# Internet Interventions for Family Caregivers of People with Neurocognitive Disorder
## *A Literature Review*

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Abstract:     Taking care of a loved one can be a new, yet challenging role for caregivers. However, these caregivers are usually overbooked and do not have the time needed to reach for help. Internet interventions are a great way to offer psychoeducation, support and tools for caregivers, in the comfort of their home. This literature review explores the impact of internet intervention programs. Twenty-two studies were found in PsychNet, Medline and Google scholar using "family caregiver, dementia, neurocognitive disorder, internet, technology, web" as keywords. A review of these studies showed that internet intervention for caregivers have an impact on the caregiver's psychological health (e.g. feeling of burden, stress, depression, anxiety, etc.), on their relation to the care receiver (reaction to disruptive behaviors, self efficacy, positive aspects of caregiving, better understanding of the illness, etc.) and even of the care receiver himself (disruptive behaviors occurrence and severity). However, internet intervention programs for caregivers show a great versatility in their effectivity results, but they still appear to be a good way to provide psychoeducation on neurocognitive disorder, to reduce negative emotion associated with caregiving and improve the caregiving relationship itself.

## 1 INTRODUCTION

It is well-known that caring for a loved one affected by a neurocognitive disorder can lead to negative consequences for the caregiver, such as a feeling of burden (Glueckauf, Ketterson, Loomis and Dages, 2004; Griffiths, Whitney, Kovaleva and Hepburn, 2016; Lorig et al., 2016), depression (Blom, Zarit, Groot Zwaaftink, Cuijpers and Pot, 2015; Griffiths et al., 2016) and anxiety (Beauchamp, Irvine, Seeley, and Johnson, 2005; Griffiths et al., 2016). Caregivers often feel lost and overwhelmed with this new role (Collins and Swartz, 2011). In addition to memory and functional loss associated with neurocognitive disorder, caregivers also have to deal with disruptive behavior like aggression, agitation, wandering, etc. (Kamiya, Sakurai, Ogama, Maki and Toba, 2014). These behaviors appear to be the most distressing for caregivers, contributing to the feeling of burden and depression symptoms (e.g. Brodaty Woodward, Boundy, Ames, Balshaw and PRIME Study Group, 2014; Kamiya et al., 2014).

Many interventions type exist to reduce the burden of care, like respite, support groups or psychoeducation or internet intervention programs. Interventions designed for caregivers have multiple benefits. In addition to improving the caregiver's well-being, this kind of intervention can help them offer a better care for their loved one and delay their institutionalization, which is very costly in terms of quality of life and healthcare costs (Keefe and Manning, 2005). In this sense, these positive outcomes are not limited to the caregivers and their loved one, but also offer an economic and personalized solution for society (Åkerborg et al., 2016; Keefe and Manning, 2005).

Among all intervention aimed to reduce negative consequences of caregiving, internet intervention programs appear to be the ones most suited for the caregiver's reality. In fact, with all the tasks and responsibilities associated with care, caregivers often do not have the time needed to seek for help. The lack of accessibility of interventions is an obstacle to the participation of caregivers. One study reported that up to 60% of caregivers contacted for an intervention refused to participate because of the time required (Wiprzycka, Mackenzie, Khatri, and Cheng, 2011).

With internet intervention, they have the opportunity to choose the service and use it at their

suitability. Internet interventions reduce time travel, they are adapted to the caregiver schedule and allow caregivers to select the types of services they need (Blom, Bosmans, Cuijpers, Zarit, and Pot, 2013). Studies show that the majority of participants are comfortable with computers and appreciate their virtual participation in the group. The majority of participants say the web sessions are comparable to traditional face-to-face meetings and would recommend the intervention to their friends (Chiu et al., 2009; Finkel et al., 2007).

Despite the ease of access to internet interventions, recent studies show conflicting results on the efficacy of these programs. This article proposes a review of the literature of the characteristics of internet intervention programs and their impacts on caregivers. This article may help researchers in creating effective internet interventions for caregivers. Clinicians seeking evidence on which to build treatment may also draw on the findings of this article.

## 2 METHOD

The search for this review was made mainly though PsychNet Medline and Google Scholar. We used "family caregiver, dementia, neurocognitive disorder, the internet, technology, web" as keywords. These are the combinations used: Family caregivers, dementia, and technology; family caregivers, dementia and internet, family caregivers, dementia and web-conference; family caregivers, intervention, dementia and internet. The snowball method was used to identify articles from the reference list of articles already included in the review.

### 2.1 Inclusion Criteria

The selected studies needed to be aimed at family caregivers of individuals affected by a major neurocognitive disorder and use computers to offer an intervention program. They also had to be written in French or English.

There was no limit on the age of articles, however, articles were closely analyzed to ensure their technological methods were still relevant, for example a study using videophones or VHS was excluded (studies using smartphones were included).

### 2.2 Exclusion Criteria

Studies with no use of computers (traditional face-to-face meetings or telephone calls), studies that included caregivers of all older adults with no specification concerning the presence of major neurocognitive disorder were excluded. We also excluded studies with attrition superior to 45% were excluded.

### 2.3 Selection of the Studies

When we searched through the databases, 1725 articles were found. There were 1096 articles left after removing duplicates. Then, 574 articles were excluded after reading the title and abstract. Among the 55 articles fully red, 36 papers were excluded because they did not meet the inclusion criteria or covered additional facets of studies already included in the review. In the end, 19 articles were selected from a database and three more were added from the articles reference list, for a total of 22 articles.
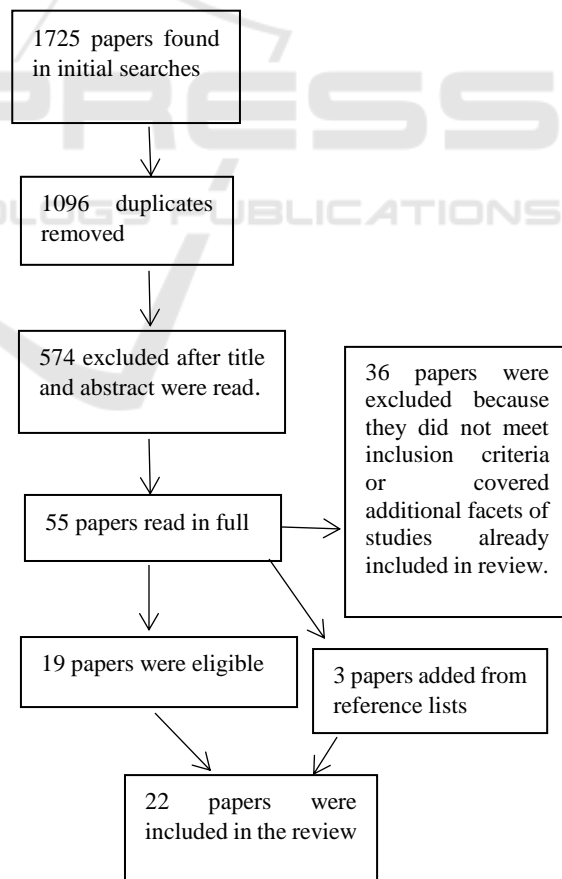
Figure 1: Flow diagram of article selection process.

## 2.4 Studies' Description

We identified 22 studies of internet intervention for caregivers of a person affected by a neurocognitive disorder. These studies were published between 1995 and 2017. These studies are specific to internet intervention programs designed to reduce the negative impact of caring, improve the caregiving relationship or reduce the disruptive behaviors. The passive intervention includes a website, video capsule or for psychoeducation. Interventions could also be active like group meetings by web conference forums, emails or even web support groups to encourage communication between caregivers or caregivers and resources. Certain studies may include multiple intervention types (Bass, Mcclendon, Brennan, and Mccarthy, 1998; Blom et al., 2015; Boots, de Vugt, Withagen, Kempen and Verhey, 2016; Chiu et al., 2009; Glueckauf et al., 2004 ; Kelly, 2003; Lai, Wong, Liu, Lui, Chan and Yap., 2013; Lorig et al., 2010; Marziali, Damianakis and Donahue, 2006)

In this sample, twelve studies used a randomized protocol, eight had a pre-experimental protocol (of which three are pilot studies), one used a qualitative methodology (O'Connell et al., 2014) and an other used a mixted method (Kelly 2003). Control groups included routine care (Cristancho-Lacroix, Wrobel, Cantegreil-Kallen, Dub, Rouquette and Rigaud, 2015; van der Roest, Meiland, Jonker and Dröes, 2010), waiting lists (Beauchamp et al., 2005) leaflets with various information (Blom et al., 2015; Finkel et al., 2007, Hicken, Daniel, Luptak, Grant, Kilian and Rupper, 2016; Lai et al., 2013; Marziali and Garcia, 2011) and a placebo website (Brennan, Moore, and Smyth, 1995). Sample sizes of intervention groups varied widely from 3 (Lai et al., 2013) to 700 (Kelly, 2003) with an average of 71,36 caregivers. The control groups, meanwhile, had an average of 57,15 caregivers (8 to 149). Attrition also varied from 0% (Torkamani et al., 2014) to 41% (Boots et al., 2016), with a mean of 19.4%. Attrition was not mentioned in four of the 22 studies.

Where possible, studies were compared using the effect sizes (Cohen's d). Among the randomized studies, this was done with the following formula (mean of post-test control group - mean of the experimental group at post-test) / common standard deviation. For single-group protocols, the following formula was used; (mean pre-test - mean post-test) / common standard deviation.)

## 3 RESULTS

### 3.1 Intervention's Modality

Most aid programs used several modalities to reach caregivers. The most popular method was the interactive website, used in 18 studies. In general, websites were used to facilitate psychoeducation and participants visit the site individually, where appropriate. The material was accessible for 6 weeks (Lorig et al., 2010) and one year (Bass et al., 1998; Brennan et al., 1995), depending on the study. Web sites generally offered information on neurocognitive disorder and on various care skills. In addition, some offered more specialized tools, for example, to facilitate decision-making (Brennan et al., 1995), to help the caregiver better identify their needs (van der Roest et al., 2010) or to teach emotional management strategies (Beauchamp et al., 2005).

Seven authors pointed out that some of the material was presented via video capsules (Beauchamp et al., 2005; Glueckauf et al., 2004; Griffiths, Whitney, Kovaleva and Hepburn, 2016; Hicken et al., 2016; Jajor et al., 2016; Kajiyama et al., 2013; Lorig et al., 2010; Torkamani et al., 2014). Sometimes, asynchronous communication modalities were also added to the website to encourage sharing between caregivers. A forum or the option to communicate with other participants via emails was present on 12 websites (Bass et al., 1998; Brennan et al., 1995, Blom et al., 2015; Boots et al., 2016; Glueckauf et al., 2004; Jajor et al., 2016; Kelly, 2003; Lai et al., 2013; Lorig et al., 2010; Marziali et al., 2006; O'Connor, Arizmendi et Kaszniak, 2014; Torkamani et al., 2014). With the use of email between the participant and a health professional, the studies of Chiu et al. (2009) and Kwok et al. (2014) also provided individual psychotherapy sessions at a distance. Finally, the assistance program of Marziali et al. (2006) included 12 group meetings with web conference to encourage social support. The 4 studies that do not use a website offered psychoeducation via audio conferences (Finkel et al., 2007) and web conferencing (Griffiths et al., 2016) or social support groups via audio conferencing (O'Connell et al., 2014) or with a virtual reality tool (O'Connor et al., 2014). These authors emphasized that these modes of communication are synchronous, which facilitates exchanges between the participants.

Overall, the majority of studies offered complex assistance programs that address a variety of needs and use several modalities. Their results were mixed. As noted in Boots, Vugt, van Knippenberg, Kempen, and Verhey (2014), it is difficult to interpret the

specific effects of each study since the characteristics of the programs are not always well detailed. In addition, data on usage rates and adhesion are rare. Some of the findings from the meta-analyzes of traditional caregiver programs can still inform programs remotely. For example, it appeared that the studies which target specific difficulties also have encouraging results when offered at a distance. In fact, the aid program of Glueckauf et al. (2004), by web site and audio conference, led to significant changes in perceived personal effectiveness for different caring activities.

## 3.2 Intervention's Utilization

Among the studies included in this review, 10 offered information on participation rate or rates of use. In synchronized interventions, the numbers of sessions attended are one way to convey participation rate. For example, in Finkel and colleagues' study, 94% of participants attended 7 or more out of a possibility of 8 sessions (2007). An other study also mentions high participation rates but fail to provide them (O'Connell et al., 2014) . Web site based programs reported using in different ways. Some authors report the number of visits; websites were consulted on average between 5.14 and 6.98 times per month (Bass et al., 1998; Kajiyama et al., 2013; van der Roest et al., 2010). Others report the average amount of time spent consulting the web-site, they ranged from 14:36 min to 106.41 minutes (Bass et al., 1998; Beauchamp et al., 2005; van der Roest et al., 2010). The number of modules or sessions completed are also reported, they ranged from 70 to 83% of participants completing sections (Cristancho-Lacroix et al., 2015). Finally, studies with forums did report the number of posts by participants, with a mean of 36.9 (Lorig et al., 2010).

## 3.3 Intervention's Content

The intervention's structure was missing in most of the studies and protocol's description was missing in all of the studies. Therefore, some studies shared the themes discussed in their intervention.

Most studies included an educational theme on neurocognitive illness and/or caregiving role (e.g. Bass et al., 1998; Beauchamp et al., 2005; Blom et al., 2013; Brennan et al., 1995; Chiu et al., 2009; Cristancho-Lacroix et al., 2015; Glueckauf et al., 2016; Griffith et al., 2016; Hockem et al., 2016; Kajiyama et al., 2013; Kwok et al., 2014; Lorig et al., 2010; O'Connell et al., 2014; O'Connor et al., 2014). Many studies also added problem solving skills or decision-making, especially oriented towards

behavioral problems (Blom et al., 2013; Cristancho-Lacroix et al., 2015; Kajiyama et al., 2013; Kwok et al., 2014; Lorig et al., 2010), daily difficulties (Beauchamp et al., 2005; Brennan et al., 1995; Chiu et al., 2009; Cristancho-Lacroix et al., 2015) or to enhance communication with the care receiver (Blom et al., 2013; Hicken et al., 2016). Dealing with emotions or even their care receiver's emotions were frequent themes too (Beauchamp et al., 2005; Chiu et al., 2009; Hicken et al., 2016; Kajiyama et al., 2013; Lorig et al., 2010). Some studies added a self-care theme (Griffith et al., 2016; Hicken et al., 2016; Kajiyama et al., 2013), which could contain sleeping habits, alimentation habits (Lorig et al., 2010), pleasant activities (Kajiyama et al., 2013) and physical exercise (Lorig et al., 2010). Three studies included information and exercises about relaxation (Blom et al., 2013; Hicken et al., 2016; Kajiyama et al., 2013). Planning the future also seemed to be a recurrent theme (Kajiyama et al., 2013; Lorig et al., 2010). In addition to these more frequent themes, some studies included education or discussion on seeking help (Blom et al., 2013; Cristancho-Lacroix et al., 2015; Lorig et al., 2010), respite (Cristancho-Lacroix et al., 20015), social and\or financial support (Cristancho-Lacroix et al., 2015), pharmacotherapy, non-pharmacotherapy and avoiding falls (Cristancho-Lacroix et al., 2015).

Finally, most studies included emotional support, by other caregivers or by health professionals, which emerges to be central for caregivers, (Hicken et al., 2016; Kajiyama et al., 2013) even when the study's results were inconclusive. This support could be offered by email (Chiu et al., 2009) or telephone (Hicken et al., 2016). One study also mentioned that participants needed more dynamic interactions (Cristancho-Lacroix et al., 2015).

Even though most studies showed great acceptability of the internet format, one study showed that man might have more positive feedback for online intervention than women (Cristancho-Lacroix et al., 2015). Furthermore, Bass and colleagues found that online intervention is more effective if the caregiver has a larger informal support network is caring for a spouse or did not live alone with the care receiver (1998), supposing that isolation might an important issue for caregivers. In Kajiyama and collegues' study, caregivers mentioned they would need more contacts with other caregivers and the health professionals (2014).

## 3.4 Effect of Internet Interventions

Variables used to measure the effectiveness of aid programs are also varied. These studies measured one or many of those variables: feeling of burden, depression, anxiety, stress, self-efficacy, fatigue, distress, ability to reach objectives, confidence in decision, ability to ask for help, positive aspects of caregiving, perception of caregiving, occurrence and severity of disruptive behaviors, reaction to disruptive behaviors and distress related to disruptive behaviors. Significant results were obtained in 12 of the 21 quantitative studies.

Three out of 12 studies (25%) identified a significant reduction in the emotional burden, 60% (3 out of 5) decreased stress, 25% (3 out of 12) decreased depressive symptoms, 100% anxiety (3 out of 3), 67% (4 out of 6) showed an increase in self-efficacy, 50% (3 out of 6) showed a decrease of the disruptive behaviors and 33% showed a decrease of the caregiver's reaction to disruptive behaviors (1 out of 3). Beauchamp et al. (2005) also reported a significant increase in the intention to seek help and positive aspects of caregiving, while (Brennan et al., 1995) obtain an increase in confidence in decision-making. (Boots et al., 2016) reported that caregivers increased their achievement of goals. (Van der Roest et al., 2010) have also reported an increase in perceived competence in their sample.

When the intervention had a significant effect on caregivers, Cohen's d were calculated to ease the comparison of studies. Caregiver's feeling of burden is a recurrent variable. In three studies found Cohen's d between 0.43 (Griffiths et al., 2016) and 0.57 (Torkamani et al., 2014) with a mean of 0.49. Self-efficacy is also frequently measured and in two studies the Cohen's d found are between 0.28 (Beauchamp et al., 2005) and 0.77 (Lorig et al., 2010) with a mean of 0.52. Cohen's d for stress in present in three studies and is between 0.13 (Beauchamp et al., 2005) and 0.5 (Lorig et al., 2010), with a mean of 0.24. For anxiety, Cohen's d is between 0.15 (Beauchamp et al., 2005) and 0.51 (Griffiths et al., 2016) with a mean of 0.38 in three studies. Cohen's d for depression is measured by two studies and the result found was 0.26 (Blom et al., 2015) and 0.52 (Griffiths et al., 2016), with a mean of 0.39. The Cohen's d was also available for four studies on disruptive behavior studies. The Cohen's d was between 0.11 (Kajiyama et al., 2013) and 0.71 (Kwok et al., 2014), with a mean of 0.49. Single studies also provides Cohen's d for many variables. Internet intervention seems to have a small effect on fatigue (0.08; Beauchamp et al., 2005), depressive symptoms

(0.10; Beauchamp et al., 2005), trust in decision (0.31; Brennan et al., 1995), asking for help (0.25: (Beauchamp et al., 2005), positive aspects of caregiving (0.25; Beauchamp et al., 2005), reaction (0.43; Griffiths et al., 2016) and distress (0.47; Kwok et al., 2014) associated with disruptive behaviors. Moderate Cohen's d was found in the perception of caregiving demands (0.49), obtaining respite (0.59) and cognition with caregiving role (0.52; Glueckauf et al., 2004).

## 4 DISCUSSION

### 4.1 Conclusions of This Review

In conclusion, this review presented an overlook of 22 studies measuring the effectivity of internet interventions for caregivers. It showed that internet interventions include a large diversity of intentions, from synchronous psychoeducation to web therapy. The variables used to measure the effectiveness of these programs also differ from one to another. Some studies focused on caregiver variable (ex. feeling of burden, stress, depression, anxiety, etc.), on their relation to the care receiver (ex. reaction to disruptive behaviors, self-efficacy, positive aspects of caregiving, better understanding of the illness, etc.) and even of the care receiver himself (disruptive behaviors occurrence and severity).

Theses internet intervention programs showed their versatility with their improvement of the caregiver's psychological well-being (Blom et al., 2015; Glueckauf et al., 2004; Griffiths et al., 2016; Lorig and al., 2010), with promoting tools to improve the caregiving relationship (Beauchamp et al., 2005; Boots et al., 2016; Glueckauf et al., 2004; Griffiths et al., 2016; Lorig et al., 2010) and even with improving the care receiver's behavior (Griffiths et al., 2016; Kajiyama et al., 2013; Kwok et al., 2014). However, we found a great variability in the effectivity measured. In fact, 57% of the studies showed a significant impact of the program on the caregivers. Even if a majority of studies showed significant impact on stress, anxiety and self-efficacy, more studies are needed to measure the impact of these programs on the burden, depressive symptoms and reaction to disruptive behaviors. As internet intervention programs will probably increase in the next years, further studies will need to document the effect of these kinds of interventions with a larger number of studies to compare and less variability in the programs assessed and variables measured.

## 4.2 Reflexion on Internet Intervention

In a larger view, literature shows issues with the description and classification of interventions. In fact, the authors differ in their way of describing their interventions, so what ones consider psychoeducation can be considered therapy by one another. This therefore brings an important limitation in the comparison of studies.

A standardization proposing clear descriptions for each type of intervention would be preferred in order to unify the literature. It would also be appropriate to encourage authors to provide a more detailed description of the intervention delivered. This description is unfortunately missing in most of the articles (Gaugler, Jutkowitz, Shippee and Brasure, 2017). Moreover, the complexity of the interventions offered complicates the interpretation of the results. In fact, the majority of studies combine several modalities of intervention (e.g. a website and a forum). It is therefore difficult to identify which modality has beneficial results for caregivers. New studies aiming at isolating the active agent from the treatments offered would therefore be necessary in order to clarify the conclusions on the interventions by the Internet.

Finally, the increasing popularity of Internet interventions brings some challenges with updating the knowledge of caregivers. In this sense, studies are rapidly outdated due to technological advances. Therefore, new updates will always be required.

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