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## Psychoeducational programs for informal caregivers of dependent older adults: Barriers to participation

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### Abstract

Psychoeducational programs (PEP) are recommended to provide support to informal caregivers. Evidences show low levels of participation in such programs. Removing barriers is necessary to promote effective programs. The research questions were as follows: what are the barriers to the participation of caregivers of dependent older adults in a PEP? What are the factors that motivate caregivers to participate in a PEP? The main purpose of this study was to analyze the barriers to the participation of informal caregivers of dependent older adults in a PEP and to identify the factors that promote the participation of informal caregivers of dependent older adults in a PEP. A qualitative approach was used for this study, conducted with twenty-four informal caregivers of dependent older adults registered at a Family Health Unit in Trofa County, Portugal. Data were collected using semi-structured interviews. For the analysis of empirical material, the content analysis technique proposed by Bardin was used. The “situational” barriers to the participation were most prevalent (need to escort the care recipient to medical visits, cost of transportation, lack of time due to caregiving tasks, or professional activity). The factors that favored participation mostly corresponded to the “psychosocial” (interest in acquiring additional knowledge and skills) and “institutional” categories (interest in the program content). The results demonstrate that inclusion of the participants in the design, implementation, and assessment of the program, as was the case, did not suffice to facilitate the program participation - the multiple barriers to their participation should also have been taken into account. Only by recognizing such barriers will the program become more effective and efficient for the caregivers.

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## 1. Introduction

Psychoeducational programs (PEP) have been widely recommended as a strategy to provide information and support to informal caregivers of dependent people (Monahan, 2011; Thompson et al. 2007; Hepburn, Lewis, Sherman & Tornatore, 2003). Nevertheless, the literature points to very poor levels of participation in such programs as a function of several barriers (Cherry, 2012; Fall, 2009; Won, Fitts, Favaro, Olsen & Phelan, 2008). Recent research shows that the most common barriers to the participation of informal caregivers in programs include difficulties with transportation, costs of care, lack of time due to caregiving tasks or professional activities, the caregivers' own health problems, and the lack of awareness of the need for specific training (Winterton & Warburton, 2011; Houtven, Ez, & Weinberger, 2010; Li, 2006; Ostroff, Ross, Stenglass, Ronis & Singh, 2004).

The interest in this subject was triggered by the poor attendance to a PEP for informal caregivers of older adults registered at a Family Health Unit (FHU) in Trofa County, Portugal. The PEP resulted from an action research study based on Morin's (2004) conceptual guidelines aimed at elaborating, implementing, and assessing a program of intervention focused on informal caregivers of dependent older adults registered at that FHU.

The integral action research process formulated by Morin (2004) is based on five basic dimensions that support the full method: (1) contract; (2) participation; (3) change; (4) discourse, and (5) action. Relative to the first dimension of the action research process (contract), the PEP was elaborated with the caregivers (n= 24) and FHU nurses (n= 2), who agreed to participate in the program. The number of sessions (11 two-hour sessions) as well as the program length (11 months), content, and setting were negotiated with the participants. The topics included were as follows: caring for caregivers of dependent older adults I and II; care relative to the hygiene of dependent older adults; mobility of dependent older adults; healthy nutrition; preparation and administration of drugs; feelings and emotions of caregivers; and relaxing techniques for caregivers well-being I and II. We systematically encouraged the formal and informal caregivers to take part in all of the sessions and reserved time enough for questions, comments, and the sharing of experiences. Although we stipulated a minimum attendance of 75%, the level of participation of the informal caregivers was poor. At the end of the PEP, nineteen out of the twenty-four included caregivers had not achieved 75% of attendance. As a consequence, two research questions emerged: (1) What are the barriers to the participation of caregivers of dependent older adults in a PEP? (2) What are the factors that motivate caregivers of dependent older adults to participate in a PEP?

According to the World Health Organization (WHO) (2001), the term "participation" is subjective and thus difficult to define. Desrosiers et al. (2005) define participation as the performance of and engagement in the activities of daily living and social roles. We chose to follow Morin's (2004) approach to the notion of participation. In Morin's approach, participation demands personal involvement, awareness of the human role and human activity, independence from hierarchical relationships, and predominance of dialogue in cooperative or collaborative relationships. Although the term "participation" might be defined in many different ways, there is a consensus on the need of the involvement of patients or caregivers and on the fact that high levels of participation are appropriate, desirable, and beneficial. Within that context, the participation of caregivers in PEP has attracted the attention of researchers.

The study follows the classification of barriers formulated by Lavoie, Levesque, Aubin-Horth, Roy and Roy (2004): institutional, psychosocial, situational and informational. The main purposes of this study were (i) to analyze the barriers to the participation of informal caregivers of dependent older adults in a PEP conducted at a FHU in Trofa County, Portugal and (ii) to identify the factors that favored the participation of informal caregivers of dependent older adults in a PEP conducted at a FHU in Trofa County, Portugal.

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