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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.

## 2. Methodology, data collection and analysis

A qualitative approach was used, conducted with twenty-four informal caregivers of dependent older adults registered at a FHU in Trofa County, Portugal. Trofa County is located in Northern Portugal and has approximately 38,999 inhabitants distributed across eight rural parishes. The FHU provides healthcare services to around 10,790 people from eight parishes in Trofa area. Participants were allocated to two groups: Group 1 – caregivers who did not achieve 75% attendance to the PEP sessions (n= 19) and Group 2 – the caregivers who did achieve 75% attendance (n= 5). Only thirteen caregivers in Group 1 and all five in Group 2 agreed to participate in the present study. The reasons for refusing to participate were unavailability, death of the care recipient, and having moved to another place.

The study was approved by the Ethics Commission of the Northern Region Health Administration (ruling no. 144.2011). The participants signed the contract, expressing their agreement with all its items, particularly the ones that guaranteed their anonymity, and the confidentiality of information. Data were collected using semi-structured interviews between June and July 2012. The participants were divided in two groups (identified above). The first, with the participants who did not achieved 75% attendance to PEP sessions. The second, with those who achieved this percentage. Thus, two different interview guides were elaborated. The first part of the guides was focused on the participants' characterization. The second part included common questions to both group (reasons for caregiving and participating) and specific ones (reasons of absence to participation in the PEP- first group; and motivation to systematic participation, to the second group). All interviews were entirely transcribed. Data were analyzed following Bardin's (2004) content analysis technique, which includes the following stages: (i) pre-analysis; (ii) exploration of the materials; and (iii) treatment of the results, inference, and interpretation.

## 3. Findings

The average age of the participants in Group 1 (n= 13) was 51.3 years, varying from 33 to 75 years, and the average age of the participants in Group 2 (n= 5) was 53.6 years, varying from 27 to 77 years. In both groups, most of the participants were female, n= 13 (Group 1), and n= 4 (Group 2). Most of the participants were married in Group 1 (n= 12) but single in Group 2 (n= 3). The participants in both groups had low educational levels, as nine in Group 1 and four in Group 2 had only attended grades one to four. With respect to occupation, most participants in Group 1 were housemaids (n= 6), and the remainder were unemployed (n= 3) or retirees (n= 3). Group 2 included two nuns (Slaves of the Sacred Heart of Jesus- Congregação das Escravas do Sagrado Coração de Jesus), and two participants were unemployed. With respect to the relationship with the care recipient, most participants in Group 1 were daughters (n= 6), whereas in Group 2, two were daughters and two had other degrees of kinship. The time in caregiving varied from six to eleven years in five participants from Group 1, five or fewer years in four participants, and more than twelve years in three. In Group 2, two participants had engaged in caregiving for five or fewer years, and two participants had engaged in caregiving for six to eleven years. One participant in each group was a caregiver only sporadically.

The barriers most frequently reported by the caregivers in Group 1 (n= 9) were "situational", i.e., having to escort the care recipients to medical visits, the cost of transportation, and lack of time due to caregiving tasks or professional activity. Following are two representative caregivers' comments that support this category: "...I couldn't go because I had to take my aunt (the dependent older adult) to the doctor "(C6); "A round trip taxi fare (to attend the PEP at the FHU) costs approximately 12 Euro. However, if I go and stay there, it's 12 Euro each way, and it's too much money" (C16). Two caregivers reported "psychosocial" barriers, i.e., lack of interest in learning. A representative comment from caregivers include: "I don't know why I came here (PPE); I already know this stuff" (C14). Finally, two other caregivers reported "informational" barriers, i.e., did not know the session schedule. A

caregiver states that "...I missed (one PEP session), and as I missed that session, I didn't get to know when the next ones were scheduled..." (C11).

The factors that facilitated the participation of the caregivers in Group 2 in the PEP corresponded to the "psychosocial", "institutional", and "situational" categories. The caregivers who attended 75% of the sessions reported more than one facilitating factor. The factors more frequently reported corresponded to the "psychosocial" category, i.e., the participants exhibited a positive attitude relative to the acquisition of additional knowledge. Following are two representative caregivers' comments that support this category: "I was here, that (PEP) occurred, and I liked it because it's an occasion to learn all the time; we'll learn until we die." (C2); "I have nothing to lose, as I do nothing at home; one goes there to learn, and learns." (C3). The next most cited reasons were the "institutional" factors, i.e., the ones related to transportation, interest in the program content, and liking the teachers' characteristics. A representative comment from caregivers include: "I like your program; you're great; you teach well..." (C3). Finally, the less mentioned factors were the "situational" ones, i.e., the support received by the caregivers as a function of the family structure. A caregiver said: "I ask my sister here (to care for the dependent older adult) so I can go to the healthcare center (to attend the PEP) once a month..." (C5).

#### 4. Discussion

The results agree with those reported by Hudson, Aranda & Hayman-White (2008), who found that the participants who did not participate to their program were on average younger than those who did adhere (56.2 and 59.8 years old, respectively). Our results, however, disagree with those of Winterton & Warburton (2011) and Desrosiers et al. (2005), who reported that older people exhibit less social participation. Hudson et al. (2008) found that in both groups, most caregivers were female and had low educational levels. Findings are also divergent in matter of the type of relationship with the care recipient, the caregivers' occupation, and the time spent as caregivers.

According to Morin (2004), participation requires awareness, engaging, and taking responsibility. The present study identified some barriers that hindered participation, mostly "situational" barriers, followed by the same frequency of "psychosocial" and "informational" barriers. Findings agree with other studies, identifying several barriers related to the use of support services. Tin Ng (2009) asked the participants in his study to name the barriers hindering them from using the supplied service, and the answers were subsumed under three categories: related to the caregivers, to the care recipients, and to the service providers. The answers related to the caregivers included time constraints, lack of awareness of the services, transportation, cost of care, the caregivers' sense of duty and attitudes, and distrust. Li (2006) also found that the individuals with higher educational levels were more aware of their needs, as well as of the community-based services. Cherry (2012) describes emotional, concrete (expensive or inconvenient services), and systemic (too rigid inclusion criteria, teams with poor levels of knowledge) barriers to the participation of caregivers in community programs.

Among the facilitators of participation, the "psychosocial" factors stood out, followed by the "institutional" and "situational" ones. These results give support to the recommendations formulated by Brookman, Holyoke, Toscan, Bender & Tapping (2011), according to whom caregivers must be provided appropriate rest and transportation, and the program must be amenable in the terms of time, setting, and receptivity. Meilan, Drees, Lange, Mirra & Vernooij-Dassen (2005) identified several factors that exerted a facilitating role in all the stages of the implementation of their program, such as the participants' motivation, available financial resources, variety and continuity of the activities, and cooperation among organizations.

#### 5. Conclusion and implications

Currently, families represent the first line of support of dependent older adults. Family caregivers require support services that meet their physical, emotional, and social needs. These were the grounds to elaborate and implement a PEP at a FHU in Northern Portugal. However, the participation in the program was poor.

The results of the present study demonstrate that the main barriers to participation in the PEP corresponded to the “situational” category (need to escort the care recipients to medical visits, cost of transportation, and lack of time due to caregiving tasks or professional activity). The two main categories of factors facilitating participation were “psychosocial” (interest in acquiring additional knowledge and skills) and “institutional” (transportation available, interest in the program content, liking the teachers’ characteristics).

This study demonstrates also that inclusion of the participants in the design, implementation, and assessment of the program did not suffice to facilitate their 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.

We strongly recommend that, to remove the barriers to participation, future PEP might include partnerships with other community-based institutions to solve, e.g., the transportation problems, or alternatively, the programs might be conducted at places closer to the caregivers’ homes. To further enhance the caregivers’ participation in PEP, the caregivers should be encouraged to ask the help of other relatives and acquaintances, thus establishing a support network, and the programs should include home visits and telephone calls.

Some caregivers might believe their knowledge is sufficient and thus refuse to participate in group-based interventions conducted too far from their homes. Caregivers need help to understand that this group-based activity affords a much needed pause in their difficult caregiving routine, as well as an appropriate source of additional information on the subject of family caregivers (Monahan, 2011).

One final recommendation, after this study, is that PEP should be shaped by the local culture, families demographic characteristics and caregivers’ needs. This way, the programs would include interventions associate with satisfactory outcomes, and assess the impact of the interventions on the caregivers’ quality of life.

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