

Empowering Aging Caregivers: The Role of Social Capital in Disability Care

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ABSTRACT: *Caregiving for adult children with disabilities presents unique challenges, especially for aging parents who face the dual burden of managing their own aging-related limitations while fulfilling the demanding role of caregiver. This narrative review explores the impact of social capital on the well-being of aging caregivers, emphasizing the crucial role that social networks play in providing emotional and practical support. The paper concludes by emphasizing the need to recognize and strengthen various forms of social capital to enhance social cohesion and mitigate isolation among aging caregivers. Strengthening these networks not only alleviates the stress and isolation experienced by caregivers but also contributes to building a more resilient and supportive community. Investing in social capital is essential for improving the quality of life for caregivers and ensuring the overall health and well-being of society.*

KEYWORDS: *Aging caregivers, Social capital, caregiving, disability, social networks, elderly*

Date of Submission: 28-08-2024

Date of Acceptance: 05-09-2024

I. INTRODUCTION

Caregiving is inherently challenging, demanding significant patience, knowledge, sacrifice, adjustments, and emotional stability. Providing care for an adult child with disability at old age can be even more exhausting. Typically, old age is characterized by adult children caring for their elderly parents. However, in this situation, the roles are reversed, requiring the parents to care for their children with disability. This reversal presents unique challenges and demands significant adaptability and emotional resilience from the aging parents. The family caregiving literature includes a small amount of research focused on elderly caring for an adult relative with disabilities. Transition to old age may increase the risk of health and financial problems for the caregivers, aggravating the overall situation. Long-term co-residence with an adult child with disability can impact parental psychological health, becoming apparent as they enter old age.

II. METHODOLOGY

A comprehensive search was conducted across multiple electronic databases using keywords such as social capital, aging caregivers, social networks, and caregiving. After an initial screening through a peripheral analysis of the content, a selection of articles was made for review. This paper adopts a narrative review approach. Insights and findings from the selected articles were documented and compared to extract relevant information. Only articles written in English were included in the review. The gathered data was subsequently organized into thematic categories.

Aged parents as caregivers of adults with disabilities

As aged parents plan for their adult child's future care and struggle with their own functional limitations, they are likely to be more vulnerable to experience of depression that may not visibly seen in midlife (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). While it is often presumed that caregiving duties lead to heightened stress throughout the family member's life, research shows that this care is influenced by a complex combination of contextual and personal factors (Baumbusch, Mayer, Phinney, & Baumbusch, 2017).

The major problems and challenges faced by elderly people caring for their adult children with disability are discussed below.

1. Physiological changes and related problems of aging

Aging is a biological process, which everyone needs to go through. The population of individuals aged 60 and older is rising. In 2019, there were 1 billion people in this age group, and this number is projected to reach 1.4 billion by 2030 (WHO, 2018). Neurological alterations, decline in cognition, memory and intelligence, sensory impairments, changes in musculoskeletal system and body composition and reduced immunity are common among old age population (Amarya, Singh, & Sabharwal, 2018), which are not different in the case of those caring for adults with disability. A study of the health profile of family caregivers of adults with developmental disabilities reported high prevalence of arthritis, high blood pressure, obesity, and activity limitations among middle-aged and old age female caregivers compared to the same age group in general population (Yamaki, Hsieh, & Heller, 2009). Similar findings are presented by the (Centre for Disease Control and Prevention, 2019), showing that 22.2% of caregivers aged 65 and older reported having coronary heart disease and/or stroke, compared to 10.3% of caregivers aged 45 to 64. Therefore, in addition to the physical changes and illnesses that typically accompany aging, caregivers are at a higher risk of being diagnosed with these conditions. As they age, caregivers not only face their own health challenges but also the added stress and demands of caregiving, which further increases their susceptibility to health issues.

2. Emotional burden of caregiving

Families supporting a member with a disability often experience low self-esteem due to the challenges they encounter. This low self-esteem leads to a vicious cycle where individuals become hesitant to seek help causing their social networks to shrink, further intensifying the caregiving burden (Kim, 2017). A Canadian study found that over half of the respondents experienced stress while caring for a family member in their old age, particularly when their children no longer lived with them (Minnes & Woodford, 2005). Research has also shown that aged parents of adults with severe mental illness typically experience significant levels of burden and increased general medical and psychiatric symptoms (Aschbrenner, Greenberg, Allen, & Seltzer, 2010). Emotional burden can be understood in terms of depression, anxiety, stress, helplessness, fear, denial and stigma experienced by the parents of adult children with developmental disabilities (Marsack-Topolewski & Church, 2019).

3. Financial burden of caregiving

Caring for an adult child with a developmental disability can significantly strain the entire family's financial stability. The care demands of children with developmental disabilities often prevent their mothers from having a full-time employment, even as the children reach adolescence. Consequently, the reduced earnings of these mothers during their 30s can lead to lower savings levels for their families by mid-life (Parish, Seltzer, Greenberg, & Floyd, 2004). Thus, there is a direct association between caregiving and reduced income in later part of their lives (Lee & Zurlo, 2014). When examining the economic status, social security benefits are the primary income source for the elderly. Since the 1960s, there has been a shift from reliance on earnings to greater dependence on retirement income from social security, pensions, and assets (National Research Council, 1988). Elderly caregivers often have to cope with meager social security benefits and pensions or depend on family members for support. On top of this, they face the additional financial burden of caring for their adult child with a disability.

4. Time constraints for self-care

Time restrictions for personal activities and self-care due to the demands of caregiving is known as time dependence burden (Sheikhbardsiri, Tavan, Afshar, Salahi, & Jamebozorgi, 2022). Cohabiting with a relative has the most significant impact, as it increases the likelihood that the caregiver will spend more time providing care (MarcÈn & Molina, 2009). This will result in less personal time for oneself. For elderly caregivers, spending less time on their own needs can place them at risk for poor physical and mental health.

5. Social isolation

Due to the significant demands of caregiving, there is a possibility that caregivers might withdraw from social activities, eventually leading to social disengagement. This happens because caregiving limit their chances to socialize with others outside the home. This involuntary reduction in social interactions can lead to feelings of loneliness (Ekwall, et al., 2005). Loneliness is commonly observed among older adults in general. Holmén et al. (2000) found no significant differences in emotional loneliness across different age groups; however, they observed that older individuals tended to experience greater social isolation.

Supporting an adult with disability can be particularly frustrating when caregivers encounter significant challenges in completing daily tasks and responsibilities. Mental health support is essential for elderly

caregivers as they navigate the demands of caregiving while dealing with the frustration of recognizing their own limitations. Overall, the cumulative impact of physical, emotional, financial, and social challenges underscores the need for social support systems and networks for elderly caregivers. Providing adequate resources, respite care, and opportunities for social engagement can help alleviate some of these burdens and improve the well-being of elderly caregivers and their families.

Social Capital and Caregiver Well-being

A person's social networks play a crucial role in their life. As inherently social beings, humans are shaped and influenced by the relationships and connections they form from birth. These social ties can have both beneficial and detrimental effects on an individual's life. However, people frequently leverage these networks for personal growth and development, often without even realizing it. Consequently, social networks can be considered a significant source of well-being. This concept holds true for elderly caregivers as well, who can derive considerable support and benefits from their social connections.

Why do we seek help when we are vulnerable? It's because we anticipate receiving some form of assistance to navigate through our challenging circumstances. However, we tend to seek support from individuals who are either capable of providing the necessary help or who possess knowledge of the resources needed to address our issues. Having social connections enables us to access these resources. For elderly caregivers, many of their challenges can be alleviated by identifying and utilizing these resources with the assistance of their social networks, both formal and informal. These connections can provide vital support, information, and solutions that can significantly ease their caregiving burden. There comes the importance of social capital and its influence on caregivers.

i. Social Capital

Social capital is an evolving concept in the health field, though its origin and usage can be traced back to sociology and economics. The concept applied to the individual level regards social capital as the capacity of the individual to possess influential social connections. The 'Nan Lin's Position Generator' is one of that kind which measures powerful social ties of the individual (Olives & Kawachi, 2015). If viewed collectively, social capital can be seen as a set of resources embedded within the social structure that are accessible to its members. Several definitions of social capital are available relative to the authors' discipline of study.

Robert D. Putnam refers social capital to the "connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them". Social capital can thus be perceived as a measure of inclusion and participation within a society. A distinction has also been made by Putnam between two types of social capital: bridging social capital and bonding social capital (Olives & Kawachi, 2015). Bonding social capital consists of an exclusive strong network of like-minded people with similar backgrounds within a closed system and bridging social capital are loose and weak networks with people from different backgrounds and networks creating an inclusive and open system (Vannebo & Ljunggren, 2021). Access to both types of social capital is essential because they serve as valuable resources, but possessing bridging social capital, in particular, can help reduce inequality and the exclusion of marginalized and vulnerable populations.

ii. Social Capital of Aging Caregivers of Adults with Disabilities

Informal or family caregiving requires a sustained commitment from the caregiver, which necessitates ongoing dedication and effort. This responsibility can be demanding and burdensome, making it crucial for the caregiver to receive additional support from their social connections. The assistance from friends, extended family, and community resources can provide much-needed relief and help the caregiver manage their duties more effectively, ensuring both the caregiver and the care recipient are well-supported. Social network of the caregiver can act as a point of resources of information and advice. These connections can assist the caregiver in finding information about available health care options and psychological aid, thus facilitating easier access to necessary services. Individuals with higher social capital tend to seek help from their social network instead of depending on other forms of support programmes (Thiel, 2016).

The social networks in which families are embedded are crucial sources of support and have the potential to help re-establish connections. Families are part of larger social networks, whose strength can be understood in terms of social capital, encompassing trust and cooperation that shape the ability to offer mutual support, as well as the community resources that deliver direct assistance. The amount of social capital, or existing social relationships, affects both the potential and the actualization of support (Mirfin- Veitch, Bray, & Ross, 2003). Evidence suggests that social capital has direct impact on the physical and mental health of older individuals (Planas, et al., 2017). The caregiver's personal resources can impact their well-being by influencing their capacity to be resilient to stress and meet the demands of the caregiving role. The ability to advocate on both an individual and political level can be viewed as a reflection of the social capital resources that a family possesses.

III. DISCUSSION

Aging caregivers face a dual burden. They struggle with their own physical and emotional limitations brought on by aging while simultaneously striving to meet the ongoing demands of caring for their adult children. This double strain often leads to heightened social isolation, a condition commonly associated with old age, but exacerbated in aging caregivers who devote most of their time to the care recipient. The lack of social interaction can further deepen their sense of isolation and emotional distress. However, access to appropriate social networks can serve as a crucial source of support for these caregivers, helping them to manage their emotional challenges more effectively. Both formal and informal social networks, which function as forms of social capital, can connect aging caregivers to valuable resources, easing their caregiving responsibilities and lightening their burden. Research indicates that these networks can play a significant role in reducing caregiver burden and enhancing the psychological well-being of caregivers.

The bonding social capital available to caregivers plays a crucial role in providing emotional support. Communication within the family, especially with spouses, positively influences the emotional well-being of the elderly (Shenbakam&Sathyamurthi, 2019). Family members and friends, who are often the closest connections, offer caregivers an outlet to share their challenges and gain emotional backing, which can significantly reduce the strain of caregiving. On the other hand, bridging social capital provides caregivers with strategies to manage stress and anxiety associated with their caregiving responsibilities. Although these connections might be weaker or less frequent, identifying and strengthening them is essential, as they can offer valuable support and resources, helping caregivers navigate their demanding roles more effectively and encouraging greater community participation. Community participation can address the issues of inequality through inclusion (Kuruvilla&Sathyamurthi, 2015). Additionally, linking social capital, which facilitates access to government resources, often presents challenges for caregivers. However, these limitations can be addressed through targeted governmental interventions, ultimately improving the caregivers' ability to access the support they need. Healthcare professionals working with caregivers must recognize the importance of these forms of social capital in enhancing caregivers' quality of life. Nonetheless, more studies are needed to explore how different forms of social capital contribute to alleviating caregiver stress and improving their mental health.

IV. CONCLUSION

Recognizing and strengthening various forms of social capital is crucial for enhancing social cohesion and mitigating social isolation. For caregivers, particularly those who are aging, these connections are vital. Strengthening these social networks can provide the necessary emotional and practical support that helps reduce the burdens of caregiving. By fostering stronger bonds within families, communities, and broader social networks, we can ensure that caregivers, especially aging ones, are not left to face their challenges alone. These connections not only alleviate the stress and isolation that often accompany caregiving but also contribute to a more resilient and supportive community environment. Ultimately, investing in social capital for caregivers is an investment in their well-being and the overall health of society.

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