Redefining Parental Identity: Caregiving and Schizophrenia

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When parents try to assume responsibility for an ill adult-child with schizophrenia, the law, mental health practitioners, and often the ill person reject their right to do so. Consequently, these parents regard themselves as disenfranchised, i.e., lacking the rights required to care properly for their loved ones. Redefining Parental Identity, a grounded theory of caregiving and schizophrenia, traces changes in a parent’s identity and caregiving during the erratic course of the child’s mental illness. Participants were a purposive sample of 29 parent caregivers from 19 families in British Columbia, Canada, caring for 20 adult children. This understanding of their experience will be helpful to parents of people with schizophrenia, professional practitioners, and those involved in mental health care reform.

Schizophrenia causes disability in the form of impaired social functioning that lasts for a protracted period, often the rest of the individual’s life. Community care for the mentally ill has proven effective where there is appropriate discharge planning, coordinated case management, and the necessary social supports, both formal and informal, for patients and their families (Stein & Test, 1980; Reynolds & Hoult, 1984). Unfortunately, reports of patients’ “falling through the cracks” of the mental health care system (Isaac & Armat, 1990; Torrey, 1995, 1997) remain prevalent. The consequences of this include homelessness or inadequate housing (Mechanic & Rochefort, 1990; Torrey, 1988), poverty (Lurigio & Lewis, 1989), victimization, and/or criminalization of the mentally ill (French, 1987), as well as a “revolving door” cycle of hospital admission-discharge-readmission (Geller, 1992). In the process of deinstitutionalization, a significant amount of care has been transferred from professionals to inadequately prepared lay people—frequently the ill person’s family. Consequently, with schizophrenia having its onset in adolescence or young adulthood, the burden of providing consistent care generally falls by default to the individual’s parents.

Studies of family care for mentally ill persons are, for the most part, either descriptive or focused on identifying the tasks required to provide technical aspects of care (see, for example, Hatfield & Lefley, 1987; Thornton & Seeman, 1991; Torrey, 1995). Theoretical models of caregiving generally follow the stress paradigm (Biegel, Sales, & Schulz, 1991; Maurin & Boyd, 1990) and emphasize both ongoing
family disruption (Terkelsen, 1987) and the endless duration of caregiving (Howard, 1994). Many researchers have measured caregiver burden (Pickett, Cook, & Solomon, 1995; Wright, 1994) or the degree of expressed emotion in the family as a risk factor for the sufferer’s relapse (Brooker, 1990; Hogarty, 1985).1

Research employing interpretive methodologies is less common. Tuck, du-Mont, Evans, and Shupe (1997) outline the phenomenological transformations in family life and the grief suffered by parents when an adult-child has schizophrenia. They note that these parents must reformulate what it means to be a parent to their changed relative. The present study revealed parents undergoing this reformulation sporadically in response to the erratic course of their adult-child’s illness. Chesla (1991) identified a typology of four approaches to parental caregiving for schizophrenia: engaged care, conflicted care, managed care, and distanced care. We agree with Chesla’s conclusion that conventional research into caregiver burden misses the distinctions among these groups of parents; however, we suggest that by grouping parents’ caring practices in this way, we can describe a particular family only at a given point in time. Over the course of the illness, parents are likely to vary their caring practices in response to the adult-child’s illness trajectory and the involvement of mental health professionals. Consequently, we saw the need for a grounded theory study to explain the subjective and emotional experience of parental caregiving in schizophrenia. As an exploratory method, grounded theory, with its emphasis on social interaction, is “the method of choice when we want to learn how people manage their lives in the context of existing or potential health challenges” (Schreiber & Stern, 2001, p. xvii).

Due to the unforeseen but often tragic consequences of deinstitutionalization, health care professionals and policy makers need a more thorough understanding of caregiving for people with serious mental illnesses. Knowledge of the consequences of caring for a mentally ill family member is essential in planning for better psychosocial rehabilitation services. To this end, the Canadian Alliance for Research on Schizophrenia called for psychosocial research “to evaluate the concrete and complex interactions of specific families in order to identify positive attributes which could, in turn, predict improved outcome” (1994, p. 14). This study directly addresses these points, to help us understand the challenges of schizophrenia for families and to inform mental health researchers with interests in grief, caregiver burden, and quality of life.

METHOD

Following university research ethics approval, we recruited participants through the newsletters of the British Columbia Schizophrenia Society and the Caregivers Association of British Columbia. Others were recruited through snowballing or, in one case, after the study was mentioned on a local radio program. We interviewed 29 parents from 19 middle- or working-class families, many of whom were retired (mean age = 62)—both parents in 10 families, the mother in 6 families, and the father in the remaining 3.

In total, the interviewed parents had 6 daughters and 14 sons afflicted with schizophrenia, two of whom had died in the 5 years prior to the study. Of the remaining 18, daughters averaged almost 30 years of age (range = 21-38), having been diagnosed on average at just over age 20, whereas the sons averaged 32 years
(range = 23-42) and were diagnosed about 6 months earlier on average than the daughters (mean = 19.6). None of these young adults had ever been married and none were employed at the time of the interview. Most had lived with their parents for extended periods during their illness, but only four did so at the time of the study. The rest were about equally divided between group homes and semi-independent or independent apartments. In total, these parents had been caregiving for schizophrenia for an average of 11.5 years (range = 0.5-23 years) after their child’s diagnosis; however, many of these children were also ill for a lengthy period before being diagnosed.

If roughly one third of people with schizophrenia recover, one third have a variable disease course, and one third remain chronically ill (Walsh, 1985), this group is more chronic than average. Nevertheless, this study examines a wide variation in parental experience. The grounded theory of redefining parental identity that emerged from this study illustrates their diverse caregiving experiences and should help us understand caregiving by other parents in similar circumstances.

In-depth, audiotaped interviews of approximately 1.5 to 2 hours were held in a private setting chosen by each participant. This was generally the parents’ home. Couples, except for one, were interviewed separately. We guaranteed confidentiality and anonymity, and informed participants of their right to withdraw at any point. Near the end of the project, several participants had follow-up interviews, which were aimed at theoretical elaboration, saturation of incomplete categories, and verification of the theory. The final tally was 32 interviews, for a total of 53 hours. The interviews were transcribed verbatim to preserve the richness of the data.

Initially, we asked participants broad, open-ended questions to elicit both the positive and negative consequences of caring for a family member with schizophrenia. In keeping with the constant comparative method of grounded theory, data collection and analysis proceeded concurrently. We coded transcripts phrase by phrase and collapsed similar codes into increasingly broad categories. Over time, the interview questions changed as analytic categories became saturated or participants introduced new categories that generated new hypotheses to be explored during further data collection. As the theory developed, we validated the emerging concepts against the stories of new interviewees and in follow-up interviews with selected respondents, using theoretical sampling. Data collection ended when the interviews produced no new categories and the analysis revealed the basic social problem experienced by these parents and the ways in which they work through it.

A GROUNDED THEORY OF REDEFINING PARENTAL IDENTITY

In general, a grounded theory serves to explain the process through which a social problem common to the participant group is resolved. The basic social problem identified in this study is that parents believe they have the right and responsibility to care for, protect, and make decisions for children whom they do not see as capable of caring for and protecting themselves or making appropriate decisions in their own best interests. However, when a child is deemed an adult, this belief is not sanctioned by society, which denies parents that right. In response, parents whose adult-
children suffer from schizophrenia engage in the basic social process (BSP) of redefining their parental identity and thus adapting their caregiving.

The socially prescribed change in parental caregiving for teens and young adults is toward freedom from management and direction. Parents are expected to socialize their children toward independence, and as this happens, parents anticipate that their own responsibilities will decrease accordingly. Ultimately, parents expect to be emancipated from active parenting.

After a child is diagnosed with schizophrenia, the parents’ identity shifts. Initially, they find themselves disenfranchised from the role they expected to fulfill; then, they find new ways to exert their rights and responsibilities, thus establishing a new parental role. We have identified four parental identities, and the transitions between them, that constitute seven stages of a BSP called Redefining Parental Identity. The stages, parent of a teen or young adult, becoming marginalized, the disenfranchised parent, embracing the collective, the reenfranchised parent, evaluating my life, and the emancipated parent, are summarized in the following sections of this article.

**Parent of a Teen or Young Adult**

Adolescence, characterized by young people’s testing the limits of their independence, can be challenging for both parents and teenagers. Parents need to find a comfortable balance between granting freedom and providing supervision, with a gradual increase in freedom and a corresponding decrease in supervision, until the child achieves independent adult status. Accordingly, parents expect that the adolescent period will be time limited and that eventually they will be able to invest more time and effort on their personal interests and adult relationships. This anticipation of freedom from the constraints of parenting is rooted in the promise of their children’s aspirations and remembrance of their children’s early achievements, behavior, and personality. Thus, parents of teens and young adults can be described as anticipating liberty while tolerating adolescent challenges. Participants in this study described their children’s early development as normal, with positive traits outweighing negative qualities and lacking any indication of impending mental illness. None of these parents was overly surprised when grades began to slip and/or behavior deteriorated during adolescence, and only two of the parents suspected antisocial attributes as signaling mental health problems. Eventually, however, all of these parents found that they could no longer view their son’s or daughter’s conduct as normal teenage behavior.

**Becoming Marginalized**

This initial status passage, or transition, for these parents involves becoming alarmed and assuming responsibility for the child, but also encountering barriers. Parents in all but four of these families reached a crisis point when the child’s personality, behavior, and relationships with family and friends became so disruptive, bizarre, or dangerous that the changes could no longer be disregarded. Their children became excessively angry, depressed, anxious, isolated, or preoccupied, and family relationships suffered. Insomnia and street drug use were common, as was an attraction to nonmainstream religious groups and a propensity to disappear abruptly, often to
live on the streets. When contacted by the child for money or by the police or social workers, parents willingly rescued their children and brought them home, often at considerable expense.

Rising concern compelled the parents to assert more control and assume responsibility for helping and protecting their child. Reluctantly, parents admitted to suspicions of mental illness and consulted a doctor or mental health professional, often taking the young person involuntarily to the hospital, sometimes with the help of the police. Still, a diagnosis and treatment were not always obtained. Some of the young people, fearing hospitalization, were able to cover up their symptoms long enough to fool the authorities. For example, the police released one daughter, who immediately disappeared again and was returned much later by an elderly couple who found her wandering on the beach. At home, after being revived from the cold, she

became completely hysterical, throwing herself on the floor, hiding from monsters, and just totally disorganized, [with] paranoid delusions. She was again convinced that Michael the archangel was after her and was going to gouge out her eyes. She thought that I had murdered her brother and chopped him up and buried him in the backyard, that I had murdered Teresa [her mother] and replaced her with an android. I went downstairs . . . and phoned the police again. They came with two cars, four officers, and an ambulance. They took her to the hospital. This time they realized that she was ill and she was admitted. (Bruce)

Once the diagnosis of schizophrenia was made, parents found that their influence on their children’s care was severely limited. These “children” had reached the age of majority or were otherwise deemed to be responsible for their own decisions. Parents learned that even when a psychotic person loses the right to self-determination, professional caregivers, rather than parents, have the authority to direct care. 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 child. When these parents realized that they had no formally recognized right to assume that responsibility, they had, indeed, become marginalized and, consequently, they assumed a new parental identity. They now saw themselves as disenfranchised.

The Disenfranchised Parent

Parents felt obliged to safeguard their loved one’s health and welfare and to ensure that professional help was obtained early to avoid another crisis. Nevertheless, they continually met obstructions whenever they tried to intercede on their child’s behalf. At this stage, they described a miserable existence composed of maintaining vigilance, grieving alone, and grasping at straws. One father observed,

The only thing that keeps her alive during those periods is our resourcefulness. You know, our vigilance. So even though she is an intelligent 26-year-old woman, it is still as though you have a 2-year-old you’re worried is going to run out in front of a car, because she does do things like that. (Bruce)
Life revolved around constant surveillance, watching carefully for signs that the hallucinations, delusions, and bizarre behavior that characterize schizophrenia were returning or worsening. Watching a loved one deteriorate and feeling powerless to intervene is painful for parents, who see a young person becoming increasingly socially withdrawn, emotionally deprived, and lacking in motivation. A mother whose son committed suicide after a decade of illness said,

As he got sicker and sicker his personal hygiene went down the drain. He frequently smelled bad the last few years of his life because I guess he just didn’t have energy to shower. One of the people that came to his memorial service was the barber. The barber was a big deal in our life because when we could get him to agree to go to the barber, quite often he went to the barber’s home so he wouldn’t have to meet other people, and this man was very understanding. (Sue)

Parents watched over their child’s psychiatric treatment, trying to ensure compliance with medication and keeping track of developing side effects. In an underfunded system, many parents become, by default, their child’s case manager. Although a few were able to establish communication with practitioners, most either lacked access to health care providers or perceived that practitioners did not respect their opinions. Gwen knew the pattern of her son’s illness well. When he stopped taking his medication, fired his psychiatrist, and switched to a psychologist, she tried to avert a relapse:

I had phoned his counselor who actually had an MA in psychology, and I said to him, “You know, Colin was definitely becoming ill again, heading for a breakdown. I don’t know if you realize this because he is very clever at concealing it.” And he said, “Oh well, what makes you think he is?” And I said, “Well, one of the things is that he is reading the Bible constantly and this has always been one of the early symptoms.” So he said in a very sarcastic voice, “Oh, I see. Because your son is reading the Bible, you think he should be on medication?” (Gwen)

A parent’s vigilance is also motivated by fear: fear of schizophrenia, fear for the ill child’s safety and future, and sometimes fear of his or her violent behavior. Parents feared that they would be unable to cope or that they might provoke a relapse, that their child would never recover, and that another child or grandchild would also become ill. The unpredictability of schizophrenia was particularly difficult, as one mother’s story illustrates:

I’ve realized that it’s not so much the things that happen, though a lot of really painful disturbing instances have happened, but they are quite short, the instances in themselves. It’s the fear in between. It’s the remembering and the anticipation and the wondering if you can cope with it. It’s like waiting for the other shoe to fall all the time. If you could just get that under control, you would be stronger to deal with the instance and you would recover from them more quickly because you wouldn’t be anticipating the next one. (Maggie)

Initially, most parents learn about schizophrenia from the media, where violent behavior is often emphasized. In these families, violence was relatively infrequent and seldom reached the severity found in the press. Still, several of these parents were attacked by their offspring—one mother fatally. More commonly, violent acts were directed at property or themselves. Eight of these young people had attempted suicide—one successfully.
Furthermore, especially when they stopped taking medication, the ill persons’ lifestyle made them vulnerable to victimization. Many of these young people ran away from home, took illegal drugs, and lived on the streets for months at a time. Three of these young people were beaten up in major cities far from home. Several had money and belongings stolen. Parents worried about their contracting sexually transmitted diseases. Even those living semi-independently or in apartments were easy targets for burglary.

Not surprisingly, these parents reported high levels of stress, born out of feelings of frustration, powerlessness, and poor self-esteem:

> Elaine and I watched the powerlessness that we sensed, that grew in over the 2-year period. You know how sometimes you have a gut feeling you are in a losing situation? That’s how I felt the entire time. Every time we’d lose something. (Fred)

Extra expenses, such as supplementing their child’s limited social assistance, airline tickets to bring a runaway home, replacing damaged belongings, and moving expenses following eviction, add financial strain. Frequent crises, coupled with their determination not to give up and to try to normalize life for the rest of their family, only add to the pressure.

From the diagnosis of their child’s schizophrenia onward, these parents experienced emotions that are associated with grief, as described below:

> What I grieve every day is [her lack of a] functional life. I grieve that every day, for Anne. Every day. Anne is never out of my thoughts and I say, “How could that happen?” How could that happen to others too? Not just Anne, but how could the illness be so cruel? Cruel, right in the bloom days, that’s when it flares up. Anne will never see those years again. (Teresa)

Disenfranchised in their caregiving, their grief is also disenfranchised (Doka, 1989). This child is not dead but instead has become like a stranger. Although parents grieve for the child that they once had, our society provides only rituals to help ease grief following physical death. In addition, totally preoccupied with caring for their ill child, many parents become socially quite isolated. Consequently, although they grieve for the person their child once was and for the life that they hoped their adult-child would have, they have little opportunity to communicate or share their grief with others. They grieve alone.

At this point, parents will grasp at any straw, looking for answers and, especially, for a cure. They desperately seek out second opinions, new and experimental treatments, and more knowledge about schizophrenia. Whether these parents learned anything about schizophrenia from their child’s psychiatrist was a matter of luck. Some had doctors who were helpful and forthcoming in giving them information and describing the possibilities in terms of prognosis. Others—like Gwen and Irwin, who were told only to prepare for a “bumpy ride”—were given the diagnosis and nothing else. Information gleaned from various sources was often conflicting or overly technical. Instead, these parents needed practical advice from others in similar circumstances. Reaching out for that kind of help signaled a redefinition of parental identity beyond being disenfranchised.
Embracing the Collective

Requiring practical information about caring for someone with schizophrenia and an opportunity to communicate with people who understand their plight leads many parents to a support group. In British Columbia, the B.C. Schizophrenia Society usually provides this service. By connecting with others, they quickly learn that they no longer face mental illness alone. They find empathic people with whom they can speak honestly. In addition, they learn useful ways to approach people, either personal acquaintances or mental health service providers, who are less understanding. The Schizophrenia Society also offers a library of books and videotapes, organized educational programs, and monthly meetings with knowledgeable guest speakers. As a bonus, they make new friends.

If you want to get on top of the disease, you have to get access to that information, and experience, and counseling, and support. And the monthly meetings for some people are tremendous. Right off the bat they can unburden themselves and people will just understand and they will say, “Well, when you do so and so,” “If you try such and such” or “This piece of information will tell you how to access that.” And that’s when the support starts to roll out. [long pause] That’s the one piece of advice that just stands a mile high in my view. [You need to] talk to people that have been there. (Michael)

In time, these new friends become their primary reference group, which leads parents to redefining their child. Having been blocked so often in their attempts to help their own ill child and to influence his or her care, these parents began working for the betterment of all those who suffer from this devastating illness. They realized that helping everyone with schizophrenia in turn benefits their own child. Thus, they appear to have expanded the scope of their parenting and to have symbolically redefined their “child” as the community of people affected by schizophrenia, both patients and other families. Once they have fully embraced the collective, they have entered the next identity, the Reenfranchised Parent.

The Reenfranchised Parent

The identity of Reenfranchised Parent allows these parents to regain their parental rights and responsibilities by taking on the “system” through doing volunteer work, advocating for the mentally ill, and providing public education about schizophrenia. These parents develop and apply their personal skills and efforts toward mental health care reform, improving community services, raising public awareness about schizophrenia, and trying to reduce the stigma against mental illness. For example, they advocate for low-cost housing that supports varying degrees of independence; culturally appropriate care for ethnic minorities; family services, including respite care; and the promotion of research. Because of their efforts, parents (and other family members) are increasingly being included in treatment planning:

When I spoke to the staff at [the psychiatric hospital], I said that finally family members are being included in a discussion and a treatment plan and, I said, it’s a little bit like women getting the vote, that it was something they had to fight for, and it should have been a natural process. And so I say the whole question of including family in the treatment and discussion isn’t something that should have been fought for. It should have been there from day one. (Willow)
Although parents approach their volunteering and advocacy with enthusiasm, change is not easily won and the difficulties inherent in taking on an entrenched bureaucracy soon become apparent. Being disillusioned with the system centers around three broadly defined problem areas. First, parents observe limited funding for mental health services in comparison to the technologically exciting fields of health care. They also perceive poor accountability in the mental health system when policy makers, program directors, and individual therapists make promises that they fail to deliver. Finally, they observe the political maneuvering involved in health care reform and become discouraged when changes in mental health programming appear to be based on either political pressure or economic restraints rather than clear scientific evidence of efficacy. As Teresa wryly noted, politicians can afford to ignore the mentally ill because few psychiatric patients vote.

On a positive note, parents no longer have to grieve alone; instead, they are mourning together. The work that they do is valued and shared by others in the Schizophrenia Society and represents an acceptable public expression of their loss, at last allowing them to accept their situation and come to terms with their grief. According to Michael, acceptance means that you might still experience sadness and discouragement, but you never return to really deep despair.

With time, often many years, the ill son or daughter improves somewhat, and perhaps benefits from supportive housing and community services. The parents are older. Although their volunteer activity was satisfying, they become tired. Many have developed their own health problems, some of which might be stress related. Confronting their aging, they begin to reassess how they wish to spend their remaining years.

Evaluating My Life

At this time, parents engage in two evaluative processes: acknowledging realities and identifying their personal needs. Realistic expectations for their child’s future evolve from their recognition of the ill person’s social functioning and the acceptance of the chronic nature of schizophrenia. In essence, the parents adopt the stranger but continue to hope for a better future; however, these more limited hopes center on their child’s achieving contentment and what Margaret referred to as “reasonable times of happiness.” After years of being preoccupied by their child’s illness, they can begin to focus more on themselves or on other long-ignored interests and move toward the status of the Emancipated Parent.

The Emancipated Parent

How parents periodically reconstruct their parental identity can be interpreted as a journey toward the ideal type of the Emancipated Parent, when parents expect to maintain a relationship with their children but withdraw from direct control and decision making. They anticipate eventually enjoying the successes of their self-sufficient offspring, content in a significant amount of well-earned mutual independence. When a child is ill, the parents’ journey toward emancipation is delayed, and their position depends on the location of the child on his or her individual illness trajectory (Strauss, 1975). Although the lives of all of the parents who participated in this study and their ill children improved, mutual independence was an
unattainable goal. Once a child’s diagnosis is confirmed, the specter of schizophrenia never completely disappears. Evelyn stated it in this way:

I guess for every person, you bring the baby home from the hospital and you teach them to be independent and you look forward to the wedding day when they are totally off your hands, and yet if you have a child who is affected with an illness, a chronic illness like schizophrenia, the pattern is going to be slightly different. In a sense, you are never totally the emancipated parent.

For these parents, the end point was a hybrid identity combining (in various degrees) The Reenfranchised Parent and movement toward Emancipation. Indeed, parental emancipation can be a relative thing for all parents, and complete independence is a myth that occurs only in what Willow called the “airy fairy TV family.” Perhaps no parent ever truly gets there, whether the children are healthy or not. Still, for parents of children with schizophrenia, emancipation remains more elusive than it is for many others.

DISCUSSION AND CONCLUSION

Although the above overview describes Redefining Parental Identity as a linear process, it seldom (if ever) is. The self-identities of these parents respond to the fluctuating course of the child’s schizophrenia illness trajectory. With each relapse, parents tend to regress toward disenfranchisement; with improvement, they once again move forward.

Although the terms *caring* and *caregiving* are often used interchangeably in the caregiving literature, some authors draw a distinction that is important for this grounded theory. For example, Fisher and Tronto (1990) define four interconnected components of caring: caring about, taking care of, caregiving, and care-receiving. *Caring about* involves paying attention to a person’s needs. *Taking care of* implies assuming responsibility for those needs, whereas *caregiving* is “the hands-on work of maintenance and repair” (p. 40). *Care-receiving* is the child’s response to caregiving and is influenced by the extent to which the caregiver and receiver agree about what is required.

For these families, the connections among the four components of caring were disrupted, and conflicts arose among parents, the ill adult-child, and other caregivers. Parents cared about their loved one and tried to take care of and provide caregiving to the adult-child. Unfortunately, they frequently lacked basic resources, including time, knowledge, and the necessary skills. More fundamentally, they lacked legal and societal permission to do so. Thus, the vital “taking care of” link between parents’ caring about and their caregiving was disrupted. Their lack of authority blocked the connection between their moral and legal responsibilities for caring.

Fisher and Tronto (1990) state, “One of the most pervasive contradictions involved in taking care of concerns the asymmetry between responsibility and power” (p. 43). They contend that bureaucratic requirements for a division of labor, a hierarchy of power and authority, and the standardization of routines and policies cause contradictions and poor integration among the phases of caring. Such features are characteristic of the mental health system. In Fisher and Tronto’s
estimation, resolving these conflicts requires us to consider caring to be a contextual process. The immediate context of schizophrenia is the family within which it occurs and, to address the contradictions that exist among the components of caring, care for people with schizophrenia must incorporate the needs of their families.

Instead, the tendency has been to disregard and silence families. Feminists explain that oppression hinges on the silencing of women and other marginalized groups by those with power (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1993). A parallel can be drawn to the experience of these parents whose voices are silenced when professional caregivers decline to consult, inform, or even listen to them in regard to their child’s illness, treatment, and prognosis. As a result, these parents are similar to other oppressed and marginalized groups. At the same time, like women more generally in our society, they are expected to care for their ill children. Even if not overtly asked to do so, they are driven to assume that responsibility when no one else takes a perpetual interest in the child’s well-being.

The concept of disenfranchisement of rights is important in conceptualization and measurement of caregiver burden. Statistical models of caregiver burden should incorporate a measure of powerlessness or, alternatively, mastery—something that few researchers besides Noh and his associates have done (Noh & Avison, 1988; Noh & Turner, 1987). Similarly, the suggestion by Reinhard (1991) to include grief in any study of caregiver burden is supported here. Finally, caregiving for someone with schizophrenia lasts for a protracted period, often decades. Most studies of caregiver burden provide us with a snapshot understanding of subjective and objective burden measured once, usually relatively soon after the patient has left the hospital. Only Pai and Kapur (1982) measured burden over time and then for only 6 months. If burden and mastery are assessed later in the process, when a caregiving parent has reached the stage of The Reenfranchised Parent, mastery will likely have increased and burden will have decreased. Thus, there is a need for long-term studies of caregiving to track the changes in burden over time.

One means of testing and refining a grounded theory is to investigate how well the theory can be extended to other groups with similar experiences. Changes in parental identity might help explain caregiving for parents’ adult children who are disabled by other mental illnesses like bipolar illness, by catastrophic accidents causing quadriplegia or brain injury, or by drug or alcohol addiction. The theory may also extend to sibling caregivers, who must redefine their identity as brothers and sisters. As well, the applicability of the model to parent caregivers from diverse cultural backgrounds should be assessed.

In addition to the above implications for research, the study highlights a number of issues for mental health care reform. Professional caregivers must recognize the contribution that families make to the patient’s therapy but also accept professional responsibility to provide care for family caregivers. Respect, compassion, and education for family members, including practical advice about how to interact and communicate with a psychotic person, should be included in the treatment plan, not left for family members to obtain on an ad hoc basis. Case management and assertive community treatment are the cornerstones of a safe and comprehensive community program rather than the responsibility of parents. Care must come to the ill person and his or her family, not the other way around. To accomplish this, community programs must be staffed sufficiently well to ensure that caseloads are manageable.
Finally, in-patient treatment should be readily available whenever a mentally ill person is psychotic, to ensure that parents are not forced to try to manage a son or daughter who has been turned away from the emergency department. Parents told me that policy makers must address how the legal system defines “danger to oneself and others” and institute a more liberal application of commitment to psychiatric care. Refusal of treatment combined with an inability to provide an appropriate level of self-care should be considered as dangerous to self. Although such measures might be perceived by some as patriarchal and an infringement of patients’ rights, they are necessary to achieve more humane treatment of the mentally ill and vital for countering the disenfranchisement of caregiving parents. With mental health care improvements that more fully incorporate the needs of families, parents who might never become emancipated from caregiving would at least be less disenfranchised.

NOTES

1. Milliken (2001) describes selected characteristics of this caregiving experience that are particularly difficult for mothers.

2. Within each stage of this BSP are secondary social processes that define the parent’s activities in that stage. Throughout this article, italics are used to identify these subprocesses.

3. The final phase of the constant comparative method is to link a new grounded theory with the relevant literature. In doing so, we discovered that Redefining Parental Identity is an empirical example of the formal grounded theory of status passage (Glaser & Strauss, 1971). According to Glaser and Strauss, status passage involves a change from one social status to another with “a loss or gain of privilege, influence, or power, and a changed identity and sense of self, as well as changed behavior” (p. 2).

4. Four of the ill adolescents accessed medical help before their parents recognized the need, one of them following a suicide attempt. One young woman was successful in hiding her delusions and hallucinations from her family until her psychiatrist admitted her to the hospital. In the other three cases, the parents were preoccupied with additional family problems. For example, the father in one family was terminally ill.

5. Pseudonyms have been used to ensure anonymity of participants and their family members.

6. All parents talked of how their son or daughter had changed since becoming ill and about how difficult it was to know how to react to or talk to this new person. Seven parents used the term “stranger” or said that someone else had taken over their child's body. Other authors have also used the same term when referring to how a family member with schizophrenia has changed (Hatfield, 1978, p. 358; Tuck, du-Mont, Evans, & Shupe, 1997, p. 118).

7. To emphasize Willow’s point, we originally called this identity Parental Suffrage, to underscore the parents’ own suffering, their tolerance of others, and their engagement in a cooperative and political process aimed at obtaining better understanding and treatment of people affected by schizophrenia. Ultimately, enhancing these collective rights introduces opportunities for parents to reclaim some individual rights and responsibilities with regard to their adult offspring.

REFERENCES


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