Global Perspective of Burden of Family Caregivers for Persons With Schizophrenia

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Schizophrenia is a severe form of mental illness that affects about 7 per 1,000 of the adult population. It is estimated that globally about 29 million people have schizophrenia. With the advent of deinstitutionalization, most persons with schizophrenia are now being cared for in the community by their families. Living with a relative with severe mental illness is stressful. Burden of care is a global issue affecting family caregivers in both developed and developing countries. This article aims to examine the burden of family caregivers for persons with schizophrenia and the socioeconomic factors that influence the caregivers’ perception of burden. There is a general agreement that family interventions are beneficial to family caregivers. Therefore, this article examines two of the most commonly investigated interventions: psychoeducation and support groups, for family caregivers of persons with schizophrenia.

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family caregivers’ preparation and knowledge and the availability of community resources. If caregivers do not have adequate knowledge and support, they might not be able to take up the responsibilities of taking care of the ill persons, thus leading to relapse or readmission. Some individuals with schizophrenia have impaired cognitive and social functioning and residual symptoms, and these could be a significant family concern (Chien & Chan, 2005). Living with a relative with severe mental illness is stressful. Numerous studies have demonstrated that family caregivers of persons with severe mental illness experience significant stresses and have a high level of burden (Saunders, 2003).

The problem of family burden of caring for persons with schizophrenia is a common challenge in both developed and developing countries. Different health care and social systems in different countries may influence family’s commitment to care. Families may have to take full responsibility in taking care of the clients or assist in taking care of the clients to certain extent depending on the available services, resource, and support to the persons with schizophrenia and their family caregivers. Family care burdens are echoed and encountered in many parts of the world. This article aims to examine the burden of family caregivers for persons with schizophrenia and the socioeconomic factors that influence the perception of burden from a global perspective. Research evidences from various cultures will be analyzed. There will be discussion on family interventions that aim to reduce family burdens. Service and knowledge gaps will be identified, and recommendations for services and research development will be suggested.

FAMILY CAREGIVERS’ BURDEN

Recognizing that caregivers’ burden is a global issue, the World Federation of Mental Health has issued a report supporting that caring for those with a chronic condition requires tireless effort, energy, and empathy and indisputably greatly impacts the daily lives of caregivers. Many often, family caregivers receive little recognition for this valuable work, and policies in most countries do not provide financial support for the care services they provide. As caregivers struggle to balance work, family, and caregiving, their own physical and emotional health is often ignored. In combination with the lack of personal, financial, and emotional resources, many caregivers often experience tremendous stress, depression, and/or anxiety in the year after caregiving begins (World Federation of Mental Health, 2010).

The adverse consequences of taking care of relatives with severe mental illnesses have been studied since early 1950s, when psychiatric institutions began discharging patients to the community (Chan, Mackenzie, Ng, & Leung, 2000; Reine, Lancon, Simeoni, Duplan, & Auquier, 2003). Burden on the family refers to the consequences for those in close contact with a severely disturbed person with mental health problems. Some authors further distinguish between objective and subjective burden. Objective burden relates to the patient’s symptoms, behavior, and sociodemographic characteristics, and factors such as changes in household routine, family or social relations, work, leisure time, and physical health. Subjective burden is the mental health and subjective distress among family members (Reine et al., 2003). From the 1970s to 1980s, the term caregiver burden has been used to describe the adverse consequences of mental disorders for family caregivers. Caregivers’ burden has been studied for determining the feasibility of discharging a patient into community or to refine the concept of caregiving and its underlying structure and contents (Chien et al., 2007). In recent years, the view of caregiving burden has been broadened to involve the physical, psychological, social, and financial problems experienced by families caring for a relative with a chronic or mental illness. This view has been accepted by the global community (World Federation of Mental Health, 2010).

Research evidences from different countries on family caregivers of persons with schizophrenia generally support that there is inadequate help and support to the family caregivers (Chan, Yip, Tso, Cheng, & Tam, 2009). Research has also consistently indicated that family caregivers report high levels of burden related to caring for their mentally ill family members. Family caregivers’ mental health may become seriously impaired (Cuypers & Stam, 2000). Many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of caregiving for these relatives. Thus, they are unable to cope with a considerable amount of the caring roles and responsibilities (Chan et al., 2009). Families often face daily stressors of unpredictable and bizarre
behaviors of their relative with schizophrenia, external stressors of stigma and isolation upon the family, emotional frustration such as guilt and loneliness, and family conflicts in the caring process. Marked negative effects are often reported by the family caregivers, including depression, anxiety, grief, and somatic complaints. Client relapse and readmissions are common (Chan & Yu, 2004; Martens & Addington, 2001).

The perceived burdens among family caregivers of people with schizophrenia have been studied in various regions and cultures. In Europe, Canive et al.'s (1996) Spanish study described several major effects of caring, which included poor health of family members, disruptions to social and leisure activities and domestic routines, and reduction in household income. In Italy, Magliano et al. (1999) investigated the burden and coping strategies of key relatives in schizophrenia and found that the levels of burden on key relatives did not differ significantly from those on other relatives. They concluded that it is necessary to provide supportive interventions for as many relatives as possible. In Switzerland, Lauder, Eichenberger, Lugibihl, Keller, and Rössler (2003) identified that the most important predictor of burden is the relationship between the caregiver and the patient with exacerbating schizophrenia. There are significant changes in the relationship during the acute phase of the illness. Other determinants of burden included threats, nuisances, time, and restricted social and leisure activities. Lauder et al. suggested that relatives should be taught to deal with the burden. They should learn how to cope with disturbing behavior and make necessary changes in the relationship with the patient. The relatives should be included in deciding whether the patient should be admitted to a hospital. In a Swedish study (Ostman, Hansson & Andersson, 2000), family burden and participation in care of relatives to both voluntarily and compulsorily admitted patients were investigated. It was found that interventions for establishing a well-functioning network in families where relatives experienced mental health problems are useful. Another Swedish study by Hjartag, Hellin, Karlilampi, and Norlander, 2010 identified that increased family burden could be associated with increased severity of the patient’s mental symptom, and impaired functioning was considered the single most impact on family burden. It was suggested that professional support to control mental symptoms and improve daily functioning of the patient could reduce family burden.

A comparative study of Euro-Americans and Latinos (Jenkins, & Schumacher, 1999) suggested that the types and levels of family burden could be correlated to contextual factors including gender, ethnicity, diagnosis, and living situation. A study of Mexican Americans (Magaña, Ramírez García, Hernández, & Cortez, 2007) reports that between 12% and 18% of family caregivers meet the cutoff for being at risk of depression. Younger caregiver age, lower levels of caregivers’ education, and higher levels of the patients’ mental illness symptoms were predictive of higher levels of caregivers’ depressive symptoms. Caregivers’ perceived burden mediated the relation between patients’ psychiatric symptoms and caregivers’ depression. Caregivers’ perceived stigma was significantly related to caregivers’ depressive symptoms. A U.S. study (Biegel, Shafran, & Johnsen, 2004) described that the frequency of client behavioral symptoms and the lower the amount of perceived support from family members, the higher the level of overall caregiver burden.

In Asian regions, many societies are dominated by Confucian principles with a strong emphasis on specific roles and proper relationships among family members, thus maintaining equilibrium. The occurrence of mental illness in a family member usually results in psychological and emotional disturbances of the whole family (Chien & Chan, 2005). A study in Malaysia (Chang & Horrocks, 2006) found that family caregivers have to cope with the impact of stigma of their relatives’ mental illnesses. A study of Hong Kong Chinese families found that much of the burden was related to stigma and lack of mental health and rehabilitation services. The consequences of care included social isolation of the families and financial difficulties. Subjective burden resulting from social stigma included frustration, anxiety, low self-esteem, and helplessness (Tsang, Tam, Chan, & Chang, 2003). In Thailand, the families preferred taking care of their mentally ill relatives at home. A qualitative study found that the families nevertheless perceived caring as suffering. The “suffering” referred to the negative experiences in caregiving, which included physical burdens, emotional distress, economic problems, stigma about mental illness, and knowledge deficit about mental illness and its symptoms (Sethabouppha & Kane, 2005). In India, Gururaj, Math, Reddy, and...
Chandrashekar’s (2008) study highlighted that the family burden and financial burden were significantly higher in persons with schizophrenia when compared with other mental disorders, such as obsessive–compulsive disorder. The greatest burden was felt for disruption in family routine and leisure activities.

The above discussion provides evidence that the problem of family burden of caring for persons with schizophrenia is a common challenge in both developed and developing countries. It appears that the major effects of caring, such as emotional distress and depression, reduction in social contact, and financial difficulties, are common across different cultures. Mental illness comes with the additional burden of a negative label. The most commonly mentioned burden of care across studies is the stigma related to mental illness. Stigma toward mental illness is still a global phenomenon and is a very real problem for people who have a mental illness and their families. Stigma can pose a threat to the self-esteem, relationships, and employment of the person with schizophrenia. It can also pose similar threats to family members. Stigma results in prejudice and discrimination. It may also discourage family caregivers from seeking help. There is a need to help the family caregivers and the persons with schizophrenia to cope with the stigma. Reducing stigma also requires community education and a willingness among individuals to challenge the stigma associated with mental illness.

Sociodemographic and Cultural Characteristics and Family Caregivers’ Burden

Relationships between sociodemographic and cultural characteristics of families and burden have been studied in many countries. Studies found caregivers’ burden score was negatively correlated with their household income. Families with lower socioeconomic status experienced higher level of burden (Chien et al., 2007; Martens & Addington, 2001; Ohaeri, 2001). The problem of lower socioeconomic status is further compounded by the fact that most countries do not provide financial support for the care services that family provide for their mentally ill relative (World Federation of Mental Health, 2010). The poor financial status in the family may further increase the risk or vulnerability for perceiving burden and the resulting distress and negative consequences such as mental health problems (Chien et al., 2007).

Social support is considered to be of great value in families who experience the burden associated with caring for an individual with schizophrenia. More family support was positively related to higher levels of family functioning (Saunders, 1999). Lower level of social support from other family members and friends of persons with schizophrenia has been found to be strongly associated with higher scores in need assessments and more unmet needs (Caudle, 1993). Social support was found to be the best predictor of caregiver burden in family caregivers in an Asian study (Chien et al., 2007). Magliano et al.’s (2003) study also demonstrated that a supportive social network is found in relatives who reported lower levels of burden and pessimism about schizophrenia. Thus, strengthening the families’ social network may represent a useful strategy to alleviate family’s care burden.

The majority of family caregiving is usually provided by parents, spouses, or relatives. Studies found that most family caregivers of adult clients with schizophrenia are their parents, and they are of older age. In Asian studies, it is also found that caregivers’ burden score was positively correlated with their age (Chan et al., 2009; Chien et al., 2007). However, the results of these studies differed from the Mexican Americans’ study that caregivers with younger age experienced higher level of family burdens (Magaña et al., 2007). The differences could be related to the traditional Asian culture, which regards the older people in a family are the “heads of household” who have the major responsibility to take care of other family members and are responsible for their health condition (Chien et al., 2007). Thus, older family members may perceive higher level of burden as they have to shoulder the majority of care burden. The high levels of burden in caregivers with older age may also be related to their poor health condition. Some parents may also worry that no one would take care of their adult children when they are too old or after they die. A Hong Kong study found that some parents tried to arrange marriage for their adult children with schizophrenia. The parents hope that the spouse would be able to look after their adult child after they die. However, in these parent-arranged marriages, it was not uncommon that it ended up with problems
such as divorce, domestic violence, or even homicide and suicide (Chan et al., 2009). Effective measures to reduce older parent caregivers’ burden could include periodical respite care and sharing caregiving tasks among family members (Chien et al., 2007). Thus, one of the common challenges in many countries is to develop community resources and services to provide continuous support to adult persons with schizophrenia so that their older parents could have peace of mind about the future care of their adult children.

Caregivers are more likely to be women in many parts of the world. For example, in the United Kingdom, about 58% of the caregivers are women (Nolan, 2001). Asian studies found about 70% of family caregivers are females (Chan et al., 2009; Cheng & Chan, 2005). The World Federation of Mental Health (2010) estimated that globally, about 80% of the caregivers are women. They could be the mother, wife, or daughter of the clients and are usually with low income. The impact of the women’s intensive caregiving can be substantial. Studies showed that middle-aged and older women who provided care for an ill spouse or a spouse with disability were almost six times as likely to have depressive or anxious symptoms as were those who had no caregiving responsibilities (World Federation of Mental Health, 2010). Thus, the other global challenge is the need to have an in-depth understanding of the needs and concerns of female caregivers and to develop ways to support female caregivers.

The World Federation of Mental Health (2010) suggests that as additional caregivers will be needed worldwide in the future, more males are likely to become caregivers. Taking on a caregiving role could mean a role reversal, a change in traditional gender roles within the family in many cultures. At present, there is a paucity of research on the male caregiving role, and little is known about the number and the condition of male caregivers. Additional research needs to be conducted to see how the male caregiving role impacts their lives.

There are evidences suggesting that culture could have an influence on the expression of needs of culturally diverse family members caring for a relative with acute mental illnesses. Caudle (1993) found that Latin American families place particular emphasis on encouraging open expression of needs and feelings. On the contrary, in Asian countries where traditional Confucian and Buddhist concepts dominate, there is a belief in keeping secret something that is unfortunate or degrading to the family name (Tseng, Lu, & Yin, 1995). A full understanding of the specific way that culture could influence family caregivers’ burdens and the ways that these burdens are expressed in relation to caring for a relative with schizophrenia may play an important part in the development of a holistic model for family-centered care.

Most of the reviewed studies were cross-sectional. Caregivers may experience different levels of burden at different stages of the clients’ illness. Thus, there is a need for longitudinal studies to have a better understanding of the family caregivers’ burdens and needs at different illness stages in different regions and cultures.

Past studies on family caregiving for persons with severe mental illness focused on the burden of care. It could be criticized as focusing only on the negative aspects of caring. Nolen (2001) comments that the dominance of the stress-burden model in family services has meant that interventions have focused almost exclusively on stress reduction with little attention to more expanded range outcomes. There is a need to turn around to look at the more positive aspects of caregiving, such as the protective factors that could mediate or moderate caregiver burden or ways to promote caregivers’ resilience. An Australian family caregiver study has identified that hopefulness in the caregiver is a crucial part of the coping process in long-term coping with mental illness in a family member. The study suggests that hopefulness appears to be central to a family’s coping with the impact of mental illness. Families drew their hopefulness from both formal and informal supports, from within and without (Bland & Darlington, 2002). An Asian study also supports that family caregivers had a strong emphasis on the need to instill hope (Tseng et al., 1995). Thus, nurses need to be respectful of the family’s hopes and their time in the process of grief and acceptance. Nurses should be mindful of their capacity to sustain or diminish the hopes of family members (Bland & Darlington, 2002). A study in Japan found that patient’s satisfaction with daily life and their ability to perform tasks had a strong impact on reducing the sense of burden felt by the caregivers. The study suggested that providing support that would enhance the quality of life of the patients could indirectly help to alleviate the burden felt by family members caring for them (Fujino & Okamura,
A U.S. study found positive cognitions could promote resourcefulness and sense of coherence in women family caregivers for adults with serious mental illness. The study recommended the need to develop interventions to encourage positive thinking among family caregivers (Zausziewski, Bekhet, & Suresky, 2009). Research evidences suggest that there is a global movement toward enhancing the positive and protective factors that could mediate or moderate the negative aspects of family caregiving.

In summary, the literature on family caregivers of persons with schizophrenia provides evidence that mental illnesses such as schizophrenia create continuing burden to families, and this is not limited to any particular societies or cultures. Stigma toward mental illness is a major source of stress for family caregivers. The literature supports that family caregivers’ burden is a multidimensional phenomenon, involving their mental health, physical condition, social life, and financial status and the functioning of the family as a whole. When analyzing caregiver burden, we need to examine the social context and understand the family’s experience within that context. There is also a need for continued research with lower socioeconomic caregivers to fully understand their needs. Social support appears to be an important protective factor of family burdens in diverse cultures. Helping families to maintain and enhance a supportive social network could be a useful means to reduce family caregivers’ burden with persons with schizophrenia. A more in-depth understanding of the specific needs and concerns of female and male family caregivers is essential to support these family caregivers. Ways to help those older age caregivers is essential to give them peace of mind knowing that their adult children will be well cared for in the future. Cultural perspectives have to be taken into account to understand the expressed burden and needs of culturally diverse family caregiver groups. Future studies on family caregiving could focus on protective factors that promote resilience in caregivers and ways to instill positive experiences in caregiving.

FAMILY INTERVENTIONS

There is an increasing acceptance that family is the primary long-term caregiver and an important resource for persons with schizophrenia. Research has shown that nurses can help by better assessing the family’s needs in caring for clients with schizophrenia and providing education particularly to elicit family members’ understanding and expectations of the illness and care provision (Cheng & Chan, 2005). Despite individual and cultural differences in needs and concerns, studies in the United Kingdom found that a number of common needs emerge from the caregivers. They are emotional support, relief from isolation, receipt of reliable and satisfactory services, information, and recognition of their role and contribution; these can all work well in supporting caregivers (Department of Health, 1999). Family interventions have been implemented to improve the current care. There are a growing number of empirical evidences supporting that some family intervention strategies, such as psychoeducation and support groups, demonstrate a beneficial impact on the course of schizophrenia (Bäuml, Froböse, Kraemer, Rentrop, & Pitschel-Walz, 2006).

Psychoeducation

Psychoeducation is defined as a strategy of teaching patients and families about mental disorders, their treatments, personal coping techniques, and resources. This form of intervention has been developed based on the observation that people can be better participants in their own care if knowledge deficits are removed. By teaching skills such as problem solving and communication, it would increase carers’ coping ability with their situation (Pekkala & Merinder, 2008). The various psychoeducation models developed in different parts of the world have included individual consultation and family psychoeducation (Atkinson & Coia, 1995; Muser et al., 2001); family therapy (Marsh, 2001); professionally led, short-term family education programs (Mannion, 2000; Amenson, 1998); and family-led support groups (Pickett-Schenk, Cook & Laris, 2000). The program developed by the Psychoeducational Working Party of the Early Psychosis Prevention and Intervention Center (EPPIC, 2001) in Australia focused on early intervention for clients with schizophrenia.

A review of the literature has found that psychoeducation intervention has been conducted in a variety of ways. In previous studies, the durations of psychoeducation programs ranged from 1 to 18 months (Atkinson et al., 1996; Bäuml, Kissling, & Pitschel-Walz, 1996; Chan...
et al., 2009; Cheng & Chan, 2005; Herz, 1996; Hornung et al., 1995; Macpherson, Jerrom, & Hughes, 1996; Merinder et al., 1999). These programs consisted of 10 or more sessions, and most had group interventions that included clients and their family members (Atkinson et al., 1996; Bäuml et al., 1996; Chan et al., 2009; Cheng & Chan, 2005; Hornung et al., 1995; Macpherson et al., 1996; Merinder et al., 1999). Despite adopting different models and frameworks, these programs have certain contents in common, such as nature and treatment of schizophrenia, management of problem behavior, related resources and ways of accessing these resources, and problem solving and coping skills.

Previous studies demonstrated that psychoeducation interventions generally had positive outcomes on family caregivers and clients. For examples, the interventions were effective in reducing family caregivers’ burden (Chan et al., 2009, Cheng & Cheng, 2005), and the interventions were effective in reducing relapse (Dixon, Adams, & Lucksted, 2000; Klingberg et al., 1999) and had positive effects on clients’ mental state, insight into their illness, and adherence to medication (Bäuml et al., 1996; Chan et al., 2009, Merinder et al., 1999). A recent systematic review on 10 studies of the effectiveness of psychoeducation programs (Pekkala & Merinder, 2008) further supports that psychoeducational approaches are useful as a part of the treatment program for people with schizophrenia and related illnesses in both Asian and Caucasian populations. The fact that the interventions are brief and inexpensive should make them attractive to health care services managers.

Pekkala and Merinder (2008) recommended that more well-designed randomized studies should be carried out. Some studies could not demonstrate long-lasting changes in family caregivers (Barrowclough et al., 2001; Cheng & Chan, 2005; Kelly & Newstead, 2004; McDonell, Short, Berry, & Dyck, 2003). It could be related to the fact that simply providing facts in psychoeducation sessions might be insufficient to change beliefs and behavior. To sustain the effects of psychoeducation interventions, it should be an ongoing intervention, and its outcomes should be constantly evaluated. Furthermore, some studies had a high dropout rate. The stigma related to mental illness may also have deferred people to come forward for psychoeducation intervention. The difficulty of engaging clients and their carers in the psychoeducation programs has made the outcomes of the programs inconclusive (Barrowclough et al., 2001; Kelly & Newstead, 2004; McDonell et al., 2003). Innovative strategies need to be developed to promote participation. More studies on different models of psychoeducation interventions and their effectiveness in diverse cultures need to be conducted to improve the psychoeducation interventions.

**Mutual Support Groups for Family Caregivers**

The development of mutual support groups in the 1990s was part of the larger social movement of self-help organizations for people affected by a variety of chronic diseases, whose needs had been inadequately addressed by traditional health care interventions (Heller et al., 1997; Norton, Wandersman, & Goldman, 1993). Mutual support groups are characterized as client-led interventions to the professional-controlled mental health interventions. They are participatory and involve giving and receiving help and learning to help themselves, as well as sharing experiences and knowledge about common concerns (Chien & Chan, 2005). Building on an empowerment-oriented model, mutual support groups for family caregivers of persons with schizophrenia provide opportunities for family caregivers to develop knowledge and skills on caring for a relative with schizophrenia with peer support, establishing a harmonious family life, and engaging professionals as collaborators instead of authoritative experts. The empowerment in the support group can be enforced by the provision of a peer-based support system, allowing individuals to take on meaningful roles within the group and their own family and inculcation of a belief system that inspires members to strive for better mental health. The advantage of support groups is that it requires less intensive training for health professionals to serve as facilitators as compared with other treatment approaches. They also provide a flexible, interactive client-directed approach to help families cope with their caregiving role (Chien, Chan & Thompson, 2006).

A variety of mutual support group programs that provide social support and enhance the social networks of family caregivers have been implemented. There is strong evidence supporting the
value of a support group for family caregivers of persons with schizophrenia (Saunders, 2003). Research evidences appear to support that support group intervention is helpful to people from different cultural backgrounds. For example, studies in the Western and Asian populations found that family caregivers who participated in family support groups are associated with considerable improvement in psychological adjustments of families (Budd & Hughes, 1997). Support group interventions are associated with significant improvements in the family caregivers’ ability to cope and in their caregiving role and, consequently, an improvement in the clients’ physical and mental conditions and functioning (Chien et al., 2006; Citron, Solomon, & Draine, 1999; Heller et al., 1997; Mueser et al., 2001). These studies indicate the importance of peer support and empowerment among the families who, within a mutual support group, are able to feel themselves “all in the same boat” with fellow caregivers (Chien et al., 2006; Citron et al., 1999; Heller et al.). Support groups provide a more flexible, interactive, and peer-led approach and therefore may be more feasible for community mental health services, where there are resource constraints and a requirement to respond to family needs (Chien & Chan, 2005).

A study in the United States found that although support groups could be beneficial to caregivers, lack of time, insufficient respite care, hesitation of sharing feelings in the group, worry about being welcomed and accepted, getting along with other members, and transportation are barriers to support group participation especially for lower socioeconomic caregivers (Biegel et al., 2004). Studies on access barriers should be further taken to gain a better understanding of those who accept the intervention and those who do not.

Many of the family caregiver intervention studies focused on family caregivers’ burden or pathology of care and coping as main outcome measures. Nolan (2001) criticized this narrow focus and suggested other dimensions of outcomes that caregivers could see as important, such as the quality of life of the cared-for persons, their own quality of life, and the feeling of being recognized and supported and being valued as an individual. To achieve these outcomes, an individual approach to an assessment that balances the needs of the caregivers and cared-for persons is essential for care planning (Nolan, Keady & Grant, 1995). In the future, family interventions could have more creative and multidimensional approaches in supporting caregivers and clients with diverse needs. More studies into these areas could contribute to developing effective strategies to ease family burden.

**CONCLUSION**

This article draws on literature and studies conducted in various regions and cultures to examine the burden of family caregivers for persons with schizophrenia. Empirical evidences came up with useful findings of what these families need. These evidences support that despite cultural variation, family burdens echoed and were encountered by family caregivers in various parts of the world. Family caregivers’ burden is a global issue. Recommendations commonly made in these studies are to meet the needs of these families to ease their burden, and family orientation interventions need to be developed. Many authors highlighted that professional support could, apart from meeting needs of the families and easing their burden, help the families become more effective carers at home. Such an idea should become a core value for making policies of mental health care today.

To improve the mental health services, involvement of the families in policy making and service planning becomes essential. In the UK, the standards for service planning designed to support family caregivers highlighted that caregivers should be involved in the organization of services (Department of Health, 1999, 2000). In many parts of the world, family caregivers are gathering momentum to influence policy related to family caregiving. For example, the International Alliance of Carers organization was launched in 2004 by family caregiving organizations from Australia, the UK, Sweden, the Netherlands, and the United States with the mission to promote sharing of good practices and promote visibility of family caregiving as an international issue. Another organization, EUROCARERS, composed of representatives from 18 organizations and research bodies from different countries, was formally launched in 2006 to provide a united voice at the European level. This group actively influences health policies nationally and within the European Union (Cavaye, 2006). For the other parts of the world, such as in some countries of Southeast Asia, caregivers’
involvement in policy making and service development remains not common (Chan et al., 2009).

Kleinman (2009) presented a very strong message that the global mental health is a reflection of failure of humanity. He rightly pointed out that families of the individuals with mental illnesses are not only sharing the suffering from the illnesses but are actually key carers for the affected individuals. As professional services for helping the families are inadequate, families simply fail to offer the desired care by themselves. The families under great stress would give up and reject the mentally ill individuals who would become outcasts socially. The mentally ill individuals would rarely participate in daily social activities such as festivals, marriage, celebrations, or even family shopping. Such a nonperson life ends with the mentally ill individuals becoming further stigmatized. This is a worldwide phenomenon.

Mental health professionals need to develop more innovative programs for families. Instead of supporting the families and easing their burdens, it could be more effective to involve the families as active members of the health care team by assigning specific tasks for the families and allocating the necessary resources for performing such tasks. Examples of such tasks include planning the care program, observing and reporting the patient’s behaviors, supervising medication, and daily life skill training. With this approach of formal involvement of family in caring for the mentally ill, a major policy change would need to be implemented. Legislations need to be passed for protecting the rights of both mentally ill people and their families, access to mental health support for both the ill people and families, and the availability of professionals competent for supporting the ill people and families. Nurses worldwide are often in the best position to assist family caregivers at critical times. They could be the advocate for family caregivers by taking small and gradual steps to help family caregivers to get involved in health planning.

Despite the increasing number of quality research that has enhanced our understanding of caregivers’ burden, it is essential to continue to generate knowledge in this area. Future studies could focus on examining the resilience of families in various regions and cultures, which include the strengths and protective factors. Many persons with schizophrenia have a long duration of illness, and they require long-term care from their family. We need more in-depth understanding of the long-term consequences of caregiving for a relative with schizophrenia and the support and training that are essential to families in various stages of clients’ illness. There is a necessity to examine the social context of the family caregivers and to understand their experience within that context. We also need to explore models of family interventions that are sensitive to social and cultural diversity.

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