Unheard Voices: Mothers of Adult Children With Schizophrenia Speak Up

Catherine White and Anita Unruh Dalhousie University

ABSTRACT

The occupations of a mother are significantly disturbed or restricted when her child is diagnosed with schizophrenia. Emerging family-centred practice models consider the role of mothers as caregivers, but do not adequately address their personal needs. This qualitative study explores the occupational challenges faced by mothers as they navigate the experience, highlighting the impact of the devastating experience of having a child diagnosed with schizophrenia, and draws attention to the need for improved methods of knowledge translation if research findings are to better guide services for them.

Keywords: schizophrenia, mothers, family-centred care, caregiving

RÉSUMÉ

C'est à la mère que le rôle de personne soignante est le plus souvent imposé lorsqu'un enfant adulte est diagnostiqué de schizophrénie. C'est un rôle qui a le potentiel d'affecter le bien-être de la mère. Quoique les nouveaux modèles de pratique axés sur la famille considèrent le rôle que joue la mère en tant que personne soignante, ils n'abordent pas suffisamment leurs besoins personnels ni l'impact négatif de ce rôle. Cette étude qualitative a pour but d'explorer, du point de vue de la mère, les défis associés à l'expérience difficile d'avoir un enfant vivant avec la schizophrénie. Elle met en valeur le besoin de mieux traduire les données empiriques afin d'améliorer les services qui leur sont offerts.

Mots clés : schizophrénie, mères, soins axés sur la famille, rôle de personne soignante

Motherhood remains one of the most challenging roles women undertake, taxing physical and emotional resources but offering immeasurable rewards. One of the greatest challenges to mothers begins when families—an estimated 1.5 million worldwide each year—receive the distressing news that the unusual

Dr. Catherine White, Assistant Professor, School of Occupational Therapy, Dalhousie University, Halifax, Nova Scotia; Dr. Anita Unruh, Professor and Associate Dean-Research and Academic, Faculty of Health Professions, Dalhousie University, Halifax, Nova Scotia.

Correspondence concerning this article should be addressed to Catherine White, PhD, School of Occupational Therapy, Room 306, Forrest Building, Dalhousie University, Halifax, NS B3H 4R2. Phone: 902-494-6578; Fax: 902-494-1229; Email: Cathy.white@dal.ca

changes they have observed in a young adult family member are the result of the onset of schizophrenia (Schizophrenia.com, 2010).

In recent decades, substantial improvements in medication management and a focus on recovery have led to deinstitutionalization and a shift towards community living, increasing expectations on families as caregivers (Glynn, Cohen, Dixon, & Niv, 2006), a role which most often falls to mothers (Awad & Voruganti, 2008). Some mental health services profess support through family-centred care and a range of family supports have emerged, but the focus is commonly on how to deal with the individual with the illness, while the personal needs of other family members go unnoticed (Lefley, 1996). If mothers are to preserve their own well-being when they are thrust into this caregiver role, attention to their own needs is essential. This paper gives a voice to mothers who have a son or daughter diagnosed with schizophrenia.

BACKGROUND

Schizophrenia is commonly diagnosed in young adulthood, a time when mothers are expecting to launch offspring towards independence and free themselves to pursue aspects of life which may have been deferred during childrearing. There is increasing evidence that individuals with schizophrenia can and do recover (Lysaker, Roe, & Buck, 2010). However, secondary to cognitive impairment, relapse, and incomplete remission of symptoms, few reach premorbid levels of function, and many struggle to achieve adult developmental milestones such as developing and maintaining long-term reciprocal relationships, obtaining and sustaining meaningful employment, and living independently (Tandon, Nasrallah, & Keshavan, 2009). The impact reverberates through the family system, often requiring realignment of family resources and redefining of roles, the brunt of which is most commonly felt by mothers who are more likely to assume an informal caregiving role and provide personal and emotional support (Clow, Pederson, Haworth-Brockman, & Bernier, 2009). An ongoing paradigm shift from mothers as pathogenic agents to mothers as crucial partners for sustaining health care provides the backdrop for the experience (Lefley, 1996; Miller, 2000).

The specific brand of caregiving required in this situation differs considerably from other family caregiving situations, such as end-of-life care. Stengard (2002) proposed that in mental health caregiving there are different caregiving types (supervising, anxious, coping, resigned, and activating), each generating specific information and support needs. In a phenomenological study, Tuck, du Mont, Evans, and Shupe (1997) found caregiving to involve watching, protecting, seeking help, and the sacrifice of personal needs. Howard (1994) studied maternal caregivers of adult children with schizophrenia, and developed a cyclical model that suggests watching (vigilance), working (engaging in physical or mental caregiving tasks) and waiting (a balance between hope and dread or despair) as the key caregiving tasks. These are cyclical rather than linear because of the potential for relapse. With few role models and little validation or support, mothers are expected to undertake these clearly demanding tasks without specialized training, skills, or knowledge.

The literature has further explored this challenge from the perspective of burden, identifying both objective or tangible impacts such as financial ones and subjective or perceived impacts such as worry (Awad & Voruganti, 2008; Jones, 1996; Maurin & Boyd, 1990). The experience of mental health caregiving commonly confers a negative impact on the physical, emotional, social, spiritual, occupational, and financial well-being of the family. The situation is made worse when the legal system, mental health practitioners, and at times the person with the illness do not adequately acknowledge parents in this caregiver role (Milliken, 2001). Overwhelming and unresolved grief over the loss of who the child was prior to the onset of mental illness, or who the child might have become, add to the experience (Tuck et al., 1997). Karp and Tanarugsachock (2000) described how the circumstance affects daily routines and upsets the coherence of everyday life for the family. Mothers in this situation tend to revise their own goals downward and restrict their own activities, sacrifices which place their own health at risk (Song, Biegel, & Milligan, 1997). While fathers also participate in caregiving, they spend less time doing so, and are more likely to organize caregiving tasks around their existing routines (Clow et al., 2009).

Clearly, mothers are vulnerable as they struggle to preserve their well-being when they have a child diagnosed with schizophrenia. A variety of self-help, advocacy, and support resources have emerged, such as the Schizophrenia Society of Canada's (2008) Strengthening Families Together program, but the focus remains on how to navigate the caregiver role, without an adequate appreciation of the implications for individual family members. If mothers are to be effective as caregivers and maintain their own well-being, their experiences must be understood and their voices heard collectively, beyond the confines of support groups. Thus, the question posed by this study was: What is the impact on a mother when her child is diagnosed with schizophrenia?

METHOD

This exploratory, qualitative study used semi-structured in-depth interviews, loosely based on the HOPE framework (Farran, Herth, & Popovich, 1995; Farran, Wilken, & Popovich, 1992), which clarifies the complexity of finding hope in the face of challenging life circumstances. This framework includes experiential, relational, spiritual, and rational thought processes. The field-tested interview guide was designed to take participants chronologically through a process of describing their initial and ongoing interpersonal and intrapersonal experiences of having a child diagnosed with schizophrenia.

Following ethics approval from a university ethics review board, a convenience sampling approach was used whereby mothers were recruited through a mailout from the president of the Schizophrenia Society (a national support and advocacy group) in one Canadian province. Each of the eight mothers who replied was invited to participate in a private 60- to 90-minute interview. The interviews were recorded and transcribed verbatim. An inductive approach to data analysis was used. It involved immersion in the data, coding, development of categories, and finally merging the categories into themes that clarified the experiences of the mothers (DePoy & Gitlin, 1998). Member checking was done at the data collection stage by asking mothers to verify quotations through telephone or email contact, and at the analysis stage with a focus group and telephone or email contact. Mothers were provided with the major themes, and all confirmed that the themes accurately reflected their experiences. To enhance truth value, many direct quotations from the mothers have been included.

The mothers ranged in age from 51 to 84 years, and their children with schizophrenia ranged from age 24 to 55. The time since the diagnosis of their child ranged from 6 to 32 years. Two mothers had their adult children living with them. Three of the adult children lived in assisted living situations, and three lived on their own. Two of the adult children were employed, two were in vocational programs, and four

were unemployed or very sporadically employed. Five mothers had a supportive partner or husband in the home, and three mothers were divorced and single. All mothers reported some additional support from their other children, or from their own siblings or parents, and from Mental Health Services. Seven of the adult children with schizophrenia were male, and only one was female. Therefore, all will be referred to as male to protect confidentiality.

FINDINGS

Mothers in this study described an experience that can be likened to a recovery journey, trying to regain a meaningful life in the face of ongoing challenges (Anthony, 1993). Having a child diagnosed with schizophrenia was experienced figuratively, and in some cases literally, as an assault. They never truly recovered from the assault and lived in fear of its recurrence. The findings highlight experiences specific to receiving the diagnosis and becoming a caregiver, and the ways in which the mothers carried these experiences forward.

Diagnosis: "A Shot Between the Eyes"

The period surrounding their child's diagnosis was for all mothers an unpleasant and confusing pivotal event which forever changed the trajectory of their lives. For some, the illness came on gradually, with symptoms initially dismissed as adolescent aberration, while for others a worrisome incident of acute psychosis marked the change. As the diagnosis meshed with existing beliefs and newly acquired information, the reality of the lifelong implications and bleak future for mother and child emerged. "That felt like a shot between the eyes," reported one mother. The world of psychiatry was new to them, and very frightening. One mother described her son's first experience:

He was hospitalized, and to see him in the room with no windows and the door permanently locked and you weren't allowed out unless you needed the toilet, no shoes on his feet.

Mothers were scared, frightened, upset, shattered-strong emotions that would not soon pass.

Initial Treatment: The Roller-Coaster Ride

As treatment (primarily pharmacological treatment) began, a process best described as a roller-coaster ride began with it. All of the mothers eventually grew to expect this unending series of ups and downs linked to compliance with and effectiveness of the medications. One mother described the process:

When we first started with his first medication, everything seemed to go very well, and he was doing very well with it, and then he stopped taking it, and we went through a rough time . . . and he got sick again.

Mothers found the setbacks hard to accept:

The setbacks. The setbacks. We tried so hard. As soon as you think things are going great, some little thing, well you'd know.

Another mother said,

I'm always afraid to be hopeful because things have been such a roller coaster. I'm just . . . making the most of the life that we have right now. Whether it lasts or not, I don't know. I'm terrified.

Thus, periods of stability were viewed with a skeptical eye, and even during those times mothers could not fully relax.

Accepting the Caregiver Role: "A Life Sentence"

It was through this process that mothers gradually became aware that schizophrenia was a lifelong illness and perceived their children as having lost not only their potential but the very essence of who they were. As one mother explained,

And then we realized he is not coming back. It takes quite a few years before you come to accept it . . . they are not the same person that they were. It is very difficult.

Mothers experienced a devastating loss as they relinquished the notion that treatments would fully restore their children.

The mothers described how they found the challenges associated with schizophrenia particularly frustrating because their well-established methods of dealing with life's problems were ineffective. One mother described the process she went through as she gave it priority in her life:

I'll give it two years of my life and we'll get it better you know, make it better. Well, after a year and a half I thought five years . . . and you know, finally I had to come to grips with the fact that this was a lifelong thing. It was a life sentence.

This sense that the diagnosis was a "life sentence," a severe punishment, captured the complexity of her perception that caregiving in this context was unending and difficult.

Experiences such as these led mothers to adjust expectations for themselves and for their children, processes which were not easy:

He was talking about being a lawyer or a minister, and then we realized he was never going to achieve those dreams.

I know I can't hope for him to have a relationship with someone and have a normal life with another person. I know that's not going to happen . . . and that's disappointing.

With no end in sight, quality of life suffered as they struggled to fulfill the demands of the caregiver role, and find balance with other previously valued occupations.

Caregiver and ...: "His Illness Has Affected Everything"

The caregiver role was challenging in itself, but also became the lens through which other roles were viewed. One mother summed it up, stating that "his illness has affected everything in my life." The experience had a great impact on other activities, either restricting them as a function of time use or disturbing them as a function of emotional impact.

Mothers with other children described guilt, feeling that other children were neglected once their sibling was diagnosed with schizophrenia. One mother said,

I can remember breaking down in tears when my other son asked me "do you know such and such" about him, and I didn't have a clue. I was just so consumed.

Relationships with partners varied, with some mothers experiencing support while for others it was an added stress. For example, one mother spoke of marital difficulties which arose as a result of their son's illness:

My husband couldn't cope with it, and I couldn't cope with him as well as my son.

Her husband exited the marriage and had little involvement in ongoing parenting, leaving her alone in the caregiving role by default. Another snuck food and money behind her husband's back to her son who was living on the street. "My husband had forbidden me . . . but I couldn't bear it," she said, highlighting their differing views on what would be helpful for their son.

For others, husbands or partners were supportive and actively involved in caregiving. One mother spoke of the supportive role of her partner (not her son's father):

He understands, and he is of great assistance, not only with advice, but also with emotional support.

Another spoke of her husband's involvement:

We dealt with it in different ways, but we dealt with it together.

Three of the mothers were employed on a full-time basis, two worked seasonally or sporadically, and three were either unemployed or retired. Clearly, having a child with schizophrenia had affected their work role. One mother said,

I still go to work. I don't think I ever said "no" to work, and that still is my therapy because I know I'm going to be forced to focus on something else.

However, maintaining a work role was not always easy. One mother described an experience of visiting her son in the hospital each morning before work:

The nurse would take me off to a little room where I would dissolve in tears, until I could get myself together to go to work, and then I'd go to work and I'd cry there.

She was thankful that her colleagues were supportive, but the situation took its toll, causing her to face the financial implications of early retirement.

Friendships and social interactions were also coloured by the experience. Mothers were often so preoccupied they could no longer engage in social/leisure or other day-to-day activities. For example, one mother said,

We don't socialize like we used to any more. I don't know when the last time is that we had people in. It's just too awkward to have people in with him around, and before that we were just so stressed out we didn't care anyway. . . . I even have trouble getting a meal or making a bed, or whatever around here, and there's times, well my one social activity is my bridge club, and sometimes, I just call a spare to go in for me because I just couldn't face playing bridge.

Another mother described the impact on her personal care and her leisure:

I couldn't get much sleep, because he wasn't sleeping very well. He was hearing people being murdered in the basement at night you see, so he would come into my room and wake me up. . . . My social life, I just didn't have the time and energy . . . and the situation was so bad, I couldn't have friends in, I mean not easily.

Some mothers described trying to keep the diagnosis a secret by avoiding social situations where they might be asked about their son or daughter. For others, friends became supportive confidants. Mothers felt

limited in their choice of social supports as a result of stigma by association, and they placed a high value on interactions with others in similar circumstances:

You can't go to a neighbour. If you say something, they're going to be scared of him. You can't give that kind of information, so you have to find someone who is experiencing the same thing as you.

Some mothers forfeited previously enjoyed social/leisure activities for support and advocacy groups where they could be around people whom they could relate to better. As one mother put it,

They've become sort of like a family to me. I look forward to those meetings, believe it or not. The misery around that table you wouldn't believe, but maybe talking about it helps.

Most of the mothers reported that at this point the actual hands-on caregiving primarily involved monitoring, respite care, vacations, and support. Even so, one mother said,

It's very difficult because you never completely relax and there's always a kind of a feeling in the pit of your stomach, wondering what's going to happen, and it's just very, very hard to go through, that's for sure.

The ongoing unpredictability and uncertainty caused an emotional impact that influenced their occupations and affected quality of life.

Overwhelmed: "Screaming My Head Off"

For many, the occurrence of emotionally charged incidents became too much to bear, particularly when the child's symptoms were not well controlled. Some mothers experienced depression with suicidal feelings when they felt it was no longer possible for them to cope with the overwhelming burden. They were devastated by what their children were experiencing, and overwhelmed by the impact it had on themselves, as illustrated by the comments of two mothers. One said,

I went into a real despair and even thought of suicide once, not in an active way, but as a measure of how despairing I was. I thought I can't do this any more. I cannot do this any more. I'll have to kill myself.

The other mother shared a similarly distressing experience:

I was literally screaming my head off and banging it against the wall because I was in such a bad situation.

Gaining control over the strong emotions was not easy. One mother described how she coped:

I'd take a drive out into the country and I'd scream at the top of my voice in order to vent and get rid of all of my anger and get rid of the frustration, just scream and scream and scream where nobody could hear me. I wasn't affecting anybody else, and then I'd come home and everything would be fine, and then the next period like that I'd get in the car and go for another drive.

Another said,

You don't talk about everything, because it is stressful. You just do what you have to do. Deal with one thing at a time, but you can't put it all together.

This mother graphically described the stressful situation when her son lived in institutional care:

It was horrible. I would go down every weekend to see him. I was exhausted. I would wake up in the middle of the night just practically screaming in pain thinking about him there because the conditions were so awful.

There were some staff members she did not trust, and she did not like seeing her son tied down. She removed her son against medical advice, not knowing what the future would hold. She concluded, "If I'd known ahead of time, I don't think I would have had a child," a powerful testament to the way she felt.

Another mother said,

It's made my old age hell. There's no doubt about that.

She was unable to adjust expectations for her son in a way that was still positive for her:

I am just not hopeful for [my son]. His life is ruined.

She associated hopelessness with what she felt was no longer possible for him:

The hopelessness of it all, knowing that man is never going to have anything. He's unhappy, helpless to do anything about it.

This mother was upset as she reflected on her son's losses, and his own awareness of them:

He is aware that he has lost everything. He has no friends, no wife, no children, no job. He's aware that he is stripped.

She was very angry about it, but seemed not to know where to direct her anger. She later added,

I sometimes wonder what it would be like not to have been tortured by the mental illness of [my son].

Quality of life and occupational well-being were significantly affected in the lives of some of the mothers, as their own health suffered. Many described an underlying anxiety or worry that was always with them. In some cases the child had been violent or threatened violence, and the mother lived in fear:

He would come into my room and wake me up, or maybe he would think I was somebody else, a threat to him, so he would come in, in an intimidating way, and I'd wake up with him standing over me you know, with his arms raised or something. It was horrible.

This mother, who relayed other incidents of threats and violence including one in which she sustained a serious physical injury, had to have a lock placed on her bedroom door. Another mother also described a frightening incident:

The first time he showed any kind of anger and fear about things that were happening to him at the time . . . he set a fire in the basement. It went out, but he took off. He figured the house was going to burn down.

All of these traumatic experiences were difficult for the mothers, and some of them resulted in changes to the care for the child as mothers feared for themselves and for the well-being of other family members in the home. While alternative living situations seemed necessary, when a mother had to make such arrangements she nonetheless felt as if she were turning her back on her ill family member.

Shared Care: "I'm Not Alone Any More"

For some mothers, it was a turning point when they finally obtained appropriate help to share in caregiving. In some cases, shared care was in the form of supported living such as a special care home. In others, it was intermittent support from a case manager or mental health support worker. This relief improved quality of life for mothers and gave them more freedom. One mother described how the extra support influenced her own activities now that her son lived in a supported living situation:

We've really been able to enjoy . . . being able to go out for an hour, an hour and a half walk together, because we were never able to trust [our son] in the house alone.

Another mother was relieved that her son now lived in a supported living situation, had access to a vocational program, and had a case manager:

I'm lucky now because I have a team of caregivers that meets regularly. . . . I'm not alone any more. I was for years, but now I'm not and boy, that feels good.

The changes have significantly affected her quality of life:

Now I don't have the total care. I have the freedom, and my health is getting better. I have the freedom now to look at new things for myself . . . so I'm really excited about that, and I'm having fun with my friends now. We get together and we just have fun.

Her comments, like others, imply that appropriate shared care opened opportunities to develop other meaningful but previously limited roles.

Moving Forward: "I Appreciate Simple Things"

Throughout the process, the mothers described how they realigned their values. Appreciation and enjoyment of the simple things in life made it possible for some of the mothers go on day by day. As one mother said,

I appreciate simple things in life. I think we're all kind of spoiled, and when things aren't running too good, it's a waker-upper. It made me appreciate life more, I would say.

Another mother described her appreciation of simple things:

You know how you have good friends and you can be quiet and not say anything, and just watch the water or a sunset or just walk and be quiet.

Another described her strategy for regaining hope when it was threatened:

Taking a respite from it, that can be simply, I used to go and sit down by the river on one of those benches because the water renewed me, or listening to certain music . . . those are things that . . . they take you away from the worry, the anxiety, the fear. They nurture you.

Peace and tranquility, though at times elusive, were deeply valued and appreciated.

DISCUSSION

This study explored the ways in which mothers endured the challenging process of being and becoming caregivers for adult children with schizophrenia. As in the literature, these mothers confirmed the pervasive sense of burden. Their experiences mirrored the cycle suggested by Howard (1994), as when they were not actively engaged in caregiving tasks (working), they were clearly ever vigilant (watching) with a balanced measure of hope and dread (waiting). Although they identified ways in which other activities were either restricted or disturbed as a result, *disturbed* was clearly the frontrunner.

Mothers in this study described devastating experiences, such as seeing an adult child locked up or tied down, having the family home set on fire, being attacked or injured by the child in response to delusions that she was a threat, or seeing the child react to a belief that someone was being murdered in the basement. It became obvious that these mothers had experienced trauma, in some cases repeatedly, and because of the potential for relapse mothers lived in fear that something ominous would happen again. Although people with schizophrenia are more likely to be victims of assault than assailants (Fitzgerald et al., 2005), the fact remains that psychosis, particularly when untreated, breeds unpredictability which can be manifested in violence. These mothers were apologetic that they at times lived in fear of their own children, but acknowledged psychosis as something out of their control.

Beyond chronic sorrow, which the mothers also experience, they must recover from what has been described as an ongoing trauma (Davidson, O'Connell, Tondora, Staeheli, & Evans, 2005; Fadden, Bebbington, & Kuipers, 1987). To compound the experience, they experienced it not only for themselves but also vicariously, witnessing the suffering of their child. They were truly tormented by what their children experienced—as one mother said, "tortured" by her son's mental illness—and felt helpless and frustrated because they could not alleviate it. Although the mothers were able to resume some previously enjoyed activities, schizophrenia was to cast a foreboding shadow over the rest of their lives.

This study, which used a convenience sampling method, included a relatively small group of participants, all connected in some way with the Schizophrenia Society in one Canadian province; thus the results are not generalizable, and the possibility of bias is acknowledged. However, the findings suggest directions for further study. The gendered nature of the mothers' experiences could be examined in more detail, and compared to the experiences of fathers and siblings. Other variables such as living situation, socioeconomic status, presence or absence of partners and other supports, mental health services available, and length of time since the child's diagnosis could all be explored in more detail to shed light on the family caregiving experience.

In health care, family-centred models of care have emerged as a natural outgrowth of client-centred care (Van Benthem, 2004), but are underused (Doornbos, 2002). Family members such as mothers are credited with having valuable information that is relevant for planning, evaluation, and delivery of mental health services (Ward-Griffin, Schofield, Vos, & Coatsworth-Puspoky, 2005), but there are few avenues for mothers' collective voices to be heard. Furthermore, their own needs, as they relate to health promotion, have been described as "forgotten" (Ward-Griffin et al., 2005, p. 141).

The literature supports the reciprocal link between maternal health and the health of children (Coyle, 2009; Scaffa, Reitz, & Pizzi, 2010; Song et al., 1997). Clearly, in the face of such pervasive stress, the physical and mental health of mothers is at risk. Beyond support, Dunbar and Roberts (2006) suggest that greater attention to the actual needs of the mother/caregiver could assist in more fully enacting the ideals of family-centred care. Acknowledging the importance of addressing personal needs as well as providing validation and guidance, such relationships should encompass caring, partnering, informing, and directing, (Clark, Corcoran, & Gitlin, 1995). Dunbar and Roberts (2006) concluded that mothers could benefit as clients of health-related services such as occupational therapy in their own right, addressing such issues as nurturing the self and occupational balance. Chaffey and Fossey (2004) confirmed the importance of enabling caregivers to focus on other meaningful roles and occupations, highlighting the need for "a balance between caring for each other, and each family member having a life" (p. 205). For some, personal counselling may

be needed to deal with loss and grief. Acknowledging that mothers are possible victims of post-traumatic stress may enable them to get more appropriate psychological help.

The Mental Health Commission of Canada, and specifically the Family Caregivers Advisory Committee, has emerged in recognition of the need for family caregivers to preserve their own well-being and holds promise for the development of more comprehensive approaches. Some policies and programs, such as Canada's Compassionate Care Benefit, have been created to support informal caregiving. However, these programs are poorly suited to many women, such as those who are unemployed or who have seasonal or part-time employment (Clow et al., 2009), and do not meet the needs of those engaged in mental health caregiving, where demands fluctuate significantly over time. A recent study of caregiver needs (Askey, Holmshaw, Gamble, & Gray, 2009) confirmed that caregivers of individuals with mental illness have ongoing unmet needs, and do not feel adequately acknowledged or involved. Furthermore, Askey et al. emphasized that, although most of the issues raised in their study have been identified in the literature for the past 20 years, little has changed. In spite of increased government activity and policy focused on these areas, caregivers still feel disempowered, and their voices are not heard.

CONCLUSION

With recovery-oriented care increasingly guiding mental health services, the need for informal caregiving, most commonly provided by mothers, continues to increase. Clearly, as suggested by Clow et al. (2009), policies, programs, services, and supports to address the health and well-being of caregivers themselves are needed. Integrated knowledge translation and processes to ensure both bottom-up and top-down communication must be addressed if the voices of mothers are to be heard and meaningful change is to be realized. Simply making information available is not sufficient to bring about change (Straus, Tetroe, & Graham, 2009). The collective voices of mothers must be heard if their needs are to be met. Moving forward, an eye to family recovery stands to improve the quality of life for all involved.

REFERENCES

- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health services system in the 1990's. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.
- Askey, R., Holmshaw, J., Gamble, C., & Gray, R. (2009). What do carers of people with psychosis need from mental health services?: Exploring the views of carers, service users and professionals. *Journal of Family Therapy*, 31(3), 310-331.
- Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers: A review. *PharmacoEconomics*, 26(2), 149-162.
- Chaffey, L., & Fossey, E. (2004). Caring and daily life: Occupational experiences of women living with sons diagnosed with schizophrenia. Australian Occupational Therapy Journal, 51(4), 199-207.
- Clark, C. A., Corcoran, M., & Gitlin, L. N. (1995). An exploratory study of how occupational therapists develop therapeutic relationships with family caregivers. *American Journal of Occupational Therapy*, 49, 587-594.
- Clow, B., Pederson, A., Haworth-Brockman, M., & Bernier, J. (2009). *Rising to the challenge: Sex- and gender-based analysis for health planning, policy and research in Canada*. Halifax, NS: Atlantic Centre of Excellence for Women's Health.
- Coyle, S. B. (2009). Health-related quality of life of mothers: A review of the research. *Health Care for Women International*, 30(6), 484-506.

- Davidson, L., O'Connell, M. J., Tondora, J., Staeheli, M., & Evans, A. (2005). Recovery in serious mental illness: Paradigm shift or shibboleth? In L. Davidson, C. Harding & L. Spaniol (Eds.), *Recovery from severe mental illnesses: Research evidence and implications for practice*. Boston, MA: Center for Psychiatric Rehabilitation.
- DePoy, E., & Gitlin, L. N. (1998). Introduction to research: Understanding and applying multiple strategies. Toronto, ON: Mosby.
- Doornbos, M. M. (2002). Family caregivers and the mental health care system: Reality and dreams. Archives of Psychiatric Nursing, 16(1), 39-46.
- Dunbar, S. B., & Roberts, E. (2006). An exploration of mothers' perceptions regarding mothering occupations and experiences. *Occupational Therapy in Health Care, 20*(2), 51-73.
- Fadden, G., Bebbington, P., & Kuipers, L. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, 150, 285-292.
- Farran, C. J., Herth, K. A., & Popovich, J. M. (1995). *Hope and hopelessness: Critical clinical constructs*. Thousand Oaks, CA: Sage.
- Farran, C. J., Wilken, C. S., & Popovich, J. M. (1992). Clinical assessment of hope. *Issues in Mental Health Nursing*, 13, 129-138.
- Fitzgerald, P. B., de Castella, A. R., Filia, K. M., Filia, S. L., Benitez, J., & Kulkarni, J. (2005). Victimization of patients with schizophrenia and related disorders. *Australian and New Zealand Journal of Psychiatry*, 39(3), 169-174.
- Glynn, S. M., Cohen, A. N., Dixon, L. B., & Niv, N. (2006). The potential impact of the recovery movement on family interventions for schizophrenia: Opportunities and obstacles. *Schizophrenia Bulletin*, 32(3), 451-463.
- Howard, P. B. (1994). Lifelong maternal caregiving for children with schizophrenia. *Archives of Psychiatric Nursing*, 8, 107-114.
- Jones, S. L. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, 10, 77-84.
- Karp, D. A., & Tanarugsachock, V. (2000). Mental illness, caregiving and emotion management. *Qualitative Health Research*, 10, 6-25.
- Lefley, H. P. (1996). Family caregiving in mental illness. Thousand Oaks, CA: Sage.
- Lysaker, P. H., Roe, D., & Buck, K. D. (2010). Recovery and wellness amidst schizophrenia: Definitions, evidence, and the implications for clinical practice. *Journal of the American Psychiatric Nurses Association*, 16(1), 36-42.
- Maurin, J. T., & Boyd, C. B. (1990). Burden of mental illness on the family: A critical review. Archives of Psychiatric Nursing, 4, 99-107.
- Miller, E. T. (2000). Partnering: A remedy for the emerging caregiving crisis? *Rehabilitation Nursing*, 25, 124-125.
- Milliken, P. J. (2001). Disenfranchised mothers: Caring for an adult child with schizophrenia. *Health Care for Women International*, 22(1–2), 149-166.
- Scaffa, M. E., Reitz, S. M., & Pizzi, M. A. (2010). Occupational therapy in the promotion of health and wellness. Philadelphia, PA: F. A. Davis.
- Schizophrenia.com. (2010). Schizophrenia facts and statistics. Retreived from www.schizophrenia.com/szfacts.htm
- Schizophrenia Society of Canada. (2008). Strengthening families together (3rd ed.): Helping Canadians live with mental illness. Ottawa, ON: Author.
- Song, L., Biegel, D. E., & Milligan, S. E. (1997). Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community Mental Health Journal*, 33, 269-286.
- Stengard, E. (2002). Caregiving types and psychosocial well-being of caregivers of people with mental illness in Finland. *Psychiatric Rehabilitation Journal*, *26*(2), 154.
- Straus, S., Tetroe, J., & Graham, I. (2009). Knowledge to action: What it is and what it isn't. In S. E. Straus, J. Tetroe & I. Graham (Eds.), *Knowledge translation in health care: Moving from evidence to practice* (pp. 3-9). Oxford, England: Blackwell.
- Tandon, R., Nasrallah, H. A., & Keshavan, M. S. (2009). Schizophrenia, "just the facts" 4: Clinical features and conceptualization. Schizophrenia Research, 110, 1-23.
- Tuck, I., du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. Archives of Psychiatric Nursing, 11(3), 118-125.
- Van Benthem, K. (2004). Family-centred practice: Am I giving what it takes? Occupational Therapy Now, 6(1), 5-9.
- Ward-Griffin, C., Schofield, R., Vos, S., & Coatsworth-Puspoky, R. (2005). Canadian families caring for members with mental illness: A vicious cycle. *Journal of Family Nursing*, 11(2), 140-161.