression, bipolar affective disorder, or schizophrenia.

The majority of participants were accessed through a support group which has several implications. For example, they may have been unduly influenced by the discussions that had taken place in previous support group meetings. Nevertheless, since the interviews were based on the personal experiences of the parents, it is less likely that their descriptions of their experiences changed as a result of having attended a support group meeting. Further research involving a more diverse group of participants would help to elucidate possible influences and biases of those who had attended a support group. Furthermore, recruiting through the support group resulted in a well-educated, primarily white, middle-class sample. Further research with other socioeconomic and ethnic groups will be needed to gain a broader understanding of the central issues.

CONCLUSION

The experience of an initial psychiatric hospitalization was indeed a crisis in the life of the parents interviewed. They reported emotions ranging from temporary relief to profound shock to longer lasting grief. To make the situation worse, emotional and educational support was often hard to come by. The stigma of mental illness made their dilemma a difficult one to discuss with friends and even with other family members. They further felt ignored by and invisible to the professionals caring for their children. Because parents need to be active members of the caregiving “team” as their child heads out on the road to recovery, early engagement between parents and mental health professionals is crucial. Furthermore, health care providers must recognize that “just another admission” for them is a profound life-changing crisis for the patient and their family and, as such, represents the classic opportunity accorded to a crisis—the potential for disaster versus the potential for life-giving growth.

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REFERENCES


