

Barriers to Social Participation in Caregivers of Older People: A Systematic Review

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Abstract

Some aspects of care contribute for decreased quality of life, health status and well-being among caregivers of older people. Care conditions may affect caregivers' social participation increasing the odds of those negative outcomes. Then, to maintain a high level of social engagement configures a strategy to protect caregivers against burden and allow them to provide a better care. This study aimed at investigate what are the barriers to social participation in caregivers of older people. A systematic review of the literature was performed in PubMed, Web of Science, PsycINFO and Abstracts in Social Gerontology databases, using social participation, social involvement, social engagement, social activities, social relations, elderly, aged, aging, older people, seniors and caregivers as terms. Twenty-three articles fit the inclusion and exclusion criteria. The barriers to social participation were: characteristics and tasks related to care, caregiver's mental health, low social support, sex, care receiver's health, concurrent paid work, age, caregiver's physical health, financial situation, education and quality of life. Those barriers need to be approached by professionals and politicians in order to prevent social isolation and promote better quality of life among caregivers.

Keywords

social support, family caregivers, health of elderly, aged

1. Introduction

Physical or mental problems related to aging are common conditions that require some type of care (Tebb et al., 2000). Family members usually are the first attempt to support their elderly (Brodaty, 2009). Therefore, number of family caregivers has increased in response to populational aging. Although care is known as an important social role in life course which provide occupation, self-esteem and general well-being, it has been more frequently described as a hard task that leads people to refer burden, poor healthy behaviors, social disadvantages and decreased quality of life (Otis-Green, 2012). Some aspects of care contribute for decreased quality of life, health status and well-being among caregivers of older people. They include the amount of care provided, previous health conditions and concurrent responsibilities (Pinquart et al., 2007). These features also compromise the quality of care offered and lead care recipient to institutionalization and early mortality.

Health and quality of life promotion for caregivers certainly is a good strategy to reduce impact of aging in health services (Brodaty, 2009). Further support and opportunities for healthy behaviors, quality of life and well-being would help them maintain their own great health and provide a better and more supportive care for elderly. In addition, it may avoid additional costs with health resources.

Social participation consists in involvement in social activities in family, community or society (Levasseur et al., 2010). Several researchers have agreed that being socially involved provides better physical and mental health, social and emotional support while prevents disability and mortality (Pynnonen et al., 2012). Caring responsibilities as well as time and energy spent in care taking can result in loss of social networks, loss or reduced time spent in paid work, changes in family roles and decreased time spent in self-care and leisure activities (Otis-Green, 2012). Decreasing in social participation is a relevant and modifiable risk factor for social isolation. In caregivers, social isolation implies additional issues such as depression, withdrawal, low self-esteem and confidence, increase in perceived burden and potentially abuse and negligence of care recipients (O'Connell et al., 2003). Being socially isolated is seen as one of the most relevant consequences of providing care to others especially because it has been related to health decline and mortality in caregivers (Tebb, 2000; Stevens et al., 2004). Poor social participation was found to be related to lower level of life satisfaction, health problems and mortality in those groups (Roth et al., 2015).

The knowledge about the aspects that contribute for social participation among caregivers can be useful, then, our purpose was to identify barriers to social participation in caregivers of older people and highlight modifiable factors which should be approached by politicians in order to attend caregiver's needs allowing them remain involved in social activities.

2. Method

A systematic review of the literature was conducted in four databases (PubMed, Web of Science, PsycINFO and Abstracts in Social Gerontology). The following search terms were used: social participation, social involvement, social engagement, social activities, social relations, elderly, aged, aging, older people, seniors and caregivers.

The included articles were all of ones that mentioned in their title or in their abstract some intention to study social participation in caregivers of older people. During the reading of abstracts and full texts the following exclusion criteria were applied: year of publication before 2000; population of study was not caregivers; participants who were receiving care were not 65 years or older; there were no results regarding to social participation; and, study design was limited in abstract for conferences and congress (there was no full text available).

Two authors independently screened all titles and abstracts to assess the eligibility of articles based on the inclusion criteria. All discrepancies were discussed and consensus reached based on opinion of another author. The most common reason for exclusion was the age of people who was receiving care. Often this information was not found in the articles.

3. Result

3.1 Characteristics of Included Articles

The articles selected to this study were published between 2000 and 2013. Continents of publication were North America, Europe, South America and Oceania, mostly of them from United States, Brazil and Canada.

Primary and secondary data were extracted from the articles. In general, the majority of caregivers were female and younger than care receivers. The majority of care receivers were male and older than their caregivers. Regarding to measurements, quality of life questionnaires were predominant. These instruments evaluate general and individual perception about health, environment and social relations. In this case, social participation is only a domain of these instruments, however, some researchers have used them considering social domain separately, which provided relevant results for this review.

3.2 Barriers to Social Participation

All barriers to social participation of caregivers mentioned in the articles were listed. Then, we grouped in categories as follow: characteristics and tasks related to care, caregiver's mental health, low social support, sex, care receiver's health, concurrent paid work, age, caregiver's physical health, financial situation, education and quality of life.

4. Discussion

Although caregiving to older adults is recognized as a normative and not necessarily negative social role, it has been often described as a source of stress leading people to burden, unhealthy behaviors, worsening of quality of life and mortality (Otis-Green, 2012). Circumstances on which care is performed play a key role in those negative outcomes. Contextual aspects that affects care's dynamic, such as, time spent in care tasks, relationship with care receiver and living with care receiver were found to influence negatively caregiver's social participation. Those conditions can compromise caregivers' availability to perform other important roles in their work and family life. Care responsibilities, as well as, time and energy spent in care tasks can result in loss of social networks, loss or reduction of time in paid work, changes in family roles, decreasing of time spent in self-care and leisure activities and general reduction of the engagement in physical, mental and social activities (Chappell et al., 2014).

Rochette et al. (2007) observed changes in social participation in spouse caregivers of partners who suffered their first stroke. They found that changes in involvement with friends and family members, employment and recreational activities were related to higher level of burden and strain in caregivers. Compared to non-caregivers, family caregivers exhibit significantly higher levels of loneliness, greater social isolation and lower levels of psychological well-being (Pinquart et al., 2007; Miller, 1990). These restrictions can isolate caregivers from previous, current and potential sources of social and emotional support, and restrict their opportunities to relax and engage in hobbies. According to Tebb (2000), social isolation in caregivers exacerbates negative outcomes by cutting them off from potential

support and assistance social participation.

In general population, social support has been recognized as a protective factor against several negative outcomes regarding to health, well-being and quality of life (Neri et al., 2012). Support provides a buffer against burden and stress for caregivers by increasing the perception that there exists availability of resources to coping with stressors associated to caregiving. Lack of social support may contribute to negative outcomes among caregivers. Participating in social activities provides more contact with sources of social support. Then, less time spent with others may result in perceptions of worse social support.

Gender differences among caregivers have been shown to be small in magnitude, however, it is widely accepted that women experience more burden (Pinquart et al., 2006), worse physical and mental health (Penning et al., 2015) and poor social support (Ajrouch et al., 2005) when compared with men. According to Pinquart (2007), female caregivers spent significant much time caring for others and were more likely found to quit job because of care responsibilities. Also, more women than men reported that caregiving has affected their social activities, holiday plans and extra expenses (Lahaie et al., 2012).

The ecology theory argues that individual aspects and physical and social contexts are in constant interaction and may influence human adaptation to life events. Some personal and contextual circumstances are beyond personal control and can affect behavior positively or negatively (Keating et al., 2008). Faced with care responsibilities, the way how caregivers handle their family and social roles would be key factor to deal with potential adversities. In general, negative outcomes presented by caregivers reflect a poor handling and adaptation between care tasks and competing responsibilities. Theory also supports that people's profile of involvement in social activities, including their choices, preferences and opportunities depends essentially on personal/individual and environmental/contextual aspects. People can be more or less socially engaged or involved according to their personal and social conditions.

Social participation changes along the caregiving process. Rochette et al. (2007) observed changes in social participation in spouse caregivers of partners who suffered their first stroke. They found that changes in involvement with friends and family members, employment and recreational activities were related to higher level of burden and strain in caregivers. Compared to non-caregivers, family caregivers exhibit significantly higher levels of loneliness, greater social isolation and lower levels of psychological well-being (Stewart et al., 2006). These restrictions can isolate caregivers from previous, current and potential sources of social and emotional support, and restrict their opportunities to relax and engage in hobbies (Miller, 1990). Social isolation in caregivers exacerbates negative outcomes by cutting them off from potential support and assistance social participation.

Over the time, people leave social relations and activities in order to avoid situations that provide unnecessary stress and waste of physical and psychological energy. They prefer maintain a narrow network by selecting meaningful relationships (Miller, 1990). This is part of an adaptive process named

socioemotional selectivity. This process depends on previous and cumulative experience that is influenced by culture and social patterns (Carstensen, 1992). Although this adaptive process brings benefits it can exacerbate negative outcomes related to aging process and caregiving, mostly social isolation. The implications of age to social participation in caregivers were little explored in literature and were somewhat controversial. Some findings pointed that the youngest caregivers may provide less frequent care than older caregivers (Borg et al., 2006), and then, they can have more time to spend in social activities than the oldest. On the other hand, as midlife is a period often marked by active parenting and elder caregiving, the contacts with the social network can be limited because of concurrent responsibilities. Older caregivers have less competitive responsibilities and are more engaged.

The importance of social participation to health was largely documented in the literature, including caregivers (Tebb, 2000). People avoid complex activities when perceive themselves as cognitive and physically unable. Then, people with more health problems were found to be less social engaged.

Combining work and caregiving may implies additional difficult for caregivers (Covinsky et al., 2001). Reporting of competing responsibilities is common among caregivers. Adverse effects of care and work combination on caregivers include: lethargy, tiredness and lack of concentration; concerns about caring responsibilities at work; and stress brought on by trying to manage the often incompatible roles of employee and career, each with its own pattern of conflicting demands and expectations. Burden experienced by workers who try to combine working and caring can also have influence on their employers, in face of lowered production, increased absenteeism and higher staff turnover. Caregiver's characteristics associated with reduction of work hours or quit working due to care included being daughter or daughter-in-law of the patient and living with the patient. Daughters were more likely to reduce work hours than sons (Miller, 1990).

Some arrangements and facilities should be built, in order to preserve caregiver's health and well-being, as well as, contribute to the provision of adequate care for the elderly. For instance, availability of flexible schedule at work which may help caregivers dealing with concurrent tasks and having free time to take care of themselves. In addition, health and social programs aiming at prevention of stress and promoting well-being should be created and encouraged by employers and governments. Better results can be achieved by improvements in information, education and social support offering.

This study provides guidance for health and well-being promotion in caregivers of older people. Personal and contextual aspects related to caregiving that imply barriers to social participation should be approached by politicians, professionals and managers aiming at better use of social resources while promote higher quality of life for both, seniors and their caregivers.

Acknowledges

To Coordination for the Improvement of Higher Education Personnel (CAPES)—Brazil, for financial support.

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