



Effectiveness of Web-Based Psychosocial Interventions for Family Caregivers of Older People: What Do We Know?

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Abstract

The contribution of family caregivers to long-term care of older people is a relevant issue. Family caregivers may face different psychological and social needs arising from the challenging caregiving situation. In this respect, web-based psychosocial programs are progressively being refined and demonstrating they can be effective in supporting caregivers. This commentary describes the main types of web-based interventions for family caregivers of older people and available evidence on their effectiveness. Psychoeducational, peer and multicomponent programs have been the main object of research so far and can improve, under certain conditions, psychological wellbeing and social inclusion of caregivers. General integration, user and transferability issues are also discussed and call for future research in the field.

Keywords: Caregivers; Frail elderly; Internet; Health education; Social support

Introduction

The world is facing the emerging challenges of an ageing population without precedent, including a rising number of older people with long-term care (LTC) needs. For instance, in the European Union (EU) – whose overall population is around 504 million people – there were around 30.8 million older people with disability (36% of population over 65 years old) in 2012 [1] and even higher figures are estimated in the United States (US) (26.1 million older people with disability in 2014, 61% of older population) [2]. It is known that the LTC demand is actually met in most countries worldwide by the contribution of family caregivers, who constitute the most important resource of help and support for older people [3,4]. Caregivers generally provide unpaid care on the basis of personal, traditional and moral obligations and can be older spouses, adult children or other relatives of the dependent person. They perform a wide range of care tasks, assistance in activities of daily living, home help, transportation, emotional and social support [4,5]. Such contribution compensates and even substitutes in some cases the possible lack of formal care services, with caregivers estimated to be twice the number of the formal LTC workforce in the EU [3].

It has been largely demonstrated that providing care to a dependent person might negatively impact on the caregiver's wellbeing. In particular, depression, stress and reduction of subjective well-being have been identified as most occurring negative outcomes of caregiving [6]. On one hand, the duty to care directly generates stress, worries and pressure impacting directly their psychological wellbeing. On the other hand, caregivers constantly struggle in conciliating their private, social and working life with the caring activities. The combination of physical, psychological, emotional, social and financial problems that caregivers experience subjectively because of their caring responsibilities is commonly defined caregiver's burden [7].

Research evidence demonstrated that support services delivered via the web can effectively support family caregivers of older people in needs of help, sustaining their psychological and social wellbeing, enhancing confidence and self-efficacy [8-12]. Among the advantages, these services allow caregivers also to overcome time and logistic barriers to access support services [13]. This commentary aims at summarising main evidence emerged so far in the field of web-based

support services for family caregivers of older people with LTC needs, reviewing main types of psychosocial support delivered on-line and their potential effectiveness.

Evidence

Psychoeducational programs

Concerning programs mostly focused on psychoeducational purposes, research has been concentrating so far on caregivers of people with dementia. In particular, psychoeducational interventions for dementia caregivers mostly rely on e-learning modules with information, multimedia and training materials combined eventually with periodical guidance and advice by a psychologist or care professional. Psychoeducational programs seem to be effective in improving dementia caregivers' psychological wellbeing [8,14-17]. Most effective programs are usually structured (with a fixed number of lessons or sessions) and short-term, from 1 to 4 months [14,17,18]. One study on the Tele-Savvy program [16] delivered daily video modules to caregivers and organized weekly videoconferences, with good preliminary results in reducing subjective burden, depression, anxiety, frequency and upset of behavioral and psychological symptoms of dementia (BPSD), as well as increasing caregiver's competence. Another research [19] combined online information with telephone support (AlzOnline program), but with weak results.

Some randomized controlled trials (RCTs) reported that psychoeducational intervention reduced perceived burden [15] and symptoms of depression [8,14,17], anxiety [8,14], stress and strain [14], compared to the control group. For instance, a RCT with 251 caregivers

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assessed the Mastery over Dementia program in the Netherlands [8], showing significant reduction of both anxiety and depression sub-scales of the Hospital Anxiety and Depression Scale (HADS), respectively -1.7 (3.3) and -2.4 (8.2), with a medium effect size (Cohen's D: 0.48 and 0.26). One study, focusing on the 'Caregiver's Friend: Dealing With Dementia' program in the US [14], came to the conclusion that even a low exposure to multimedia educational modules (32 min) by dementia caregivers was sufficient to improve almost all psychological wellbeing outcomes. This fact was probably due to the knowledge and consequent relief that an easy, flexible support tool was available should they need it.

Few studies on psychoeducational programs for caregivers of older people with dementia have come instead with mixed or inconclusive results [18-22]. In two cases, STAR in the EU and AlzOnline in the US, the outcome improvements were quite weak, concerning only better empathy feeling between caregivers and intervention staff [18] and self-efficacy [19]. One study, focused on the Caring Web program for family caregivers of stroke survivors [23], conducted a RCT involving 103 users but without demonstrating improvements in psychological outcomes, showing instead significant reductions in emergency department visits and hospital readmissions.

Furthermore, there is little, but interesting, evidence of potential side effects of short-term educational interventions, which can lead some users to report higher levels of perceived stress [21] and decreased sense of competence [18]. These results suggest that an increased role awareness by users, stimulated by web programs, could lead to an immediate, negative self-appraisal of personal situation, but with the potential benefit of recognizing own needs of support and develop and using adaptive coping strategies.

Peer support programs

Interventions bringing peer caregivers together in on-line group support are raising interest among health professionals. In this respect, different reviews pointed out that programs addressing family caregivers of older people should take advantage of interactivity, connecting caregivers to peers and professional staff [11,24]. The online group component seem actually to be the most used and valued one of any given website, application or intervention [13].

Such group interactions can occur in a structured way – including the presence of a moderator or therapist and with a fixed number of sessions [17] – or unstructured – where users are free to enter and contact each other whenever they want and feel comfortable [25]. Peer support can be organized in different formats, including: text-based synchronous interactions, like in chat rooms [26] and social networks [27]; text-based asynchronous interactions, where messages are exchanged mostly with some time lapse, in on-line groups and fora [25]; audio- and video-communication synchronous interactions with real-time exchanges through dedicated web tools [26].

Available evidence seems suggesting that a structured group support for dementia caregivers is effective in improving mental health [17,26], quality of life [17] and decreasing distress in managing instrumental activities of daily living (IADL) [26]. One study [17] enrolled 86 caregivers and compared two experimental groups (respectively psychoeducational and moderated peer support) and one control group. Significant improvements were found in both experimental groups, compared to caregivers in the control group and inactive participants. Another paper [26] compared by means of mixed-methods the outcomes of two on-line peer support interventions

with a moderator, i.e., a chat group and a video group, proposed to 91 dementia caregivers. Results showed that, in both cases, self-efficacy increased and IADL distress decreased significantly. Between the two interventions, the video group reported greater improvements than the chat group in mental health and distress scores associated with care recipient's cognitive declining.

Unstructured text-based support groups do not show similar effectiveness, but qualitative research suggests that they might impact positively the caregiver-older person relationship, users' social inclusion and role awareness [25]. Short-term structured videoconferencing group sessions seem to be effective also for improving personality, self-efficacy and perceived social support [26].

Multicomponent programs

Web-based multicomponent programs refer to those interventions including a mix of peer and professional support for different informational, educational, counseling and therapy purposes. Caregiver research on traditional forms of support already demonstrated that tailored and multicomponent interventions are the most effective for improving psychological wellbeing [28]. Evidence on web-based programs for caregivers confirms this indication [9,11-13] and also suggests that improved on-line social connections can lead to more active coping strategies [29]. In this latter case, the Comprehensive Health Enhancement Support System (CHESS) for caregivers of people with cancer reported a significant association between perceived social bonding and three coping strategies – namely active behavior, positive reframing and instrumental support – which result from the mediating role of the CHESS intervention [29].

Furthermore, it is recognized as extremely beneficial also the presence of a professional coach or moderator, able to guide group discussions and therapies, and to provide tailored individual advice, counseling and support [9,30,31].

Conclusion

Overall, psychosocial programs delivering on-line support for caregivers of older people seem to be progressively improved and made more effective by care professionals. The main indications emerging concern the need to integrate different kinds of support (e.g. information, education, communication), to organize structured on-line peer groups with a moderator, to keep into consideration potential side effects (linked to a possible re-appraisal of caregiver's situation) in short-term and manage them adequately. Furthermore, it seems that interventions based on theoretical frameworks and targeting caregivers at the very beginning of the onset of their needs are the most promising strategy [32].

Despite the promising results described, there is still need for further research in the field [11-13,32]. In particular, most studies focused so far on dementia caregivers and few on other chronic diseases (mostly stroke and cancer), which indeed calls for new commitment in under-investigated areas.

Finally, from a socio-cultural perspective, the majority of research has been concentrating on settings in the US, with fewer studies in Europe and other areas worldwide. The transferability issue of how to adapt a successful web-based program from one country to another (but also in different social, economic and cultural contexts within a same nation) is still not discussed, with few examples of international comparative research [18,30].

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