The Intergenerational Transfer of Continuum Care Responsibility of the Individuals with Severe Mental Illness

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Abstract

The study aims to explore the influential factors of intergenerational transfer of continuum care responsibility for aging people with severe mental illness. These vulnerable populations need a continuously informal resource involved when their major support system is in decline such as the primary caregiver aged, loss of function, or passed away. Based on the traditional ethics of an Eastern culture, the sibling’s legitimacy responsibility is viewed as a prior guardian. This study indicated the predictors (i.e. socioeconomic characteristics, family relationship, the needs of parents’ expectation or the mentally ill sibling, role identity, the attitude toward illness and caring responsibility, health and psychological status, living etc.) of an intergenerational care giving model to be constructed by the healthy siblings. The mental health professionals are better aware of the healthy siblings who play an important role to sustain the supportive resources over the life course for the mentally ill sibling. To include the healthy siblings in the treatment planning, crisis management, psycho educational interventions, and information exchange in the process of primary care would be essential for the best practice model.

Keywords: Sibling; Aging; Severe Mental illness; Care giving responsibility

Introduction

With deinstitutionalization, many individuals with severe mental illness turn to their family looking for support because of the absence of adequate community-based services [1]. The parent caregivers often step in the gaps in the service system to become the most commonly informal support for an individual with severe mental illness. However, without parental caregivers, those people with severe mental illness who tend to rely on their parents for support may find themselves either homeless, turning to additional family members for assistance, or needing more community services. Since few people with mental illness have spousal, intimate relationship, or have children, their healthy siblings are often called upon to become the major caregivers as the aging parents relinquish or unable to perform the care giving role capacity [3-7].

Family Burden and Obligation

Family members are likely to experience stress and burden associated with caring for relatives who suffer from severe mental illness [8]. Levels of subjective burden are associated with worries about their ill family member’s care, fear of their harm to the self or others, and feelings of stigma [9]. This kind of burden may impact the motivation of caring involvement. The healthy family’s health and living condition, and the perception of the self, however, even in highly problematic circumstances, the major caregivers, parents, still feel obligated to provide housing, money, and other materials supplies as well as much emotional support [10]. Among the parental caregivers, mothers rather than fathers assume the primary care giving role [11]. The mother caregivers tend to experience the psychological consequences associated with caring obligation and the bonds of affections insured them to provide intensive care over long periods. The strength of obligation norms differs as a function of kinship role (e.g. greater obligation towards parents than towards siblings). The obligation to support one’s brothers or sisters in contemporary Western societies is weaker than the duty to assist parents, children, or spouses [12]. The adult healthy siblings are assumed to be the next in line to take care giving responsibilities for an ill sibling [13]. The issue of future care giving
may be particularly important in forecasting the needs of continuum care for individuals with severe mental illness by whom.

**The Intergenerational Transfer of Care Giving Responsibility**

When the elderly parents would not be able to care for their mentally ill adult children, the bond of social network including cousin, friends, or neighbors do not strong enough to take on long-term care giving obligations, informal care must transfer from parents to the healthy siblings. Beyond spouses, parents, and children, responsibilities for care become much more ambiguous [14]. The long-term care giving tasks and support are culturally defined as appropriate for close kin and not for more distant members of the social network [15]. Only kin ties have the permanency and strong bonding required for the long-term commitment involved in caring for the seriously disabled [16]. The healthy siblings are hence considered logical replacements for aging parental caregiver of persons with severe mental illness based on the hierarchy of obligations [7,17]. The healthy siblings are the most identified to have more contact, intimacy, and support with their family members while mothers still alive than their mothers deceased [7,8]. Apparently, mother’s help to maintain support network sand convey more obligations that may increase their burden and stress than the siblings. The aging people with severe mental illness may be at risk for diminished family contact as their mother passing away. The study found that only one-third of siblings of people with severe mental illness expect to assume future care giving involvement and responsibilities for several reasons (i.e. the closeness of the family of origin; the time of care giving needed; the parents’ needs and expectation) [18]. Due to the healthy siblings tended to be neglected by the mental health and healthcare systems and commonly believe not talking about something to prevent from being painful [18]. Many health siblings have incurred greater life burden (i.e. financial expenditure, caring activity involvement) and encountered more negative experiences with the mental health system and difficulties in looking for help after taking the care giving responsibility [19,20]. This would minimize motivation of care involvement for the healthy siblings.

**Factors of Care Involvements**

The important predictors of future care involvement and level of burden for healthy family including the gender, social class, educational level, health, psychological well-being, the sense of duty and obligation, the age and the symptoms control of the mentally ill family, the family constraints, the stronger tie between the siblings, the positive attitudes toward ill siblings, and alternative role involvements [15,21-23]. Especially in gender differences, studies indicate that informal care giving is mainly defined as women’s work stems from the belief that women are particularly suited to care giving duties and generally reported higher levels of obligation than did men. Women generally feel greater distressed in the care giving role than men do [17,24]. The female tends to be more likely to provide support to the mentally ill sibling than the male does [25]. The age of the mentally ill sibling impacts the level of care burden. The healthy siblings caring for a younger sibling reported less subjective burden than did those caring for an older one [21]. Most healthy siblings who have threatened by their sibling with schizophrenia may fear the ill sibling receptivity losing control over their behavior and being a threat to their safety or the safety of their family [26]. The healthy siblings who experience these fears are likely to distance themselves from their mentally ill sibling, thus negatively affecting the quality of relationship [1]. Many of the elderly caregivers who lack of knowledge about planning the future for the mentally ill family, resisting to change, and refusal to use available resources [5]. However, healthy siblings with higher educational level reported more subjective burden than did those with lower level counterparts [21,27]. The healthy siblings often concern that knowledge of what is happening on the severely mentally ill siblings might be frightening [19]. Health status was one of the most powerful predictors of well-being to impact the involvement of care [21]. The feelings of stress, fear or mental illness, anxiety, worried about the future, and impaired sense of self on the healthy siblings influence the role of caregiver taking [28]. Under conditions of enduring mental and physical hardships (e.g. depression, insomnia, hypertension, heart attacks), the self-concept may be also damaged [29]. Healthy siblings who may want to give assistance to a mentally ill sibling also have to weigh the alternative obligations of being married, having children, and working full- or part-time [15]. Individual who have their own families, job, and careers should have less time involved in care giving activities for the mentally ill siblings [30].

**Conclusion and Implication**

Studies suggest the influential factors of continuing care involvement for a mentally ill family. The mental health professionals need become more aware of the important role that healthy siblings can play over the life course and help them sustain the supportive resources for the mentally ill sibling. The healthy siblings have to be included in the treatment planning, crisis management, psycho educational interventions, and information exchange in the process of primary care. The clinicians have to facilitate the participation of healthy siblings who wish to become more actively involved in the lives of their sibling with mental illness. The service providers have to offer help as siblings take on new responsibilities for the support and care of a family with mental illness. The health siblings’ perceptions of the need for assistance of the mentally ill family and parents should take into consideration.

Moreover, assessing whether sibling have been threatened or physically hurt by their sibling with mental illness is an important first step in determining how best to engage siblings as collaborators in the treatment process. By discussing openly with siblings about past difficulties, providers may be able to help siblings put their previous behaviors in perspective. The clinicians can help siblings learn more effective strategies for responding to or managing these behaviors, and thus reduce their fears, which in turn should foster a closer sibling relationship.

Well siblings’ care giving concerns archoncic deception behaviors are often intermingled with concern over aging parents. Sibling care giving may also be influenced by feelings of obligation toward parents and perceived needs of parents for assistance. The clinicians could educate parents about the care giving concerns of healthy siblings and the aspects of family relationships that may impact care giving for an ill sibling. However, the siblings should not expect to be a full substitute for parental care. Connecting siblings to other siblings if they are interested and the beginning to discuss future planning are important during the intergenerational transfer of care giving responsibility.

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