Navigating the landscape of Dementia care: iSupport Swiss as a case study

A doctoral dissertation presented by
Anna Messina

Under the supervision of
Prof Emiliano Albanese
Dr. Maddalena Fiordelli

Submitted to the
Faculty of Biomedical Sciences
Università della Svizzera italiana

For the degree of
Ph.D. in Biomedical Sciences

December 2023

Acknowledgments

I would like to express my gratitude to all people who have been by my side throughout these years, particularly to Federico, for his love and support, and to my friends and family. A special thanks goes to my colleagues here at the Institute, whose companionship has transformed a study project into a journey of friendship and personal growth.
I extend my sincere appreciation to Maddalena Fiordelli for her unwavering support, guiding me step by step and accompanying me in the world of research with both gentleness and determination. I am also grateful to Professor Albanese for his guidance and for allowing me to pursue additional educational paths concurrently.
My thanks go to Katrin Seeher from the WHO and to the members of iSupport network for the collaboration demonstrated and the international perspective they brought to the project. Lastly, I extend my gratitude to all the caregivers and professionals who shared their stories, allowing us to delicately enter their lives and enrich our understanding.

Table of Contents

Chapter 1: Outline

Outline

This PhD dissertation aims to shed light on the intricate mosaic of informal caregivers of people with dementia, along with the secondary aim of locally adapting and implementing iSupport, a WHO digital intervention to support caregivers. To reach these aims, we employed mixed methods and techniques, including cross-sectional surveys, focus group discussions and a systematic review.

Chapter 2 serves as a compass, providing a summary of the pivotal themes central to this thesis. It includes a review of the literature on 1) dementia and its relevance at a public health level; 2) the prevalence and characteristics of informal care; 3) the existing traditional and digital interventions dedicated to caregivers; 4) the challenges of implementation science; and 5) the background and structure of iSupport.

Based on the findings of a published cross-sectional study, **chapter 3** presents an exploration of the mental health of informal caregivers of people with dementia living in Switzerland (Ticino) and Italy. Specifically, the work explored symptoms of burden, stress, anxiety, depression, and loneliness experienced by caregivers during the initial wave of the COVID-19 pandemic.

Chapter 4 is a published qualitative study on the attitudes of informal caregivers towards support interventions and seeking help behaviours. It offers a perspective on the potential barriers and facilitators to the access and adoption of support measures.

Chapter 5 is a recently submitted systematic review that focused on the adoption of participatory methods in designing and developing digital interventions dedicated to informal caregivers.

Chapter 6 is a mixed-methods study, submitted and currently under revision, describing the cultural adaptation process of iSupport in Ticino. This study provides insights into the integration of a community-based participatory approach and offers preliminary results of the iSupport adaptation process.

In **Chapter 7** we summarized the main findings across the studies, drawing overarching conclusions and offering recommendations for future research endeavours.

Finally, **Chapter 8** (appendix) serves as a showcase, illustrating examples of the outputs and materials related to iSupport Swiss. This section provides concrete examples of the process of adaptation and dissemination of iSupport in Switzerland.

Chapter 2: Introduction

Dementia

Definition

Until recently, cognitive decline that characterizes dementia was considered a normal part of the biological aging process. Only in recent years, there was a progressive shift in the public understanding of dementia. The term dementia as used in common language is now much closer to the clinical term that denotes a class of diseases that affect brain functions and the abilities to perform daily activities (World Health Organization, 2017; Peng FC, 2003), typically in late life and characterized by a subtle and progressive decline. Dementia is considered and best conceived as a syndrome that can be caused by several diseases which affect the structure and function of neurons, with associated progressive decline in cognitive functions including memory, executive functions, language, and spatial navigation, behavioural and psychological symptoms, and functional deficits that lead to reduced autonomy (Corey-Bloom J, 2002).

Alzheimer's disease (AD) is the most common form of dementia, accounting for the 60-70% of all dementia cases (Van Der Flier, 2005). The neuropathology of AD is well-known. The pathological hallmarks of AD are extra-cellular amyloid oligomers (β42 and others) and plaques, and intracellular fibrillary tangles of phosphorylated microtubular tau proteins. AD typically manifests with progressive memory loss and declining spatial navigation skills, particularly in late-onset cases (Van Der Flier, 2005). Other symptoms of AD may include, especially in moderate and severe phases of the disease, difficulties in the executive functions, and language (Corey-Bloom J, 2002), and behavioural symptoms including apathy, depression, and disrupted sleep, among others. Other common types of dementia encompass vascular dementia, dementia with Lewy bodies; and frontotemporal dementia and Parkinson disease (National Institute on Aging, 1988). Each of these have specific cluster and dynamics of cognitive and behavioural symptoms. The term "Alzheimer's disease" is often erroneously used in everyday language as a synonym for dementia. Senile dementia is also commonly used. Aside from the confusion, the term "dementia" has, in most languages, negative connotations, which may contribute to the associated stigma and discrimination (Jellinger, 2010; Perminder Sachdev, 2000; Assal, 2019).

Diagnostic criteria for dementia have greatly evolved in recent years. To achieve a more accurate consensus over the disease and its diagnosis, the most recent edition of The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) has introduced the term "Major Neurocognitive Disorder" (MND) as a replacement for dementia. MND is defined as a significant decline in at least one of cognitive domain, including executive function, complex attention, language, learning, memory, perceptual motor, or social cognition, and associated functional decline and reduced ability to perform activities of daily living (American Psychiatric Association, 2013). The DSM distinguishes between the

“Major Cognitive Disorder” and “Mild Neurocognitive Disorder” (or Mild cognitive impairment- MCI), based on the number of affected cognitive domains and the impact on daily activities (American Psychiatric Association, 2013). In both cases the cognitive impairment must represent a decline from a previously higher level and must not occur in the context of a delirium of another mental disorder (Hugo & Ganguli, 2014; American Psychiatric Association, 2013). Nevertheless, despite the reframing and its implications for a more accurate comprehension and diagnosis of the disease, the term “dementia” remains widely accepted and employed within the scientific community. Aware of these important implications, we decided to maintain in this thesis the term dementia for a better readability, and in alignment with the prevailing literature on this subject. This is also consistent with stances of the World Health Organization (WHO) and Alzheimer Disease International (ADI), the worldwide highest public health and policy organizations in the field.

Symptoms

The neurodegenerative processes of dementia affect various brain regions, including the frontotemporal cortex. This brain region is implicated in higher cognitive functions such as decision making, motivation, planning and attention. Additional affected region are the limbic regions that are involved in motivation, emotion, learning process and memory (Müller-Spahn, 2003). The progressive impairment of these and other regions results in the loss or deterioration of the ability to perform basic activities (ADLs) or instrumental activities of daily living (IADLs). ADLs encompass essential tasks for independent living such as bathing/showering; brushing teeth; grooming, and toileting; getting dressed; mobility and eating. Conversely, IADLs entail the ability to maintain a good quality of life and include housekeeping; managing finances; handling medications; cooking; shopping; transportation and communication using devices. In addition, up to 90% of people affected by dementia also experience behavioural and psychological symptoms (BPSD) at some point through the disease course (Pinyopornpanish et al., 2022). Common BPSD include personality changes; apathy; depression; anxiety; delusions; hallucinations; agitation; aggression; wandering; disinhibition; incontinence; aberrant motor behaviour and sleep disorders. Although the symptoms of dementia may follow a certain order and a relatively predictable progression, especially within the same type of disease, the speed and intensity of their manifestation can vary significantly. This variability is influenced by a complex combination of factors, including the individual characteristics of person living with dementia and the environment in which they live (Prince et al., 2016)). Therefore, every person living with dementia presents a unique interplay of factors which shape how dementia manifests and progresses (Livingston et al., 2017). This complex variability has relevant implications for healthcare provision, and planning, and must be carefully accounted for in the design, adaptation and implementation of interventions aimed at reducing the impact of dementia on those who are affected, their family, and the communities in which they live. This is discussed in detail in the following paragraphs.

A global public health priority

Dementia poses enormous public health challenges, and on a global scale. According to the World Health Organization (WHO) more than 55 million people are affected by dementia worldwide, with nearly 10 million new cases every year (World Health Organization, 2021). Dementia represents the seventh leading cause of death and one of the major causes of disability and dependency among people aged more than 60 years old (World Health Organization, 2021). Dementia prevalence increases steadily with age, and the number of cases is expected to triple in the coming decades because of population aging alone (World Health Organization, 2021). The public health implications are huge also because dementia has an impact not only on the people affected, but also on their caregivers, families, society, and care systems. Numbers and proportions will pose unprecedented pressure on nations and populations, including costs.

Global costs of dementia include three main components: i) direct medical costs that cover expenses related to treatment, hospital care, drugs, diagnostic tests and visits; ii) direct non-medical costs that include care in residential or long-term care facilities, home care, food supply and transportation, and iii) indirect costs that refer to informal care, which involves unpaid hours of assistance provided by family members or friends to support the person with dementia in her daily life, and the repercussion of cut back on work caused by care provision (OECD, 2017). The huge costs of dementia represent a great challenge for all societies and care systems and require interventions and clear strategies to be effectively tackled (World Health Organization, 2017).

More specifically, in 2019, the annual global societal costs of dementia, estimated for all 194 WHO member states, were calculated at US $1313.4 billion for 55.2 million people with dementia, corresponding to US $23,796 per person with dementia, with informal care costs representing 50% of the total costs (Wimo et al., 2023). These sums are too high to be factually grasped and will further increase because of the expected trends in population demographics, characterized by both an aging and population growth (Nichols et al., 2019; GBD, 2022). The provision of informal support to people with dementia by family members accounts for an increasing share of these costs, but it also entails consequences that outdo the boundaries of the economic realms (Wimo et al., 2023). Moreover, although informal unpaid care plays a vital role in reducing public spending on formal care services, it tows many hidden costs. If not adequately supported in their role, informal carers can face negative impacts on their physical and mental health (Kasuya et al., 2000). The negative impacts of intensive caregiving can consequently result in higher demand and costs for health care, reduced labour market participation and consequently higher risks of poverty and social exclusion (UNECE, 2019). Thus, the challenges tied to informal caregiving extend beyond the caregivers themselves and impact society at large.

Given the current very limited access to the few available effective disease-modifying treatments for dementia, it is imperative for public health policies to target disease prevention through multi-facet interventions (Jeffrey L Cummings, 2014; M Waite, 2015). In line with this urgent need for action, in 2017 the WHO released the

"Global action plan on the public health response to dementia 2017-2025" (World Health Organization, 2017). This policy document provides recommendations across seven key action areas: dementia policy (area 1); awareness and friendliness (area 2); risk reduction (area 3); diagnosis and treatment (area 4); support for carers (area 5); health information system (area 6); and research and innovation (area 7) (World Health Organization, 2017). Within the scope of this thesis and the research undertaken throughout this doctoral project, our specific emphasis will be on action area 5. This area aligns with the pressing need to develop a deeper and more comprehensive understanding of informal caregiving and the strategies for effectively providing support to this group of individuals.

Informal care

Prevalence and characteristics

Informal caregivers play a pivotal role in the assistance of individuals with dementia. Indeed, the WHO estimated that two-thirds of people affected by dementia receive care at home mainly or only from family members or friends (World Health Organization, 2017). Numbers about informal care provided to people with dementia slightly varies across countries and cultures but are very high in all world regions. For instance, in the United States and Canada more than 80% of care is provided by family members or friends of the person living with dementia (Alzheimer's Association, 2021; Canadian Institute for Health Information, 2018). In Europe, the proportion of informal care ranges from 60% to 90%), while in Asia the prevalence of informal care accounts for 90% of the global care provided to people with dementia (Alzheimer Europe, 2020). These variations can only partially be explained by differences in healthcare system capacity and offerings. Indeed, literature shows that patterns and prevalence of informal care are deeply influenced by variations on cultural norms and family structures (Mccleary & Blain, 2013; Friedman et al., 2015). For instance, in eastern countries, including Japan and China, caring for older family members is traditionally seen as a moral obligation, often leading to multiple generations cohabiting in the same household (Friedman et al., 2015). In contrast, western cultures place a stronger emphasis on independence and autonomy, which can lead to greater reliance on formal professional assistance or healthcare providers when available (Hashimoto & Ikels, 2005).

Despite variations in the prevalence and distribution of informal caregivers, certain common characteristics emerge. Typically, the role of primary caregiver is usually assumed by a close family member, often adult children or spouses of people living with dementia who provide an average amount of 20-30 hours of assistance per week (Schulz & Martire, 2004). The number of "young caregivers" is also increasing. These are children and adolescents who actively participate in caregiving responsibilities for a parent or a grandparent (Santini et al., 2020; Masterson-Algar et al., 2023). According to a survey conducted in the United States by the National Academies of Sciences, Engineering, and Medicine (NASEM, 2016) one-third of family caregivers are older than sixty-five years old, of these two-thirds are women, and one-fourth provide simultaneously care both to a person living with dementia and to children under the age of eighteen. Similarly, the National Alliance for Caregiving & American Association for Retired Persons (National Alliance for Caregiving (NAC), 2015) estimated that while most informal caregivers are women, the number of male caregivers is increasing. These varying scenarios must be considered to quantify and characterize the burden of caregiving, and for interventions aimed at reducing this burden.

Caregiver’s role and journey

Given the progressive nature of dementia and the large and varying spectrum of its clinical manifestations, the role of informal caregivers in dementia care is multifaced and varies over time. Informal assistance can include support with instrumental activities of daily living, such as housework, transportation medication and money management or with basic activities such as personal hygiene, toileting, locomotion and feeding (Jutkowitz et al., 2017). As the disease advances, caregivers often experience lifestyle changes, adapting their roles and life plans to the levels of autonomy of the care recipient (Leocadie et al., 2020). Although each caregiver’s experience is unique and may vary across cultures, literature has coined the term “caregiver journey” or “caregiving trajectories” to describe the common stages that family caregivers may go through during the different stages of dementia (Gaugler et al., 2004; Peacock et al., 2010). This journey may range from pre-diagnostic to advanced phases, and is somewhat well characterized and consistent across settings, cultures, and contexts.

In the first pre-diagnostic stage, caregivers usually start noticing changes in their relative’s cognitive abilities, behavior, or memory. This phase may last months before seeking professional help and a formal diagnosis. A focus group study reported an average delay of thirty months between symptom recognition and diagnosis (Boise et al., 1999). Factors contributing to this delay include a lack of awareness, limited access to healthcare, and educational resources (Werner et al., 2014).

When caregivers actively seek help, usually for diagnosis, they enter in the second stage of the caregiver journey, involving physical exams, blood tests, genetic tests, cognitive assessments, and brain imaging of the person with dementia they take care of (McKhann et al., 2011). In a cross-sectional study conducted with a sample of almost 700 caregivers of people with fronto-temporal dementia (Besser & Galvin, 2019), the authors found that patients and caregivers experienced great frustration and burden during the diagnostic process. Another study reported the feelings of anxiety, bewilderment, helplessness, and uncertainty experienced by caregivers during the diagnostic disclosure (Chen & Lin, 2022).

The next stage of the journey is the early caregiver phase, marked by transition and adjustment. Caregivers adapt to their new roles and responsibilities as the care recipient remains relatively autonomous, requiring little assistance with ADL but usually substantial with IADLs such as medication, meal preparation or mobility. This is usually the phase where caregivers seek information and explore available resources and support networks. Help seeking behaviors during this phase can be greatly influenced by enabling and contextual factors. Service accessibility, fear of stigma, and the level of acceptance of the disease are major drivers of access and use of services and support in general (Ng et al., 2021). Evidence is though mixed in this area, and very limited in Switzerland. **In study 2 (chapter 4), we explored caregivers' experiences, beliefs, and attitudes towards seeking help.**

In the subsequent phase caregivers become fully engaged in providing care as symptoms worsen. Need of care increases with reduced autonomy of the person with dementia who progressively needs assistance and care not only with IADLs but also ADLs. Care provision becomes more pressing and challenging not only for the intensifying care needs but also to manage challenging behaviors related to the BPSD. Caregivers adapt their lives to changing circumstances and may reduce work and social engagement.

Finally, in the final advanced stage, the care recipient is usually fully dependent on the caregiver, leading to decisions about institutionalization, end-of-life and palliative care. These decisions have ethical, economic, legal, and other complex implications that require conscientious consideration, knowledge and understanding of the available and viable options for both the caregiver and the person living with dementia. Importantly, caregivers may experience a significant psychological distress in this phase due to feelings of loss, guilt, frustration and hopelessness related to anticipatory grief (Holley & Mast, 2010). Anticipatory grief is defined as a specific pre-death grief in respond to the serial losses that occur during dementia process (Blandin & Pepin, 2015). Although there's not much evidence on anticipatory grief in dementia literature, some studies suggest that caregivers experience pre-grief reactions at various points along the caregiver journey (Holley & Mast, 2010).

The challenges of caregiving

Considering the multiple challenges and responsibilities that informal caregivers frequently undertake during the various stages of the disease, the potential impact across different areas of life can be significant. Moreover, caregivers can face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships (Brodaty & Donkin, 2009). Numerous studies have demonstrated that caregivers of people with dementia are at higher risk of developing physical and psychological distress compared to non-caregivers or caregivers of other chronic diseases (Pinquart & Sörensen, 2003; Schulz & Martire, 2004; Gilhooly et al., 2016; Ory et al., 1999; Vitaliano et al., 2003). Caregivers of people with dementia report high levels of anxiety, depression and social isolation, and lower levels of subjective wellbeing and self-efficacy (Brodaty & Hadzi-Pavlovic, 1990; Cassie & Sanders, 2008). Furthermore, dementia caregivers are at an increased risk of developing health problems including cardiovascular complications and weakened immune systems (Schulz & Martire, 2004; Baumgarten et al., 1992; Vitaliano et al., 2003). Evidence also suggests that psychological morbidity and strain mediate associations of caregiving with poor physical health and a mortality (Brodaty & Hadzi-Pavlovic, 1990; Lee et al., 2003). **In study 1 (chapter 3), we investigated the levels of burden, anxiety, stress, depression, and perception of loneliness in a sample of Swiss and Italian caregivers.**

Caregiver burden is a popular and widely accepted term that encapsulates the broad-ranging impact that informal care may wield over carers. In fact, the concept of caregiver burden has evolved into a multidimensional construct with no single definition (Springate & Tremont, 2014; Liu et al., 2020). Initially described by Zarit and colleagues in 1980, caregiver burden is defined as "the extent to which caregivers perceive the adverse effect that caregiving has on their emotional, social, financial, and physical functioning" (Zarit et al., 1980). In recent years, the term caregiver burden is being employed to define the overall stressful experience of caregivers, extending beyond their caregiving responsibilities to affect various aspects of their lives, including personal relationships, social interactions, and professional pursuits (Rigby et al., 2019; Kasuya et al., 2000). Several studies have consistently reported that attributes and characteristics of both the caregiver and the care recipient play a role in determining the level of burden. For example, female gender, older age, lower socioeconomic status of the caregiver, and longer hours of care have all been associated with higher levels of caregiver burden (Xiong et al., 2020; Teahan et al., 2021, Ku et al., 2019; Tulek et al., 2020; Konerding et al., 2019). Dementia severity, behavioural disturbances, and the level of dependence in daily life activities (ADL) are known factors that contributed to an increased level of caregiving burden (Tsai et al., 2021;Covinsky et al., 2003). In recent years, research has also focused from the specifics of the caregiving situation itself towards more subjective aspects of caregiving (Gräßel & Adabbo, 2011). This approach is aligned with one of the most used stress theories in literature, namely the Lazarus and Folkman transactional model (Lazarus & Folkman, 1984). According to this model, stress reactions result from ongoing transactions between individuals and their environments. Therefore, the authors particularly emphasize the role of cognitive appraisal in determining how individuals experience and respond to stressors (Lazarus & Folkman, 1984). More recently, Pearlin and colleagues (1990) developed a model of stress specifically adapted for caregivers, where the stress reaction is the result of the combination of four different areas: i) the background context (e.g the level of support or the impact of other life events); ii) the primary stressor (e.g. the level of dependency of the care recipient and the severity of the disease); iii) secondary role strains (e.g. social life restrictions or conflict in familial relationships), and iv) intrapsychic strain such as caregivers' perceived competence, personality and role captivity, defined as the "perceived feeling of being trapped in a role" (Pearlin et al., 1990; Campbell et al., 2008). Both Lazarus and Folkman and Pearlin's models suggests that caregivers' perceptions and evaluations of the caregiving situation play a crucial role in determining the emotional and psychological responses.

In conclusion, while there is agreement on the potential negative effects of informal caregiving on caregivers' physical and psychological well-being, it is still difficult to define key components and effects of the distress experienced by informal caregivers. Aligned with the effort of understanding the multifaceted dimensions of the caregiving experience, a new body of literature has started investigating the positive aspects of caregiving, which had been relatively understudied until recently (Yu et al., 2018). This perspective not only enriches the understanding of caregiving dynamics but also paves the way for a new research trajectory, promising valuable insights into the intricate interplay between caregiving, well-being, and cultural context.

Positive aspects of caregiving

In literature, positive aspects are defined as the degree to which the role of caregivers is experienced as inspiring and rewarding, yielding positive consequences, and enhancing the individual's life journey (Wang et al., 2022). A recent review aimed at exploring positive aspects in dementia caregiving, identified four key domains: a sense of personal accomplishment and gratification, feelings of mutuality the caregivers-care recipient relationship, an increase in family cohesiveness and functionality, and a sense of personal growth and purpose in life (Yu et al., 2018). Similarly, Lloyd and colleagues (2016) identified additional categories including emotional rewards, a sense of competence and mastery, sense of duty and reciprocity (Lloyd et al., 2016). The authors suggested that positive aspects involved a conscientious reflection on the caregiver journey and a positive appraisal response with the challenging situation. Cultural context and values can also influence how caregivers perceive and therefore experience positive aspects of caregiving (Yuan et al., 2023). As anticipated, in eastern societies the responsibility of caring for old people is traditionally placed on family members (Friedman et al., 2015). For example, filial piety, a Confucian value, emphasizes the moral obligation of children to respect and care for their parents (Hashimoto & Ikels, 2005). Studies among Asian caregivers have found that a strong sense of filial piety can alleviate caregiver burden and enhance positive aspects of caregiving (Lai, 2010; Yu et al., 2018)). However, feeling obliged to take on the caregiver role can also negatively impact other aspects of caregiving, such as help-seeking behaviours and attitudes toward research participation (Sun et al., 2012).

Another interesting, yet little explored, issue to consider when unravelling the positive aspects of caregiving is the relevance of the dyadic aspects. Several studies suggested that the past and current quality of the relationship between caregiver and care recipient have an impact on both caregivers' and care recipient well-being and quality of life (Quinn et al., 2012; Mortazavizadeh et al., 2020). Cheng and colleagues analyzed 669 diary narratives over an 8-week period written by family caregivers on their daily positive experience related to caregiving. The authors found that the feelings of mastery and gratification were intensified when the care recipient was responsive and expressed gratitude to the carer (Cheng et al., 2016). These results suggest that the emergence of positive aspects in one's role as a caregiver is a dynamic process that depends not only on the caregiver itself, but also on how the effort invested is met by the care recipient.

In conclusion, although there is no single definition of the positive aspects associated with caregiving and their various facets, the literature recognizes their protective role in shaping the caregiver's perception of their role over time. Acknowledging the benefits of caregiving is essential for understanding the caregiver's journey and developing more effective support resources. Indeed, rather than viewing the positive aspects of caregiving and its challenges as opposing extremes along a continuum, they can be seen as coexisting elements. This perspective encourages a paradigm shift in developing support resources more focused on optimizing positive caregiving experience rather than only reducing the challenges and improving stress responses. More specifically, it is important to advocate for an empowerment approach that reinforces existing skills and competences and strengthens the relationship between caregivers and the individuals they care for.

Interventions for informal caregivers

Traditional interventions

The large corpus of evidence illustrated in the previous paragraphs has triggered an increasing and expanding set of actions to respond to the needs of caregivers. A plethora of interventions and programs dedicated to informal caregivers of people with dementia exists (Alzheimer's Disease International, 2022). Evidence on the efficacy of several interventions was already consolidated and critically appraised more than 10 years ago. Based on the meta-analysis of 127 studies, Pinquart & Sorensen (2006) identified different types of interventions according to the content. These descriptions allowed grouping of interventions across: i) psychoeducational interventions, aiming at providing caregivers with information on the disease and effective techniques; ii) psychological interventions that focus on reducing the distress and increase self-efficacy; iii) general support interventions that can include support groups where caregivers can share experience, exchange advice, and receive emotional support, and iv) multicomponent interventions, that combine different forms of interventions and may include psychoeducation, support and case management (Sörensen et al., 2006), and referred to, more broadly, as "psycho-social interventions" (Thuve Dahm et al., 2011). More recent interventions include mindfulness-based programs, which increase caregivers' awareness of emotional distress and coping strategies (Lo et al., 2022), and reminiscence interventions, focusing on past events and experiences to stimulate memory and enhance the relationship between caregivers and their loved ones (Derbring et al., 2021).

Sorensen (2006) highlighted that, when compared to other types of interventions, multicomponent programs proved to be the most effective in reducing psychological distress, enhancing caregivers' knowledge, and reducing the risk of institutionalization. Furthermore, the authors concluded that longer interventions were more effective in reducing depression than shorter or single-session programs (Sörensen et al., 2006). Similarly, in a previous meta-analysis, Brodaty and colleagues (2003) had showed a modest but statistically significant impact of psychosocial interventions in reducing caregiver burden, improving knowledge and abilities, enhancing psychological well-being, and alleviating care recipients' symptoms. According to the authors, the most robust predictor of an intervention's success was its inclusion of both the patient and caregiver in a structured program (Brodaty et al., 2003). Additional factors associated with more successful interventions in literature include the customization of contents to individual needs and the active engagement of both the caregiver and the care recipient (Brodaty et al., 2003;Selwood et al., 2007).

Despite the large number of interventions, and the promising effects for caregivers, the evidence on their effectiveness remains controversial in literature. Both interventions characteristics and their effectiveness are heterogenous (Vandepitte et al., 2016). While certain studies have shown positive impacts on different dimensions such as on burden; stress reduction; improved quality of life and delayed hospitalization (Gitlin et al., 2003; Gavrilova et al., 2009), null results have also been reported (Dias et al., 2008; Phung et al., 2013). These inconsistencies may be attributed to variations in intervention length, characteristics and number of caregivers involved (Nehen & Hermann, 2015). Further potential explanations of the mixed results are the varying characteristics of the caregivers and care recipients, and different degrees of and magnitude of biases in selection and measurement across studies. In addition, beyond the clinical outcomes, literature emphasizes the need of assessment of the economic value of interventions, and considerations about the scalability and sustainability of effective interventions. Evidence on cost-effectiveness can inform decisions on resources allocation (Huo et al., 2021). Nevertheless, the evidence in this area has remains inconsistent and somewhat outdated (Phillipson & Jones, 2011). A recent systematic review (Huo et al., 2021) showed that, despite their potential effectiveness, psychosocial interventions brought significant increases in total societal cost, and their future implementation largely depends on the society’s willingness to pay, or better to invest. More evidence on the economic (return) and clinical value of interventions is required. Technology-based interventions have already proved to be a more cost-effective and flexible alternative to in-person interventions.

Digital health interventions

The extensive use of technology to address health needs has contributed to creating a new field known as digital health. Digital health is commonly defined as “the field of knowledge and practice associated with the development and use of digital technologies to improve health” (World Health Organization, 2021) In the context of dementia, a range of innovative tools and resources have been developed to lighten the burden of informal care, such as assistive technology tools (AT) and digital interventions (Sriram et al., 2019). Traditionally, interventions are considered digital when they are delivered through technology (Ritterband & Thorndike, 2006). According to their ways of delivery, digital health interventions can be classified into two categories: web-based interventions, which are typically administered via internet platforms, and mHealth interventions, which utilize mobile devices like smartphones, tablets, or other wireless devices (World Health Organization, 2018). Like traditional interventions, digital interventions can be grouped in different categories, according to their core elements. In addition to psychosocial and social support components, digital interventions can be integrated with AI, including tracking devices and supporting memory tools, that aim at reducing the complexity of caregiving tasks and at improving the safety and security of care recipients (Lindeman et al., 2020).

Compared to traditional face to face interventions, digital interventions offer caregivers several advantages. Among these, they provide the possibility of accessing resources on their own convenience, overcoming geographical and time constraints (Christie et al., 2018). Not surprisingly, several studies showed that the COVID-19 pandemic has contributed to an increased interest in digital solutions for health, including videocall meetings and mobile applications (Bertuzzi et al., 2021). The acceptance and use of digital solutions has significantly increased among informal caregivers (Blumenstyk G., 2010; Bertuzzi et al., 2021). Indeed, during home restrictions, digital resources allowed caregivers to access information and professional consultations at their own pace, better aligning with their daily responsibilities (Semonella et al., 2022). According to some authors, another advantage is the increased privacy that digital interventions can facilitate compared to face-to-face initiatives (Semonella et al., 2022). This finding aligns with existing literature, which demonstrates that caregivers frequently experience feelings of shame and courtesy stigma, leading to a hesitancy in utilizing support services and resources (Springate & Tremont, 2014; Werner et al., 2014) An additional significant advantage of digital interventions lies in the possibility to tailor the contents and ways of delivery to the preferences of the users (Dickinson et al., 2017). Personalization can range from basic features such as incorporating the caregiver's and care recipients' name in the contents, to more advanced methods including creating culturally relevant content, individualized communication, real-time chats with professionals, progress tracking, and guidance to local services or support groups based on user-specific needs and location (Morrison, 2015; Sebri & Savioni, 2020). Despite the potential for tailored interventions to enhance acceptability and efficacy, their implementation remains limited. This discrepancy may be explained by the costs and resources associated with required technological infrastructures and content development, but also issues related with data privacy and ethical considerations (Maeckelberghe et al., 2023; Sebri & Savioni, 2020).

While technology has the potential to facilitate caregivers in the assistance, with providing increasingly more advanced and sophisticated tools, it seems crucial to recognize and address the barriers that hinder their adoption in real world contexts (Christie et al., 2019). A noteworthy challenge resides in a relatively low digital literacy level among informal carers who, often older adults themselves, may lack digital skills or knowledge to adopt technologies in their life (Águas et al., 2023). Another critical barrier is also represented by the unequal access to technological resources or infrastructures. Indeed, while most people with dementia live in low middle income countries, most digital interventions are available for populations living in high income countries (James et al., 2021). Additionally, while digital interventions are proved to be more cost-effective compared to traditional ones, the maintenance of digital resources is costly and may limit the length of the intervention. Finally, while in-person interventions require a more direct exposure of caregivers in seeking help, technologies may raise concerns over the privacy and security of sensitive personal data and limit the use of online digital solutions and tools (Hassan et al., 2022). In conclusion, addressing these barriers require a multifaceted approach that ranges from improving technology literacy and accessibility, to designing user-friendly, secure, and culturally sensitive technology solutions. Adapting interventions and support resources to caregivers' needs, expectations, and experiences appears crucial to enhance the use and uptake of technology solutions**.**

Implementation science

Implementation research and the Medical Research Council framework

Implementation science is defined as the "scientific study of methods to promote the systematic uptake of research findings and other evidence-based practice into routine practice and, hence, to improve the quality and effectiveness of health services" (Eccles & Mittman, 2006). Aligned with this assumption, the aim of implementation science is not to establish the health impact of an innovation, but rather to identify the factors affecting its uptake into routine use (Bauer & Kirchner, 2020). However, in the last decades, implementation research has mainly focused on the efficacy of interventions, driven by the binary paradigm that "an intervention works whether it reaches intended outcomes" (Skivington et al., 2021). Several authors claim that research that is primarily driven by this question may not succeed in delivering interventions that are implementable, cost effective and scalable in real world conditions and across different fields (Skivington et al., 2021). Indeed, the literature suggests that, despite their innovation and efficacy, interventions rarely align perfectly with the organization or system in which it is being embedded, with the risk of remaining unused or underutilized (Cabassa & Baumann, 2013)

In the context of dementia interventions, the literature highlights that despite the increasing development of support resources for dementia caregivers, they often go underutilized (World Health Organization, 2021). Several reasons appear to contribute this phenomenon. Some studies suggest that informal caregivers often reject recommended support until they perceive emotional burden in coping with the situation (Ashworth & Baker, 2000; Brodaty et al., 2005). Additional already mentioned factors may include a lack of acknowledgement in needing help; limited awareness of available support measures, and the presence of strong family norms about caregiving (Werner et al., 2014; Zwingmann et al., 2020). In conclusion, whatever the underlying reasons may be, it is established that, despite the proven effectiveness of interventions, their long-term adoption and utilization can be a challenging endeavour. In recent years, these findings have prompted a reconsideration of implementation research, suggesting that adapting complex interventions to real world contexts encompasses more than just proving their efficacy and disseminating knowledge for delivery (Cabassa & Baumann, 2013). Some authors claim that implementation should be considered as a collaborative adaptation process where both the intervention and stakeholders (providers and consumers) are actively engaged in exchanging knowledge, attitudes, and social norms, with the aim of facilitating the uptake of the intervention (Damschroder et al., 2022; Cabassa & Baumann, 2013). Aligned with the need of changing the paradigm in conducting implementation research, in 2021 the Medical Research Council Guidance (MRC) released a new framework for developing and evaluating complex interventions. According to this framework (Skivington et al., 2021), intervention research should be considered in terms of iterative rather than sequential phases. The phases included i) the development or identification of an intervention, based on research evidence and theory; ii) the assessment of the feasibility and acceptability of the intervention and design; iii) the process of the evaluation, based on the research question; and iv) the implementation, the efforts to increase the impact and uptake of successfully measured interventions. During each phase, the researchers should consider a set of core elements that include the i) context in which the intervention is developed such as physical, organisational; social and political dimensions; ii) the stakeholders involved, namely individuals who are directly targeted by the intervention, those involved in its development or those who have professional or personal interests in the topic; iii) the programme theory, namely how an intervention is expected to work and under what circumstances, iv) and the economic evaluations of the intervention's costs (resources) and consequences (outcomes and effects). Considering all these aspects allow researchers to iteratively refine the process and increase the potential success of the final intervention.

While the MRC framework for complex interventions represents a significant step forward in the implementation of programs that are successfully used in real-world situations, another process appears to be essential in achieving this goal: the process of cultural adaptation (Cabassa & Baumann, 2013)

Cultural adaptation

Aligned with the core elements of the MRC framework, the process of cultural adaptation is crucial to develop interventions that meet the specific cultural, social, and contextual needs of caregivers. Cultural adaptation can be defined as the "systematic modification of an interventions to consider language, culture, and context in such a way that is compatible with the user's cultural patterns, meanings, and values (Bernal et al., 1995). It refers to the process of collecting cultural beliefs, values, attitudes, and linguistic preferences of the target population to ensure that the intervention is culturally and contextually targeted. In literature, several frameworks for cultural adaptation exist, particularly for psychosocial interventions (Perera et al., 2020). Frameworks vary according to the number and type of dimension considered. A recent systematic review (Day et al., 2023) identified twelve content-specific frameworks categorized according to five core elements: i) content, which involves changes made to the intervention procedures, materials or delivery (Stirman et al., 2013); ii) context, which includes changes made to delivery of the same program content, with modifications to format, setting, stakeholders involved or the target population (Stirman et al., 2013); iii) fidelity, which preserves the core elements of the intervention in order to maintain the efficacy of the original intervention (Stirman et al., 2013), iv) the engagement, the ability to successfully reach and involve participants (Barrera & Castro, 2006); and v) cultural competence, incorporating behaviours, attitudes and policies that allow systems to be sensitive to cultural differences and needs (Cross & Others, 1989). Additionally, Reniscow and colleagues (2000) introduced a framework based on two dimensions: surface and deep adaptations. While surface adaptation involves superficial modifications to the intervention such as adjusting the language (character names, reference to foods, clothing, or leisure activities) or the images (icons or symbols) to help the user relate and familiarize with the intervention, deep adaptation involves more profound changes to the content and its structure or way of delivery to ensure the intervention addresses cultural beliefs, values and norms (Resnicow et al., 2000). Another well-known framework for adapting interventions is the Ecological Validity Model (EVM) proposed by Bernal and colleagues (1995). This model emphasizes the importance of achieving ecological validity, ensuring that the adapted intervention is not only culturally sensitive but also relevant and effective within the specific cultural context (Bernal et al., 1995). The authors considered eight dimensions: 1) the language, of both materials or the facilitator that should be appropriate and syntonic; ii) the persons, the role of ethnic similarities and differences; iii) the metaphors, the figures of speech and symbols shared within a group; iv) the content, the examples, traditions and costumes included in the program; v) the concepts, the ideas and notions behind the content; vi) the goals, the transmission of positive and adaptive cultural values; vii) the methods, the formats of delivery, and techniques; and iix) the context, the changing socio-political characteristics of the environment (Bernal et al., 1995). Despite variations across the different theories, all authors recognize that simply translating materials or adjusting the superficial aspects of an intervention may not be sufficient to make it effective in a new cultural context. Cultural adaptation frameworks guide researchers and practitioners in developing culturally informed interventions, ultimately improving their effectiveness and relevance across different populations and contexts and supporting the belief that “one size does not fit all” (Alegria et al., 2010).

The fidelity-adaptation dilemma

The consideration that “one size does not fit all” is particularly relevant when developing interventions for caregivers of people with dementia. Indeed, as previously mentioned, the beliefs, knowledge, and attitudes towards dementia and the role of the caregiver can vary significantly across different cultural backgrounds and societies (Friedman et al., 2015). For instance, in cultures where dementia is regarded as shameful or stigmatized, interventions may face disapproval and resistance (Berwald et al., 2016). Furthermore, interventions delivered via the Internet require, not only access to technological infrastructure, but also a sufficient level of digital literacy, that can differ significantly across populations and contexts. However, despite the established importance of cultural adaptation, there is a lack of literature systematically reporting the details of the process during the adaptation of psychosocial interventions (Perera et al., 2020). The existing literature on caregivers’ interventions often focuses on feasibility and evaluation of the intervention, rather than its cultural adaptation (Perera et al., 2020). Moreover, most available studies were conducted with ethnic majorities in high-income countries (HICs), and not all authors described in detail how interventions were tailored or adapted to the target population (James et al., 2021; Prince et al., 2016). The evidence that most interventions are developed and tested in HICs, normally conceived in Western contexts, makes the need for cultural adaptation even more urgent to address the so called “fidelity-adaptation dilemma”. This dilemma arises from the conflict between maintaining fidelity to an evidence-based intervention's original design and making necessary adaptations to cater to the specific needs and preferences of a subcultural group (Bernal & Scharrón-del-Río, 2001; Castro et al., 2004, Elliott & Mihalic, 2004). While it's understandable that a theory-based intervention should be implemented with a high degree of fidelity to uphold its efficacy, it's also worth acknowledging that a certain level of adaptation becomes necessary to ensure its continued effectiveness (Castro et al., 2004). Castro and colleagues (2004) identified several sources of mismatch that can occur in translating an evidence-based intervention from the original validation group to the current consumer group. These include: i) the group characteristics such as the language, the ethnicity, the socioeconomic status, the urban-rural context, risk factors and family systems; ii) the program delivery staff, namely their professional background, their cultural sensitivity, and competence; and finally, iii) the administrative/community factors that include community level of readiness and consultation. Failure to attend to these factors can potentially lead to resistance and reduced adherence when it comes to accepting and utilizing the intervention.

In conclusion, maintaining a high fidelity to the original program while simultaneously adapting it to the target context doesn't seem necessarily contradictory. To achieve this, it is essential to shift from a top-down, nomothetic approach to a bottom-up, person-centered approach that allows for the identification and addressing of the most culturally sensitive components. To do this effectively, it is imperative that experts and researchers directly engage with the community and the final users of the intervention (Marsiglia & Booth, 2015). This collaborative approach holds the promise of bridging the gap between fidelity and adaptation, ultimately leading to more scalable and effective interventions. **In study 3, chapter 5, we conducted a systematic review to explore how digital interventions dedicated to caregivers were designed and developed, with a specific focus on the use of participatory research methods.**

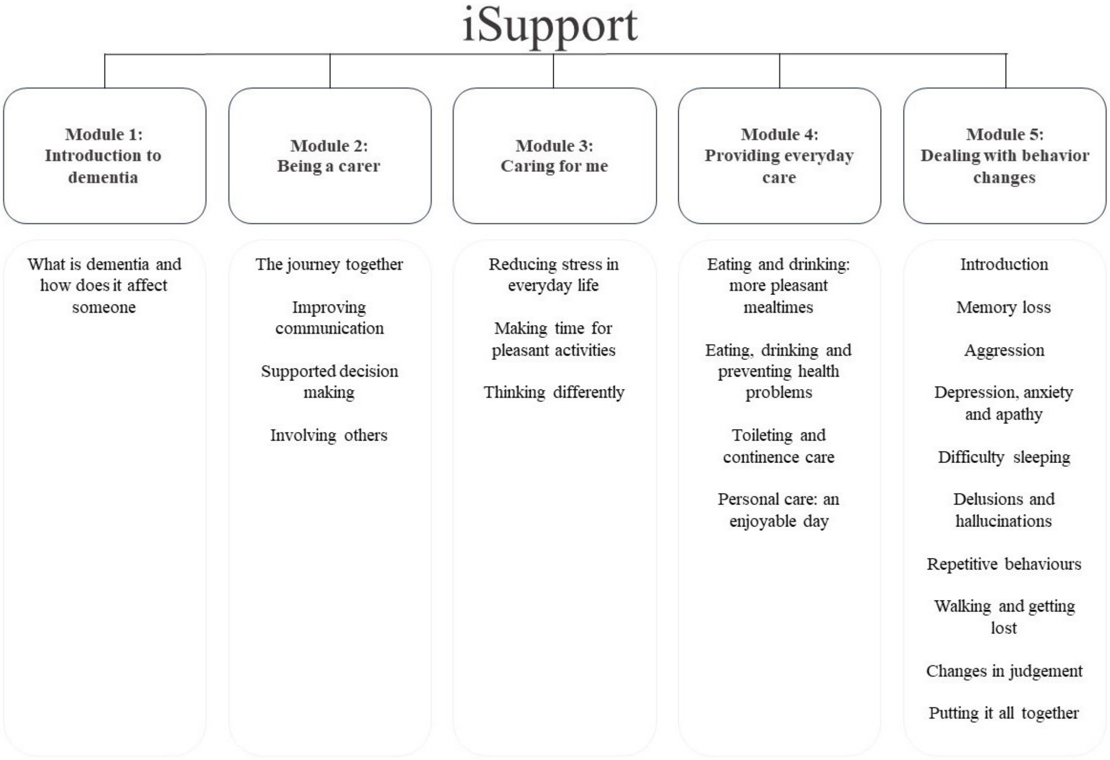
iSupport for informal caregivers

Background and structure

To reduce the impact of dementia on people living with dementia and their families, the World Health Organization (WHO) introduced the iSupport program in 2019, in response to the action area 5 of the Global Action Plan on the Public Health Response to Dementia (World Health Organization, 2017). iSupport is an evidence-based psychosocial online intervention designed to provide support and education to informal caregivers of people living with dementia (Pot, Gallagher-Thompson, Xiao, Willemse, Rosier, M. Mehta, et al., 2019). The program is rooted in evidence-based guidelines for caregivers of individuals with dementia, included within the WHO Mental Health Gap Action Programme (mhGAP). iSupport aligns with the mhGAP's mission to provide scientific education, training, and psychosocial support to all individuals, even in resource limited environments (World Health Organization, 2017). The development of the program involved the collaboration of an international committee of experts and various professional and informal caregiving groups (Pot et al., 2019; Metha et al., 2019). The contents of iSupport are based on the guidelines published by the National Institute of Aging (NIH) and on the Kitwood's person-centered care approach for people with dementia. The latter emphasizes the importance of treating people with dementia with respect and dignity, focusing on their remaining abilities rather than their deficits (Kitwood, 1997).

iSupport was designed to address caregivers' needs by offering a combination of techniques that include psychoeducation; relaxation; problem-solving, and cognitive-behavioral techniques (Egan et al., 2018). The contents of the program are centered on five major topics or modules: i) What is dementia; ii) Being a caregiver; iii) Caring for me; iv) Providing everyday care, and v) Dealing with challenging behavior. Each module includes several subtopics or lessons. Each lesson presents information about the topic, and interactive exercises where the user is provided with instant feedback (Fig.1). The original iSupport program was developed in two formats: either as a self-help manual or as an online web-based program. To implement the program worldwide, the WHO provide a standardized guide for culturally adapt iSupport to other contexts (Pot, Gallagher-Thompson, Xiao, Willemse, Rosier, M. Mehta, et al., 2019). Nowadays, iSupport has been adapted or implemented in 40 countries and 37 languages across all continents.

Fig.1: iSupport structure (Pot et al., 2019)



Dementia and informal care in Switzerland (Ticino)

Epidemiological data on the prevalence and impact of dementia in Switzerland are limited. Based on approximations and according to the last estimates, the number of residents affected by dementia is around 153000 people, whom 8110 living in Ticino Canton (Alzheimer Schweiz, 2023). Furthermore, it is estimated that a significant proportion of people affected by dementia may not have received a clinical diagnosis (Alzheimer Europe, 2011). Since Ticino has a highest proportion of elderly individuals compared to the general population, and considering the global estimates (Wimo et al., 2018), it is predicted that the number of people affected by dementia could double by 2035 (Ufficio di Statistica (USTAT) & Borioli M, 2020). Similarly to other countries, approximately 50% of people affected by dementia is cared at home by relatives. The indirect cost associated with informal care constitutes 47% of the annual costs spent in dementia care (Ufficio Federale della Sanità Pubblica (UFSP), 2023). According to last estimates, nearly 45% of informal caregivers range between 45 and 64 years old; 55.3% are women, and 72.5% provides care more than one day per week (Ufficio di Statistica (USTAT) & Borioli M, 2020).

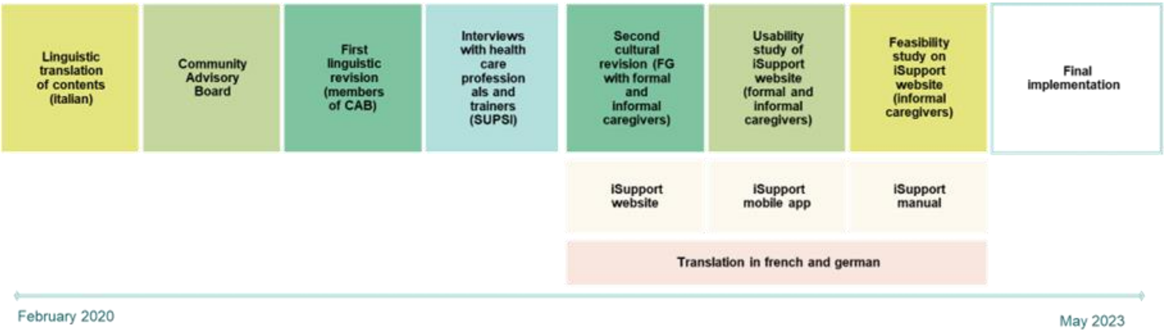
In 2016, and in accordance with the national dementia strategy (UFSP (Ufficio federale della Sanità Pubblica), 2013), the Department of Health and Social Affairs (Dipartimento della Salute e della Socialità; DSS) of the Ticino Canton developed a cantonal dementia strategy, with the aim of ensuring to all individuals living with dementia and their families access to high-quality and tailored support at every stage of the disease (Strategia cantonale sulle demenze, 2016). People living with dementia in Ticino can rely on various forms of practical assistance in their daily care, such as therapeutic day facilities, home care services, domiciliary therapies, and various services such as transportation, meal delivery, and assisted holidays. Local Alzheimer associations and healthcare providers also offer support dedicated to informal caregivers themselves, by offering financial and psychological consultation and organizing self-help groups and psychoeducational meetings. In 2013, the DSS established a family caregiver platform, with the aim of bringing together non-profits entities and organizations supporting family caregivers in Ticino.

However, despite the number of available initiatives to support caregivers in their role, there was a lack of structured and continuous programs. The decision to adapt iSupport in Ticino stemmed from the need to provide a flexible and stable support tool in various phases of caregiving. More specifically, and in line with the cantonal dementia strategy, the project aimed at providing training and improving knowledge to informal caregivers, recognizing the importance and unique role in dementia care.

iSupport adaptation in Ticino

A relevant part of this doctoral project focused on the cultural adaptation process of iSupport in Ticino. **In study 4, chapter 6, we described the process in detail**. In summary, the project started in February 2020 and concluded in May 2023. It was conducted by the Institute of Public Health (USI), with the financial support of the Department of Health and Social Affairs (DSS) and Pro Senectute, and in collaboration with Alzheimer Ticino and University of Applied Sciences and Arts of Southern Switzerland (SUPSI). The adaptation of iSupport was conducted in accordance with the WHO adaptation guidelines, based on the Ecological Validity Model (Bernal et al., 1995), and following recommendations from other iSupport implementors in other countries (Teles et al., 2020; Mehta Kala et al., 2018) The methodological approach included several research steps (See Fig.2) and employed both the use of quantitative and qualitative methods.

Fig.2: Timeline of the cultural adaptation of iSupport in Ticino



The aim of culturally adapt iSupport to Switzerland, was to develop an adapted version of iSupport available in the three national languages (Italian, German and French) that would be easily accessible through a website and mobile application for smartphone and tablets (iSupport Swiss). From the beginning of the project and throughout the process, we were in contact with the WHO team and the members of iSupport international network, that involved iSupport implementors across the globe. We decided to adopt a Community Based Participatory Approach (CBPR) since the starting of the project and all along the research process. In September 2020, we set out a Community Advisory Board (CAB) with a total of 11 members, which included family caregivers of individuals with dementia, local stakeholders who had already been engaged as partners (Pro Senectute), representatives from the funding organization (DSS), educational institutions (SUPSI), and experts involved in the graphic design and digital development of iSupport (eLab). Our decision to create a CAB was rooted in the determination to ensure that iSupport was community-driven, culturally adapted, and capable of effectively addressing the needs of caregivers, thereby remaining faithful to its original vision. The entire process was conducted in collaboration and under the guidance of the WHO team.

Aim of the PhD project

The overarching aim of this PhD project was to shed light on the wellbeing of informal caregivers of people living with dementia while understanding their support needs and preferences. The cultural adaptation of iSupport, along with the accompanying research, acted as a consistent thread guiding a deeper exploration and comprehension of caregivers' needs and ways to support them, with the ultimate objective of enhancing their mental well-being and that of their loved ones.
More specific aims of this PhD thesis are discussed and presented in each chapter as follows:

- **Chapter 3**: To investigate informal caregivers' mental health in Switzerland (Ticino) and Italy (study 1)
    - What are the levels of burden, depressive symptoms, stress, anxiety and perception of loneliness in caregivers during the first wave of the COVID-19 pandemic?
    - What are the differences between Swiss and Italian caregivers?
- **Chapter 4**: To explore the caregivers' experiences and attitudes towards support interventions and measures (study 2)
    - What are caregivers' experiences, beliefs, and attitudes towards seeking help?
    - What are the potential barriers and facilitators to the access and use of support measures?
- **Chapter 5**: To explore how digital interventions for caregivers are designed and developed (study 3)
    - What are the main characteristics of digital interventions dedicated to caregivers?
    - How are they developed? Do they employ participatory research methods?
- **Chapter 6**: To develop a linguistic and culturally adapted version of iSupport for Switzerland (specifically for Ticino) (study 4)
    - How can a community based participatory approach being integrated in iSupport adaptation in Switzerland?
    - What are the preliminary results of adapting iSupport in Ticino?

References

Águas, D., Paço, M., Henriques, A., Coelho, A., & Costa, A. (2023). Informal Caregivers: Helping Those Who Help (E. Moguel, L. G. de Pinho, & C. Fonseca, Eds.; pp. 351–361). Springer Nature Switzerland. https://doi.org/10.1007/978-3-031-29067-1_33

Alegria, M., Atkins, M., Farmer, E., Slaton, E., & Stelk, W. (2010). One Size Does Not Fit All: Taking Diversity, Culture and Context Seriously. *Administration and Policy in Mental Health*, *37*(1–2), 48–60. https://doi.org/10.1007/s10488-010-0283-2

Alzheimer's Disease International. (2022). World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support. https://www.alzint.org/resource/world-alzheimer-report-2022/

Alzheimer Europe. (2011). *Who Cares? The state of dementia care in Europe. Alzheimer Europe*. https://www.alzheimereurope.org/sites/default/files/alzheimer_europe_survey_2006_who_cares_the_state_of_dementia_care_in_europe.pdf

Alzheimer Schweiz. (2023). *La demenza in Svizzera*. Https://www.Alzheimer-Schweiz.Ch/It/Sulla-Demenza/Articolo/La-Demenza-in-Svizzera/.

Alzheimer's Association. (2021). *Alzheimer's Association Annual Report*. https://www.alz.org/media/Documents/annual-report-2021.pdf

American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Ashworth, M., & Baker, A. H. (2000). 'Time and space': carers' views about respite care. *Health & Social Care in the Community*, *8*(1), 50–56. https://doi.org/10.1046/j.1365-2524.2000.00221.x

Assal, F. (2019). History of Dementia. *Front Neurol Neurosci.*, *44*, 118–126. doi: 10.1159/000494959.

Author links open overlay panel GBD 2019 Dementia Forecasting Collaborators†. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, *7*(2), e105–e125.

Barrera, M., & Castro, F. G. (2006). A Heuristic Framework for the Cultural Adaptation of Interventions. *Clinical Psychology: Science and Practice*, *13*(4), 311–316. https://doi.org/10.1111/j.1468-2850.2006.00043.x

Bauer, M. S., & Kirchner, J. (2020). Implementation science: What is it and why should I care? *Psychiatry Research*, *283*, 112376. https://doi.org/10.1016/j.psychres.2019.04.025

Bernal, G., Bonilla, J., & Bellido, C. (1995). Ecological Validity and Cultural Sensitivity for Outcome Research: Issues for the Cultural Adaptation and Development of Psychosocial Treatments with Hispanics. In *Joumal of Abnormal Child Psychology* (Issue 1).

Bernal, G., & Scharrón-del-Río, M. R. (2001). Are empirically supported treatments valid for ethnic minorities? Toward an alternative approach for treatment research. *Cultural Diversity and Ethnic Minority Psychology*, *7*(4), 328–342. https://doi.org/10.1037/1099-9809.7.4.328

Bertuzzi, V., Semonella, M., Bruno, D., Manna, C., Edbrook-Childs, J., Giusti, E. M., Castelnuovo, G., & Pietrabissa, G. (2021). Psychological Support Interventions for Healthcare Providers and Informal Caregivers during the COVID-19 Pandemic: A Systematic Review of the Literature. *International Journal of Environmental Research and Public Health*, *18*(13), 6939. https://doi.org/10.3390/ijerph18136939

Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia." *PLOS ONE*, *11*(4), e0151878. https://doi.org/10.1371/journal.pone.0151878

Besser, L., & Galvin, J. (2019). Diagnostic experience reported by caregivers of patients with frontotemporal degeneration. *Neurology: Clinical Practice*, *10*, 10.1212/CPJ.0000000000000738. https://doi.org/10.1212/CPJ.0000000000000738

Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia*, *16*(1), 67–78. https://doi.org/10.1177/1471301215581081

Blumenstyk G. (n.d.). *Why Coronavirus Looks Like a 'Black Swan' Moment for Higher Ed* (The Chronicle).

Boise, L., Morgan, D., Kaye, J., & Camicioli, R. (1999). Delays in the diagnosis of dementia: Perspectives of family caregivers. *American Journal of Alzheimers Disease and Other Dementias - AM J ALZHEIMERS DIS OTHER DEM*, *14*, 20–26. https://doi.org/10.1177/153331759901400101

Brodaty, H., & Donkin, M. (2009). *Dialogues in Clinical Neuroscience Family caregivers of people with dementia*. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Brodaty, H., Green, A., Sc Hons, B., & Koschera, A. (2003). Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. In *JAGS* (Vol. 51).

Brodaty, H., & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. *The Australian and New Zealand Journal of Psychiatry*, *24*(3), 351–361. https://doi.org/10.3109/00048679009077702

Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, *20*(6), 537–546. https://doi.org/10.1002/gps.1322

Cabassa, L. J., & Baumann, A. A. (2013). A two-way street: bridging implementation science and cultural adaptations of mental health treatments. *Implementation Science: IS*, *8*, 90. https://doi.org/10.1186/1748-5908-8-90

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P., Jones, L., & Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry*, *23*(10), 1078–1085. https://doi.org/10.1002/gps.2071

Canadian Institute for Health Information. (2018). *Unpaid caregiver challenges and supports*. https://www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports.

Cassie, K. M., & Sanders, S. (2008). Familial caregivers of older adults. In S. M. C. Kropf Nancy P. (Ed.), *Handbook of Psychosocial Interventions with Older Adults: Evidence-based approaches* (pp. 293–320). Routledge.

Castro, F. G., Barrera, Jr. , M., & Martinez, Jr. , C. R. (2004). The Cultural Adaptation of Prevention Interventions: Resolving Tensions Between Fidelity and Fit. *Prevention Science*, *5*(1), 41–45. https://doi.org/10.1023/B:PREV.0000013980.12412.cd

Chen, M.-C., & Lin, H.-R. (2022). The experiences of family caregivers in response to a dementia diagnosis disclosure. *BMC Psychiatry*, *22*(1), 475. https://doi.org/10.1186/s12888-022-04126-4

Cheng, S.-T., Mak, E. P. M., Lau, R. W. L., Ng, N. S. S., & Lam, L. C. W. (2016). Voices of Alzheimer Caregivers on Positive Aspects of Caregiving. *The Gerontologist*, *56*(3), 451–460. https://doi.org/10.1093/geront/gnu118

Christie, H. L., Bartels, S. L., Boots, L. M. M., Tange, H. J., Verhey, F. R. J., & de Vugt, M. E. (2018). A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. *Internet Interventions*, *13*, 51–59. https://doi.org/10.1016/j.invent.2018.07.002

Christie, H. L., Martin, J. L., Connor, J., Tange, H. J., Verhey, F. R. J., de Vugt, M. E., & Orrell, M. (2019). eHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready? *Internet Interventions*, *18*. https://doi.org/10.1016/j.invent.2019.100260

Corey-Bloom J. (2002). The ABC of Alzheimer’s disease: cognitive changes and their management in Alzheimer’s disease and related dementias. *Int Psychogeriatr.*, *14*(1), 51–75.

Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*, *18*(12), 1006–1014. https://doi.org/10.1111/j.1525-1497.2003.30103.x

Cross, T. L., & Others, A. (1989). *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*. CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Rd. https://eric.ed.gov/?id=ED330171

Damschroder, L., Rapport, F., Clay-Williams, R., & Braithwaite, J. (2022). *Implementation science: the key concepts*. Routledge.

Day, S., Laver, K., Jeon, Y.-H., Radford, K., & Low, L.-F. (2023). Frameworks for cultural adaptation of psychosocial interventions: A systematic review with narrative synthesis. *Dementia*, *22*(8), 1921–1949. https://doi.org/10.1177/14713012231192360

Derbring, S., Nordström, M. B., Svenningsson, J.-A., Ekström, A., Ingebrand, E., Samuelsson, C., Laakso, K., & Buchholz, M. (2021). Effects of a digital reminiscing intervention on people with dementia and their care-givers and relatives. *Ageing & Society*, *43*(9), 1983–2000. https://doi.org/10.1017/S0144686X21001446

Dias, A., Dewey, M. E., D’Souza, J., Dhume, R., Motghare, D. D., Shaji, K. S., Menon, R., Prince, M., & Patel, V. (2008). The Effectiveness of a Home Care Program for Supporting Caregivers of Persons with Dementia in Developing Countries: A Randomised Controlled Trial from Goa, India. *PLoS ONE*, *3*(6), e2333. https://doi.org/10.1371/journal.pone.0002333

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017). Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. In *International Psychogeriatrics* (Vol. 29, Issue 1, pp. 31–43). Cambridge University Press. https://doi.org/10.1017/S1041610216001447

Eccles, M. P., & Mittman, B. S. (2006). Welcome to Implementation Science. *Implementation Science*, *1*(1), 1. https://doi.org/10.1186/1748-5908-1-1

Egan, K. J., Pinto-Bruno, Á. C., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E., & Pot, A. M. (2018). Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. In *Journal of the American Medical Directors Association* (Vol. 19, Issue 3, pp. 200-206.e1). Elsevier Inc. https://doi.org/10.1016/j.jamda.2017.10.023

Elliott, D. S., & Mihalic, S. (2004). Issues in disseminating and replicating effective prevention programs. *Prevention Science: The Official Journal of the Society for Prevention Research*, *5*(1), 47–53. https://doi.org/10.1023/b:prev.0000013981.28071.52

Friedman, E. M., Shih, R. A., Langa, K. M., & Hurd, M. D. (2015). US prevalence and predictors of informal caregiving for dementia. *Health Affairs*, *34*(10), 1637–1641. https://doi.org/10.1377/hlthaff.2015.0510

Gaugler, J. E., Anderson, K. A., Leach, C. R., Smith, C. D., Schmitt, F. A., & Mendiondo, M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer’s Disease & Other Dementias®*, *19*(6), 369–380. https://doi.org/10.1177/153331750401900605

Gavrilova, S. I., Ferri, C. P., Mikhaylova, N., Sokolova, O., Banerjee, S., & Prince, M. (2009). Helping carers to care--the 10/66 dementia research group’s randomized control trial of a caregiver intervention in Russia. *International Journal of Geriatric Psychiatry*, *24*(4), 347–354. https://doi.org/10.1002/gps.2126

Gilhooly, K. J., Gilhooly, M. L. M., Sullivan, M. P., McIntyre, A., Wilson, L., Harding, E., Woodbridge, R., & Crutch, S. (2016). A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatrics*, *16*(1). https://doi.org/10.1186/s12877-016-0280-8

Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M. P., Schinfeld, S., & Hauck, W. W. (2003). Effects of the Home Environmental Skill-Building Program on the Caregiver–Care Recipient Dyad: 6-Month Outcomes From the Philadelphia REACH Initiative. *The Gerontologist*, *43*(4), 532–546. https://doi.org/10.1093/geront/43.4.532

Gräßel, E., & Adabbo, R. (2011). Perceived Burden of Informal Caregivers of a Chronically Ill Older Family Member. *GeroPsych*, *24*(3), 143–154. https://doi.org/10.1024/1662-9647/a000042

Hashimoto, A., & Ikels, C. (2005). Filial piety in changing Asian societies. In M. L. Johnson (Ed.), *The Cambridge Handbook of Age and Ageing.* (pp. 437–442). Cambridge University Press.

Hassan, J., Shehzad, D., Habib, U., Aftab, M. U., Ahmad, M., Kuleev, R., & Mazzara, M. (2022). The Rise of Cloud Computing: Data Protection, Privacy, and Open Research Challenges—A Systematic Literature Review (SLR). *Computational Intelligence and Neuroscience*, *2022*, 1–26. https://doi.org/10.1155/2022/8303504

Holley, C. K., & Mast, B. T. (2010). Predictors of Anticipatory Grief in Dementia Caregivers. *Clinical Gerontologist*, *33*(3), 223–236. https://doi.org/10.1080/07317111003793443

Hugo, J., & Ganguli, M. (2014). Dementia and Cognitive Impairment. Epidemiology, Diagnosis, and Treatment. In *Clinics in Geriatric Medicine* (Vol. 30, Issue 3, pp. 421–442). W.B. Saunders. https://doi.org/10.1016/j.cger.2014.04.001

Huo, Z., Chan, J. Y. C., Lin, J., Bat, B. K. K., Chan, T. K., Tsoi, K. K. F., & Yip, B. H. K. (2021). Supporting Informal Caregivers of People With Dementia in Cost-Effective Ways: A Systematic Review and Meta-Analysis. *Value in Health*, *24*(12), 1853–1862. https://doi.org/10.1016/j.jval.2021.05.011

James, T., Mukadam, N., Sommerlad, A., Guerra Ceballos, S., & Livingston, G. (2021). Culturally tailored therapeutic interventions for people affected by dementia: a systematic review and new conceptual model. In *The Lancet Healthy Longevity* (Vol. 2, Issue 3, pp. e171–e179). Elsevier Ltd. https://doi.org/10.1016/S2666-7568(21)00001-5

Jeffrey L Cummings, T. M. K. Z. (2014). Alzheimer's disease drug-development pipeline: few candidates, frequent failures . *Alzheimers Res Ther* , *6*(4), 37.

Jellinger, K. A. (2010). Should the word 'dementia' be forgotten? *Journal of Cellular and Molecular Medicine*, *14*(10), 2415–2416. https://doi.org/https://doi.org/10.1111/j.1582-4934.2010.01159.x

Jutkowitz, E., Kane, R. L., Gaugler, J. E., MacLehose, R. F., Dowd, B., & Kuntz, K. M. (2017). Societal and Family Lifetime Cost of Dementia: Implications for Policy. *Journal of the American Geriatrics Society*, *65*(10), 2169–2175. https://doi.org/10.1111/jgs.15043

Kasuya, R., Polgar-Bailey, P., & Takeuchi, R. (2000). CAREGIVER BURDEN AND BURNOUT A guide for primary care physicians. *Postgraduate Medicine*, *108*(7). https://doi.org/10.3810/pgm.2000.12.1324

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, *1*(1), 13–22. https://doi.org/10.1080/13607869757344

Konerding, U., Bowen, T., Forte, P., Karampli, E., Malmström, T., Pavi, E., Torkki, P., & Graessel, E. (2019). Do Caregiver Characteristics Affect Caregiver Burden Differently in Different Countries? *American Journal of Alzheimer's Disease & Other Dementias®*, *34*(3), 148–152. https://doi.org/10.1177/1533317518822047

Ku, L.-J. E., Chang, S.-M., Pai, M.-C., & Hsieh, H.-M. (2019). Predictors of caregiver burden and care costs for older persons with dementia in Taiwan. *International Psychogeriatrics*, *31*(6), 885–894. https://doi.org/10.1017/S1041610218001382

Lai, D. (2010). Filial Piety, Caregiving Appraisal, and Caregiving Burden. *Research on Aging - RES AGING*, *32*, 200–223. https://doi.org/10.1177/0164027509351475

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping* (11. [print.]). Springer.

Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women. *American Journal of Preventive Medicine*, *24*(2), 113–119. https://doi.org/10.1016/S0749-3797(02)00582-2

Leocadie, M.-C., Morvillers, J.-M., Pautex, S., & Rothan-Tondeur, M. (2020). Characteristics of the skills of caregivers of people with dementia: observational study. *BMC Family Practice*, *21*(1), 149. https://doi.org/10.1186/s12875-020-01218-6

Lindeman, D. A., Kim, K. K., Gladstone, C., & Apesoa-Varano, E. C. (2020). Technology and Caregiving: Emerging Interventions and Directions for Research. *The Gerontologist*, *60*(Suppl 1), S41–S49. https://doi.org/10.1093/geront/gnz178

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, *7*(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., … Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, *390*(10113), 2673–2734. https://doi.org/10.1016/S0140-6736(17)31363-6

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, *15*(6), 1534–1561. https://doi.org/10.1177/1471301214564792

Lo, H. H. M., Au, A., Cho, W. V., Lau, E. N. S., Wong, J. Y. H., Wong, S. Y. S., & Yeung, J. W. K. (2022). Mindfulness-Based Intervention for Caregivers of Frail Older Chinese Adults: A Study Protocol. *International Journal of Environmental Research and Public Health*, *19*(9), 5447. https://doi.org/10.3390/ijerph19095447

M Waite, L. (2015). Treatment for Alzheimer's disease: has anything changed? *Aust Prescr* *38*(2). doi: 10.18773/austprescr.2015.018.

Maeckelberghe, E., Zdunek, K., Marceglia, S., Farsides, B., & Rigby, M. (2023). The ethical challenges of personalized digital health. *Frontiers in Medicine*, *10*, 1123863. https://doi.org/10.3389/fmed.2023.1123863

Marsiglia, F. F., & Booth, J. M. (2015). Cultural Adaptation of Interventions in Real Practice Settings. *Research on Social Work Practice*, *25*(4), 423–432. https://doi.org/10.1177/1049731514535989

Masterson-Algar, P., Egan, K., Flynn, G., Hughes, G., Spector, A., Stott, J., & Windle, G. (2023). iSupport for Young Carers: An Adaptation of an e-Health Intervention for Young Dementia Carers. *International Journal of Environmental Research and Public Health*, *20*(1). https://doi.org/10.3390/ijerph20010127

Mccleary, L., & Blain, J. (2013). Cultural values and family caregiving for persons with dementia. *Indian Journal of Gerontology*, *27*, 178–201.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Kawas, C. H., Klunk, W. E., Koroshetz, W. J., Manly, J. J., Mayeux, R., Mohs, R. C., Morris, J. C., Rossor, M. N., Scheltens, P., Carrillo, M. C., Thies, B., Weintraub, S., & Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 263–269. https://doi.org/10.1016/j.jalz.2011.03.005

Mehta Kala, M., Gallagher-Thompson, D., Varghese, M., Loganathan, S., Baruah, U., Seeher, K., Zandi, D., Dua, T., & Pot Anne, M. (2018). iSupport, an online training and support program for caregivers of people with dementia: study protocol for a randomized controlled trial in India. *Trials*, *1*, 271. https://doi.org/10.1186/s13063-018-2604-9

Morrison, L. G. (2015). Theory-based strategies for enhancing the impact and usage of digital health behaviour change interventions: A review. *DIGITAL HEALTH*, *1*, 205520761559533. https://doi.org/10.1177/2055207615595335

Mortazavizadeh, Z., Maercker, A., Roth, T., Savaskan, E., & Forstmeier, S. (2020). Quality of the caregiving relationship and quality of life in mild Alzheimer's dementia. *Psychogeriatrics*, *20*(5), 568–577. https://doi.org/10.1111/psyg.12546

Müller-Spahn, F. (2003). Behavioral disturbances in dementia. *Dialogues in Clinical Neuroscience*, *5*(1), 49–59. https://doi.org/10.31887/dcns.2003.5.1/fmuellerspahn

NASEM. (2016). Families Caring for an Aging America . *Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, & National Academies of Sciences, Engineering, and Medicine*. (R. Schulz & J. Eden, A c. Di; p. 23606). National Academies Press. https://doi.org/10.17226/23606

National Alliance for Caregiving (NAC), & A. P. P. I. (2015). *Caregiving in the U.S. 2015 report*. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

National Institute on Aging. (1988). *National Institute on Aging*. Bethesda, Md. : National Institutes of Health, National Institute on Aging, [1988]. https://search.library.wisc.edu/catalog/999659327902121

Nehen, H. -G., & Hermann, D. M. (2015). Supporting dementia patients and their caregivers in daily life challenges: review of physical, cognitive and psychosocial intervention studies. *European Journal of Neurology*, *22*(2), 246. https://doi.org/10.1111/ene.12535

Ng, C. K. M., Leung, D. K. Y., Cai, X., & Wong, G. H. Y. (2021). Perceived help-seeking difficulty, barriers, delay, and burden in carers of people with suspected dementia. *International Journal of Environmental Research and Public Health*, *18*(6), 1–11. https://doi.org/10.3390/ijerph18062956

Nichols, E., Szoeke, C. E. I., Vollset, S. E., Abbasi, N., Abd-Allah, F., Abdela, J., Aichour, M. T. E., Akinyemi, R. O., Alahdab, F., Asgedom, S. W., Awasthi, A., Barker-Collo, S. L., Baune, B. T., Béjot, Y., Belachew, A. B., Bennett, D. A., Biadgo, B., Bijani, A., Bin Sayeed, M. S., … Murray, C. J. L. (2019). Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, *18*(1), 88–106. https://doi.org/10.1016/S1474-4422(18)30403-4

OECD. (2017). Informal carers. In *Health at a Glance 2017: OECD indicators*. OECD. https://doi.org/10.1787/health_glance-2017-en

Ory, M. G., Hoffman III, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (n.d.). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. In *In the Public Domain The Cerontologist* (Vol. 39, Issue 2). https://academic.oup.com/gerontologist/article/39/2/177/610023

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipert, B. D., & Henderson, S. R. (2010). The Positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology*, *29*(5), 640–659. https://doi.org/10.1177/0733464809341471

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). *Caregiving and the Stress Process: An Overview of Concepts and Their Measures* https://academic.oup.com/gerontologist/article/30/5/583/564941

Peng FC. (2003). Is dementia a disease? *Gerontology* , *49*, 384–391.

Perera, C., Salamanca-Sanabria, A., Caballero-Bernal, J., Feldman, L., Hansen, M., Bird, M., Hansen, P., Dinesen, C., Wiedemann, N., & Vallières, F. (2020). No implementation without cultural adaptation: A process for culturally adapting low-intensity psychological interventions in humanitarian settings. *Conflict and Health*, *14*(1). https://doi.org/10.1186/s13031-020-00290-0

Perminder Sachdev. (2000). Is it time to retire the term “dementia”? *J Neuropsychiatry Clin Neurosci*, *12*(2), 276–279.

Phillipson, L., & Jones, S. C. (2011). “Between the Devil and the Deep Blue Sea”: The Beliefs of Caregivers of People With Dementia Regarding the Use of In-Home Respite Services. *Home Health Care Services Quarterly*, *30*(2), 43–62. https://doi.org/10.1080/01621424.2011.569522

Phung, K. T. T., Waldorff, F. B., Buss, D. V, Eckermann, A., Keiding, N., Rishøj, S., Siersma, V., Sørensen, J., Søgaard, R., Sørensen, L. V, Vogel, A., & Waldemar, G. (2013). A three-year follow-up on the efficacy of psychosocial interventions for patients with mild dementia and their caregivers: the multicentre, rater-blinded, randomised Danish Alzheimer Intervention Study (DAISY). *BMJ Open*, *3*(11), e003584. https://doi.org/10.1136/bmjopen-2013-003584

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*(2), 250–267. https://doi.org/10.1037/0882-7974.18.2.250

Pinyopornpanish, K., Soontornpun, A., Wongpakaran, T., Wongpakaran, N., Tanprawate, S., Pinyopornpanish, K., Nadsasarn, A., & Pinyopornpanish, M. (2022). Impact of behavioral and psychological symptoms of Alzheimer’s disease on caregiver outcomes. *Scientific Reports*, *12*(1). https://doi.org/10.1038/s41598-022-18470-8

Pot, A. M., Gallagher-Thompson, D., Xiao, L., Willemse, B., Rosier, I., M. Mehta, K., Zandi, D., & Tarun, D. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. *World Psychiatry*, *18*, 3. https://doi.org/10.1002/wps.20683

Prince, M., Ali, G.-C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y.-T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer’s Research & Therapy*, *8*(1), 23. https://doi.org/10.1186/s13195-016-0188-8

Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012). The impact of relationships, motivations, and meanings on dementia caregiving outcomes. *International Psychogeriatrics*, *24*(11), 1816–1826. https://doi.org/10.1017/S1041610212000889

Resnicow, K., Soler, R., Braithwaite, R. L., Ahluwalia, J. S., & Butler, J. (2000). Cultural sensitivity in substance use prevention. *Journal of Community Psychology*, *28*(3), 271–290. https://doi.org/10.1002/(SICI)1520-6629(200005)28:3<271::AID-JCOP4>3.0.CO;2-I

Rigby, T., Ashwill, R. T., Johnson, D. K., & Galvin, J. E. (2019). Differences in the Experience of Caregiving Between Spouse and Adult Child Caregivers in Dementia With Lewy Bodies. *Innovation in Aging*, *3*(3), igz027. https://doi.org/10.1093/geroni/igz027

Ritterband, L. M., & Thorndike, F. (2006). Internet Interventions or Patient Education Web sites? *Journal of Medical Internet Research*, *8*(3), e580. https://doi.org/10.2196/jmir.8.3.e18

Santini, S., Socci, M., D’Amen, B., Di Rosa, M., Casu, G., Hlebec, V., Lewis, F., Leu, A., Hoefman, R., Brolin, R., Magnusson, L., & Hanson, E. (2020). Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice. *International Journal of Environmental Research and Public Health*, *17*(18), 6593. https://doi.org/10.3390/ijerph17186593

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry*, *12*(3), 240–249.

Sebri, V., & Savioni, L. (2020). An Introduction to Personalized eHealth. In G. Pravettoni & S. Triberti (Eds.), *P5 eHealth: An Agenda for the Health Technologies of the Future* (pp. 53–70). Springer International Publishing. https://link.springer.com/10.1007/978-3-030-27994-3_4

Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, *101*(1–3), 75–89. https://doi.org/10.1016/j.jad.2006.10.025

Semonella, M., Andersson, G., Dekel, R., Pietrabissa, G., & Vilchinsky, N. (2022). Making a Virtue Out of Necessity: COVID-19 as a Catalyst for Applying Internet-Based Psychological Interventions for Informal Caregivers. *Frontiers in Psychology*, *13*. https://www.frontiersin.org/articles/10.3389/fpsyg.2022.856016

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *The BMJ*, *374*. https://doi.org/10.1136/bmj.n2061

Sörensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). *Dementia care: mental health eff ects, intervention strategies, and clinical implications*. http://neurology.thelancet.comVol

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *22*(3), 294–300. https://doi.org/10.1016/j.jagp.2012.09.006

Sriram, V., Jenkinson, C., & Peters, M. (2019). Informal carers' experience of assistive technology use in dementia care at home: A systematic review. In *BMC Geriatrics* (Vol. 19, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s12877-019-1169-0

Stirman, S. W., Miller, C. J., Toder, K., & Calloway, A. (2013). Development of a framework and coding system for modifications and adaptations of evidence-based interventions. *Implementation Science*, *8*(1), 65. https://doi.org/10.1186/1748-5908-8-65

Sun, F., Ong, R., & Burnette, D. (2012). The Influence of Ethnicity and Culture on Dementia Caregiving. *American Journal of Alzheimer's Disease & Other Dementiasr*, *27*(1), 13–22. https://doi.org/10.1177/1533317512438224

Teahan, Á., Lafferty, A., Cullinan, J., Fealy, G., & O'Shea, E. (2021). An analysis of carer burden among family carers of people with and without dementia in Ireland. *International Psychogeriatrics*, *33*(4), 347–358. https://doi.org/10.1017/S1041610220000769

Teles, S., Ferreira, A., Seeher, K., Fréel, S., & Paúl, C. (2020). Online training and support program (iSupport) for informal dementia caregivers: Protocol for an intervention study in Portugal. *BMC Geriatrics*, *20*(1). https://doi.org/10.1186/s12877-019-1364-z

Thuve Dahm, K., Landmark, B., Kirkehei, I., Gundro Brurberg, K., Sporstøl Fønhus, M., & Merete Reinar, L. (2011). Interventions to Support Caregivers of People with Dementia Living in the Community. In *NIPH Systematic Reviews: Executive Summaries*. Knowledge Centre for the Health Services at The Norwegian Institute of Public Health (NIPH). http://www.ncbi.nlm.nih.gov/books/NBK464777/

Tsai, C.-F., Hwang, W.-S., Lee, J.-J., Wang, W.-F., Huang, L.-C., Huang, L.-K., Lee, W.-J., Sung, P.-S., Liu, Y.-C., Hsu, C.-C., & Fuh, J.-L. (2021). Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatrics*, *21*(1), 59. https://doi.org/10.1186/s12877-021-02007-1

Tulek, Z., Baykal, D., Erturk, S., Bilgic, B., Hanagasi, H., & Gurvit, I. H. (2020). Caregiver Burden, Quality of Life and Related Factors in Family Caregivers of Dementia Patients in Turkey. *Issues in Mental Health Nursing*, *41*(8), 741–749. https://doi.org/10.1080/01612840.2019.1705945

UFSP (Ufficio federale della Sanità Pubblica) (2023). *Fatti e cifre sulla demenza*. Https://Www.Bag.Admin.Ch/Bag/It/Home/Zahlen-Und-Statistiken/Zahlen-Fakten-Demenz.Html.

UFSP (Ufficio federale della Sanità Pubblica) (2013). *Strategia nazionale sulla demenza 2014-2019*. https://www.bag.admin.ch/bag/it/home/strategie-und-politik/nationale-gesundheitsstrategien/demenz/nationale-demenzstrategie.html

USTAT (Ufficio di Statistica) & Borioli M. (2020). *Tra assistenza informale e familiari curanti in Ticino*. https://www3.ti.ch/DFE/DR/USTAT/allegati/articolo/2683dss_2020-2_2.pdf.

United Nations Economic Commission for Europe (UNECE). Policy Brief on Aging (2019). *The challenging roles of informal carers*. https://unece.org/DAM/pau/age/Policy_briefs/ECE_WG1_31.pdf

Van Der Flier, W. M. (2005). Epidemiology and risk factors of dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *76*(suppl_5), v2–v7. https://doi.org/10.1136/jnnp.2005.082867

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K., & Annemans, L. (2016). Effectiveness of Supporting Informal Caregivers of People with Dementia: A Systematic Review of Randomized and Non-Randomized Controlled Trials. In *Journal of Alzheimer's Disease* (Vol. 52, Issue 3, pp. 929–965). IOS Press. https://doi.org/10.3233/JAD-151011

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*(6), 946–972. https://doi.org/10.1037/0033-2909.129.6.946

Wang, J., Li, X., Liu, W., Yang, B., Zhao, Q., Lü, Y., & Xiao, M. (2022). The positive aspects of caregiving in dementia: A scoping review and bibliometric analysis. *Frontiers in Public Health*, *10*. https://doi.org/10.3389/fpubh.2022.985391

Werner, P., Goldstein, D., Karpas, D. S., Chan, L., Rsw, C. K., & Lai, C. (2014). *Help-Seeking for Dementia A Systematic Review of the Literature*. www.alzheimerjournal.com

Wimo, A., Gauthier, S., & Prince, M. (2018). *Global Estimates of Informal Care.* Alzheimer's Disease International and Karolinska Institute. https://www.alzint.org/u/global-estimates-of-informal-care.pdf.

Wimo, A., Seeher, K., Cataldi, R., Cyhlarova, E., Dielemann, J. L., Frisell, O., Guerchet, M., Jönsson, L., Malaha, A. K., Nichols, E., Pedroza, P., Prince, M., Knapp, M., & Dua, T. (2023). The worldwide costs of dementia in 2019. *Alzheimer's and Dementia*. https://doi.org/10.1002/alz.12901

World Health Organization. (2017). *Dementia: a public health priority.* ttps://www.who.int/mental_health/neurology/dementia/en/

World Health Organization (2021). *Global status report on the public health response to dementia.* http://apps.who.int/

World Health Organization (2018). *Use of appropriate digital technologies for public health (A71/20) Seventy-first World Health Assembly*. https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_20-en.pdf

World Health Organization (2021). *Global strategy on digital health 2020-2025.* https://apps.who.int/iris/handle/10665/344249

World Health Organization (2017). *mhGAP training manuals Mental Health Gap Action Programme.* (2017). http://apps.who.int/bookorders.

Xiong, C., Biscardi, M., Astell, A., Nalder, E., Cameron, J. I., Mihailidis, A., & Colantonio, A. (2020). Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLOS ONE*, *15*(4), e0231848. https://doi.org/10.1371/journal.pone.0231848

Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, *79*, 1–26. https://doi.org/https://doi.org/10.1016/j.ijnurstu.2017.10.008

Yuan, Q., Zhang, Y., Samari, E., Jeyagurunathan, A., Goveas, R., Ng, L. L., & Subramaniam, M. (2023). Positive aspects of caregiving among informal caregivers of persons with dementia in the Asian context: a qualitative study. *BMC Geriatrics*, *23*(1), 51. https://doi.org/10.1186/s12877-023-03767-8

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Zwingmann, I., Dreier-Wolfgramm, A., Esser, A., Wucherer, D., Thyrian, J. R., Eichler, T., Kaczynski, A., Monsees, J., Keller, A., Hertel, J., Kilimann, I., Teipel, S., Michalowsky, B., & Hoffmann, W. (2020). Why do family dementia caregivers reject caregiver support services? Analyzing types of rejection and associated health-impairments in a cluster-randomized controlled intervention trial. *BMC Health Services Research*, *20*(1). https://doi.org/10.1186/s12913-020-4970-8

Chapter 3: Caregivers of people with dementia and mental health during COVID-19: findings from a cross-sectional study (study 1)

Anna Messina, Martina Lattanzi, Emiliano Albanese and Maddalena Fiordelli

Institute of Public Health, Faculty of Biomedical Sciences, Università della Svizzera Italiana.

Published in BMC Geriatrics (2022) 22:56.

Abstract

Background: There is sparse evidence on the impact on vulnerable populations of the COVID-19 pandemic. The aim of our study was to explore burden and mental wellbeing (including depressive, anxiety, and stress symptoms) in caregivers of people with dementia during the first wave of the pandemic in Italy and southern Switzerland, two bordering regions severely hit by the COVID-19 pandemic.

Methods: We conducted an online cross-sectional survey with family carers of people with dementia between May and June 2020. We registered socio-demographic characteristics, and information about the relationship with the care recipient, dementia subtype, care inputs from others, and the need of care of the person with dementia. We measured caregiver burden with the Zarit Burden Interview (ZBI), psychological distress with the Depression, Anxiety and Stress Scale (DASS-21), and perceived isolation with the 3-item UCLA Loneliness Scale (UCLALS3).

Results: Caregivers (N=571) reported moderate to severe care-related burden (mean=45.30; SD=18.33), moderate anxiety symptoms (mean=10.04; SD=6.93), mild depressive symptoms (mean=11.79; SD=6.12) and mild stress (mean=12.95; SD=5.53), and 72.3% of participants reported to feel lonely. All scores were significantly more severe in Swiss compared to Italian caregivers (all *p values*<0.001).

Conclusions: We found that caregivers' burden, anxiety symptoms, depression and perceived loneliness were marked during the first wave of the COVID-19 pandemic, in two severely hit bordering countries. Regional differences in the impact of the epidemic on caregivers could be due to contextual, societal, and cultural circumstances. As the pandemic endures, support to caregivers of people with dementia should be proportionate and tailored to needs and adapted to contextual factors.

Keywords: Caregivers, Dementia, Mental health, COVID-19, Cross-sectional study

Introduction

Dementia influences those who are affected and the family members who very often care for their relatives at home [1]. Friends and relatives who provide non-professional and un-paid care to help a person, usually with long-term needs are defined as “informal carers” [2]. In 2019, according to the World Health Organization (WHO), informal caregivers worldwide spent over 89 billion hours assisting a family member with dementia in basic personal activities of daily living, with women contributing to 70% of global hours of care [3]. Informal care provision generally reflects more factors, from the scarcity or lack of resources and formal support services for people with dementia, to social and cultural expectations that family members, especially women, have the obligation to take care of a relative in need [4]. Even if there is evidence that caring duties can also lead to a sense of personal accomplishment and gratification [5], many informal caregivers deal with social, financial, and psychological strain that increases the likelihood of developing mental and physical distress [6].

Indeed, literature shows that caring for someone with dementia is associated with feelings of burden perceived stress, depression, loneliness, poorer immune function, and cognitive decline [7–10]. The COVID-19 pandemic brought new challenges to caregivers. Worldwide, governments enforced restrictions measures such as physical distancing, stay at home orders and travel restrictions that often limited the access to health-care facilities and caregivers support interventions such as respite services [3] . The disruption or abrupt suspension of social and medical support forced informal caregivers to take over multiple and additional responsibilities to meet the needs of the person with dementia [11]. In addition, since older age and premorbid conditions represent a risk factor for COVID 19 mortality [12], caregivers felt additional pressure to protect themselves from infection to prevent transmission to the person they cared for [13]. Taken together, all the changes imposed by the pandemic have likely exacerbated already taxing caring conditions and may have contributed to increase and worsen psychological distress of caregivers, potentially in the long term.

Longitudinal studies [14,15] suggest that the impact on mental health on the general population varies through the waves and various phases of the COVID-19 pandemic, from outbreaks to relapses of mitigation public health measures, with marked geographic variations. However, there is scant evidence about caregivers’ mental health during the pandemic, particularly during the first wave of the outbreak and lockdown periods. Moreover, evidence on cross-country comparisons in psychological distress of caregivers is extremely thin [16], and inexistent from northern Italy and southern Switzerland, two regions that were very severely hit during the first pandemic outbreak. In addition, most of the few available studies on dementia caregivers during the pandemic, focused only on some psychological outcomes, mainly stress or caregiver burden [17–20] and varied in methods; psychological distress was often not measured using previously validated scales [21–23]. It is indispensable to expand and advance the current knowledge on the impact of the pandemic on caregivers of people with dementia to inform the design and provision of appropriate measures and interventions aimed at supporting this vulnerable population for the current and in view of future pandemic crises.

We conducted a cross-sectional survey in Italian and Swiss informal caregivers of people with dementia during the first wave of the COVID-19 pandemic (May- June 2020). We aimed to explore levels of burden, depressive symptoms, stress, anxiety, and perception of loneliness in caregivers of people with dementia during the first peak of the pandemic, in two hardly hit bordering countries, where preventive public health measures, including personal limitations and home confinement were strictly enforced. Public health preventive measures varied in the two countries, but according to the Oxford University's stringency index were almost identical at the time of data collection of the present study [24].

Methods

Study participants and procedures

We conducted an online cross-sectional survey in family caregivers of people with dementia in two bordering, Italian-speaking regions: Italy and southern Switzerland. We used snowball technique to recruit a convenient sample of both Italian and Swiss informal caregivers by advertising our research via three different channels. An invitation message was prepared and circulated in 32 social media pages on Facebook and Instagram related to ageing and/or dementia and Facebook private groups of informal caregivers, and through 53 day-care centres for people with dementia in the two regions. Inclusion criteria were being 18 years of age or older, Italian-speaker, and informal (i.e. non professional) caregiver of a non-institutionalized family member with previously diagnosed dementia. Participants were excluded from the study if they did not match all inclusion criteria.

The online survey, implemented in RedCap (Research Electronic Data Capture), was active between May 25th, 2020, and June 25th, 2020. The estimated compilation time was 15 minutes. All participants received an informed consent to participate prior to filling out the survey, online. All methods were performed in accordance with the relevant guidelines and regulations.

Measures

Sociodemographic variables

We collected socio-demographic data of caregivers, including age, gender, place of residence, level of education, and work. We also asked carers about their relationship with the person with dementia, and inquired whether care provision was their only occupation, and if they received any care inputs from other formal or informal caregiver. Information about the care recipient elicited from the carers included the clinically diagnosed dementia subtype and level of autonomy in activities of daily living. All questions were asked and data collected in Italian.

Psychological measures

All psychological measures were already available in Italian, were previously validated, and have been extensively used in Italian. We used three main standardized questionnaires. The Italian version of the Zarit Burden Interview (ZBI) [25] to assess the level of caregiver burden. For each of the 22 items, respondents reported their perceived strain associated to the provision of care on a Likert scale ranging between zero (never) and four (nearly always). We computed total scores and applied standard cut-offs of low (<21), mild to moderate ($21 \leq x \leq 40$), moderate to severe ($41 \leq x \leq 60$), and severe burden (>60) [26]. The Italian short version of the Depression, Anxiety and Stress Scale (I-DASS-21) [27], to assess the mental health of caregivers. DASS-21 is commonly used to assess negative emotions in community samples, including in informal caregivers [28]. We changed and extended, from the original questionnaire delivery, the time reference of the items from “the past week” to “the past months of COVID-19 outbreak”. Respondents reported frequency of symptoms on a four-point Likert scale (never; sometimes; often; and almost always), and we calculated the separate scores of depressive, anxiety and stress-related symptoms (mild; moderate; severe; extremely severe) according to standard cut-offs [29]. Finally, we explored the frequency (hardly never; some of the time; often) of feelings of loneliness during the COVID-19 outbreak in the region, with the three items (lack of companionship, exclusion, and isolation) Italian version of the UCLA Loneliness scale (UCLALS3) [30, 31]. This scale has been previously used in population-based studies to measure social isolation, including in caregivers of people with dementia [32], and during the COVID-19 pandemic [33] . We asked participants to answer the items referring to the past months of COVID-19 outbreak. We computed an overall loneliness score, which ranged from three to nine, with higher scores indicating higher perception of loneliness.

Statistical analyses

We computed means and proportions for descriptive statistics of the sociodemographic variables, Chi squared tests for all socio-demographic variables, and the main scales. We tested assumptions of normality and linearity, and we calculated correlations between the psychological distress measures, education, and years of caregiving experience using Pearson’s correlation coefficient and univariate and multivariate ANOVA regressions, setting statistical significance at 0.05. We assessed differences in ZBI, DASS-21, and UCLALS3 scores by country and sociodemographic characteristics using independent samples t-test. Finally, in a set of sensitivity analysis we ran linear regressions to model the effect of study site (i.e. Switzerland/ Italy) separately on each of the psychological distress scores adjusting for relevant socio-demographic and care characteristics. We used SPSS 25.0 statistical software for Windows for all statistical analyses.

Results

Sociodemographic characteristics

Of the 646 caregivers contacted, 571 completed the survey and formed the analytic sample (response rate 87%). Table 1 shows the sociodemographic characteristics of the overall study sample, and by country. Of the 571 caregivers, 425 were Italian (74.4%) and 146 (25.6%) were Swiss, with a mean age of 53 years (SD=11.99) and a range of 24 to 89. The majority of caregivers were female (81.6%), and the mean number of years spent in caregiving was 6 (SD=3.95). Most participants cared for a family member affected by Alzheimer’s Disease (55.3%), followed by Vascular (16.6%), Parkinson’s (12.6%), Frontotemporal dementia (7.7%), Lewy-Body dementia (3.3%), and other or unspecified types of dementia (4.5%). Most caregivers were children (71.8%), or spouse of the person with dementia (20.7%) and referred to care for a person not autonomous in most daily life activities (79.9%). Almost two thirds of participants admitted getting help from others in caring (58.7%), especially from other family members (32.2%) or professional carers (22.8%). More than half of participants had at least higher secondary education (56.4%), and almost half of the caregivers were employed with a full time or part-time job (49.6%).

Table 1: Sociodemographic characteristics of informal caregivers by country (N=571)

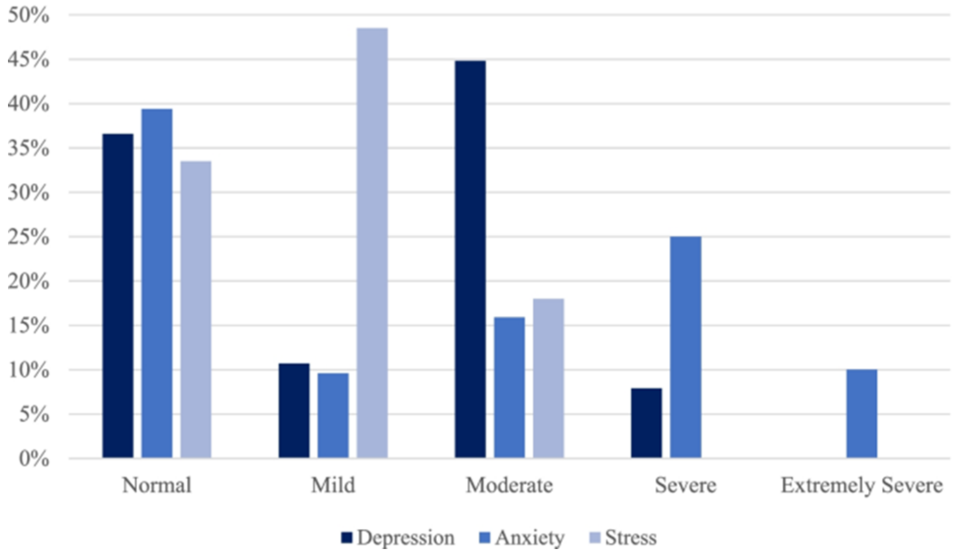
Variable	Total sample (N=571) N (%)	Italy (N=425) N (%)	Switzerland, Ticino (N=146) N (%)	**p-value***
Gender				
Female	466 (81.6)	381 (89.6)	85 (58.2)	p<0.001
Male	104 (18.2)	43 (10.1)	61 (41.8)	
Not specified	1 (0.2)	1 (0.2)		
				p-value**
Age Mean (SD)	53.54 (11.99)	51.85 (10.72)	58.49 (13.99)	p<0.001
Years of caregiving Mean (SD)	6.07 (3.95)	5.08 (3.68)	8.83 (3.31)	p<0.001
Caregiver as sole occupation				
Yes	292 (51.1)	176 (41.4)	116 (79.5)	p<0.001
No	279 (51.1)	249 (58.6)	30 (20.5)	
Employment Status				
Unemployed/Housewife	202 (35.4)	132 (31.1)	70 (47.9)	p<0.001
Full-time Job	253 (44.3)	228 (53.6)	25 (17.1)	
Part-time Job	30 (5.3)	25 (5.9)	5 (3.4)	
Retired	86 (15.1)	40 (9.4)	46 (31.5)	
Relationship with the care-recipient				
Child	410 (71.8)	328 (77.2)	82 (56.2)	p<0.001
Spouse	118 (20.7)	59 (13.9)	59 (40.4)	
Other	43 (7.5)	38 (8.9)	5 (3.4)	
Education				
Compulsory education	107 (18.7)	70 (16.5)	37 (25.3)	p<0.001
Higher Secondary education	322 (56.4)	231 (54.4)	91 (62.3)	
University education	142 (24.9)	124 (29.2)	18 (12.3)	
Care recipient type of dementia				
Alzheimer	316 (55.3)	247 (58.1)	69 (47.3)	p<0.001
Vascular dementia	95 (16.6)	82 (19.3)	13 (8.9)	
Parkinson's Disease	72 (12.6)	24 (5.6)	48 (32.9)	
Frontotemporal dementia	44 (7.7)	44 (10.4)		
Dementia with Lewy Bodies	19 (3.3)	17 (4.0)	2 (1.4)	
Other	25 (4.5)	11 (2.6)	14 (9.6)	
Autonomy in basic function of the care recipient				
Yes	116 (20.3)	105 (24.7)	11 (7.5)	p<0.001
No	455 (79.7)	320 (75.3)	135 (92.5)	
Help from others				
Yes	335 (58.7)	285 (67.1)	50 (34.2)	p=0.197
Relative	184 (32.2)	159 (55.8)	25 (50.0)	
Professional carers (nurse/domestic worker)	130 (22.8)	106 (37.2)	24 (48.0)	
Friends/neighbours	21 (3.7)	20 (7.0)	1 (2.0)	

P values were calculating using *Chi Squared tests, and **Independent t-test, as appropriate

Psychological measures

Overall, caregivers had a mean Zarit burden score of 54.3 (SD=18.3), which corresponds to “moderate to severe”. Mean scores from DASS-21 showed mild depression (mean=11.79; SD=6.12), moderate anxiety (mean=10.04; SD=6.93), and mild stress (mean=12.95; SD=5.53), according to standard cut-offs [29]. However, the severity of reported symptoms was more pronounced for anxiety, intermediate for depression, and less marked for stress (Fig. 1). According to past categorizations of the UCLALS3 scale [34], 72.3% of caregivers fell into the ‘lonely’ category, 99.3% among Swiss and 63.1% in Italian caregivers.

Fig. 1: Proportion (%) of participants with depressive, anxiety, and stress (DASS-21) symptoms according to severity



Proportion (%) of participants with depressive, anxiety, and stress (DASS-21) symptoms according to severity. Cut-offs scores [29]: Depression (normal: 0-9, mild: 10-12, moderate: 13-20, severe: 21-27, extremely severe: 28-42); Anxiety (normal: 0-6, mild: 7-9, moderate: 10-14, severe 15-19, extremely severe: 20-42); Stress (normal: 0-10, mild: 11-18, moderate: 19-26, severe: 27-34, extremely severe: 35-42).

All psychological variables were positively correlated to each other (r^2 values ranging from 0.59 to 0.85, all *p* values <0.001) (Table 2). Correlations did not vary between countries and are presented for the full sample. More specifically, multiple linear regressions showed that stress was significantly associated with depression levels (β=0.52; *p*<0.001) and burden (β=0.43; *p*<0.001); depression explained a significant proportion of variance in perception of loneliness (β=0.49; *p*<0.001), anxiety (β=0.42; *p*<0.001), and stress scores (β=0.53; *p*<0.001); anxiety was significantly associated with depression (β=0.33; *p*<0.001), loneliness (β=0.27; *p*<0.001) and stress (β=0.26; *p*<0.001); perception of loneliness was significantly associated with symptoms of depression (β=0.17; *p*<0.001) and anxiety (β=0.12; *p*<0.001). In addition, higher levels of education and years of experience in caregiving slightly predicted better mental health on all outcomes (all *p* values <0.001) (Table 2).

Table 2: Multiple linear regressions for psychological variables

Variable	R	R^2 (p-value)	Caregiver burden	Depression	Anxiety	Stress	Loneliness	Education	Years of experience
Caregiver burden	0.79	0.62 (<0.001)		0.08 (0.20)	0.20 (0.16)	0.43 (0.20)***	0.02 (0.36)	-0.09 (0.31)**	0.11 (0.13)***
Depression	0.92	0.85 (<0.001)	0.03 (0.01)		0.33 (0.03) ***	0.52 (0.04)***	0.17 (0.07)***	-0.00 (0.06)	-0.25 (0.03)
Anxiety	0.90	0.82 (<0.001)	0.10 (0.01)**	0.42 (0.05)***		0.30 (0.05)*	0.12 (0.09)***	-0.07 (0.08)**	0.05 (0.03)*
Stress	0.91	0.84 (<0.001)	0.19 (0.01)*	0.53 (0.03)***	0.26 (0.03)***		0.00 (0.07)	0.06 (0.06)**	0.02 (0.03)
Loneliness	0.77	0.59 (<0.001)	0.03(0.00)***	0.49 (0.02)***	0.27 (0.02)***	0.01 (0.02)		-0.02 (0.04)	0.01 (0.02)

Beta standardized coefficients (β) are reported with Beta standard errors in parentheses.
*, **, *** indicates p values <0.05, <0.005, <0.001, respectively

Independent t-test showed that all psychological symptoms were more pervasive in Swiss caregivers with higher scores for burden depression, stress, anxiety, and loneliness than the Italian counterparts (all *p* values < 0.001) (Table 3).

Table 3: Comparison of psychological variables between Swiss (N=146) and Italian (N=425) caregivers

Variable	All sample	Italians	Swiss	T statistics* (df)	P-value
	Mean (SD) [min/max]	Mean (SD) [min/max]	Mean (SD) [min/max]		
ZBI					
Caregiver burden	54.30 (18.33) [6-88]	48.75 (16.90) [6-88]	70.46 (11.48) [33-88]	-14.41 (569)	<0.001
DASS-21					
Depression	11.79 (6.12) [0-21]	10.23 (6.17) [0-21]	16.36 (2.76) [10-21]	-11.61 (569)	<0.001
Anxiety	10.04 (6.93) [0-21]	7.82 (6.48) [0-21]	16.50 (3.05) [4-21]	-15.59 (569)	<0.001
Stress	12.95 (5.53) [0-21]	11.60 (5.60) [0-21]	16.89 (2.71) [8-21]	-10.97 (569)	<0.001
UCLALS3					
Loneliness	6.77 (2.06) [3-9]	6.29 (0.10) [3-9]	8.20 (0.79) [5-9]	-10.62 (569)	<0.001

ZBI= Zarit Burden Interview (possible range, 6 to 88); DASS-21= Depression Anxiety and Stress Scale (possible range, 0-21); UCLALS3= Ucla Loneliness Scale 3 items version (possible range, 3-9).
* Students' t test for independent samples
P values were calculated using *Chi Squared tests, and *Independent t-test, as appropriate

The linear regression models of the effect of country of residence on the psychological distress measures confirmed that anxiety, depression, stress, and burden were, respectively, 55% ($\beta=0.547$), 44% ($\beta=0.438$), 42% ($\beta=0.418$), and 52% ($\beta=0.517$) higher in Switzerland compared to Italy (all p values < 0.001). All associations remained significant also after we adjusted for relevant covariates (all p values $<$ 0.001). We also found significant differences for social support, with caregivers who got help from others showing lower levels of burden (mean=49.27; SD=16.41), depression (mean=10.66; SD=6.02), loneliness (mean=6.34; SD=2.08) and anxiety (mean=8.65; SD=6.65) than caregivers who took care of their relatives alone (mean=13.40; SD=5.89); (mean=7.39; SD=1.85); (mean=12.02; SD=6.84) (all p values < 0.001). Similarly, spouses' caregivers reported significantly higher scores in all psychological outcomes than children caregivers (all p values < 0.001).

Discussion

Our study aimed to explore psychological distress in carers of people with dementia during the first wave of COVID-19 pandemic in two severely hit bordering countries. We found that levels of burden, anxiety, depression, and perception of loneliness were marked in caregivers of people with dementia. All psychological symptoms, including loneliness were positively correlated to each other, and were more pervasive in Swiss compared to Italian caregivers, and in spouse compared to children caregivers. Education, employment status and social support were inversely associated with psychological distress.

Previous evidence suggested that providing care for a person with dementia can cause strain and can affect both the psychological and physical health of the carer [8]. Caregivers generally report higher levels of perceived stress, depression, loneliness, burden and lower levels of self-efficacy and well-being compared to the general population [7]. Our results on the inverse association between educational level, social support, employment status, and psychological distress are consistent with those of pre-pandemic studies [35]. Nevertheless, disruption of healthcare facilities and social restriction measures imposed by the pandemic altered care routines and practices, with plausible detrimental consequences on caregivers' physical and mental health [11]. Direct comparisons with literature are not straightforward because few studies have been conducted on caregivers of people with dementia since the beginning of the pandemic, and in particular during the lockdown, in spring 2020 [36]. However, previous studies [37,38, 39] found that high variations in social support services were associated with increased levels of anxiety, burden, and depression in samples of caregivers from Italy and the UK respectively.

We found some variations in the reported psychological symptoms. While severe levels of reported burden and anxiety were common, more than half of the caregivers in our sample reported only mild to moderate levels of stress and depressive symptoms. The COVID-19 pandemic may affect caregivers' mental health on multiple levels. The disruption of health care services may led to a sudden and unexpected increase in responsibility. Caregivers had to provide more types of care inputs and for longer hours, with a consequent lower sense of competence and mastery [40], which in turn are associated to a greater experience of burden [41]. Suspension of respite care and breaks may have altered coping mechanisms and pre-pandemic recover opportunities, contributing to “chronic stressor felt by caregiver with respect to physical and emotional well-being, family relations and financial status” [42], rather than the more transitory experience of stress to which caregivers can adapt over time. In addition, fear of infecting a loved one can trigger worry and anxiety [43]. Moreover, the uncertainties about infection risks and the very limited knowledge about COVID-19, especially during the first wave of the pandemic, were likely responsible of increases in cognitive alertness, which may shadow or counterbalance depressive symptoms or their perception. Indeed, depression rates in the general population increased during the second wave of the pandemic compared to the first wave, probably because of the prolonged psychological distress and long-term social dislocations [44].

In our study, we also focused on perceived loneliness. We found that most caregivers reported to feel lonely. This may be explained by the almost complete lack of social interactions imposed by restriction measures, which was abrupt and unprecedented. The reported feeling of being alone and trapped at home with few external support was probably consequent to an actual condition of forced confinement [45]. These findings suggest that caregivers of people with dementia are likely vulnerable to lockdown and social restriction measures, and could suffer remarkable loneliness, which may compromise their ability to provide care [46]. Next, psychological measures correlated to each other, correlations between depression and anxiety were particularly strong, and with higher scores in reported anxiety, predicting higher scores in depression and vice versa. Since a third of our sample reported from severe to extremely severe levels of anxiety, there is a concrete risk of increasing levels of depression in caregivers as the pandemic endures.

We investigated mental health in caregivers during the pandemic in two different countries and Swiss caregivers reported significantly higher distress in all mental health outcomes than their Italian counterparts did. During the first wave, the Italian Government adopted slightly stricter public health measures to contain the pandemic compared to the Swiss Confederation [24]. The extent to which and potential causal role of preventive measures on caregivers’ mental health are not easy to disentangle. However, the variation in the timing and severity of the restriction measures adopted in the two countries may have contributed, at least to some extent, to explain the differences we found between Swiss and Italian caregivers. The presence of prompt preventive measures to reduce the risk of infection, especially for the elderly and vulnerable populations, may have contributed to lessen the anxiety and fear of contagion in Italian caregivers of people with dementia. On the other hand, the latency and minor severity of restrictions adopted by the Swiss Federal Council may have triggered a sense of personal unsafety for both the caregiver and the care-recipient. Nonetheless, other socio-cultural and contextual factors may contribute to explain the fact that Swiss caregivers reported significantly higher distress in all mental health outcomes than Italian carers did. Evidence suggests that social support is a protective factor towards burden and psychological distress in dementia caregivers [47, 48]. Since in our study Italian caregivers reported to receive more help in caring duties compared to Swiss caregivers (Table 1), the differences in use and availability of emotional and practical forms of support during the pandemic may lead the burden due to the disruption of services and the additional care responsibilities. A further investigation on specific restrictive measures and services available during the lockdown for caregivers of people with dementia in the two different countries is needed to clarify the differences.

The present study is not free from limitations. The lack of longitudinal or pre-pandemic data on the burden, mental health, and loneliness of caregivers limits causal inference. However, we found exceptionally high levels of burden and psychological distress according to commonly used and standardized scales. Further, although the sample of our study was large it was not representative of the target population. We cannot exclude selection bias also because only caregivers who had access to the internet and to our recruitment channels could participate in the survey. Nevertheless, the study population had a broad sociodemographic spectrum, which provides support at least to some extent to the external validity of our results. We measured psychological distress using robust and valid measures, and participants self-reported a wide range of their socio-demographic and care characteristics. However, people with dementia were less thoroughly characterised. We did not measure behavioural and psychological symptoms of dementia (BPSD), and we used a binary question to measure autonomy and not a standard measure of activities of daily living (ADL). BPSD and ADL impairments are associated with strain and psychological distress in caregivers [49, 50], and may have worsened because of self-sheltering, quarantine, and other personal and social restrictive measures [51].

Our results confirmed that people with dementia and their caregivers have faced serious challenges during the pandemic. Local authorities must consider, locally adapt, and apply the recommendations of issued by the Technical Advisory Board on Mental Health in the WHO European region to reduce the impact of COVID-19 crisis on mental health in vulnerable populations [52].

Conclusions

The present study showed that family caregivers of people with dementia have experienced psychological distress during the first wave of COVID-19 pandemic. Since we found severe feelings of burden and anxiety, rapid and targeted measures are required to enable carers to continue provide care and cope with uncertainty, while maintaining their own well-being. Further interventions should address feelings of loneliness accounting for contextual and cultural circumstances.

Availability of data and materials

The dataset generated and analysed during the current study are available in the Zenodo open access repository, DOI:10.5281/zenodo.4748652.

References

1. Alzheimer's Disease International (ADI). Global estimates of informal care. 2018. https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf. Accessed May 2021.

2. OECD. Health at a Glance 2017. 2017. https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2017_health_glance-2017-en. Accessed June 2021.

3. World Health Organization. Global status report on the public health response to dementia. 2021. http://apps.who.int/. Accessed September 2021.

4. Mccleary L, Blain J. Cultural values and family caregiving for persons with dementia. Indian J. Gerontol. 2013;27:178–201.

5. Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. Int. J. Nurs. Stud. 2018;79:1–26.

6. Bullock R. The Needs of the Caregiver in the Long-Term Treatment of Alzheimer Disease. Alzheimer Dis Assoc Disord. 2004;18 Suppl 1:17-23.

7. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am J Geriatr Psychiatry. 2004;12:240–9.

8. Gilhooly KJ, Gilhooly MLM, Sullivan MP, McIntyre A, Wilson L, Harding E, et al. A meta-review of stress, coping and interventions in dementia and dementia caregiving. BMC Geriatrics. 2016;16:106.

9. Kovaleva M, Spangler S, Clevenger C, Hepburn K. Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. J Psychosoc Nurs Ment Health Serv. 2018;56:36-43.

10. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. Psychol. Bull. 2003;129:946–72.

11. Wang H, Li T, Barbarino P, Gauthier S, Brodaty H, Molinuevo JL, et al. Dementia care during COVID-19. Lancet. 2020;395:1190–1.

12. O'Shea E. Remembering people with dementia during the COVID-19 crisis. HRB Open Res. 2020;3.

13. Bonanad C, García-Blas S, Tarazona-Santabalbina FJ, Díez-Villanueva P, Ayesta A, Sanchis Forés J, et al. Coronavirus: the geriatric emergency of 2020. Rev Esp Cardiol. 2020;73:569–76.

14. Ramiz L, Contrand B, Rojas Castro MY, Dupuy M, Lu L, Sztal-Kutas C, et al. A longitudinal study of mental health before and during COVID-19 lockdown in the French population. Glob. Health. 2021;17:29.
15. Pierce M, McManus S, Hope H, Hotopf M, Ford T, Hatch SL, et al. Mental health responses to the COVID-19 pandemic: a latent class trajectory analysis using longitudinal UK data. Lancet Psychiatry. 2021;8:610-619.

16. Bergmann M, Wagner M. The Impact of COVID-19 on Informal Caregiving and Care Receiving Across Europe During the First Phase of the Pandemic. Public Health Front. 2021;9:590.

17. Giebel C, Cannon J, Hanna K, Butchard S, Eley R, Gaughan A, et al. Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. Aging Ment Health. 2020;25:1281-1288.

18. Cohen G, Russo MJ, Campos JA, Allegri RF. Living with dementia: Increased level of caregiver stress in times of COVID-19. Int. Psychogeriatr. 2020;32:1377-1381.

19. Park SS. Caregivers' Mental Health and Somatic Symptoms During COVID-19. J Gerontol B Psychol Sci Soc Sci. 2021;76:235–40.

20. Borelli WV, Augustin MC, de Oliveira PBF, Reggiani LC, Bandeira-de-Mello RG, Schumacher-Schuh AF, et al. Neuropsychiatric Symptoms in Patients with Dementia Associated with Increased Psychological Distress in Caregivers During the COVID-19 Pandemic. J Alzheimers Dis. 2021;80:1705–12.

21. Carcavilla N, Pozo AS, Gonzalez B, Moral-Cuesta D, Roldan JJ, Erice V, et al. Needs of Dementia Family Caregivers in Spain during the COVID-19 Pandemic. J Alzheimers Dis. 2021;80:533–7.

22. Canevelli M, Valletta M, Toccaceli Blasi M, Remoli G, Sarti G, Nuti F, et al. Facing Dementia During the COVID-19 Outbreak. J Am Geriatr Soc. 2020;68:1673–6.

23. Tsapanou A, Papatriantafyllou JD, Yiannopoulou K, Sali D, Kalligerou F, Ntanasi E, et al. The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. Int. J. Geriatr. Psychiatry. 2021;36:583–7.

24. Hale T, Angrist N, Goldszmidt R, Kira B, Petherick A, Phillips T, et al. A global panel database of pandemic policies (Oxford COVID-19 Government Response Tracker). Nat. Hum. Behav. 2021;5:529–38. doi:10.1038/s41562-021-01079-8

25. Chattat R, Cortesi V, Izzicupo F, del Re ML, Sgarbi C, Fabbo A, et al. The Italian version of the Zarit Burden interview: a validation study. Int. Psychogeriatr. 2011;23:797–805.

26. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20:649–55.

27. Bottesi G, Ghisi M, Altoè G, Conforti E, Melli G, Sica C. The Italian version of the Depression Anxiety Stress Scales-21: Factor structure and psychometric properties on community and clinical samples. Compr Psychiatr. 2015;60:170–81.

28. Ahmad Zubaidi ZS, Ariffin F, Oun CTC, Katiman D. Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. BMC Palliat. Care. 2020;19:186.

29. Lovibond, S. H., & Lovibond PF. Manual for the Depression Anxiety Stress Scales. 2nd ed. Sydney: Psychology Foundation; 1995.

30. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A Short Scale for Measuring Loneliness in Large Surveys: Results From Two Population-Based Studies. Res Aging. 2004;26:655–72.

31. Solano, L. & Coda R. Relazioni, emozioni, salute. Introduzione alla psicoimmunologia. [Relationships, emotions and health: Introduction to psychoimmunology]. Padua: Piccin; 1994.

32. Rand S, Malley J, Vadean F, Forder J. Measuring the outcomes of long-term care for unpaid carers: comparing the ASCOT-Carer, Carer Experience Scale and EQ-5D-3 L. Health Qual. Life Outcomes. 2019;17:184.

33. Groarke JM, Berry E, Graham-Wisener L, McKenna-Plumley PE, McGlinchey E, Armour C. Loneliness in the UK during the COVID-19 pandemic: Cross-sectional results from the COVID-19 Psychological Wellbeing Study. PLOS ONE. 2020;15:1–18.

34. Steptoe A, Shankar A, Demakakos P, Wardle J. Social isolation, loneliness, and all-cause mortality in older men and women. PNAS. 2013;110:5797–801.

35. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. Psychol Aging. 2003;18:250–67.

36. Greenberg NE, Wallick A, Brown LM. Impact of COVID-19 Pandemic Restrictions on Community-Dwelling Caregivers and Persons With Dementia. Psychol. Trauma: Theory Res. Pract. Policy. 2020; 12: 220-221.

37. Giebel C, Lord K, Cooper C, Shenton J, Cannon J, Pulford D, et al. A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. Int. J. Geriatr. Psychiatry. 2020;36:393-402.

38. Altieri M, Santangelo G. The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. Am. J. Geriatr. Psychiatry. 2020;29:27-34.

39. Carpinelli Mazzi M, Iavarone A, Musella C, de Luca M, de Vita D, Branciforte S, et al. Time of isolation, education and gender influence the psychological outcome during COVID-19 lockdown in caregivers of patients with dementia. Eur. Geriatr. Med. 2020;14:1-4.

40. Phillips D, Paul G, Fahy M, Dowling-Hetherington L, Kroll T, Moloney B, et al. The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. HRB Open Res. 2020;15;3:24.

41. Chan E-Y, Glass G, Chua K-C, Ali N, Lim W-S. Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. J Nutr Health Aging. 2018;22:1238–45.

42. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the Stress Process: An Overview of Concepts and Their Measures. Gerontologist. 1990;30:583-94.

43. Amsalem D, Dixon LB, Neria Y. The Coronavirus Disease 2019 (COVID-19) Outbreak and Mental Health: Current Risks and Recommended Actions. JAMA psychiatry. 2021;78:9–10.

44. Fukase Y, Ichikura K, Murase H, Tagaya H. Depression, risk factors, and coping strategies in the context of social dislocations resulting from the second wave of COVID-19 in Japan. BMC Psychiatry. 2021;21:33.

45. van Wijngaarden E, van der Wedden H, Henning Z, Komen R, The A-M. Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. PLOS ONE. 2018;13.

46. Quinn C, Nelis SM, Martyr A, Morris RG, Victor C, Clare L. Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. Aging Ment Health. 2020;24:1505–13.

47. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver Burden: a clinical review. JAMA. 2014;311:1052.60.

48. Rodakowski J, Skidmore ER, Rogers JC, Schulz R. Role of Social Support in Predicting Caregiver Burden. Arch Phys Med Rehabil. 2012;93:2229-36.

49. Kim B, Noh GO, Kim K. Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. BMC Geriatrics. 2021;21:160.

50. Kang HS, Myung W, Na DL, Kim SY, Lee J-H, Han S-H, et al. Factors Associated with Caregiver Burden in Patients with Alzheimer's Disease. Psychiatry Investig. 2014;11:152–9.

51. Pongan E, Dorey J-M, Borg C, Getenet JC, Bachelet R, Lourioux C, et al. COVID-19: Association Between Increase of Behavioral and Psychological Symptoms of Dementia During Lockdown and Caregivers' Poor Mental Health. J. Alzheimer's Dis. 2021;80:1713–21.

Chapter 4: Help-Seeking in Informal Caregivers of People with Dementia: A Qualitative Study with iSupport as a Case in Point (Study 2)

Anna Messina, Rebecca Amati, Emiliano Albanese and Maddalena Fiordelli

Institute of Public Health, Faculty of Biomedical Sciences, Università della Svizzera Italiana.

Published in International Journal of Environmental Research and Public Health (2022) 19:7504

Abstract

Background: Supportive measures and training interventions can improve the care of people with dementia and reduce the burden on informal caregivers, whose needs remain largely unmet. iSupport is an evidence-based online intervention developed by the World Health Organization to provide support and self-guided education to informal family caregivers of people with dementia. This qualitative study explored barriers and facilitators in the access and use of supportive measures for family caregivers of people with dementia living in Southern Switzerland (Ticino).

Methods: We conducted five focus groups and explored experiences, beliefs, and attitudes toward seeking help (SH), and used thematic analysis to identify key themes.

Results: . Participants (N = 13) reported a general reluctance to SH. We identified four main barriers to SH: high level of burden; sense of duty; fear of being misunderstood by others; and difficulty in reaching information. We also identified facilitators of help seeking behaviors and unveiled the need of caregivers to be assisted by a dementia case manager to facilitate access to support resources.

Conclusions: Local services and interventions should be adapted to caregivers' needs and expectations, with the aim of facilitating the acceptance of, access to, and service integration of existing and future support measures, including iSupport.

Keywords: Informal caregivers, iSupport, Dementia, Help-seeking; Training interventions

Introduction

Most people affected by dementia live at home [1] and are assisted by family members who provide instrumental support in daily living and coordinate professional care delivery. Family caregivers of people with dementia are also defined as “informal caregivers” since they provide non-professional and un-paid care to help a person in long-term need [1]. Informal care is particularly prevalent in countries with a scarcity or lack of formal support services for people with dementia [2]. Being the primary caregiver of a person with dementia exposes informal caregivers to emotional, financial, and physical strain, and promotes the development of symptoms of psychological and physical distress, including depression, anxiety, loneliness, hypertension, and breathing problems [3–6]. Moreover, the care related burden in informal caregivers is positively associated with abusive behaviors, worsening of behavioral symptoms in the care recipients [7,8], and with institutionalization [9].

Multi-component interventions can have broad-ranging benefits in improving informal caregivers’ quality of life, symptoms of anxiety, and depression, and in reducing the care-related burden [10,11]. However, caregiver services and support interventions remain underutilized [12]. Ludecke and colleagues [13] showed that of 59,323 family caregivers who took part in a study involving 6 European countries, only 3% used support services. According to Brodaty [14] the main reasons for the low use of community services for informal caregivers of people with dementia living in Australia included a perceived lack of need of and reluctance in seeking help, despite self-reported high levels of burden and resentment. Other international studies found that high levels of burden, high levels of impairment in the care recipient, the lack of an informal support network, and fear of losing the role of primary caregiver were positively associated with a reluctance to use support services [15,16]. A systematic review aimed at exploring seeking help (SH) intentions and behaviors of family caregivers of people with dementia, reported the following barriers: inadequate knowledge about dementia, strong family norms about responsibility to caretake, stigma and bad experiences with health care services [17]. Most recently, an empirical trial [18] showed that family caregivers’ decision to reject support mainly depended on personal factors (e.g., caregiver gender or time); service factors (e.g., availability and knowledge) and relational factors (e.g., preferences of the care recipient). The authors also reported that a comprehensive assessment of caregivers’ unmet needs increased the rate of users willing to use the services. Overall, despite the growing number of support initiatives for informal caregivers, many barriers to accessing and using interventions and support services for caregivers still exist [14,19,20]. A better understanding of help-seeking behaviors and needs in family caregivers of people with dementia is needed to close the gap between the availability of support measures and their access and use, with potential benefits for the caregiver and the person with dementia [21,22].

iSupport is an online evidence-based program developed by the World health Organizations to provide self-guided education and support to informal caregivers of people with dementia [23]. The program includes problem solving and cognitive behavioral techniques such as psychoeducation, behavioral activation, and relaxation to support caregivers in everyday caring and in preserving their own well-being. More than 30 countries, included Switzerland, are currently involved in iSupport implementation worldwide [12]. Preliminary findings about iSupport are promising. Teles and colleagues [24] highlighted positive results of iSupport regarding caregivers' knowledge in Portugal, while Oliveira [25] reported more positive attitudes towards the person with dementia in caregivers using iSupport in Brazil, compared to those who did not. In Switzerland, iSupport is currently being adapted in the Ticino Canton, the southern Italian speaking part of the country. Before being implemented, the program must be culturally adapted to local settings to ensure it meets the values, preferences and needs of the final users, as reported by WHO guidelines [26]. To the best of our knowledge, iSupport is the first online training intervention dedicated to the informal caregivers of people with dementia in Switzerland and there is no evidence regarding the local caregivers' needs and/or acceptance of support interventions in general. Thus, we decided to use iSupport as case in point to investigate family caregivers' perspectives about support measures and interventions, in order to collect evidence about the acceptance and potential use of support interventions.

As part of the iSupport cultural adaptation process, this qualitative study aimed to explore caregivers' experiences, beliefs, and attitudes towards seeking help of family caregivers of people with dementia living in Ticino Canton. Specifically, we aimed to identify potential barriers and facilitators to the access and use of support measures, in view of adapting iSupport to caregivers' local needs and enhancing its future use.

Materials and methods

Study Desing

We adopted a qualitative descriptive design [27] and used focus group as a data collection method to collect participants' experiences and general attitudes towards support measures and the iSupport program. Focus groups provide insight into context-specific behaviors and beliefs and facilitate the expression of dissent and disclosure of sensitive issues, allowing the emergence of potential barriers and criticalities [28]. Methods and results are reported according to the COREQ checklist for interviews and focus groups [29].

Participants

We used a snowball technique to recruit a convenient sample of family caregivers of people with dementia. Eligibility criteria were: (1) being (at present or in the past) the primary caregiver of a family member with dementia, (2) being fluent in Italian and (3) living in Ticino Canton (southern Switzerland). Between April and May 2021, we designed an invitation letter and a flyer presenting the project, the main purpose of the focus group, eligibility criteria, and contact information. We disseminated these materials in a local newspaper, to members of the iSupport community advisory board, to the local Alzheimer’s association and day care centres for people with dementia, and to participants in ongoing research projects who consented to be informed about further research activities.

Study Procedure

Eligible caregivers interested in participating could contact us either via email or by phone; they then received a detailed presentation of the iSupport project, with examples of contents included in the program. The informed consent was sent via email at least 2 weeks before the data collection. Once we received the signed consent form, the participants were sent an online survey via REDCap (Research Electronic Data Capture) [30,31] to collect sociodemographic characteristics, and information about the degree of kinship with the person with dementia, the living situation of the person with dementia, and the length of experience in caregiving. Between June and August 2021, we conducted five focus groups at the Università della Svizzera Italiana in Lugano (southern Switzerland). Focus groups lasted approximately 2 h (between 110 and 130 min), and were audio recorded. One of the researchers (AM), a PhD student and psychologist with experience in the topic of dementia and caregiving, moderated all the focus groups, with assistance from members of the research team expert in qualitative methods (MF and RA). We adapted and expanded the WHO iSupport adaptation guidelines to our study aim, and we developed a topic guide composed of semi-structured questions. After a general introduction to the topic and an initial round of presentations, the discussion focused on three main areas. In the first part of the discussion we asked participants to express their experiences and attitudes towards support measures and training interventions; in the second part, we invited participants to evaluate the relevance and perceived utility of iSupport contents, and in the last part, we asked participants to provide feedback and suggestions to enhance the use of support interventions, including iSupport. For the purpose of this study, we focused on the first and third areas. The findings related to iSupport specific contents will be discussed elsewhere.

Data Analysis

Discussions were transcribed verbatim and pseudonymised by EB, an independent research assistant. AM, RA, and MF used thematic content analysis to identify key themes in different steps. First, researchers familiarized themselves with the data by reading and re-reading notes and transcripts to get an idea of the overall meaning and started to identify the core topics. Next, each researcher independently identified codes within each focus group (vertical analysis) and across the whole dataset (horizontal analysis) to find variations and regularities within the data. Themes and subthemes were progressively refined through discussion in weekly meetings over three months (from November 2021 to February 2022), and until consensus was reached. Data management and coding processing were facilitated by the use of NVivo12 software. We tracked and stored all researchers’ reflections and decisions that were made throughout the data analysis process on an online shared document, as a basis for a meta-reflection about the inductive process.

Ethical Issues

We received the right to proceed from the Swiss Cantonal ethics committee, since our study did not fall within the scope of Art. 2 and Art. 3 of the law on human research and did not require any ethical approval.

Results

The results are structured as follows. First, we present the socio-demographic characteristics of the participants. Second, we report the overarching themes including the barriers and benefits related to seeking help, stratified by professional and informal forms. of help. Third, we describe the virtuous process between positive support experiences and seeking help behaviours, and a profile of an effective the dementia case manager is created, as defined by participants through discussion. All results are supported by comments, translated verbatim, and marked with a number indicating the participant’s ID and the type of relationship to the person with dementia. Quotations were first translated from Italian to English by a member of the research team (AM) and then revised by an external translator.

Sociodemographic Characteristics

Of the 20 caregivers who contacted us, 13 participants joined the focus group discussions. Reasons for withdrawal were lack of time and geographical distance. Most caregivers were female (N = 10), and their ages ranged from 55 to 82 years. Their care recipient was either a parent (N = 6) or the spouse (N = 7) of the caregiver. More than half of participants (N = 8) reported to have taken care of the person with dementia for at least the past 3 years. At the time of data collection, most caregivers cared for a family member with dementia living at their own residence (N = 8). Two participants reported the person they cared for had passed away.

The number of participants attending each group discussion ranged from 2 to 7 caregivers. Focus groups were attended by 6 caregivers (FG1: 14.06.21); 7 caregivers (FG2: 12.07.21); 2 caregivers (FG3: 15.07.21); 6 caregivers (FG4: 18.08.21), and 2 caregivers (FG5: 24.08.21), respectively. The majority of participants attended more than one group. Table 1 shows the number of focus groups attended and sociodemographic characteristics of the 13 family caregivers who took part to the focus groups.

Table 1: Sociodemographic characteristics of participants

ID	Gender	Age	Employment status	Relationship with the pwd[1]	Living situation of the pwd[1]	Years of caring experience	The pwd[1] has passed away	Focus grou Attended
1	Female	58	Housewife/ Retired	Spouse	Own residence	3-5	No	5
2	Female	55	Housewife/ Retired	Son/daughter	Own residence	3-5	No	1;3;4
3	Female	59	Housewife/ Retired	Spouse	Own residence	3-5	No	1
4	Male	67	Employed	Son/daughter	Own residence	3-5	No	1
5	Female	58	Housewife/ Retired	Spouse	Carer’s residence	1-2	No	2
6	Male	57	Employed	Son/daughter	Own residence	3-5	No	1;4
7	Male	74	Employed	Spouse	N/A	6-10	Yes	1;2
8	Female	55	Employed	Son/daughter	Own residence	3-5	No	2;4
9	Female	75	Housewife/ Retired	Son/daughter	N/A	> 10	Yes	1;2;4;5
10	Female	76	Housewife/ Retired	Spouse	Own residence	3-5	No	2
11	Female	82	Housewife/ Retired	Spouse	Carer’s residence	1-2	No	2
12	Female	55	Employed	Son/daughter	Own residence	1-2	No	3;4
13	Female	81	Housewife/ Retired	Spouse	Carer’s residence	3-5	No	2;4

[1] Person living with dementia. [2] Number of the focus group discussion attended. N/A not applicable.

Barriers in Seeking Help

The main emerging theme from our analysis was a general difficulty in seeking help, defined as “the active process of seeking help” [32]. In most cases, caregivers expressed the need to be supported, but faced barriers that prevented them from actively seeking and accessing both professional and informal forms of support. In our groups, professional or formal help included seeking assistance or advice from health and social care professionals including family doctors, physicians, psychologists, lawyers, and health workers. Informal or non-professional help referred to the process of seeking support at the community level, including family members, close acquaintances, and especially from other caregivers of people with dementia.

Feeling Burdened

For most caregivers (N = 7) the difficulties in balancing caregiving duties with other life and work demands represented a main barrier in seeking help. Specifically, some participants acknowledged that they needed and would benefit from support but highlighted how feeling stressed and overwhelmed prevented them from gathering information about and navigating existing services, and actively accessing and using support services. For instance, one participant used the metaphor of “drowning” to describe the feeling of burden that prevented her from even realizing the need of seeking help:

Look for help . . . sometimes you don't even think about it . . . you're so absorbed, running here and there, and you're so much drowning, you would really need someone there to tell you "come on take a break, hold still, I'll take care of it now" but you (on your own), you don't even get to look for help. (P.5, spouse)

For another participant learning about other family caregivers' experiences led to additional emotional stress:

Sometimes I said to myself, "I've got enough on my plate with my own problem. (P.7, spouse)

As a counterevidence to this, P.12 brought her experience of feeling less burdened a few months after her father's diagnosis; therefore, being willing to share positive and negative emotions with other family caregivers:

At the beginning I felt so bad, I didn't even have the strength to react, and now that I feel better it would be important for me to meet people and share these (experiences) . . . of helplessness, of resignation, of excitement, and to talk about the happy moments. (P.12, daughter)

Sense of Duty

Feeling caregiving as a family and personal responsibility contributed to preventing participants from seeking support elsewhere, especially if the relationship was between children and parents. Fulfilling caring duties alone was a common experience among participants, and was often considered as a personal responsibility, or even a moral obligation. However, one participant pointed out how considering herself as the main and sole caregiver may also lead to isolation and jealousy towards other caregivers:

Many times, I've seen people isolating themselves, craving to be the one and only shouldering the burden…then it becomes some sort of jealousy "no one else is as good as me". (P.9, daughter)

The strong sense of dedication in taking care of the person with dementia was so strongly felt by some participants as to be represented through epic metaphors, where the caregiver described himself as the "hero" and caregiving as a "mission":

But I think I'll know when it comes the time to decide (nursing home admission), and that I don't have to be the hero at all costs. (P.12, daughter)

If you decide to take care of someone, you practically dedicate your whole life to this person . . . you must find the time to tell yourself "I'm going on because this is my mission, and I have to accomplish it" (P.7, spouse)

And yet, P.7 remarked that shouldering caring responsibility alone had benefits regarding self-esteem and pride, and provided with a sense of accomplishment.

Maybe it was also a matter of self-esteem "I have this problem with my wife, and I have to fix it." (P.7, spouse)

Feeling Misunderstood by "Others"

Caring for a person affected by dementia was described, fairly unanimously, as a unique experience. A common belief among participants was that people who did not take care of a loved one living with dementia could not truly understand their needs and experiences. Therefore, caregivers preferred not to seek help and relied on their own resources, as shown in the extract below:

Sometimes it occurred, unhappily, that when I was talking with people which have never experienced such a situation (living with a person affected by dementia), they would unintentionally put me off instead of supporting me, telling me "you have to be patient . . . "they made me feel worse . . . so I decided to give up talking) with other people about it. (P.12, daughter)

Caregivers also reported that externals, either experts, friends, or relatives, tended to minimize the severity of the disease or caregiver's distress. For example, P.9 brought feelings of sorrow and loneliness after having shared her experience with other people:

Sometimes it can be very painful because you feel alone and so laden down . . . besides, other people minimize (your effort) or make comments that only confirm that you are alone and can't rely on anybody to get by. (P.1, spouse)

Difficulty in Attaining Information about Available Services and Support

Most participants reported to feel disoriented or even lost, especially at critical stages of the disease when support in decision making and problem solving were most needed, including after the disclosure of dementia diagnosis, and as symptoms evolved and worsened through the course of the disease. Caregivers looked for different kinds of information, namely assistive domestic aids, financial support measures and medical assistance for the person with dementia. P.5 for instance reported great difficulties in finding a professional domestic helper:

At some stage we needed a person (a formal caregiver) . . . I spent two months searching . . . I even asked a friend of mine who worked in a cleaning company, and

I asked her "listen, do you have someone who is really brilliant?" I was really at the end of the rope. (P.5, spouse)

P.8 needed adapted kitchen appliances for the safety of his father living with dementia, but she could not find an existing, competent provider, and eventually had to find a work around by herself:

(My father) had been turning on the heat and burning everything . . . I asked the electrician, and he didn't even know where to start . . . it took me a week to solve it. (P.8, daughter)

Some participants also highlighted a general lack of integration of, and coordination among local dementia support services that made it cumbersome for them to locate and make good use of relevant information. For instance, P.6 encountered puzzling barriers to access information about available economic support measures for people with dementia and their families:

To know how it works with disability, with the pension fund . . . Honestly, there's a lot of confusion . . . what's more, it's quite difficult to get in touch with them . . . before you get an answer, it goes on for a long time . . . You go here you go there, and nobody knows exactly how it works. (P.6, son)

Similarly, the navigation of existing services proved taxing for most participants. For example, one participant pointed out the disruption of local services, and suggested that a sole entry point, reference service or institution should be available to provide timely and appropriate responses to caregivers, coherently and comprehensively:

This is a great trouble, there is no service you can call or turn to, and that they tell you "Sir, madam, you are entitled to this and that." (P.1, spouse)

Because the dementia diagnosis was somewhat unexpected, and provoked confusion for both caregivers and care recipients, participants expressed the need for a structured, yet tailored approach to the disclosure of a dementia diagnosis, associated with the provision of key information of the main implications of diagnosis, the associated needs, and existing services and organizations, and how to approach them in a timely manner. P.6 perfectly expressed the impact of the diagnosis and the feeling of being "abandoned":

You feel really abandoned because there is no organisation behind it . . . Even because you have to deal with a person who used to do all on his/her own, just a month before or a year before, and now is completely lost. (P.6, son)

Benefits of Seeking Help

Despite the above-mentioned barriers in seeking help, some participants also reported positive support experiences, which differed according to whether they sought professional or non-professional help. Professional help mainly consisted in care provided by family doctors or health care workers. Non-professional help was informal, and it consisted mostly in seeking support from other caregivers in the community through peer-to-peer interactions. These benefits are presented, starting with professional help experiences.

Ensuring the Safety of the Person with Dementia

Participants concurred that one of the main advantages from seeking professional support was the achievement and improvement of the safety for the person with dementia. The decision to seek support from professionals often resulted from a worsening of symptoms in the care recipient and consisted in hiring a domestic worker or asking advice from a specialist or family doctor. For P.3, for example, the main concern was leaving her father alone at home and the risk of domestic accidents:

There is a paid caregiver coming in the morning and in the evening because I can't leave my father alone . . . he can fall . . . he broke his femur at home several times, and I don't feel comfortable to leave him alone . . . but I don't want to put him in a nursing home . . . not yet let's say. (P.3, daughter)

Other participants also emphasized the benefits of therapy and medications for the person with dementia, in a manner perceived as safe and accurate:

Even medicines must be administered by someone external, if necessary, because she (the mother) used to tell me "Yes I took them" then once downstairs you could see she didn't . . . she finds all the excuses, there must be an external person who has the control. (P.8, daughter)

For another participant professional support contributed not only to improved safety, but also to improved quality of life for the person with dementia:

On doctor's advice I found a paid caregiver who visits him four or five hours a week . . . it's nice because they've created a nice relationship . . . she takes him out for a walk or to the lake, they do nice things together, and at the same time she helps him to talk, she brings out many problems . . . it's a nice thing. (P.5, spouse)

Some participants stressed the importance of accessing formal support as early as possible, with respect to the clinical diagnosis of dementia and the onset of even mild symptoms. Timely support from professional caregivers can help to anticipate needs, formulate directives, and plan for mid- and long-term care whilst the care needs of the person with dementia are still relatively limited and manageable. For example, P.6 reported:

The sooner the support arrives, the better . . . I experienced it, and at a certain point you have no chance . . . you must seek help . . . you must provide care that is not only love, but medical, domestic, physiotherapeutic care. (P.6, son)

Relief

Seeking professional support and sharing caregiving duties not only brought benefits to patients, but also led to a feeling of relief for the caregiver. Participants reported how accessing respite measures enabled them to find time and energy for themselves and provided a sense of reassurance, which contributed to reduced anxiety and distress. Respite measures included for example day-care facilities where the person living with dementia can spend time doing a variety of activities while the caregiver may take a break from caregiving duties. P.2 significantly described this as “salvation”:

My mum went to a day care centre, and she has been there for seven or eight years now . . . they also involved her in the cooking . . . Fortunately there was that salvation twice a week . . . otherwise things are too long to be maintained. (P.2, daughter)

However, for other participants, relief was actually perceived only after admission to a long-term care facility. Despite some initial reluctance about institutionalization, caregivers reported that institutionalization contributed significantly to feeling released and “cared for”:

This (admission to a nursing home) was good for her, and good for me as well because I felt cared for, and this is a great support . . . it helps to feel helped by someone. (P.7, spouse)

According to P.9, sharing care responsibilities and accessing support measures also helped her to resize her role as caregiver and to see the disease itself in a more manageable way:

If you use all the supporting measures that exist, I wouldn’t say that the problem becomes small but . . . after all they are experts in this. (P.9, daughter)

Free to Speak

The interaction between caregivers as a form of reciprocal informal support provided the opportunity to express feelings and worries and to share thoughts about the caregiving experience without being judged. Differently from external supporters, such as relatives or friends, other informal caregivers were perceived as more understanding and empathic because they shared the same caregiving experiences and faced similar or even identical issues and personal concerns:

If you have never experienced caregiving, you judge . . . but if you have been through it, you won’t judge. (P.12, daughter)

For P.9 sharing the common experience of caring for a person with dementia also facilitated the expression of the challenges and negative emotions that the caregiver may feel towards the care recipient, including anger and guilt:

You realize that also other people have similar feelings . . . because you feel guilty when you go crazy, and you feel bad . . . you know it is wrong because you don’t do *it on purpose, but you realize that also the others (caregivers) do it (to get angry) . . . people understand you because they are experiencing the same situation . . . when people who don't live this tell you "yes I understand" I am convinced they can only partially understand (P.9, daughter)*

Sense of Belonging

The freedom to share both positive and negative aspects of caregiving in a nonjudgmental environment, also generated a sense of belonging to a group. Caregivers reported to feel less lonely and stressed after having interactions with peers. According to P.12, interactions with peers provided unsought opportunities to appreciate serious situations and problems to which they could compare their owns:

I'm surprised people don't join help groups . . . because there you realise that you're facing difficulties but hearing other people talking about more serious situations . . . you go home and you have recharged your batteries a bit. (P.12, daughter)

For P.2 the level of intimacy experienced with other caregivers, turned the self-help group in a group of friends with whom they could share not only caregiving experiences, but also other matters, and with whom they could enjoy some free personal time:

You realise you are not alone . . . other people have the same problems you have and talking about that helps you . . . you realise some reactions you have are shared by other people, and this reassures you a bit . . . it heartens you. Moreover, we hang out together and we became almost friends, we meet for a drink, and we cry, we laugh. (P.2, daughter)

Problem Solving

Different from professional help-seeking, sharing and listening to family caregivers' experiences fulfilled the need for emotional support and nurtured a sense of belonging to a group. Participants also reported problem solving as an additional benefit from informal help-seeking. Peers provided practical forms of support, such as help in gathering information or making decisions concerning the person with dementia based on their lived experiences. Moreover, for some participants, the interaction with other family caregivers satisfied their personal need to confirm that they were taking care of their loved one in an appropriate manner and highlighted potential improvements, as reported by P.2:

You get together with people who have the same problems . . . because you don't know if you are doing something wrong . . . you don't know anything, and personally it really helped me because there is an exchange even in simple things, in everyday practical things, and we feel part of it. (P.2, daughter)

In addition, interacting with "experienced" informal caregivers also helped participants to learn strategies and ways of coping with every-day challenges, turning the interaction into a mutual learning process. In this regard, speaking of the reason she joined the focus groups, P.1 said:

We must address people who give us help and support, and who have more experience, that is . . . I answered the question "why did you decide to participate?" like this: to be informed and to learn from those who are at an advanced stage in this experience. (P.1, spouse)

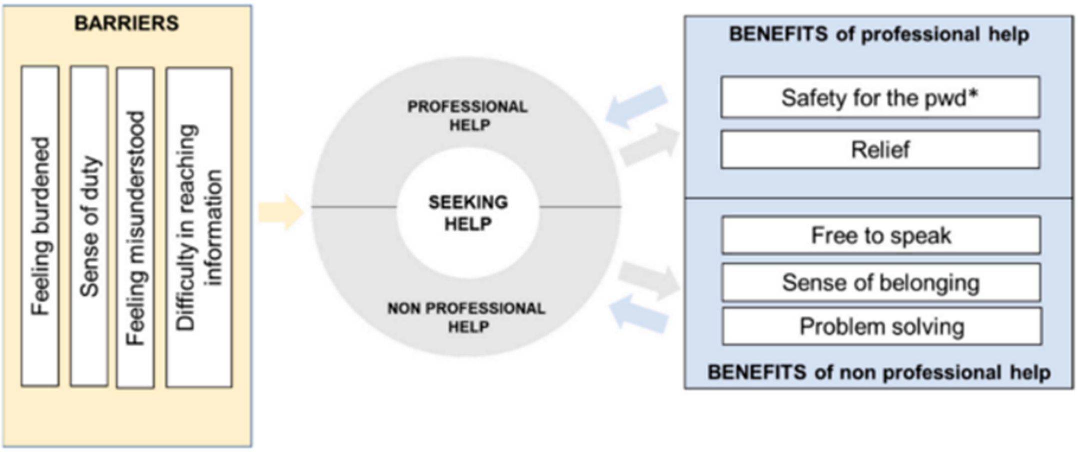
Sometimes, participants even attributed more knowledge, expertise, and availability too peers than to professionals who worked in the field of dementia. For instance, P.6 reported:

These family members all together know much more (than the experts), and are also more willing to talk . . . you see the doctor for five minutes and then you go . . . (P.6, son)

The Virtuous Cycle of Seeking Help

Despite the difficulty experienced in seeking help for the first time, caregivers reported how experiencing the benefits mentioned above from both professional and nonprofessional support, helped change their initial help-seeking attitudes and facilitated the maintenance of help-seeking behaviors over time (Figure 1).

Figure 1: The virtuous cycle of seeking help. *person with dementia



P.2 provided an accurate account of her initial skepticism about joining a self-help group with other family caregivers and how then she changed her mind:

Concerning the self-help group, I came to know about it through my sister who proposed it to me . . . honestly, I told her "but yes . . . I mean, it won't do any good" . . . I was very sceptical, and then I realised that it was really useful in our case . . . we have been participating regularly for two years now. (P.2, daughter)

Some caregivers reported the importance of seeking help from a professional who was not only expert in the field of dementia, but who was also in touch with people living with dementia. This probably helped them to overcome the fear of being misunderstood by others and to start seeking support, as shown in the extract below: *I heard that there was also a psychologist, so I approached her, and I thought it could be useful . . . but I didn't want a psychologist, let's say a generic one, I wanted someone who worked with patients . . . so they gave me a name, and now I see her once a month to talk. (P.1, spouse)*

The access and repeated use of professional care services also depended on the benefits experienced, not only by the caregiver, but also by the person living with dementia. For instance, P.8 brought the experience of her mother who attended supported holidays for people living with dementia:

We've always sent her on assisted holiday both to the seaside and in the mountains . . . they go every year to get to know each other . . . she enjoyed it a lot because they took her on trips, and even now she's looking forward to go to the mountains, and then afterwards she'll be waiting for the Christmas party . . . there will be always something to wait for . . . (P.8, daughter)

The Dementia Case Manager

Participants often referred to different needs pointing to a possible solution to overcome barriers in help-seeking behaviors, in particular the provision of a reference person to help them navigate dementia care services and manage caring duties. Caregivers identified three main features that this putative dementia case manager should have and that pertained both to professional and non-professional forms of help: knowledge of the family and caring situation, knowledge of local resources and services for dementia, and long-term availability (Figure 2).

Figure 2: Profile of the dementia case manager

Knowledge of the Family and Caring Situation

According to caregivers, a dementia care manager should be reliable, expert in the field of dementia, but also familiar with the person with dementia and their needs, resembling an “extended” member of the family. Knowledge of the caring context and contact with the person living with dementia were essential requirements for caregivers to receive tailored and need-centered support, as reported by P.8:

It is essential to rely on someone . . . a person you can count on . . . if he’s not part of the family he may be external, but someone you can really count on . . . not a doctor . . . someone who follows you as well as the person you take care of. (P.8, daughter)

Knowledge of Local Resources

Caregivers reported the need to address someone who knows what local resources are available for people dementia and to advise on which of these may be most suitable for them. Some participants stressed the importance of being able to refer to a single person, as a means of continuity of care and to find information and solutions for the person they cared for through all phases of the disease, promoting integration and coordination of care:

He should come from outside . . . we need the experience of someone who gathers all the available resources, and puts them in a network. (P.6, son)

Long Term Availability

Participants pointed out that support should be provided not only at the beginning, but throughout all phases of the disease, to help the caregiver to make decisions at different stages of the caregiving journey. Rather than a consultation from time to time, caregivers reported the need for continuous support and guidance, as expressed in the extract below:

I believe that a common thread is missing . . . someone who can stay there from the beginning to the end with advice, who knows how things work . . . But here there is no one at all, that's why there is confusion. (P.5, spouse)

Long term availability and contact with the person with dementia and his family are the elements that most distinguished the profile of the dementia case manager from other health professionals, as expressed by P.8:

We would need someone who also knows mum and sees how she is, and what she needs in different moments . . . yes, the doctor . . . they are all very nice . . . the geriatrician maybe takes a bit more time, but he visits her for an hour every six months . . . we would need a contact person who can discuss with us, the relatives, who sees how she goes on . . . who is also there for us to solve practical problems. (P.8, daughter)

More specifically, P.6 compared the role of a "dementia case manager" to that of an "architect". This suggests the need of having a professional who builds individual health-care plans based on the necessities of the person with dementia and his caregivers:

There is not even a professional figure . . . if I have to build a house I go get an architect. (P.6, son)

According to P.1, besides providing support in the organization and coordination of care, a dementia care manager may also contribute to reduce feelings of burden, uncertainty and loneliness, by "holding hands with" the caregiver throughout the progression of the disease:

There are people who feel insecure and overwhelmed because of the terrible reactions the person with dementia may have . . . you must get used to it, but you don't have so much energy because you are already busy to manage it . . . I am sorry because "to manage" is not a nice expression, but I didn't find another one because you can't say "assist" . . . you really have to "manage it" . . . So, his role should be taking them (the caregivers) by the hand and showing what in that specific moment and for that specific situation can help. (P.1, spouse)

Discussion

In this study we explored the experiences, beliefs, and attitudes towards seeking help in family caregivers of people with dementia living in southern Switzerland (Ticino). We found a general reluctance for seeking help, despite reported feeling of burden and stress due to caregiving demands. High levels of burden, fulfilling a sense of duty, feeling misunderstood by others, and difficulty in reaching information about available services were the main barriers to seeking both professional and non-professional forms of support. Caregivers also reported some benefits from support experiences including safety for the person living with dementia, emotional relief, a sense of belonging, and the freedom to speak about personal experiences in peer-to-peer interactions. Participants reported the need to refer to a dementia case manager who knows the person with dementia, their situations and needs, and who can provide caregivers with continuous support, guidance, and assistance to navigate and facilitate access to local services.

Barriers and Benefits to Seeking Help

Overall, our results are consistent with previous studies that found a general reluctance from informal caregivers of people with dementia to seeking help [11,13]. Similar to the work of Zwigmann and colleagues [18], we found that the decision to reject different forms of support depended either on personal (burden), cultural (sense of duty), relational (feeling misunderstood by others), and environmental (difficulty in reaching information) factors. In our study, high levels of burden hindered caregivers from actively seeking support. A recent work aimed at examining the relationship between perceived help-seeking difficulty and burden found positive associations between caregiver self-criticism and seeking help, but not with burden [33]. Conversely, a review showed that high levels of burden and poor health were not only associated with a reluctance to use support services, but also with a poor knowledge of the services available for caregivers [11]. Contrary to common thinking that help-seeking is primarily dictated by need, there are, in fact, complex processes that involve different and sequential steps of decision making, starting with the recognition of needing help in the first place [34]. The feeling of being overwhelmed and "drowning" (as described by one of our participants) in a usually unexpected role, may prevent caregivers from realizing the need to be supported.

Some participants in our study remarked that providing care to a family member with dementia is a moral responsibility, or a duty. The influence of cultural values and family norms on help-seeking behaviors is quite well established in the literature, and varies across countries [35,36]. A recent qualitative study [37] found that Chinese cultural belief of filial piety, the filial obligation to provide for and look after elderly parents, played a main role in coping strategies adopted by family caregivers of people with dementia. Partially consistent with our results, authors found that although it prevented them from from seeking support outside the family, filial piety motivated caregivers to accept their caring role and to adjust themselves to daily caring duties.

Indeed, besides contributing to isolation, participants in our study remarked how shouldering caring responsibility provided caregivers with a sense of accomplishment and pride. However, even if dedication and responsibility may enhance acceptance and motivation to provide care, there is also evidence that caregivers motivated by a sense of duty, guilt or social norms are more likely to progressively isolate themselves and suffer from psychological distress [38].

Another barrier we found to help-seeking was the feeling of being misunderstood by others, especially relatives or friends. Previous studies found that family caregivers who minimized or denied dementia symptoms [39], or experienced stigma [40], were less prone to seek help. However, there is no evidence regarding how social denial or minimization influence help-seeking behaviors. Our findings highlight the importance of attitudes towards dementia and caregiving of people not directly implicated in care provision and may have potential implications to ameliorate dementia awareness and prevention.

Finally, caregivers reported general difficulties in reaching information preventing them from accessing support when needed. This finding is consistent with the adapted Health Behavioral Model for family dementia caregivers [18,41] that defines availability and accessibility of services as essential facilitators of help-seeking behaviors in caregivers. Similarly, a recent study [33] found that difficulties in help seeking were largely related to the caregivers' perception of services as complex and somewhat abstruse and, thus, inaccessible. Our results confirm the importance of providing not only useful support resources, but also clear, comprehensive, and structured information on how to reach, access, and navigate these resources efficiently and effectively.

In addition to barriers, participants also reported benefits from positive support experiences. More specifically, seeking professional support, mainly consisting of consulting a doctor, hiring a formal caregiver, or accessing health-care facilities, contributed to instill a sense of increased safety for the person living with dementia and a feeling of emotional relief for caregivers. There is increasing attention being given to barriers and facilitators associated with seeking help behaviors [17,33], but evidence is thin on the benefits experienced by family caregivers who access and use support programs and measures. A qualitative study explored the perspective of family caregivers, and their beliefs and motivations to use respite services, and found that the safety of the care recipient was a primary reason to use services, but only in case of functional deficits [42]. Similarly, a cross-cultural study reported that reasons for using support services included worsening in the condition of the person with dementia and the services' ability to meet his needs [43]. Our results confirm that support conveys respite and relief to caregivers, but also suggest that caregivers may only reluctantly admit seeking help for themselves rather than for the person they care for [44]. Participants also reported benefits from reciprocal informal support, namely from interactions with other family caregivers. The opportunity to speak about personal concerns without being judged, and the sense of belonging to a group were among the main advantages reported by caregivers. In accordance with the expectation of being misunderstood by others, this finding remarks on the importance for participants to sharing their personal experiences with other family caregivers. Peers' interactions nurtured the sense of belonging to a group whose members were considered trustful and non-judgmental. According to social psychology theories, sharing a common fate shapes a group's identity, and delineates its boundaries [45].

Peer-to-peer interactions also provided opportunities to learn new coping strategies to deal with practical caring problems. Caregivers reported that peer learning helped them to develop a better confidence in their role and satisfied their need for confirmation. Indeed, low levels in self-efficacy were found to facilitate seeking help behaviors [39].

The Virtuous Cycle of Seeking Help

Even though our study identified several barriers that prevented informal caregivers from seeking support, we also unveiled benefits of professional and non-professional support experiences, which facilitated the maintenance of help-seeking behaviors over time, triggering a virtuous cycle of seeking help. Different theoretical models posit the existence of three main dimensions in help-seeking: attitudes and beliefs, intentions or willingness, and actual behavior [17]. Among these, an extended version of Andersen's Health Behavioral Model [41,46] identified four relevant dimensions for the use and non-use of services from family caregivers of people with dementia: service factors (e.g., availability, accessibility, and cost); personal factors (e.g., health belief, needs); experiential factors (e.g., caregiver burden, clinical characteristics of the person with dementia); and relational factors (e.g., relationship with the care recipient). Our results may expand the evidence on the importance that past positive support experiences have in maintaining help-seeking behaviors and overcoming potential barriers, specifically through the change of negative attitudes and beliefs.

The Dementia Case Manager

Caregivers also expressed the need of being supported throughout the progression of the disease by someone who had expertise, but also knowledge of the family context and of local resources, namely a “dementia case manager”. According to participants, the dementia case manager may mediate between caregivers' specific needs and support services, by “holding hands” with the caregiver through their caregiving journey. In public health, the implementation of case managers is a recognized means to promote an integrated and person-centered care approach [47]. Instances of application exist for diabetes and other non-communicable diseases, in which care needs and treatment require both self-care and long-term interaction with health and social care providers and services [48,49]. Preliminary evidence suggests that dementia case managers should have a professional background (nursing or social work) and interpersonal skills. The perceived benefits of case managers included the expected provision of practical and emotional support and facilitating access to health and social care services [50]. A recent review [51] found that, if in collaboration with family physicians and health care services, case managers can have a pivotal role in addressing the needs of patients and their informal caregivers. Nonetheless, despite promising results, case management interventions are rarely implemented, particularly in North America and Europe [51] or systematically evaluated [52]. Our results suggest the potential benefits of integrating dementia case management into the care pathways for people with dementia and their informal caregivers in Ticino Canton.

Implications for the Context and iSupport

Southern Switzerland (Ticino) has a health policy and legislation that aim to keep dependent older adults at home for as long as possible, offering financial support to informal caregivers to provide homecare [53,54]. In line with the national guidelines [55], in 2016, the government released a dementia strategy plan to improve the quality of life of people with dementia and their caregivers. Action areas include the improvement of dementia awareness and the extension and integration of care-paths for people with dementia and support resources and services for caregivers [56]. Caregivers can rely on different forms of support (i.e., local homecare service providers, respite services, and mutual support groups). However, resources are still poorly integrated, difficult to access, and underused.

We identified several barriers that deter family caregivers from seeking help and support. Our results can inform the re-centering of supporting measures on family caregivers' needs, values, and preferences, and can contribute to improve the accessibility, acceptability, integration and, where needed, the development, and implementation of interventions including iSupport. Indeed, we found that, independent from the nature and contents of iSupport, caregivers expressed reluctance in using and assessing support interventions.

We believe that considering caregivers help-seeking behaviours and experiences as part of the iSupport cultural adaptation process is crucial to enhance its use and acceptability. For instance, caregivers reported to having a personal and moral duty towards the loved one for whom they provide dementia care. Therefore, iSupport should aim to integrate the care provided by caregivers rather than replace it, acknowledging the pivotal role of informal caregivers. Further, if we consider caregivers difficulty in navigating information about support services, we may ensure that iSupport becomes not only a place to exchange knowledge about dementia, but also a vehicle to acknowledge and access other forms of support and facilities. Additionally, the numerous benefits reported by participants from peer-to-peer interactions, such as the chance to speak freely, the sense of belonging and problem solving, suggest the importance for caregivers to share experiences with other informal caregivers. iSupport may address this need by integrating more interactive functions, such as chats or forum sessions where participants can engage not only with exercises but with other participants. Lastly, the reference to a dementia case manager and its features (knowledge of the caring situation; knowledge of local resources and services for dementia; long term availability) suggested to us the importance that this role may have in supporting family caregivers in being informed in using iSupport. Hence, the involvement of both formal and informal caregivers in iSupport's adaptation and implementation process seems to be crucial to overcome acceptance and usability barriers. All these considerations apply to how iSupport is locally adapted and implemented, fulfilling its promise to meet informal caregivers needs, and to become a commonly and widely used resource, with local salience and pertinence.

Limitations

Some limitations are worth noting. First, our findings are limited to a small sample size and may be extended to other contexts only in part. The discrepancy in group size across focus group discussions, and the attendance of participants in more than one group, may have contributed to rapidly reach data saturation. However, group compositions varied within groups, and we found that this contributed to reduce other biases such as the social desirability effect. Second, our research focused on a narrow and specific cultural and health care setting in Switzerland, and family caregivers were not very heterogeneous in terms of gender, nationality, age, and living situation. However, we decided to use qualitative methods to elicit and explore in depth the nature of barriers in accepting and using iSupport at the local level. Similar approaches are warranted in all settings and contexts where iSupport is being implemented. Moreover, our results were highly consistent with previous evidence on caregiving experiences. This suggests that other family caregivers' needs may be similarly unmet, and analogous barriers may exist in other contexts. Third, we did not consider important factors that may have influenced help-seeking attitudes and experiences during data collection, such as the severity of symptoms of the person with dementia or the access to support services. However, we did not aim to identify potential causes and facilitators to seeking help behaviors, but rather to give voice to caregivers' lived experiences and needs. Lastly, we explored seeking support as the general process of actively seeking help, without distinguishing between the single stages included in the process (e.g.,: awareness and identification of the need; procurement of resources; and communication with others) or between the specific type of help sought (e.g., seeking professional consultation; use of respite service; access to psychosocial interventions) [17]. However, in the process of data analysis, we differentiated between professional and nonprofessional help to reveal the differences experienced by participants in terms of benefits, while this distinction was not required for the barriers.

In summary, this study provides a novel contextualized understanding of needs, beliefs, and barriers in help seeking behaviors of family caregivers of people with dementia in Switzerland, which should be considered when developing and implementing support measures, including locally adapted versions of iSupport.

Conclusions

In this study, we found that informal family caregivers of people with dementia living in southern Switzerland were reluctant in seeking help, and that several barriers exist that may deter the access and use of support measures and interventions, including iSupport. We also found evidence that positive support experiences reinforce the maintenance of help seeking behaviors over time. Local policies and dementia services should be adapted to account for the perspectives, values, preferences, and actual needs and expectations of caregivers, with the aim of facilitating the acceptance, access, and integration of existing and future support measures, including iSupport.

Author Contributions: Conceptualization, M.F., R.A. and A.M.; methodology, M.F. and R.A.; formal analysis, M.F., R.A. and A.M.; investigation, A.M.; data curation, A.M.; writing—original draft preparation, A.M.; writing—review and editing, M.F., R.A. and E.A.; supervision, M.F. and E.A. All authors have read and agreed to the published version of the manuscript.

References

1. Alzheimer's Disease International. *Global estimates of informal care;* Alzheimer's Disease International: London, 2018.

2. Health Organization, W. *Global Action Plan on the Public Health Response to Dementia 2017-2025;* The World Health Organization: Geneva, 2017.

3. Schulz, R.; Martire, L.M. Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *Am. J. Geriatr. Psychiatry* **2004**, *12*, 240–249.

4. Pinquart, M.; Sörensen, S. Differences between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis. *Psychol Aging* **2003**, *18*, 250–267.

5. Kovaleva, M.; Spangler, S.; Clevenger, C.; Hepburn, K. Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. *J Psychosoc Nurs Ment Health Serv.* **2018**, *56,* 1–8.

6. Gilhooly, K.J.; Gilhooly, M.L.M.; Sullivan, M.P.; McIntyre, A.; Wilson, L.; Harding, E.; Woodbridge, R.; Crutch, S. A Meta-Review of Stress, Coping and Interventions in Dementia and Dementia Caregiving. *BMC Geriatr.* **2016**, *16*.

7. Gimeno, I.; Val, S.; Jesús, M.; Moreno, C.; Mora, M.G.; Pérez-Jover, V.; Carrillo Murcia, I. Relation among Caregivers' Burden, Abuse and Behavioural Disorder in People with Dementia. *J. Environ. Res. Public Health* **2021**, *18*, 1263.

8. Cooper, C.; Selwood, A.; Blanchard, M.; Walker, Z.; Blizard, R.; Livingston, G. The Determinants of Family Carers' Abusive Behaviour to People with Dementia: Results of the CARD Study. *J. Affect. Disord.* **2010**, *121*, 136–142.

9. Kurasawa, S.; Yoshimasu, K.; Washio, M.; Fukumoto, J.; Takemura, S.; Yokoi, K.; Arai, Y.; Miyashita, K. Factors Influencing Caregivers' Burden among Family Caregivers and Institutionalization of in-Home Elderly People Cared for by Family Caregivers. *Environ Health Prev Med* **2012,** *17,* 474-483.

10. Pusey, H.; Richards, D. A Systematic Review of the Effectiveness of Psychosocial Interventions for Carers of People with Dementia. *Aging Ment Healt* **2001**, *5*, 107–119.

11. Brodaty, H.; Green, A.; Sc Hons, B.; Koschera, A. Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *JAGS* **2003**, *51,* 657-664.

12. Health Organization, W. *Global Status Report on the Public Health Response to Dementia*. Geneva, 2021.

13. Lüdecke, D.; Mnich, E. The Impact of Sociodemographic Factors on the Utilisation of Support Services for Family Caregivers of Elderly Dependents-Results from the German Sample of the EUROFAMCARE Study. *GMS Psycho-Social-Medicine* **2012**, *9*.

14. Brodaty, H.; Thomson, C.; Thompson, C.; Fine, M. Why Caregivers of People with Dementia and Memory Loss Don't Use Services. *Int. J. Geriatr. Psychiatry* **2005**, *20*, 537–546.

15. Brody, E.M.; Saperstein, A.R.; Lawton, M.P. A Multi-Service Respite Program for Caregivers of Alzheimer's Patients. *J Gerontol Soc Work.* **1989**, *14*, 41–74.

16. Collins, C.; Stommel, M.; Given, C.W.; King, S. Knowledge and Use of Community Services among Family Caregivers of Alzheimer's Disease Patients. *Arch Psychiatr Nurs.* **1991**, *5*, 84–90.

17. Werner, P.; Goldstein, D.; Karpas, D.S.; Chan, L.; Rsw, C.K.; Lai, C. Help-Seeking for Dementia A Systematic Review of the Literature. *Alzheimer Dis Assoc Disord* **2014**, *28*.

18. Zwingmann, I.; Dreier-Wolfgramm, A.; Esser, A.; Wucherer, D.; Thyrian, J.R.; Eichler, T.; Kaczynski, A.; Monsees, J.; Keller, A.; Hertel, J.; et al. Why Do Family Dementia Caregivers Reject Caregiver Support Services? Analyzing Types of Rejection and Associated Health-Impairments in a Cluster-Randomized Controlled Intervention Trial. *BMC Health Serv. Res.* **2020**, *20*, 121.

19. Stephan, A.; Bieber, A.; Hopper, L.; Joyce, R.; Irving, K.; Zanetti, O.; Portolani, E.; Kerpershoek, L.; Verhey, F.; de Vugt, M.; et al. Barriers and Facilitators to the Access to and Use of Formal Dementia Care: Findings of a Focus Group Study with People with Dementia, Informal Carers and Health and Social Care Professionals in Eight European Countries. BMC Geriatr. 2018, 18, 131.
20. Weber, S.R.; Pirraglia, P.A.; Kunik, M.E. Use of Services by Community-Dwelling Patients With Dementia: A Systematic Review. *Am J Alzheimers Dis Other Demen.* **2011**, *26,* 195-204.

21. Martin, A.; O'connor, S.; Jackson, C. A Scoping Review of Gaps and Priorities in Dementia Care in Europe. *Dementia* **2020**, *19*, 2135–2151.

22. Gagliardi, A.R. Tailoring Interventions: Examining the Evidence and Identifying Gaps. *J Contin Educ Health Prof.* **2011**, *31*, 276–282.

23. Pot, A.M.; Gallagher-Thompson, D.; Xiao, L.; Willemse, B.; Rosier, I.; M. Mehta, K.; Zandi, D.; Tarun, D. ISupport: A WHO Global Online Intervention for Informal Caregivers of People with Dementia. *World Psychiatry* **2019**, *18*, 3.

24. World Health Organization ISupport for Dementia. Available online: https://www.who.int/publications/i/item/9789241515863 (accessed on 13.05.2022).

25. Teles, S.; Ferreira, A.; Paúl, C. Feasibility of an Online Training and Support Program for Dementia Carers: Results from a Mixed-Methods Pilot Randomized Controlled Trial. *BMC Geriatr.* **2022**, *22*, 173.

26. Oliveira, D.; Jacinto, A.F.; Gratao, A.C.M.; Ottaviani, A.C.; Ferreira, C.R.; Monteiro, D.Q.; Barham, E.J.; Orlandi, F. de S.; de Cruz, K.C.T.; Correa, L.; et al. Translation and Cultural Adaptation of ISupport in Brazil. *Alzheimer's & Dement.* **2020**, *16*.

27. Holly, C.; Bugel, M.J.; Scuderi, D.; Estrada, R.P.; Harvey, J.; Echevarria, M.; Giuliante, M.M.; Antonio, A.S.; Duncan, K.A.; Shuler, J.B.; et al. Qualitative Descriptive Research in *Scholarly Inquiry and the DNP Capstone*; Springer Publishing Company: New York, 2014 pp. 69–82.

28. Green, J.; Thorogood, N. *Qualitative Methods for Health Research,* 4th ed.; Sage Publications Ltd, 2018.

29. Harris P.A; Taylor R; Thielke R.; Payne J.; Gonzalez N.; Conde J.G Research Electronic Data Capture (REDCap)--a Metadata-Driven Methodology and Workflow Process for Providing Translational Research Informatics Support. *Journal of Biomedical Informatics* **2009**, *42*, 377–381.

30. Harris, P.A.; Taylor, R.; Minor B.L The REDCap Consortium: Building an International Community of Software Platform Partners. *J. Biomed. Inform.* **2019**, *95*.

31. Rickwood, D.; Thomas, K. Psychology Research and Behavior Management Conceptual Measurement Framework for Help-Seeking for Mental Health Problems. *Psychol. Res. Behav. Manag.* **2012**, *5*, 173–183.

32. Ng, C.K.M.; Leung, D.K.Y.; Cai, X.; Wong, G.H.Y. Perceived Help-Seeking Difficulty, Barriers, Delay, and Burden in Carers of People with Suspected Dementia. *Int. J. Environ. Res. Public Health* **2021**, *18*, 1–11.

33. Picco, L.; Abdin, E.; Pang, S.; Vaingankar, J.A.; Jeyagurunathan, A.; Chong, S.A.; Subramaniam, M. Association between Recognition and Help-Seeking Preferences and Stigma towards People with Mental Illness. *Epidemiol. Psychiatr. Sci.* **2016**, *27.* 84-93.

34. Kane, M.N. Ethnoculturally-Sensitive Practice and Alzheimer's Disease. *Am J Alzheimers Dis Other Demen.* **2000,** *15.*

35. Kim, S.; Mortby, M. Dementia-Related Stigma, Cultural Diversity, and Help Seeking Intentions. *Innov. Aging* **2017**, *1*, 693.

36. Xiuxiang, Z.; Zhang, X.; Hockley, J. A Qualitative Study of Family Caregivers' Coping Strategies of Looking after People with Dementia in China. *JRN* **2020**, *25*, 636–649.

37. Brodaty, H.; Henry Brodaty, A.; Donkin, M. Who Are Informal Caregivers? Family Caregivers of People with Dementia. *Dialogues Clin Neurosci.* **2009**, *11,* 217-228.

38. Parker, M.; Barlow, S.; Hoe, J.; Aitken, L. Persistent Barriers and Facilitators to Seeking Help for a Dementia Diagnosis: A Systematic Review of 30 Years of the Perspectives of Carers and People with Dementia. *Int Psychogeriatr* **2020**, *32*, 611–634.

39. Su, J.-A.; Chang, C.-C. Association Between Family Caregiver Burden and Affiliate Stigma in the Families of People with Dementia. *Int. J. Environ. Res. Public Health* **2020**, *17*, 2772.

41. Andersen, R.M. Revisiting the Behavioral Model and Access to Medical Care: Does It Matter? *J Health Soc Behav* **1995**, *36*, 1–10.
42. Phillipson, L.; Jones, S.C. Between the Devil and the Deep Blue Sea: The Beliefs of Caregivers of People With Dementia Regarding the Use of In-Home Respite Services. *Home Health Care Serv.* **Q. 2011**, *30*, 43-62.

42. Jelley, H.; Kerpershoek, L.; Verhey, F.; Wolfs, C.; de Vugt, M.; Bieber, A.; Stephan, A.; Meyer, G.; Michelet, M.; Selbaek, G.; et al. Carers' Experiences of Timely Access to and Use of Dementia Care Services in Eight European Countries. *Ageing Soc.* **2021**, *41*, 403–420.

43. Queluz, F.N.F.R.; Kervin, E.; Wozney, L.; Fancey, P.; Mcgrath, P.J.; Keefe, J. Understanding the Needs of Caregivers of Persons with Dementia: A Scoping Review. *Int. Psychogeriatr* **2020**, *32*, 35–52.

44. Lewin, K. *Resolving Social Conflicts; Selected Papers on Group Dynamics*; Harper, 1948.

45. Mast, B.T. Bringing Person-Centered Care to People with Early-Stage Alzheimer's. *Generations* **2013**, *37*, 63–65.

46. World Health Organization Integrated Care for Older People (ICOPE): Guidance for Person-Centred Assessment and Pathways in Primary Care. Available online: https://apps.who.int/iris/handle/10665/326843 (accessed on 13.05.2022)

47. Monaco, A.; Palmer, K.; Marengoni, A.; Maggi, S.; Hassan, T.A.; Donde, S. Integrated Care for the Management of Ageing-Related Non-Communicable Diseases: Current Gaps and Future Directions. *Aging Clin Exp Res* **2020**, *32*, 1353–1358.

48. Drincic, A.; Pfeffer, E.; Luo, J.; Goldner, W.S. The Effect of Diabetes Case Management and Diabetes Resource Nurse Program on Readmissions of Patients with Diabetes Mellitus. *J. Clin. Transl. Endocrinol* **2017**, *8*, 29–34.

49. Iliffe, S.; Wilcock, J.; Drennan, V.; Goodman, C.; Griffin, M.; Knapp, M.; Lowery, D.; Manthorpe, J.; Rait, G.; Warner, J. Changing Practice in Dementia Care in the Community: Developing and Testing Evidence-Based Interventions, from Timely Diagnosis to End of Life (EVIDEM). *Programme Grants Appl Res* **2015**, *3*.

50. Khassanov, V.; Vedel, I. Family Physician-Case Manager Collaboration and Needs of Patients With Dementia and Their Caregivers: A Systematic Mixed Studies Review. *Ann Fam Med* **2016**, *14*, 166–177.

51. Koch, T.; Iliffe, S.; Manthorpe, J.; Stephens, B.; Fox, C.; Robinson, L.; Livingston, G.; Coulton, S.; Knapp, M.; Chew-Graham, C.; et al. The Potential of Case Management for People with Dementia: A Commentary. *Int J Geriatr Psychiatry* **2012**, *27*.

52. Dutoit, L.; Füglister-Dousse, S.; Pellegrini, S. *Soins de Longue Durée Dans Les Cantons: Un Même Défi, Différentes Solutions*; 2006.

53. Legge Sull’assistenza e Cura a Domicilio (LACD). Available online: https://m3.ti.ch/CAN/RLeggi/public/index.php/raccolta-leggi/pdfatto/atto/364 (accessed on 13.05.2022)

54. Strategia Nazionale Sulla Demenza 2014-2019. Available online: https://www.bag.admin.ch/bag/it/home/strategie-und-politik/nationale-gesundheitsstrategien/demenz/nationale-demenzstrategie.html (accessed on 13.05.2022)

55. Strategia Cantonale Sulle Demenze. Available online: https://www4.ti.ch/dss/dsp/umc/cosa-facciamo/progetti/strategia-cantonale-sulle-demenze/ (accessed on 13.05.2022)

56. Alzheimer’s Disease International. *World Alzheimer Report 2019: Attitudes to Dementia;* Alzheimer’s Disease International, 2019.

Chapter 5: Participatory methods in designing digital health interventions for informal caregivers of people with dementia. A systematic review (Study 3)

Anna Messina, Anna Maria Annoni, Rebecca Amati, Beatrice Bano, Giovanni Franscella, Emiliano Albanese and Maddalena Fiordelli

Institute of Public Health, Faculty of Biomedical Sciences, Università della Svizzera Italiana.

Submitted to Internet interventions (2023)

Abstract

Background: The growing use of technology in healthcare has contributed to the development of digital interventions for informal caregivers of people living with dementia. However, the marked heterogeneity of interventions poses challenges in evaluating their effectiveness. We conducted a review to delineate the distinctive features and development of the interventions, with focus on participatory methods.

Methods: We searched the following databases: Cochrane; Cinahl; Pubmed; Psychinfo: Scoups; Web of Knowledge, and IEEE, and screened and selected studies based on titles, abstracts and full texts. We used standardized procedure to abstract and synthetize relevant data of primary studies, and the Mixed Methods Appraisal Tool to assess their quality.

Results: Of 3136 records, 20 studies met the inclusion criteria. Most of the studies were web-based interventions, with multiple components and interactive features. The design and development of eight interventions employed participatory methods with large variations in the underlying framework and application.

Conclusions: This review sheds light on the design and development of digital interventions for dementia caregivers. The limited and heterogeneous use of participatory methods, along with inadequate reporting, hinders a clear understanding of intervention efficacy and implementation. Formal standardization of participatory action research methods is necessary improve the design, development, and evaluation of digital interventions for caregivers of people with dementia.

Keywords: Informal caregivers; dementia; internet; interventions; participatory research; implementation

Introduction

The World Health Organization (WHO) estimated that two-thirds of the sixty million people living with dementia (plwd) [1] receive care at home from family members or friends [2], referred to as informal caregivers [3]. Caring for a plwd is often burdensome and challenging, especially for informal caregivers who may lack dementia education and knowledge [4,5]. The provision of educational and training support to informal caregivers is a key area of the Global Action Plan of the Public Health Response to Dementia [6], and ample evidence supports interventions for informal caregivers. In recent years, the growing use of internet and mobile technology facilitated the transition to digital interventions [7], which are typically behaviourally based and delivered via the internet [8].

Both traditional and digital interventions for informal caregivers can contribute to reduce psychological distress and improve quality of care [9]. However, evidence remains erratic due to the heterogeneity of interventions' characteristics and of methodologies employed to design and evaluate them [10,11]. We do not know how and why interventions work, which hampers their adaptability, implementability, and tailoring to the evolving needs of plwd and their caregivers. A shift in focus from efficacy to the unpacking of the interventions inner mechanisms is needed.

Informal caregivers, can contribute significantly not only to co-design, develop, and improve digital interventions, but also to evaluate them. This is consistent with the Medical Research Council (MRC)[1] of complex interventions approach [12]. However, the involvement of informal caregivers is rare, underreported, and heterogeneous. Participatory research (PR) is a viable option to enable, engage, and involve relevant stakeholders and target groups in the design, conduction of studies, and the dissemination of results [13]. Existing PR approaches [14–16] hold the promise that the interventions are aligned with the needs of the relevant population, may increase their successful uptake and implementation [17–19], and can contribute to close the gap between evidence and practice [20]. However, evidence on the application of PR in the design and development of interventions for informal caregivers is sparse and lacks consolidation.

We conducted a systematic review to clarify and shed light on the methods and strategies used in the development of digital health interventions for informal caregivers, with a specific focus on PR methods. We aimed to 1) describe the characteristics, design, and development of digital health interventions for informal caregivers of people living with dementia and to 2) critically appraise and explore the use of PR methods from development to feasibility of interventions.

Methods

Search strategy

We systematically searched the literature in March 2023 according the PRESS Peer Review of electronic search strategies guideline [21]. We developed the search strategy in consultation with an experienced librarian. We chose and combined keywords and search terms according to our main research question (how are digital health intervention for caregivers of plwd designed?), specifying synonyms and alternative wording for digital, intervention(s), and caregivers, respectively. We adapted to and used our search syntax in the following databases: Cochrane; CINAHL; Pubmed; PsychInfo; Scopus; Web of Knowledge, and IEEE also combining Medical Subject Headings (MeSH), and/or APA Thesaurus of Psychological Index Terms as appropriate (see Annex 1).

Study selection process

Studies were included if: i) they reported the process of designing or testing a digital intervention; ii) the intervention was primarily dedicated to informal caregivers of people living with dementia; and iii) they were published in English. We excluded study protocols, secondary studies (including narrative and systematic reviews, and meta-analyses), dissertations, conferences' abstracts, editorials, and commentaries. We also excluded studies on interventions exclusively delivered face to face, and primarily targeting plwd, or caregivers of people with other medical conditions. The study selection process included several phases (see Figure 1). First, we imported the records retrieved (with titles and abstracts) from the databases into a dedicated electronic repository on Microsoft Teams and removed duplicates. In the second phase, two independent reviewers (AMA; GF) screened the titles and abstracts according to the inclusion and exclusion criteria, which were subsequently applied to the full texts. Disagreement between reviewers were resolved through discussion with a senior author (MF).

Data abstraction and study quality appraisal

The analysis of the selected studies followed a two-step approach. Initially, we conducted a descriptive examination of the studies included and of the interventions described. Subsequently, we analyzed and compared the methodologies used and participants involved according to the different stages of research process. We also formally assessed the methodological quality of the included studies with the Mixed Methods Appraisal Tool (MMAT) [22]. We followed the PRISMA recommendations to format, standardize, and structure the present manuscript (Preferred Reporting Items for Systematic Reviews and Meta-analyses) [23].

Results

The flowchart in Figure 1 illustrates the study selection process, which led to the inclusion of 20 studies after screening of the 3136 records initially retrieved. Studies characteristics, and their methodological details, are summarized in Table 1 and Table 2, respectively.

General characteristics

Types and contents of interventions

The selected articles were published between 2010 and 2023, and reported results of a large variety of studies conducted across diverse geographic regions, eight were developed and/or tested in Europe [24–31]; seven in America [32–38]; three in Oceania [39–41] and two in Asia (India) [42,43].

Half of the included studies were about web-based interventions (N=11). Four interventions were delivered only via a mobile application [28,33,36,40], one had both a web-based and a mobile version [25]; and one was based on cell-phone text messaging [38].

Four programs addressed specific subgroups of caregivers such as caregivers of people living with dementia at early stages [24] or end of life [27]; young caregivers [29], and Latinx caregivers [38]. One intervention was dedicated to both caregivers and plwd [25].

In almost all studies (N=17 out of 20) the authors specified the theoretical frameworks used for developing the interventions. The interventions' structure and contents varied but most recurrent contents included: psychoeducation; problem solving exercises and coping strategies; care coordination; care planning; social support; and self-care. One intervention included contents related to end of life and death planning [27]; one included Mindfulness based self-compassion techniques [44], and one included reminiscence activities [45] (see Table 1 for details).

Digital features and components

Also, the digital features and components of the interventions varied markedly. Based on human-computer interaction standards and previous studies [46,47], we differentiated features between passive and interactive components. While passive features usually do not require any responses or action from the user, interactive features require users to provide a response or modify contents in real time [46,48]. Almost all interventions included passive features such as educational contents; videoclips, and hyperlinks to external resources. Two programs included audiotapes such as podcasts [33] or music tracks [36]. Interactive features varied across studies. Five interventions incorporated real-time chats to interact with a health care professional [24,27,28]; a coach [38] or other users [26]. Other interventions also included personal calendars or diaries and schedule reminders [26,28,36,38,40]. Additional recurrent interactive features were training exercises and questions with immediate or automatic feedback from the program [24,29,31,41,43]. Additional features allowed the users to tailor and personalize contents of the program, such as tailored local support options and keyword-driven automatic messages [38]. One intervention [25] was specifically designed to allow users to store and select personal images, videos or notes to enhance reminiscence activities.

Methodological characteristics

Phases of the interventions

We used the MRC framework for developing and evaluating Complex Interventions to discern the phases of interventions from development to implementation, through feasibility testing and evaluation [12]. Eleven studies, out of the twenty studies included in our review, specifically focused on the development phase of the interventions. Ten studies referred to both development and feasibility stages [24–27,29,30,32–35,37,38,40–43]. Three studies focused on interventions' feasibility [28,31,36], and one included feasibility and preliminary evaluation [39].

Participants' characteristics

All studies involved informal caregivers during one or more research steps. Eleven studies involved caregivers in designing and developing the interventions [24–27,29,34,35,39–41,43]. The number of caregivers included ranged from 5 to 11, and caregivers were mainly female except for one study [42], and spouses or children of the person living with dementia. The mean age of caregivers ranged between 47 and 74 years old, with a caring experience of at least two years. Young caregivers' age ranged from 12 to 16 years old [29]. Only one study directly involved plwd in designing the intervention [25]. Within studies that included feasibility assessments caregivers were always involved [12,24,26,28,31–36,38,43]. The number of caregivers included in this phase ranged from 4 to 47. In only one study [24], the authors specified that the caregivers involved in designing or developing the intervention were also involved in further stages of usability and acceptability assessments. Inclusion criteria of caregivers were quite homogenous across studies and included: being over 18 years old (except for iSupport study for young carers) [29]; being a primary carer of a community dwelling person with a diagnosis of dementia or Mild Cognitive Impairment (MCI); having a caregiver experience of at least from 1 to 6 years; providing care for a minimum of 8 hours per week.

In addition to informal caregivers' engagement, all studies involved additional stakeholders in one or more of the research phases. Most of the studies [24,26–28,30–42] mentioned the involvement of health-care professionals or dementia care experts during the initial development of the intervention. Common experts' professional backgrounds were psychiatry, psychology, geriatrics, nursing, and social working. The number of experts involved ranged from 2 to 30. Other stakeholders were web-designers or computer scientists [25,26,33,38,40,43]; experts in digital health and health communication [27,30]; members of charity organizations or

Alzheimer associations [27,30,33,37,43] and care administrators or dementia care managers [35,41].

Participatory methods

We referred to the framework from Vaughn and colleagues [13] to identify the participatory research methods adopted in the studies. We found eight studies that explicitly referred to participatory methods or frameworks. More specifically, authors mentioned co-production methods for intervention development [27] [49–51]; stakeholders’ engagement [35] [52]; user-centred design or customer-centric approach [28,38]; and co-design or iterative co-design [25,29,33,40] [51,53].

The methods, stages and tools used to engage the different stakeholders varied significantly across studies. The stakeholders involved in the studies were grouped and labelled with several terms such as “advisory board” [34,38]; “community advisory board” [32,35]; “project advisory board” [39]; “interdisciplinary team” [33] or “research development group” [27], and often included caregivers, experts in dementia, and other stakeholders (see Table 2). Engagement strategies included nominal group techniques [27], group meetings [27,38], individual recurrent meetings [27], and co-design workshops [25,29].

The members of these groups were usually involved both at initial, development stages to pin down the key components of the intervention, and in later stages. Davies and colleagues [27] for instance, involved a research development group that identified the future key targets components of the intervention, and refined the intervention prototype. Similarly, Perales-Puchault and colleagues [38] relied on the members of an advisory board in all phases of the research process, with the aim of refining the contents in accordance with the final users’ needs and preferences. Furthermore, Boyd and colleagues [25] organized three co-design workshops with caregivers and care recipients with the aim of co-designing the application. Finally, although the authors didn’t make any explicit reference to a participatory approach, Xiao and colleagues’ interpretative study [41] relied on the involvement of different stakeholders to inform the future implementation of “iSupport for dementia” program in Australia. Indeed, sixteen caregivers and twenty between dementia care managers and care staff members were involved in separate focus group discussions to collect preliminary perspectives and attitudes towards the future intervention.

Discussion

The aim of this review was to describe the characteristics, design, and development of digital health interventions for informal caregivers of people living with dementia. We focused on the adoption of participatory research methods and found that only few studies applied them, and that methods and results were rarely reported with sufficient detail to allow replication.

General features and digital components of the interventions

Compared to web-based interventions, mHealth interventions offer the advantages of being cost-effective, personal, and highly accessible [54,55]. Only four studies were about interventions delivered by a mobile application. Because interventions were often co-designed with caregivers older than 65 years, this finding suggests that the use of mobile technology may still represent a barrier for older people, who are more familiar with computers rather than mobile devices such as smartphones and tablets [56]. Indeed, the use of mHealth applications in education and support for carers is still in its infancy, but may grow and accelerate as digital literacy improves [7].

Most of the studies included multiple components, such as psychoeducational techniques, skills training, care coordination, reminiscence, and relaxation techniques. This finding is consistent with the literature suggesting that multi-component interventions appear to be more effective in improving caregivers' well-being compared to other interventions [57].

Moreover, most interventions adopted interactive features such as real-time chats, training sessions, task reminders, shared calendar or live feedback. However, only four studies out of twenty allowed users to personalize, and only to some extent, the contents of the program. Tailoring strategies can vary from simple actions such as incorporating the user's name in the contexts, to more complex methods such as adapting the contents, and its delivery to the caregivers' preferences and needs [58]. Compared to non-tailored, tailored health messages are more likely to be read, recalled, and elaborated [59], but evidence on tailored approaches to health interventions is still limited [60]. This discrepancy may be related to different challenges associated with developing personalized digital health interventions including the costs and resources associated with the technological infrastructure and development of customized contents. Additional issues pertain to data privacy and ethical considerations [61,62].

Within the context of dementia, a potential alternative solution to the one-size-fits-all approach is the development of targeted interventions dedicated to subgroups of caregivers with common features including culture, stage of dementia, and type of relationship with the care recipient. We found that only four interventions were developed for specific subgroups of caregivers. In a previous systematic review, Van Mierlo and colleagues [63] explored the effectiveness of several interventions within subgroups of caregivers, and found that certain characteristics of the care recipient such as the type and severity of dementia or the type of relationship with the person with dementia were related to better outcomes in several interventions such as decreased caregiver burden and increased competence [63]. These findings are aligned with the criticalness of user-centred contents for better usability, acceptability, and, ultimately, effectiveness [64]. To this end, careful planning and design of digital health interventions can greatly benefit from the active and continuous collaboration between experts in the field and final users [12].

Design of the interventions and participatory methods

Half of the studies included in this review described the development phase of the intervention, and all studies involved informal caregivers of plwd in one or more stages of the intervention, but not much for the design of the intervention. Moreover, the sample size of carers involved in the intervention design phase was quite small, and smaller compared to the feasibility and evaluation phases. When other stakeholders (including healthcare workers and dementia experts) participated in the design, piloting, and testing of a new intervention, they often outnumbered informal caregivers. The difficulty in recruiting informal caregivers of plwd is well-known [65]. In a very recent study, Joshi and colleagues (2023) reported the lessons learned from recruiting caregivers to participate to a randomized controlled trial. The identified barriers pertained to three different levels: individual (i.e., carers' time constraints and motivation); community (i.e., reaching underrepresented caregivers); institutional (i.e., obtaining informed consent and navigating research registries) [66]. The authors concluded that establishing meaningful relationships with participants and collaborating with support group leaders and organizations was crucial for motivating caregivers to enrol and engage in the study.

We also found little age, gender, and type of relationship diversity in caregivers' characteristics across studies. Only one study focused on the early stages of the disease, and one on end of life. All studies involved caregivers with three or more years of caregiving experience, who were already far along in the caregiver journey. This finding raises issues of limited representativeness and external validity of the effectiveness, acceptability, and usability of interventions. Early-stage dementia caregivers are known to experience distress and depressive symptoms and have likely different needs compared to 'experienced' caregivers [67]. Boots and colleagues (2015) talked about a paradox between the need of support and the acceptance of help, whereby difficulty in acknowledging support is related to difficulties in accepting the disease and fear of stigma [68]. A further comprehension of the experiences of early-stage caregivers is crucial to develop interventions better tailored to their specific needs.

We also aimed at investigating the use of participatory methods in primary studies, including the strategies and approaches used to engage participants in decision-making processes [13]. As said, in addition to informal caregivers, all interventions were developed with different stakeholders, including health-care professionals, dementia care experts and web-designers. However, reporting of the inclusion of stakeholders and participatory methods was generally poor. Specific terminology exists, such as "community advisory board", which refers to a specific research paradigm and participatory approach, namely the community-based participatory research (CBPR) [69], but was seldomly used in primary studies. Indeed, only eight studies explicitly mentioned participatory methods or frameworks. But comparisons were not straightforward. Few authors specified in detail how and why adopting a participatory approach contributed to the development and finalization of the intervention. We argue that the harmonization of participatory research methods, frameworks and terminology is needed to facilitate a more comprehensive comparison between the existing approaches and methodologies used in designing digital health interventions.

A major finding of this review was that participatory methods and frameworks are still relatively underutilized in the development of digital health interventions for dementia caregivers. This may undermine both the research phase and the uptake of interventions of proved effectiveness [70], and impact on the their implementation and scale up [71]. When participants contribute to research since its early stages, barriers and facilitators to future uses and applications are timely anticipated and considered [20], which can fill the know-do gap, and favour the translation of research findings into new and better practices.

Limitations

Some limitations are worth noting. First, the heterogeneity in how studies reported methodological details has hindered a systematic comparison between the interventions. However, this lack of consistency may represent an incentive itself for further research to report more about the development phase of the interventions, so to inform and guide future researchers in designing digital health programs. Second, we excluded interventions that did not target informal caregivers. Further research could specifically focus on the design of digital health interventions primarily dedicated to people living with dementia.

Conclusions

This review provides an insight into digital health interventions for caregivers of people living with dementia. Different from other reviews, we focused on how interventions were designed rather than on their efficacy. We explored the use of participatory research methods, a promising yet still relatively underexplored approach. These approaches are rarely adopted during the development of digital health interventions, and when they are, they are often reported without clear practical implications or references to the underlying framework. Replications are difficult. Future research may benefit from a clearer presentation and systematization of the existing participatory methods. Indeed, despite the challenges, participatory research seems crucial to enhance the use and acceptance of digital health interventions, especially when these are designed to address a range of complex and multifaceted requirements, such as those daily faced by informal caregivers of people living with dementia.

Fig. 1. Flowchart

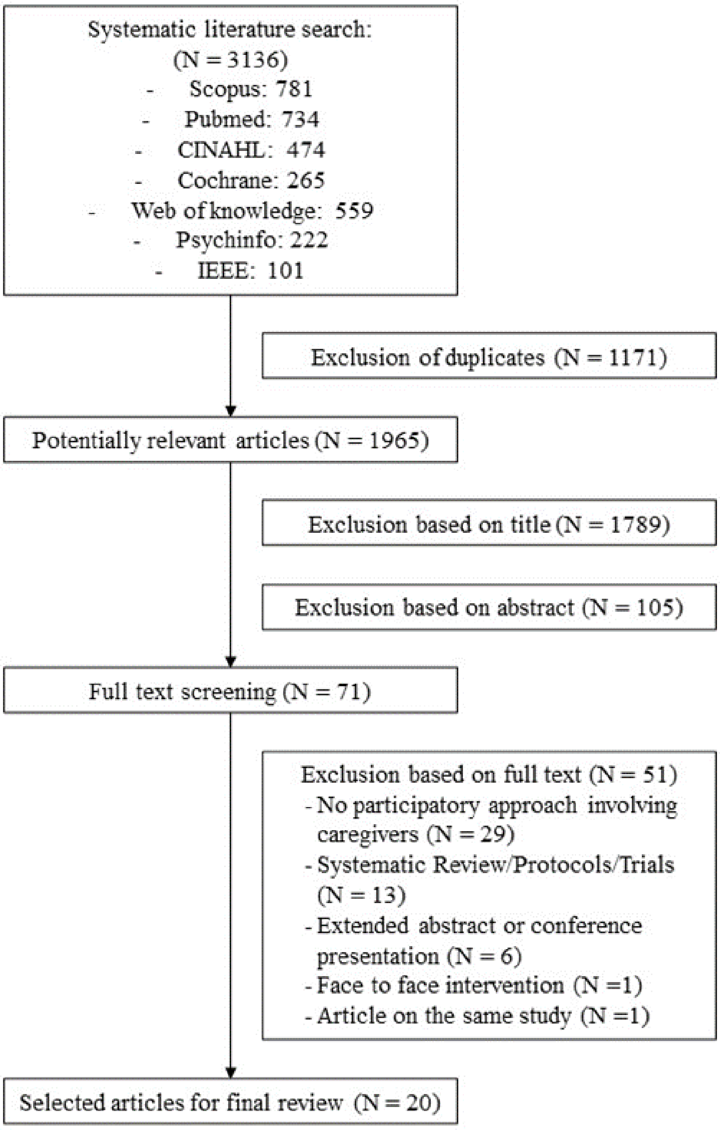


Table 1: Descriptive characteristics of the studies included (N=20)

Author(s) and year	Country	Intervention name	Target population	Content	Features	Framework of the intervention	Medium
Baruah et al., 2020, 2021	India	iSupport	Caregivers of plwd*	Psycho-education,self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person's centred care (Kitwood, 1997)	Website
Boots et al., 2016	Netherlands	Partner in balance	Caregivers of plwd* at early stage	Self-management, problem solving techniques, psychoeducation, social support.	Video-clips; exercises; discussion forum; communication with a hcp; individualized feedback.	Stress and Coping theory(Lazarus and Folkman, 1884), Self-efficacy theory (Bandura, 1997)	Website
Boyd et al., 2021	UK	InspireD	Plwd* and caregivers	Reminiscence activities	Storage and selection of personal images; videos; audios with notes.	Reminiscence therapy (Butler, 1963)	Mobile application and website
Dam et al., 2017	Netherlands	Inlife	Caregivers of plwd*	Social support; care planning.	Invitation of significant network members in the platform; chat network members; notifications; shared calendar; care book; educational video-clips; information; hypelinks to local resources.	Social support and buffering hypothesis (Cohen and Wills, 1985)	Website
Davies et al., 2019	UK	NA	Caregivers of plwd* at the end of life	Coping strategies; problem solving techniques; relaxation exercises; psycho-education; care planning; end of life; death planning.	Video clips with caregivers; talk with a health care professional; chat with carers; hypelinks to local resources; find support in your local area.	Caregiver support theory (Parkinson et al., 2016)	Website

Gaugler et al., 2016; McCarron et al., 2019	USA	Care to Plan (CtP)	Caregivers of plwd*	Care planning; care coordination; social support.	Generate tailored local support options based on a 20-item assessment and caregiver scenario; guidance to facilitate a recommended support option.	Ottawa Decision Support Framework (ODSF); Stress Process Model (Pearlin et al., 1990)	Website
Goodridge et al., 2021	Canada	NA	Caregivers of plwd*	Mindfulness based self compassion (MBSC) techniques; psycho-education; self-care; coping strategies.	Podcasts; meditations; body-based practices; hyperlinks to existing resources (Youtube videos); Daily ecological momentary assessments (EMAs).	Mindfulness based Self Compassion (MBSC) (Perez-Blasco et al., 2016)	Mobile application
Kagwa et al., 2022	Sweden	STAV	Caregivers of plwd*	Psycho-education; social support; self-care; problem solving strategies.	Tailored self-assessment tool, interactive chat with health care professionals, personal diary, mindfulness sessions, forum, hyperlinks with useful resources.	NS**	Mobile application
Lewis et al., 2010	USA	Internet-Based Savvy Caregiver (IBSC)	Caregivers of plwd*	Psycho-education; decision-making techniques; self-care; care planning; coping strategies	Video clips with family carers	Stress and coping model (Lazarus and Folkman, 1884)	Website
Loi et al., 2022	Australia	START-online	Caregivers of plwd*	Psychoeducation; Care planning; self-care; coping strategies.	Eight 1-h weekly sessions delivered by trained psychologist graduates; START-online manual; audio tracks; hypelinks to local resources.		Website

Masterson-Algar et al., 2023	UK	iSupport	Young caregivers of plwd*	Psycho-education,self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person’s centred care (Kitwood, 1997))	Website
Mishra et al., 2023	USA	Care4AD	Caregivers of plwd*	Care Coordination; care monitoring; self-care.	Schedule reminders; wireless sensor tags; eBooks; video calling; music tracks.	NS**	Mobile application
Monteiro et al., 2023	Brazil	iSupport	Caregivers of plwd*	Psycho-education, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person’s centred care (Kitwood, 1997)	Website
Perales-Puchalt et al., 2022	USA	CuidaTEXT	Latinx caregivers of plwd*	Care coordination; psycho-education; self-care; social support; end of life; problem solving strategies.	Daily automatic messages; keyword-driven messages; live chat interaction with a coach; booklet; video links; shared resources.	Social cognitive theory(Bandura and National Inst of Mental Health, 1986); Stress process framework (Pearlin et al., 1990); Seven principles of communication (Cutlip, 1952)	Text messaging cell phone
Rathnayake et al., 2021	Australia	Dementia support for carers	Caregivers of plwd*	Care coordination; psychoeducation; social support; problem solving techniques; care planning; self-care.	Calendar; task reminder function; video clips.	Adult learning theory (Knowles, 1984)	Mobile application
Teles, Napolskij, et al., 2021; Teles, Paúl, et al., 2021	Portugal	iSupport	Caregivers of plwd*	Psycho-education, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions; mood status rating; personalization of	Person’s centred care (Kitwood, 1997)	Website

					names; hyperlinks to local resources.		
Xiao et al., 2021	Australia	iSupport	Caregivers of plwd*	Psycho-education, skills training, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions; hyperlinks to local resources.	Person’s centred care	Website

*people living with dementia.
** not specified.

Table 2: Methodological details of the studies included (N=20)

Author(s) and year	Study design	Phase of the intervention	Research steps	Caregivers' or plwd* ic** and characteristics
Baruah et al., 2020	Focus group study	Development	Information gathering	Ic: formal education till 15 years old; speaking english; mean years of experience in caring= 6 months; regular computer/internet users; resident locally; having an email address. N=13. Mean age: 47.4; 61.5% males; 85% children; mean years of experience in caring: 2-2,5. Mean hours per week of care: 12.
Baruah et al., 2021	Mixed methods study	Development, feasibility	1. Preliminary adaptation design	
			2. Preliminary adaptation test onsite	Ic: ≥ 18 years old; speaking english; regular computer user. N=4. mean age: 35.75; n=3 sons; n=1 daughter. Mean experience in caring= 30 months.
			3. Preliminary adaptation test online	N=11. Mean age: 40.64; n=5 sons; n=5 daughters; n=1 spouse. Mean experience in caring: 13 months.
			4. Final refinement	
Boots et al., 2016	Exploratory mixed-method study	Development, feasibility	1. Preliminary views exploration	N=28: n=21 females; n=7 males; n=22 spouses; n=2 children; n=1 child-in law; n=1 sibling. Mean age=63.3.
			2. Development and validation of contents and structure	
			3. Usability testing	N=4 (random sample from phase 1).
			4. Pilot/Feasibility study (pre-post uncontrolled intervention)	Ic: spousal caregiver of plwd or Mild Cognitive Impairment; access to Internet. N=10: n=3 females n=7 males. Mean age= 68.10 (SD=6.54); mean hours of care per week=44.20 (SD=56.85).
Boyd et al., 2021	Mixed methods pilot study	Development; feasibility	1. User needs analysis and feedbacks	N=5 plwd. Mean age: 69.75. Mean time since diagnosis: 2.7 years.
			2. Demonstration of the prototype and feedbacks	N=6 plwd**.** Mean age: 56.83. Mean time since diagnosis: 3.08 years.
			3. Usability test	N=5 dyads (caregiver and plwd): n=4 females; n=6 males. n=6 spouses; N=1 daughter; n=1 friend.

				Mean plwd age: 66.2. Mean time since diagnosis: 8.8 years.
Dam et al., 2017	Exploratory pilot study	Development, feasibility	1. Users view exploration	N=10: n=7 females; n=3 males; all spouses. Mean age=73.7. Mean hours of care per week=37.6. Mean years of experience in caring=3.
			2. Modeling (development and validation of content and structure)	N=2; all spouses.
			3. Pilot/Feasibility	Ic: primary caregiver of plwd living in the community; access to Internet. N=25: n=12 females; n=13 males; n=8 spouses; n=16 daughters/sons; n=1 granddaughter. Mean hours of care per week=24.7. Mean years of experience in caring=2.1.
Davies et al., 2019	Mixed method study	Development and feasibility	1. Synthesis of data	Ic: caregiver of a community dwelling plwd towards the end of life; having a caregiving experience ≥ 3 years; ≥ 65 years old. N=23: 77% females; 59% spouses.
			2. Identifying intervention targets and components	N=1 caregiver (part of the research development group).
			3. Developing the intervention prototype	N=1 caregiver (part of the research development group).
			4. User testing	Ic: caregiver of a community dwelling plwd towards the end of life. N =11; mean age:74; 73% females; 55% spouses /daughters/sons.
Gaugler et al., 2016	Parallel convergent mixed methods design	Development, feasibility	1. Development and design	
			2. Feasibility and usability testing	Ic: primary caregiver of dwelling plwd; hours of care per week ≥ 8. N=21.
Goodridge et al., 2021	Participatory Feasibility study	Development, feasibility	1. Co-design of the intervention	
			2. Pre and post test	Ic: primary caregiver of a community dwelling plwd; ≥ 18 years old; access to smartphone. N=29: 91% females; 76% spouse/daughter/son of plwd. Mean age=59.6. n=13 caregiving experience < 2 years.
Kagwa et al., 2022	Qualitative explorative design	Feasibility	1. Qualitative interviews post use	Ic: speak Swedish; ≥ 18 years old; experience in caring ≥ 6 months; access to a tablet or smartphone and Internet. N=12: n=7 females; n=5 males; n=11 spouses; n=1 daughter.
Lewis et al., 2010	NS****	Development, feasibility	1. Design and development	Ic: primary caregiver of a community dwelling plwd.

			2. Feasibility and acceptability	N=47: 85% females. Mean age: 55. Mean caregiving experience= 3.8 years (range: 1-21).
Loi et al., 2022	Mixed methods unblinded before and after study	Feasibility and preliminary evaluation	1. Development	
			2. Feasibility and preliminary effectiveness	Ic: caregiver ≥ 18 years old; caregiving experience ≥ 3 years. N=18: 60% females; 75% spouses. Mean years of experience in caring = 3 years (range: 0-10). Mean age: 67.5;
Masterson-Algar et al., 2023	Adaptation study	Development	1. Consultation and feedback	Ic: young caregiver between 11-17 years old; community-dwelling plwd; experience in caring ≤ 6 months. N=6: n=5 females; n=1 male; n=3 son/daughters; n=3 nephews. Age range: 12-16.
			2. Refinement and final adaptation	Same participants
McCarron et al., 2019* following Gaugler et al., 2016	Instrumental case study	Development, feasibility	1. Translational phase	N=14 (included Community Advisory Board): n=4 spouses; n=9 daughters/sons; 77% females. Mean age=58.
			2. Feasibility and usability of the beta version	Ic: primary cg dwelling plwd; plwd diagnosed with dementia; > 8 hours of care per week. N=21.
Mishra et al., 2023	Feasibility and acceptability study	Feasibility	1. Individual interviews	Ic plwd: ≥ 55 years old; mild-to-moderately severe dementia; living in a residential facility and having an informal caregiver involved ≤ 8 hours of care per week. N pwld=10: n=4 females; n=6 males. Mean age=73.4. N caregivers= 14: n=12 females; n=2 males. Mean age=68.
Monteiro et al., 2023	Multicenter study	Development	1. Linguistic translation	
			2. Contents assessment	Ic: ≥ 18 years old; speak portoguese; live in one of the three data collection regions. N=24, all females. years of experience in caring= 7 years. Mean age= 54.6
			3. Fidelity check	
Perales-Puchalt et al., 2022	Development and Usability study-mixed-methods	Development, feasability	1. Selection of design principles	

			2. Vendor collaboration for text messaging design and delivery	
			3. Evidence-Based foundation	
			4. Advisory Board guidance	N=6 (included in the Advisory Board).
			5. Sketching and protopying	
			6. Usability testing	Ic: Spanish/English speakers; ≥ 18 years old; identified as Latinx; plwd diagnosed with clinical dementia diagnosis and Ascertain Dementia Cognitive Scoring; having a cell-phone. N=6: n=4 females/daughters; n=1 males/sons; n=1 grand-daughter. Mean age = 44.6 (SD=6.8).
Rathnayake et al., 2021	Mixed methods study	Development	1. Needs assessment	N=10
			2. Development of the application	
Teles, Napolskij, et al., 2021	Exploratory study	Development	1. Needs assessment	
			2. Content translation	
			3. Cultural adaptation	
			4. Expert panel appraisal	
			5. Fidelity check	
Teles, Paúl, et al., 2021	Mixed method usability study	Feasibility	1. User feedback	Ic: ≥ 18 years old; frequent internet users; having an email address. N=7: n=4 females; n=3 males; n=4 spouses; n=3 children/grandchildren. Mean caregiving experience: 6 years. Mean age:59.3.
			2. Usability test	Ic (same for phase 1). N=10; n=7 females; n=2 spouses; n=8 children/grandchildren. Mean years of experience in caring: 4.1. Mean age: 50.8.
Xiao et al., 2021	Interpretative description study	Development	Stakeholders’ perspectives	Ic: ≥ 18 years old; mean years of experience in caring ≥ 1. N=16: 65% females; 88% spouses. Mean years of experience in caring: 5 years. Mean age: 74.5;

*people living with dementia.
** inclusion criteria.
***health care professionals.
****Not specified.

Annex 1. Search strategy

1	Scopus	TITLE-ABS-KEY (mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND TITLE-ABS-KEY (application OR app OR intervention) AND TITLE-ABS-KEY (dementia OR alzheimer) AND TITLE-ABS-KEY (caregiver OR family OR carer OR spouse)
2	Pubmed	("Mhealth"[Title/Abstract] OR "smartphone"[Title/Abstract] OR "mobile"[Title/Abstract] OR "online" [Title/Abstract] OR "internet"[Title/Abstract] OR "health technology"[Title/Abstract] OR "smartphone"[MeSH Terms]) AND ("Application"[Title/Abstract] OR "App"[Title/Abstract] OR "intervention"[Title/Abstract] OR "Psychosocial Intervention"[MeSH Terms] OR "mobile applications"[MeSH Terms]) AND ("dementia car*"[Title/Abstract] OR "alzheimer car*"[Title/Abstract] OR "dementia famil*"[Title/Abstract] OR "alzheimer famil*"[Title/Abstract] OR "caregivers"[MeSH Terms])
3	CINAHL	mhealth OR smartphone OR mobile OR online OR internet OR “health technology”) AND (application OR app OR intervention OR) AND (dementia OR alzheimer) AND (caregiver OR family OR carer OR spouse)
4	Cochrane	(mhealth):ti,ab,kw OR (smartphone):ti,ab,kw OR (mobile):ti,ab,kw OR (online) OR (internet):ti,ab,kw OR ("health technology"):ti,ab,kw OR [mh smartphone] AND (application):ti,ab,kw OR (app):ti,ab,kw OR (intervention):ti,ab,kw OR [mh "Mobile Applications"] OR [mh "Psychosocial Intervention"] AND (alzheimer):ti,ab,kw OR (dementia):ti,ab,kw OR [mh "Alzheimer Disease"] OR [mh dementia] AND (caregiver):ti,ab,kw OR (family):ti,ab,kw OR (carer):ti,ab,kw OR (spouse):ti,ab,kw OR [mh Caregivers] AND #1-#4}
5	Web Of Knowledge	TS=(mhealth OR smartphone OR mobile OR online OR internet OR “health technology”) AND TS=(application? OR app? OR intervention) AND TS=(dementia OR alzheimer) AND TS=(caregiver? OR famil* OR carer? OR spouse?)
6	Psychinfo	(Mhealth OR smartphone OR mobile OR internet OR online OR “health technology”) AND (Application OR App OR intervention) AND ("Alzheimer car*" OR "dementia car*" OR "dementia famil*" OR "Alzheimer famil*")
7	IEEE	(((mhealth OR smartphone OR mobile OR online OR internet OR “health technology”) AND (application OR app OR intervention) AND (dementia OR alzheimer) AND (caregiver OR family OR carer OR spouse)))

References

1. GBD 2019 Dementia Forecasting Collaborators Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* **2022**, *7*, e105–e125, doi:10.1016/S2468-2667(21)00249-8.

2. Alzheimer Disease International World Alzheimer Report 2018. The State of the Art of Dementia Research: New Frontiers. Available online: https://www.alz.co.uk/research/world-report-2018.

3. Schulz, R.; Tompkins, C.A. Informal Caregivers in the United States: Prevalence, Caregiver Characteristics, and Ability to Provide Care. In *The role of human factors in home health care: workshop summary*; National Research Council (U.S.). Committee on the Role of Human Factors in Home Health Care, Ed.; National Academies Press: Washington, DC, 2010 ISBN 978-0-309-15629-5.

4. Morgan, B.N.; Windle, G.; Sharp, R.; Lamers, C.; Naunton Morgan, B. EHealth and Web-Based Interventions for Informal Carers of People With Dementia in the Community: Umbrella Review. *Journal of Medical Internet Research* **2022**, *24*, N.PAG-N.PAG, doi:10.2196/36727.

5. Robinson, A.; Eccleston, C.; Annear, M.; Elliott, K.-E.; Andrews, S.; Stirling, C.; Ashby, M.; Donohue, C.; Banks, S.; Toye, C.; et al. Who Knows, Who Cares? Dementia Knowledge among Nurses, Care Workers, and Family Members of People Living with Dementia. *J Palliat Care* **2014**, *30*, 158–165, doi:10.1177/082585971403000305.

6. World Health Organization Global Action Plan on the Public Health Response to Dementia 2017–2025 Available online: https://www.who.int/publications/i/item/9789241513487.

7. Rathnayake, S.; Jones, C.; Calleja, P.; Moyle, W. Family Carers' Perspectives of Managing Activities of Daily Living and Use of MHealth Applications in Dementia Care: A Qualitative Study. *Journal of Clinical Nursing* **2019**, *28*, 4460–4470, doi:10.1111/jocn.15030.

8. Ritterband, L.M.; Andersson, G.; Christensen, H.M.; Carlbring, P.; Cuijpers, P. Directions for the International Society for Research on Internet Interventions (ISRII). *J Med Internet Res* **2006**, *8*, e23, doi:10.2196/jmir.8.3.e23.

9. Adler, R.; Mehta, R. *Catalyzing Technology to Support Family Caregiving*; National Alliance for Caregiving.; 2014; Vol. 1–18;.

10. Boots, L.M.M.; de Vugt, M.E.; van Knippenberg, R.J.M.; Kempen, G.I.J.M.; Verhey, F.R.J. A Systematic Review of Internet-based Supportive Interventions for Caregivers of Patients with Dementia. *International Journal of Geriatric Psychiatry* **2014**, *29*, 331–344, doi:10.1002/gps.4016.

11. Parra-Vidales, E.; Soto-Perez, F.; Victoria Perea-Bartolome, M.; Franco-Martin, M.A.; Munoz-Sanchez, J.L. Online Interventions for Caregivers of People with Dementia: A Systematic Review. *ACTAS ESPANOLAS DE PSIQUIATRIA* **2017**, *45*, 116–126.

12. Skivington, K.; Matthews, L.; Simpson, S.A.; Craig, P.; Baird, J.; Blazeby, J.M.; Boyd, K.A.; Craig, N.; French, D.P.; McIntosh, E.; et al. A New Framework for Developing and Evaluating Complex Interventions: Update of Medical Research Council Guidance. *BMJ* **2021**, *374*, n2061, doi:10.1136/bmj.n2061.

13. Vaughn, L.M.; Jacquez, F. Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods* **2020**, *1*, doi:10.35844/001c.13244.

14. Wallerstein, N. Commentary on Community-Based Participatory Research and Community Engaged Research in Health for Journal of Participatory Research Methods. *Journal of Participatory Research Methods* **2020**, *1*, doi:10.35844/001c.13274.

15. Mao, J.-Y.; Vredenburg, K.; Smith, P.W.; Carey, T. The State of User-Centered Design Practice. *Commun. ACM* **2005**, *48*, 105–109, doi:10.1145/1047671.1047677.

16. Frank, L.; Basch, E.; Selby, J.V. The PCORI Perspective on Patient-Centered Outcomes Research. *JAMA* **2014**, *312*, 1513, doi:10.1001/jama.2014.11100.

17. Camerini, L.; Camerini, A.-L.; Schulz, P.J. Do Participation and Personalization Matter? A Model-Driven Evaluation of an Internet-Based Patient Education Intervention for Fibromyalgia Patients. *Patient Education and Counseling* **2013**, *92*, 229–234, doi:10.1016/j.pec.2013.04.007.

18. Lentelink, S.; Tabak, M.; van Schooten, B.; Hofs, D.; Akker, H.O.D.; Hermens, H. A Remote Home Monitoring System to Support Informal Caregivers of People with Dementia. **2018**, *5*, 94–102, doi:10.5220/0006565300940102.

19. Minkler, M.; Wallerstein, N.; Wilson, N. Improving Health through Community Organization and Community Building. In *Health behavior and health education: Theory, research, and practice, 4th ed.*; Jossey-Bass: San Francisco, CA, US, 2008; pp. 287–312 ISBN 978-0-7879-9614-7.

20. Wallerstein, N.; Duran, B. Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity. *Am J Public Health* **2010**, *100*, S40–S46, doi:10.2105/AJPH.2009.184036.

21. McGowan, J.; Sampson, M.; Salzwedel, D.M.; Cogo, E.; Foerster, V.; Lefebvre, C. PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *Journal of Clinical Epidemiology* **2016**, *75*, 40–46, doi:10.1016/j.jclinepi.2016.01.021.

22. Hong, Q.N.; Gonzalez-Reyes, A.; Pluye, P. Improving the Usefulness of a Tool for Appraising the Quality of Qualitative, Quantitative and Mixed Methods Studies, the Mixed Methods Appraisal Tool (MMAT). *J Eval Clin Pract* **2018**, *24*, 459–467, doi:10.1111/jep.12884.

23. Moher, D.; Liberati, A.; Tetzlaff, J.; Altman, D.G.; The PRISMA Group Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* **2009**, *6*, e1000097, doi:10.1371/journal.pmed.1000097.

24. Boots, L.M.; de Vugt, M.E.; Withagen, H.E.; Kempen, G.I.; Verhey, F.R. Development and Initial Evaluation of the Web-Based Self-Management Program “Partner in Balance” for Family Caregivers of People With Early Stage Dementia: An Exploratory Mixed-Methods Study. *JMIR Res Protoc* **2016**, *5*, e33, doi:10.2196/resprot.5142.

25. Boyd, K.; Bond, R.; Ryan, A.; Goode, D.; Mulvenna, M. Digital Reminiscence App Co-created by People Living with Dementia and Carers: Usability and Eye Gaze Analysis. *Health Expect* **2021**, *24*, 1207–1219, doi:10.1111/hex.13251.

26. Dam, A.E.H.; van Boxtel, M.P.J.; Rozendaal, N.; Verhey, F.R.J.; de Vugt, M.E. Development and Feasibility of Inlife: A Pilot Study of an Online Social Support Intervention for Informal Caregivers of People with Dementia. *PLoS ONE* **2017**, *12*, e0183386, doi:10.1371/journal.pone.0183386.

27. Davies, N.; Hopwood, J.; Walker, N.; Ross, J.; Iliffe, S.; Walters, K.; Rait, G. Designing and Developing a Co-Produced Theoretical and Evidence-Based Online Support for Family Caregivers of People with Dementia at the End of Life. *BMC Palliat Care* **2019**, *18*, 71, doi:10.1186/s12904-019-0455-0.

28. Kagwa, A.S.; Konradsen, H.; Kabir, Z.N. Value Co-Creation with Family Caregivers to People with Dementia through a Tailor-Made MHealth Application: A Qualitative Study. *BMC Health Services Research* **2022**, *22*, 1–10, doi:10.1186/s12913-022-08704-w.

29. Masterson-Algar, P.; Egan, K.; Flynn, G.; Hughes, G.; Spector, A.; Stott, J.; Windle, G. ISupport for Young Carers: An Adaptation of an e-Health Intervention for Young Dementia Carers. *International Journal of Environmental Research and Public Health* **2023**, *20*, doi:10.3390/ijerph20010127.

30. Teles, S.; Napolskij, M.S.; Paúl, C.; Ferreira, A.; Seeher, K. Training and Support for Caregivers of People with Dementia: The Process of Culturally Adapting the World Health Organization ISupport Programme to Portugal. *Dementia* **2021**, *20*, 672–697, doi:10.1177/1471301220910333.

31. Teles, S.; Paúl, C.; Lima, P.; Chilro, R.; Ferreira, A. User Feedback and Usability Testing of an Online Training and Support Program for Dementia Carers. *Internet Interventions* **2021**, *25*, 100412, doi:10.1016/j.invent.2021.100412.

32. Gaugler, J.E.; Reese, M.; Tanler, R. Care to Plan: An Online Tool That Offers Tailored Support to Dementia Caregivers. *GERONT* **2016**, *56*, 1161–1174, doi:10.1093/geront/gnv150.

33. Goodridge, D.; Reis, N.; Neiser, J.; Haubrich, T.; Westberg, B.; Erickson-Lumb, L.; Storozinski, J.; Gonzales, C.; Michael, J.; Cammer, A.; et al. An App-Based Mindfulness-Based Self-Compassion Program to Support Caregivers of People With Dementia: Participatory Feasibility Study. *JMIR Aging* **2021**, *4*, e28652, doi:10.2196/28652.

34. Lewis, M.L.; Hobday, J.V.; Hepburn, K.W. Internet-Based Program for Dementia Caregivers. *Am J Alzheimers Dis Other Demen* **2010**, *25*, 674–679, doi:10.1177/1533317510385812.

35. McCarron, H.R.; Finlay, J.M.; Sims, T.; Nikzad-Terhune, K.; Gaugler, J.E. Stakeholder Engagement to Enhance Interventions for Family Caregivers of People with Dementia: A Case Study of Care to Plan. *Journal of Gerontological Social Work* **2019**, *62*, 29–47, doi:10.1080/01634372.2018.1505797.

36. Mishra, R.K.; Park, C.; Momin, A.S.; Rafaei, N.E.; Kunik, M.; York, M.K.; Najafi, B. Care4AD: A Technology-Driven Platform for Care Coordination and Management: Acceptability Study in Dementia. *Gerontology* **2023**, *69*, 227–238, doi:10.1159/000526219.

37. Monteiro, D.Q.; Ottaviani, A.C.; Campos, C.R.F.; Barham, E.J.; de Oliveira, D.C.; da Cruz, K.C.T.; Pavarini, S.C.I.; de Souza Orlandi, F.; Zazzetta, M.S.; Jacinto, A.F.; et al. ISupport-Brasil: Cross-Cultural Adaptation of the Content Included in the ISupport Program for Caregivers of People Who Have Dementia. *Dementia* **2023**, doi:10.1177/14713012231152555.

38. Perales-Puchalt, J.; Acosta-Rullán, M.; Ramírez-Mantilla, M.; Espinoza-Kissell, P.; Vidoni, E.; Niedens, M.; Ellerbeck, E.; Hinton, L.; Loera, L.; Ramírez, A.S.; et al. A Text Messaging Intervention to Support Latinx Family Caregivers of Individuals With Dementia (CuidaTEXT): Development and Usability Study. *JMIR Aging* **2022**, *5*, e35625, doi:10.2196/35625.

39. Loi, S.M.; Tropea, J.; Gaffy, E.; Panayiotou, A.; Capon, H.; Chiang, J.; Bryant, C.; Doyle, C.; Kelly, M.; Livingston, G.; et al. START-Online: Acceptability and Feasibility of an Online Intervention for Carers of People Living with Dementia. *Pilot Feasibility Stud* **2022**, *8*, 41, doi:10.1186/s40814-022-00999-0.

40. Rathnayake, S.; Moyle, W.; Jones, C.; Calleja, P. Co-Design of an MHealth Application for Family Caregivers of People with Dementia to Address Functional Disability Care Needs. *Informatics for Health and Social Care* **2021**, *46*, 1–17, doi:10.1080/17538157.2020.1793347.

41. Xiao, L.D.; McKechnie, S.; Jeffers, L.; De Bellis, A.; Beattie, E.; Low, L.-F.; Draper, B.; Messent, P.; Pot, A.M. Stakeholders' Perspectives on Adapting the World Health Organization ISupport for Dementia in Australia. *Dementia* **2021**, *20*, 1536–1552, doi:10.1177/1471301220954675.

42. Baruah, U.; Shivakumar, P.; Loganathan, S.; Pot, A.M.; Mehta, K.M.; Gallagher-Thompson, D.; Dua, T.; Varghese, M. Perspectives on Components of an Online Training and Support Program for Dementia Family Caregivers in India: A Focus Group Study. *Clinical Gerontologist* **2020**, *43*, 518–532, doi:10.1080/07317115.2020.1725703.

43. Baruah, U.; Loganathan, S.; Shivakumar, P.; Pot, A.M.; Mehta, K.M.; Gallagher-Thompson, D.; Dua, T.; Varghese, M. Adaptation of an Online Training and Support Program for Caregivers of People with Dementia to Indian Cultural Setting. *Asian Journal of Psychiatry* **2021**, *59*, 102624, doi:10.1016/j.ajp.2021.102624.

44. Perez-Blasco, J.; Sales, A.; Meléndez, J.C.; Mayordomo, T. The Effects of Mindfulness and Self-Compassion on Improving the Capacity to Adapt to Stress Situations in Elderly People Living in the Community. *Clinical Gerontologist* **2016**, *39*, 90–103, doi:10.1080/07317115.2015.1120253.

45. Butler, R.N. The Life Review: An Interpretation of Reminiscence in the Aged. *Psychiatry* **1963**, *26*, 65–76, doi:10.1080/00332747.1963.11023339.

46. Donevant, S.B.; Estrada, R.D.; Culley, J.M.; Habing, B.; Adams, S.A. Exploring App Features with Outcomes in MHealth Studies Involving Chronic Respiratory Diseases, Diabetes, and Hypertension: A Targeted Exploration of the Literature. *Journal of the American Medical Informatics Association* **2018**, *25*, 1407–1418, doi:10.1093/jamia/ocy104.

47. Stephani, V.; Opoku, D.; Quentin, W. A Systematic Review of Randomized Controlled Trials of MHealth Interventions against Non-Communicable Diseases in Developing Countries. *BMC Public Health* **2016**, *16*, 572, doi:10.1186/s12889-016-3226-3.

48. Coyle, J.R.; Thorson, E. The Effects of Progressive Levels of Interactivity and Vividness in Web Marketing Sites. *Journal of Advertising* **2001**, *30*, 65–77, doi:10.1080/00913367.2001.10673646.

49. Davies, N.; Mathew, R.; Wilcock, J.; Manthorpe, J.; Sampson, E.L.; Lamahewa, K.; Iliffe, S. A Co-Design Process Developing Heuristics for Practitioners Providing End of Life Care for People with Dementia. *BMC Palliat Care* **2016**, *15*, 68, doi:10.1186/s12904-016-0146-z.

50. Greenhalgh, T.; Jackson, C.; Shaw, S.; Janamian, T. Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. *The Milbank Quarterly* **2016**, *94*, 392–429, doi:10.1111/1468-0009.12197.

51. Ward, M.E.; De Brún, A.; Beirne, D.; Conway, C.; Cunningham, U.; English, A.; Fitzsimons, J.; Furlong, E.; Kane, Y.; Kelly, A.; et al. Using Co-Design to Develop a Collective Leadership Intervention for Healthcare Teams to Improve Safety Culture. *IJERPH* **2018**, *15*, 1182, doi:10.3390/ijerph15061182.

52. Esposito, D.; Heeringa, J.; Bradley, K.; Croake, S.; Kimmey, L. PCORI Dissemination and Implementation Framework. 2015.

53. Broderick, J.; Devine, T.; Department of Health and Human Services; Lemerise, A.J.; Institute of Medicine; Lier, S.; Department of Health and Human Services; Harris, L.; Department of Health and Human Services Designing Health Literate Mobile Apps. *NAM Perspectives* **2014**, *4*, doi:10.31478/201401a.

54. Fiordelli, M.; Diviani, N.; Schulz, P.J. Mapping MHealth Research: A Decade of Evolution. *J Med Internet Res* **2013**, *15*, e95, doi:10.2196/jmir.2430.

55. Handel, M.J. MHealth (Mobile Health)—Using Apps for Health and Wellness. *EXPLORE* **2011**, *7*, 256–261, doi:10.1016/j.explore.2011.04.011.

56. O’Connor, S.; Bouamrane, M.-M.; O’Donnell, C.A.; Mair, F.S. Barriers to Co-Designing Mobile Technology with Persons with Dementia and Their Carers. *Studies in Health Technology & Informatics* **2016**, *225*, 1028–1029, doi:10.3233/978-1-61499-658-3-1028.

57. Elvish, R.; Lever, S.-J.; Johnstone, J.; Cawley, R.; Keady, J. Psychological Interventions for Carers of People with Dementia: A Systematic Review of Quantitative and Qualitative Evidence. *Counselling and Psychotherapy Research* **2013**, *13*, 106–125, doi:10.1080/14733145.2012.739632.

58. Morrison, L.G. Theory-Based Strategies for Enhancing the Impact and Usage of Digital Health Behaviour Change Interventions: A Review. *DIGITAL HEALTH* **2015**, *1*, 205520761559533, doi:10.1177/2055207615595335.

59. Lustria, M.L.A.; Noar, S.M.; Cortese, J.; Van Stee, S.K.; Glueckauf, R.L.; Lee, J. A Meta-Analysis of Web-Delivered Tailored Health Behavior Change Interventions. *Journal of Health Communication* **2013**, *18*, 1039–1069, doi:10.1080/10810730.2013.768727.

60. Beck, C.; McSweeney, J.C.; Richards, K.C.; Roberson, P.K.; Tsai, P.-F.; Souder, E. Challenges in Tailored Intervention Research. *Nursing Outlook* **2010**, *58*, 104–110, doi:10.1016/j.outlook.2009.10.004.

61. Maeckelberghe, E.; Zdunek, K.; Marceglia, S.; Farsides, B.; Rigby, M. The Ethical Challenges of Personalized Digital Health. *Front. Med.* **2023**, *10*, 1123863, doi:10.3389/fmed.2023.1123863.

62. Sebri, V.; Savioni, L. An Introduction to Personalized EHealth. In *P5 eHealth: An Agenda for the Health Technologies of the Future*; Pravettoni, G., Triberti, S., Eds.; Springer International Publishing: Cham, 2020; pp. 53–70 ISBN 978-3-030-27993-6.

63. Van Mierlo, L.D.; Meiland, F.J.M.; Van der Roest, H.G.; Dröes, R.-M. Personalised Caregiver Support: Effectiveness of Psychosocial Interventions in Subgroups of Caregivers of People with Dementia. *Int. J. Geriat. Psychiatry* **2012**, *27*, 1–14, doi:10.1002/gps.2694.

64. Kirvalidze, M.; Abbadi, A.; Dahlberg, L.; Sacco, L.B.; Morin, L.; Calderón-Larrañaga, A. Effectiveness of Interventions Designed to Mitigate the Negative Health Outcomes of Informal Caregiving to Older Adults: An Umbrella Review of Systematic Reviews and Meta-Analyses. *BMJ Open* **2023**, *13*, e068646, doi:10.1136/bmjopen-2022-068646.

65. Brangman, S.A. Achieving Diversity in Study Populations: The Importance of Community Engagement. *J American Geriatrics Society* **2022**, *70*, 3080–3086, doi:10.1111/jgs.18043.

66. Joshi, S.; Park, T.; Brody, L.; Cruz, K.; Mukhi, P.; Reid, M.C.; Herr, K.; Pillemer, K.; Riffin, C. Recruitment of Family Caregivers of Persons with Dementia: Lessons Learned from a Pilot Randomized Controlled Trial. *Front. Pain Res.* **2023**, *4*, 1125914, doi:10.3389/fpain.2023.1125914.

67. Blieszner, R.; Roberto, K.A. Care Partner Responses to the Onset of Mild Cognitive Impairment. *The Gerontologist* **2010**, *50*, 11–22, doi:10.1093/geront/gnp068.

68. Boots, L.M.M.; Wolfs, C.A.G.; Verhey, F.R.J.; Kempen, G.I.J.M.; de Vugt, M.E. Qualitative Study on Needs and Wishes of Early-Stage Dementia Caregivers: The Paradox between Needing and Accepting Help. *Int. Psychogeriatr.* **2015**, *27*, 927–936, doi:10.1017/S1041610214002804.

69. Newman, S.D.; Andrews, J.O.; Magwood, G.S.; Jenkins, C.; Cox, M.J.; Williamson, D.C. Community Advisory Boards in Community-Based Participatory Research: A Synthesis of Best Processes. *Prev Chronic Dis* **2011**, *8*, A70.

70. Ramanadhan, S.; Viswanath, K. Engaging Communities to Improve Health: Models, Evidence, and the Participatory Knowledge Translation (PaKT) Framework. In *Principles and Concepts of Behavioral Medicine*; Fisher, E.B., Cameron, L.D., Christensen, A.J., Ehlert, U., Guo, Y., Oldenburg, B., Snoek, F.J., Eds.; Springer New York: New York, NY, 2018; pp. 679–711 ISBN 978-0-387-93825-7.

71. Clemensen, J.; Rothmann, M.J.; Smith, A.C.; Caffery, L.J.; Danbjorg, D.B. Participatory Design Methods in Telemedicine Research. *J Telemed Telecare* **2017**, *23*, 780–785, doi:10.1177/1357633X16686747.

72. Kitwood, T.M. *Dementia Reconsidered: The Person Comes First*; Rethinking ageing series; 1. publ.; Open Univ. Press: Buckingham, 1997; ISBN 978-0-335-19855-9.

73. Lazarus, R.S.; Folkman, S. *Stress, Appraisal, and Coping*; 11. [print.].; Springer: New York, 1884; ISBN 978-0-8261-4191-0.

74. Bandura, A. *Self-Efficacy: The Exercise of Control*; W.H. Freeman: New York, 1997; ISBN 978-0-7167-2626-5.

75. Cohen, S.; Wills, T.A. Stress, Social Support, and the Buffering Hypothesis. *Psychological Bulletin* **1985**, *98*, 310–357, doi:10.1037/0033-2909.98.2.310.

76. Parkinson, M.; Carr, S.M.; Rushmer, R.; Abley, C. Investigating What Works to Support Family Carers of People with Dementia: A Rapid Realist Review. *J Public Health* **2016**, jphm;fdw100v2, doi:10.1093/pubmed/fdw100.

77. Pearlin, L.I.; Mullan, J.T.; Semple, S.J.; Skaff, M.M. Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist* **1990**, *30*, 583–594, doi:10.1093/geront/30.5.583.

78. Bandura, A.; National Inst of Mental Health *Social Foundations of Thought and Action: A Social Cognitive Theory*; Prentice-Hall, Inc.; 1986;

79. Cutlip, S.M. *Effective Public Relations: Pathways to Public Favor*; Prentice-Hall, 1952;

80. *Andragogy in Action*; Knowles, M.S., Ed.; The Jossey-Bass management series; 1st ed.; Jossey-Bass: San Francisco, 1984; ISBN 978-0-87589-621-2.

81. Hardyman, W.; Daunt, K.L.; Kitchener, M. Value Co-Creation through Patient Engagement in Health Care: A Micro-Level Approach and Research Agenda. *Public Management Review* **2015**, *17*, 90–107, doi:10.1080/14719037.2014.881539.

82. McColl-Kennedy, J.R.; Vargo, S.L.; Dagger, T.S.; Sweeney, J.C.; Kasteren, Y. van Health Care Customer Value Cocreation Practice Styles. *Journal of Service Research* **2012**, *15*, 370–389, doi:10.1177/1094670512442806.

83. Patient-Centered Outcomes Research Institute What We Mean by Engagement Available online: https://www.pcori.org/engagement/what-we-mean-engagement.

Chapter 6: iSupport Swiss: a community-based participatory approach to culturally adapt the WHO online intervention for family caregivers of people with dementia (study 4)

Anna Messina, Rebecca Amati, Beatrice Bano, Anna Maria Annoni, Emiliano Albanese and Maddalena Fiordelli

Institute of Public Health, Faculty of Biomedical Sciences, Università della Svizzera Italiana.

Under peer-revision process for JMIR Aging (2023)

Abstract

Background: Informal caregivers of people with dementia are at high risk of developing mental and physical distress because of the intensity of the care provided. iSupport is an evidence-based online program developed by the World Health Organization (WHO) to provide education and support to informal everyday care.

Methods: We used a mixed-methods design, with a community based participatory research approach. The adaptation of iSupport followed the WHO adaptation guidelines and was developed into five phases: content translation, linguistic and cultural revision by the members of the Community Advisory Board, validation with formal and informal caregivers, and refinement and final adaptation.

Results: Findings from each phase showed and consolidated the adjustments needed for a culturally adapted Swiss version of iSupport. We collected feedback and implemented changes related to the following areas: language register and expressions (e.g., from “lesson” to “chapter”; from “suffering from” dementia to “affected by” dementia); resources (hyperlinks to local resources for dementia); contents (e.g., from general, non-familiar scenarios to local and verisimilar examples); graphics (e.g. from generalized objects’ illustrations to featured humans’ illustrations), and extra features (e.g., glossary, interactive forum, read-aloud option; navigation survey).

Conclusions Our study provides evidence on how to culturally adapt an online program for informal caregivers of people living with dementia. Our results suggest that adopting a community based participatory approach and collecting lived experiences from the final users and stakeholders is crucial to meet local needs and to inform the further development, testing and implementation of online interventions to a specific cultural context.

Introduction

Approximately 55 million people currently living with dementia worldwide [1]. Switzerland counts for more than 150 000 cases of dementia, with an expected doubling by 2050 [2]. As in most countries, in Switzerland the majority of people living with dementia live at home assisted by an informal caregiver, who is usually a family member who provides daily support and coordinates care delivery [3]. There are positive outcomes that may be associated with the caring role, such as the perception of a better relationship and closeness with the care recipient [4]. Nonetheless, the increasing complexity of taking care of a person affected by dementia exposes informal caregivers to psychological distress and increases the risk of loneliness and developing symptoms of anxiety and depression [5,6]. Caregivers' psychological distress is also associated with a lower quality of care provided [7], and with the worsening of behavioural and psychological symptoms in the care recipients [8].

Providing guidance and support to informal caregivers is one of the priority areas identified by the World Health Organization (WHO) to reduce the global impact of dementia, and to improve the quality of life of caregivers and their families [9]. In the last decades, online educational and psycho-social interventions for caregivers have bloomed [10,11]. Internet-based interventions are more easily accessible [12,13], and adjustable to the time and geographic constraints of caregivers [14]. Some reviews suggest that multiple components of online interventions can contribute to reducing the burden and improving the quality of care, and be even more beneficial if tailored to caregivers' specific needs and contexts [10,15,16]. The active involvement of the final users and relevant stakeholders in the design, local adaptation, and testing and piloting of interventions is crucial for need-centered interventions, for their uptake, integration, and scalability at the community level [17,18]. However, more evidence is required to understand the methods and strategies most effective in involving participants in the design and adaptation of online interventions [19,20].

iSupport is an evidence-based online training intervention developed by the WHO to provide support and education to informal caregivers of people with dementia [21]. The original program consists of twenty-three thematic lessons distributed across five modules (Figure1). Each lesson covers a specific topic associated with care that ranges from the daily assistance of the care recipient (e.g., toileting; personal care; nutrition) to the self-care of the carer (e.g., reducing stress; involving others in care duties). All lessons include theoretical and informative sections and case scenarios with interactive multiple-choice questions. The WHO provides guidelines to culturally adapt iSupport contents to the local language, culture, and context in countries before implementation [22]. Reporting of adaptation processes of complex interventions is limited but extremely important [23]. Knowledge exchange of methodologies and approaches, and evidence on barriers and facilitators of local adaptation are crucial preliminary steps to inform the implementation of interventions and their mid-long-term uptake and sustainability [24].

This study aims to describe in detail the cultural adaptation process of iSupport in Switzerland. We specifically focused on the participatory strategies we used to design a culturally adapted iSupport Swiss version that informed the development of the desktop version, mobile application, and printed manual. Our purpose is to inform the implementation of not only iSupport but also other complex interventions in health, specifically in the context of the cultural adaptation process.

Materials and methods

Study setting and ethical consent

The study took place in the Italian-speaking part of southern Switzerland, namely the Ticino Canton. Before initiating the study, we sought ethical oversight by submitting our project to the cantonal ethics Committee, and we obtained a waiver of ethical approval and the official authorization to proceed with the study. Specifically, the Ethics committee determined that our project didn't fall within the scope of the Swiss Federal Human Research Act (HRA) [25], thereby granting us the permission to proceed.

Theoretical approach

The overall process of culturally adapting iSupport in Switzerland was based on principles from the Community Based Participatory Research framework (CBPR), which can be defined as "an approach to research that involves collective, reflective and systematic inquiry in which researchers and community stakeholders engage as equal partners in all steps of the research process" [26]. In intervention research, adopting CBPR has the advantage to facilitate knowledge exchange between the community and researchers, reducing potential power imbalances, and increasing the likelihood of intervention uptake and success [27].
We based the specific phases and procedures of the adaptation process on the WHO iSupport adaptation guidelines which in turn, are based on the Ecological Validity Framework by Bernal et al. [22,28] that is widely used for developing culturally sensitive interventions and strengthening their ecological validity [29–31].

Study procedure

The Community Advisory Board

At the outset, we established a Community Advisory Board (CAB), composed of community members and organization representatives who shared a common identity, geography, language, culture, and other values and principles [32]. We identified potential members of the CAB through a structured stakeholder analysis and mapping accounting for the different levels of power, importance, and interest of the stakeholders in the project. We included representatives of the project's funding agencies and other collaborating partners; caregivers of people with dementia; and members of the IT service in charge of developing the iSupport website platform and application. Once consensus among researchers was reached, we contacted and informed the identified members via email using a brief description of the project, the scope of the CAB, and their expected roles and responsibilities.

In the context of iSupport adaptation, the specific roles of establishing a CAB were: 1) help researchers to identify the needs and legitimate interests and expectations of the different stakeholders and the final users, and 2) inform the development of the intervention throughout a purposely co-designed process. The adaptation process of iSupport consisted of 4 phases: 1) Content translation; 2) Linguistic and cultural revision; 3) Validation with formal and informal caregivers; and 4) Refinement and final adaptation. Each phase was based on and adapted from the WHO guidelines. Any change or proposed addition was discussed with and approved by the WHO. The members of the CAB were constantly informed and updated on the progress of the study. A flowchart of the phases is summarized in Figure 2.

Phase 1: Content translation

The first step in the cultural adaptation of iSupport was the translation of the contents (roughly 60 000 words) from English, the original language of the program, to Italian, the local language in southern Switzerland. The process started in May 2020 and finished in August 2020. According to the WHO guidelines, the translation should be accurate while recognizing the local culture and its people. In line with this, we conducted a preliminary adaptation of cultural-sensitive terms including 1) personal names of the characters used in the case studies, 2) available information materials and local services, and 3) reference to cultural habits and leisure activities in the region [22].

One member of the research team fluent in English, AM, a psychologist with previous expertise in the dementia field, translated the original contents of the iSupport program into Italian. Subsequently, a senior member of the team, MF, with expertise in the field of health communication, checked the translations and proposed changes and modifications. All disagreements or doubts about the translation of sensitive terms and expressions were documented and discussed within the research team in meetings until a consensus was reached. We sought the support of an external professional translator to resolve some specific language locutions and terms.

Throughout the process, translators applied the international standards and available dementia guidelines to avoid stigmatizing expressions and to use a language that promotes the inclusion and dignity of people living with dementia and their carers [33]. During this phase, we did not apply any changes to the meanings of the original structure of the iSupport program, including case studies or activities. All translations were copied into secured Microsoft word files and stored in a dedicated Microsoft Teams workspace to optimize efficiency.

Phase 2: Linguistic and cultural revision

In September 2020, the first CAB meeting took place with the main goals of introducing the members of the CAB to the iSupport program and the research team, clarifying their roles, and involvement throughout the research process.

During the meeting, we answered all questions and proposed an interactive activity where participants were asked to provide the translation from English to Italian of a selection of sensitive terms and expressions used in iSupport that were noted by researchers during phase 1. At the end of the introductory meeting, participants were asked to sign a letter of intent that summarized the functioning of the CAB, and their role and commitment as members of the local iSupport CAB. We explicitly specified the structure and definition of the CAB; goals, roles, and responsibilities (of both members and the research team); and duration (Multimedia Appendix 1). All nine invited participants agreed to join the iSupport CAB: four of them were informal caregivers, and the remaining five were representatives of the Government, the local Alzheimer Association, a healthcare service provider, the IT service, and the University of Applied Sciences and Arts of southern Switzerland.

In October 2020, we shared the translated contents of iSupport with the members of the CAB and asked them to evaluate and provide feedback on each chapter and module of the program by the end of December 2020.

Based on the work of previous adaptations of iSupport [34], participants were asked to carefully go through the twenty-three thematic lessons and to assess the translation and preliminary adaptation of iSupport considering six main parameters: 1) familiarity, 2) sensitivity, 3) comprehensibility, 4) precision, 5) cultural adequacy and 6) overall evaluation, and to assess the extent to which 1) the terms used were familiar to the target group (e.g. use of idioms and figures of speech); 2) the language used respected and promoted the dignity of people living with dementia and of their carers (e.g. use of stigmatizing terms); 3) contents were intelligible and easy to understand (e.g. minimal use of technical jargon); 4) contents were presented in an accurate way (e.g. the quality of the contents was correct); 5) contents were appropriate and reflected local people experiences (e.g. case studies); 6) the content of the chapter was overall culturally appropriate. At the end of each chapter, participants were asked to fill out an online survey via REDCap (Research Electronic Data Capture) [35,36] to evaluate each of the above parameters using a Likert scale from 1 to 4 (with 1 meaning *requiring an extensive revision*, and 4 *no additional revision needed*). We also invited participants to provide additional comments about single chapters through a dedicated open question in the survey or to provide free feedback on the overall program via email. The survey was specifically designed for the purpose of this phase and was based on the work of Teles and colleagues [33] to evaluate the cultural adequacy of the contents, as recommended by the WHO adaptation guidelines [22].

After the data collection period, AM and BB (research assistant with a degree in psychology and health communication) performed the descriptive analysis for quantitative data and thematic analysis of the qualitative data. In the quantitative analysis we used SPSS 25.0 statistical software [37] for Windows to compute mean scores for each program’s module and survey’s parameters. As for qualitative analysis, we performed a thematic content analysis of open comments [38]. The maintenance of scientific rigour was ensured through regular meetings among research team members, particularly involving MF and RA, both experts in qualitative research methods.

In January 2021, the main findings of this phase were summarized in a report shared across, and approved by, all CAB members.

Phase 3: Validation with formal and informal caregivers

We adopted a qualitative descriptive design, and we used focus groups (FGs) as a data collection method [39]. Between June and August 2021, we conducted FGs with formal and informal caregivers to explore their attitudes and impressions of the iSupport adapted version. We prompted and collected suggestions for improvement, as also recommended by the WHO guidelines. In addition, we decided to expand our inquiry to caregivers' attitudes toward support measures and help-seeking behaviors, which we have previously reported in detail elsewhere [40]. Between April and May 2021, we crafted an invitation letter and a flyer presenting the project, the main purpose of the FGs, the eligibility criteria, and contact information. We disseminated these materials in a local newspaper, to members of the CAB and their associations/institutions, to daycare centers for people with dementia, and to participants of other ongoing research projects who consented to be informed about further research activities.

Eligibility criteria for both formal and informal caregivers included: 1) having (at present or in the past) experience in caring for a person living with dementia; 2) being fluent in Italian and 3) living in Ticino Canton. Caregivers who met the inclusion criteria could contact us via email or by phone and were given an overview of the iSupport program, with excerpts from the same translated material used in phase 2, and the informed consent (Multimedia Appendix 2). FGs were audio-recorded, lasted approximately two hours, and took place either online via Zoom platform, or in person at the Università della Svizzera italiana in Lugano (USI). AM moderated all FGs, with the supervision of MF and RA, an expert in qualitative research. Discussions were transcribed verbatim and pseudonymized by EB, an independent research assistant. AM, RA, and MF performed a thematic content analysis to identify key themes [38]. Initially, researchers familiarized themselves with the data through repeated reading of notes and transcripts, to get an idea of the overall meaning and begin discerning key themes. Subsequently, each researcher independently identified codes within each FG (vertical analysis) and across the whole dataset (horizontal analysis) to uncover variations and patterns within the data. Themes were progressively refined and consolidated through discussion in weekly meetings over three months (from November 2021 to February 2022), and until a consensus was reached. Data management and coding processing were facilitated by NVivo12 software [41]. Additional methodological details have been previously reported [40].

Phase 4: Refinement and final adaptation

All data collected during phase 2 and phase 3 were collated to generate a set of proposed changes and adaptations to the iSupport program. AM and BB familiarized themselves with the data and differentiated the feedback between cross-cutting and general comments and specific-chapter-related comments, and arranged them across five dimensions: language, resources, contents, graphics, and extra features. Each comment was then discussed between AM and BB and categorized as 1) rejected/not applicable, 2) possibly applicable, and 3) applicable. The categorization was based on the number and contents of suggestions received, and in accordance with the WHO adaptation guidelines [22]. The feedback data that were considered possibly applicable and applicable were then discussed with the other members of the team to agree on their potential implementation.

Subsequently, all specific and applicable comments were charted using the iSupport WHO adaptation spreadsheet (Multimedia Appendix 3). All proposals of change were then supported by a rational and by the source from which the proposal came: the research team (preliminary adaptation during phase 1); the members of the CAB (results from the linguistic and cultural adaptation during phase 2); and participants from FGs (data collected during phase 3). Attached to the adaptation spreadsheets, we also sent a list of general suggestions and feedback. The material was sent for revision to iSupport WHO authors in October 2021, and the results of their final fidelity check were received in January 2022. Subsequently, the local research team implemented all the approved changes and uploaded the new adapted contents on the beta version of the iSupport Swiss web platform.

Results

A detailed description of all final adaptations made to the original iSupport program, resulting from the four phases of the adaptation process, is presented in Table 1. The results of phase 2 and phase 3 are summarized in the following paragraphs.

Adaptations from Phase 2: Linguistic and cultural revision

All nine members of iSupport CAB revised one or more modules of iSupport and provided feedback, with each module revised by at least one CAB member. Module 5 (i.e., dealing with behavioral changes) was the most revised and commented (n=7). Descriptive analysis showed that all modules were generally positively evaluated with an overall mean evaluation score of 3.72 out of 4. Mean scores of the parameters across all modules ranged from 3 to 3.89 for sensitivity; 3 to 4 for familiarity; 3.93 to 4 for comprehensibility; 3.67 to 4 for accuracy of information; 3.59 to 4 for cultural adequacy (Figure 3).

We conducted a qualitative thematic analysis of open comments and identified seven potential areas for improvement of iSupport (for more details refer to Table 1):

1) Familiarity with terms and expressions.

The unfamiliarity with the terms referred especially to some expressions that were largely used throughout the text to designate caregivers and health care workers or dementia health and social care facilities. These remarks allowed us to improve translations. For example, “informal carers “or “paid-in-home helpers” were newly translated using local terms that were easily identifiable and familiar to participants. For instance, “informal carer” was translated into “familiare curante”, which literally means “family carer”. Importantly, the term is also used at an institutional level [42] to design people who take care of a loved one (relative or friend) affected by a chronic disease.

2) Sensitivity of the language.

Participants also suggested improving the sensitivity of the language, by removing expressions potentially stigmatizing such as “suffering from dementia”, translated with “affected by dementia” (affetto da demenza), or “show compassion”, translated with “show comprehension” (mostrare comprensione).

3) Scientific accuracy of the terms.

The jargon used was generally perceived as comprehensible and easy to understand. However, some participants, especially those working in the field of dementia, reported the need to use scientific terms to improve the accuracy of the language and ultimately the users’ literacy. As a result, the expression “memory loss” was for example replaced by “memory impairment” (difficoltà di memoria); “helpful/unhelpful thoughts” was replaced by “functional or dysfunctional thoughts” (pensieri funzionali e disfunzionali).

4) Educational approach.

The educational approach referred to the criticized use of scholastic and potentially belittling terms such as “lesson”, “learn” which were replaced with: “chapter” (capitolo), and “know more about” (conoscere di più).

5) Use of English.

Additionally, some English terms that were maintained during the content translation because they are normally used in spoken Italian, were translated into Italian, including “focus” (obiettivo) and “relax” (rilassa).

6) Use of numbers.

To make the reading smoother, some participants also suggested replacing numbers with sentences, for instance from “20/30%” to “approximately one-third” (circa un terzo).

7) Language register.

Finally, almost all participants found that the tone and prose were at times informal or even childish. For example, the original sentence at the end of each chapter “you finished the lesson, well done” was replaced by “you finished the chapter, let’s go to the next” (hai completato il capitolo, passa al successivo!).

Adaptations from Phase 3: Linguistic and cultural revision

Between May and August 2021, we conducted six FGs: one with formal caregivers, and five with informal caregivers. Most participants were female, and formal carers had longer years of caring experience compared to informal caregivers. The main characteristics of participants are reported in detail in Table 2 and Table 3.

FG with formal caregivers

Formal caregivers are professionals who are trained, hired, and get paid to provide care to a person living with dementia. In our study, all six formal caregivers actively participated in online discussions. All participants were women and domestic workers. The mean age was 44 years (ranging between 28 and 59). All participants had professional experience in taking care of a person living with dementia. Three participants reported having more than 10 years of experience in dementia care. In addition to the professional caregiving experience, three participants also reported taking care of or to have taken care in the past of a relative affected by dementia (Table 2). The main findings of the FG are summarized below.

Participants agreed that an intervention aiming to support and improve the knowledge of informal caregivers of people with dementia was much needed. A caregiver compared information learning to a safeguard, not only for the carer but also for the care recipient: “*I hope that this program will spread because information protects all of us: the carer, and especially the person who is cared of.*” (ID6)

iSupport was generally appreciated and acknowledged by participants as a useful tool. Contents were found appropriate and sufficiently comprehensive. The difficulty to accept the disease and the changes in the relationship with the care recipient were found to be the main challenges and contents to cover in the program: “*There is a great difficulty from the relatives to accept the disease and the change (…) I believe a very strong support is needed…also at a social level because the disease is often associated with shame*.” (ID1)

Similarly, one participant also suggested adding to the program specific resources for social and psychological support: “*You could mention psychological support to family members because they need it, always.”* (ID2). This quote underscored the recognition from formal caregivers of the potential emotional and psychological strain on family members as they witness the disease of their care recipients.

In light of participants’ perspectives, an important feature to add to the original iSupport format was the inclusion of a platform for caregivers to engage with each other, that facilitated the caregivers’ interactions with each other, as reported in the data excerpt below. This adaptation was also needed to differentiate iSupport from another repository of information or online available resources on dementia. “*There are a billion guides on dementia (…), I think people need to interact*” (ID4)

Regarding case scenarios, caregivers generally found that the examples were appropriate and consistent with their experiences. However, answer options often did not reflect the variety of and differences in caregiving situations and experiences, including the age of the person affected by dementia, the severity of dementia, the living situation, or the type of dementia (eg. Alzheimer’s, frontotemporal dementia). A participant suggested adding general guidelines to the examples to include more answers: “*If the examples aim to increase knowledge, they should give general indications that can apply to different caring situations.” (ID6)*

FG with informal caregivers

Of the 20 informal caregivers who contacted us, 13 participants joined the FGs. Reasons for non-participation were lack of time and geographical distance. Most caregivers were female (N=10), spouses (N=7), or sons/daughters (N=6) of a person living with dementia. The age ranged from 55 to 82 years. More than half of the participants (N=8) reported a caregiving experience of at least three years, and most participants cared for a relative who lived at their own residence (N=8). Two participants reported that the person they cared for had passed away. The number of participants attending each group discussion ranged from two to seven caregivers. FGs were attended by six caregivers (FG1: 14.06.21); seven caregivers (FG2: 12.07.21); two caregivers (FG3: 15.07.21); six caregivers (FG4: 18.08.21), and two caregivers (FG5: 24.08.21), respectively. Seven participants attended more than one group. See Table 3 for more characteristics. The main findings of the five FGs are summarized below.

Participants generally believed that iSupport holds the promise to be useful, to increase dementia knowledge, and provide information about available services and support measures for people living with dementia, and their families. A participant said about the program: "The idea is brilliant because everything can be useful (...) In my opinion, the most interesting thing is the overview of what is locally available to support caregivers." (ID9; daughter)

The need for guidance and orientation to services was supported by a perceived lack of support and direction, likely stemming from the uncertainty and confusion that frequently followed the diagnosis. This feeling of bewilderment was echoed in the following quotation: "*It's confusing outside, you don't know where to go, who to turn to… there are no guidelines, no support*." (ID2; daughter)

Regarding the contents, participants reported familiarity with most of the case scenarios.
One participant commented on a scenario (Module 3, chapter 3) representing a person affected by dementia who can't find the keys and doesn't want the carer to leave him alone at home: "*It happened to me many times, not always with the keys though.*" (ID12; daughter)

However, despite the familiarity reported and the need to get information and increase knowledge to cope with difficult situations, the original exercise format was seen as a limitation by some of the participants. One participant reported feeling diminished when choosing between wrong and right answers: "*It's almost guilt-inducing (...) There is the best solution and if you guess wrong you are doing your role wrong*." (ID8; daughter)

Additionally, some answer options were considered to be so wrong as to be offensive to the carer. For example, in Module 5, chapter 9, one case scenario described a situation where the person affected by dementia (Matteo) makes sexual remarks towards a domestic worker, and the user is asked what he/she would do in that situation. One participant commented on the option "*shout at Matteo and shame him for his conduct" as inconceivable. "Shout?!… We do know what we're doing!"* (ID9; daughter)

Similar to what formal caregivers reported about case scenarios, participants also highlighted the risk of generalizing solutions that may not be appropriate for all caregiving situations: "*It should be clear that each user has to transpose his/her* *situation by taking cues from the scenario, but unfortunately it isn't black and white."* (ID13; spouse)

Finally, also informal caregivers suggested adding interactive features to iSupport online version to minimize the risk of the caregiver isolating himself. For instance, a participant reported: "*For me, the biggest utility is in connecting people (…) there should be people behind the app*." (ID5; spouse)

Table 1: Summary of adaptations

Dimension	Issues	Original text	Proposed adaptation[a]
LANGUAGE	Familiarity: Some original expressions did not sound familiar enough or were not frequently used in the local context.	1. “Informal carer”	1. “Family carer” (familiare curante)
		2. “Community center”	2. “Day-care centre” (centro diurno)
		3. “Rural areas”	3. “Remote areas” (zone isolate)
		4. “Paid in-home helper	4. “Domestic worker” (assistente familiare)
		5. “Drugs”	5. “Medications” (medicamen
	Sensitivity: Some original expressions used to designate the person who lived with dementia or the carer were considered stigmatizing or not sensitive enough.	1. “Person with dementia”; “person who suffers from dementia”	1. “Person affected by dementia” (persona affetta da demenza); “person assisted by” (persona assistita)
		2. “It’s normal to feel frustrated”	2. “It’s comprehensible to feel frustrated” (è comprensibile sentirsi frustrati)
		3. “The person you care for”	3. “The person you take care of” (la persona di cui ti prendi cura); “the person you assist” (la persona che assisti)
		4. “Show compassion”	4. “Show comprehension” (mostrare comprensione)
	Precision: Some expressions were not considered accurate enough or correct.	1. “Alzheimer’s disease is the most common cause of dementia”	1. “Alzheimer’s disease is the most common type of dementia” (la malattia di Alzheimer è una delle forme di demenza più diffuse)
		2. “Memory loss”	2. “Memory impairment” (difficoltà di memoria)
		3. “To feel full”	3. “To feel satiated” (sentirsi sazi)
		4. “Things that can or cannot be eaten”	4. “Edible or inedible substances” (sostanze commestibili o non commestibili)
		5. “Helpful/unhelpful thoughts”	5. “Functional or dysfunctional thoughts” (pensieri funzionali e disfunzionali)
		6. “Getting confused about the time”	6. "Feel disoriented" (sentirsi disorientato nel tempo e nello spazio)

		7. “Doing things over and over”	7. “Repetitive behaviour” (comportamento ripetitivo)
		8. “Changes in the brain”	8. “Cognitive impairment” (decadimento cognitivo)
	Learning approach: Current terms that were reminiscent of an overly scholastic and educational approach were replaced by more general expressions.	1. “Lesson”	1. “Chapter” (capitolo)
		2. “Learn”	2. “Know more about dementia” (conoscere di più la demenza)
		3. “Teach skills”	3. “This chapter will help you in preventing and coping with behavior changes” (questo capitolo ti aiuterà a prevenire e gestire i cambiamenti nel comportamento della persona che assisti)
	Use of English: English expressions that are also used in spoken Italian language were replaced by Italian terms.	1. “Focus of the manual”	1. Obiettivo del manuale
		2. “Relax”	2. Rilassa
		3. “Status”	3. Condizione
		4. “Stress”	4. Preoccupazione
	Use of numbers: Percentages were transformed from a numerical to an alphabetical representation.	“20-30%”	Approximately one-third (circa un terzo)
	Informal language: Some expressions were found to be “childish” or too informal.	1. “You finished the lesson, well done”	1. “You finished the chapter, let’s go to the next” (hai completato il capitolo, passa al successivo!)
		2. “Take a nap”	2. “Rest” (riposa)
RESOURCES	Need to specify local resources for dementia. Need to specify local resources for mental health.		The names and contacts of several local organizations and Alzheimer’s associations were specified in different parts of the program and in the last chapter

			Link to psychological support resources was added in M3[b] and M5[b]
CONTENTS	Need to adapt leisure activities to local culture.		Local leisure activities added: ○ Take a trip ○ Enroll in a course ○ Visit museums ○ Go to the movies or theatre ○ Go out for dinner
	Need to adapt names to local cultures.	Olivia has dementia and lives with her husband Jacob	Anna è affetta da demenza e vive con suo marito Marco
	Case scenarios: Some answer options were found offensive for the caregiver or unfamiliar.	1. Exercise M5.09 [c]: "What would you recommend to Mateo's family?" "Shout at Mateo, shaming him for his conduct"	1. The answer option was deleted because it sounded offensive to the carer
		2. Exercise M5.04 [c]: "How do you think Sofia should react?" "Sofia could for example read the newspaper to him, cook his favorite dish or visit a shop to let him straighten the shelves with the shopkeeper's permission"	2. The text "visiting a shop to let him straighten the shelves with the shopkeeper's permission" was removed because found unfamiliar
	The description of case scenarios or answer options often did not represent the variety and differences of caregiving experiences.	Disclaimer added	"Remember that there are not always one-size-fits-all solutions to a problem; there may be others more suited to your personal situation" (Ricorda che non sempre esistono soluzioni uniche a un problema, potrebbero essercene altre più adatte alla tua situazione personale)
GRAPHICS	Cartoon illustrations were often found childish, representing inanimate objects, and not consistent with the contents.	Cartoons illustrations	Cartoons illustrations were replaced by human illustrations, representing the variety of caregiving experiences and divided per module
ADDED FEATURES		1. Glossary	1. A glossary with the main recurrent terms used

		throughout the program and their explanations was added to the user's guide
	2. Interactive Forum	2. A forum section was included at the end of each chapter where participants can interact by writing
	3. Read aloud option	3. A read-aloud option was added to the relaxation exercises
	4. Navigation survey	4. An initial short questionnaire was added to personalize the navigation of the user based on his/her situation and need

[a] proposed Italian adaptations are displayed in brackets
[b] number of iSupport module
[c] number of iSupport module and chapter

Table 2: sociodemographic characteristics of formal caregivers

ID	Gender	Age	Employment status	Years of professional caring experience	Years of personal caring experience
1	Female	52	Housewife/ Retired	> 10	> 10
2	Female	54	Housewife/ Retired	>10	> 10
3	Female	28	Housewife/ Retired	6-10	
4	Female	45	Employed	< 1	< 1
5	Female	29	Housewife/ Retired	1-2	
6	Female	59	Employed	> 10	

Table 3: sociodemographic characteristics of informal caregivers

ID	Gender	Age	Employment status	Relationship with the pwd[1]	Living situation of the pwd[1]	Years of caring experience	The pwd[1] has passed away	FG Attended[2]
1	Female	58	Housewife/ Retired	Spouse	Own residence	3-5	No	5
2	Female	55	Housewife/ Retired	Daughter	Own residence	3-5	No	1;3;4
3	Female	59	Housewife/ Retired	Spouse	Own residence	3-5	No	1
4	Male	67	Employed	Son	Own residence	3-5	No	1
5	Female	58	Housewife/ Retired	Spouse	Carer’s residence	1-2	No	2
6	Male	57	Employed	Son	Own residence	3-5	No	1;4
7	Male	74	Employed	Son	N/A	> 10	Yes	1;2
8	Female	55	Employed	Daughter	Own residence	3-5	No	2;4
9	Female	75	Housewife/ Retired	Daughter	N/A	> 10	Yes	1;2;4;5
10	Female	76	Housewife/ Retired	Spouse	Own residence	3-5	No	2
11	Female	82	Housewife/ Retired	Spouse	Carer’s residence	1-2	No	2
12	Female	55	Employed	Daughter	Own residence	1-2	No	3;4
13	Female	81	Housewife/ Retired	Spouse	Carer’s residence	3-5	No	2;4

[1] Person with dementia

[2] Number of the focus group attended

Discussion

This study described in detail the main steps taken to culturally adapt the WHO iSupport program for informal caregivers of people living with dementia, in Switzerland. Our results demonstrate the complexity as well as the necessity of adapting an evidence-based complex intervention to a specific cultural context and population. We collected feedback and implemented changes, in accordance with the WHO, from the original iSupport version in the areas of the language, resources, contents, graphics, and features used in the program. In the following paragraphs, we summarize and comment on the main lessons learned.

Valuing experiential knowledge

One of the main messages we collected during the adaptation process was the importance for informal caregivers to be recognized in their role and expertise. This finding is consistent with what other studies have identified, including the works reporting on iSupport adaptation processes in other countries [31,34,43–45]. Our participants suggested that the learning approach used in the original iSupport program was too scholastic and recommended the removal of expressions that likely resulted from a top-down approach in content and compilation. Referring to case scenarios, some caregivers felt that the simplicity of certain answer options was offensive. Informal caregivers claimed to be recognized because of their lived experience as “experts in the field” who could contribute to not only locally adapting but also integrating and shaping iSupport. This echoes the inclusive procedures used to develop iSupport in the first place [21], and the work done for the iSupport adaptation process in Portugal and the UK [34,43]. Informal caregivers can spend on average 170 hours a month providing care to a loved one affected by dementia [46]. In our study, more than half of the participants reported a caregiver experience of at least three years and up to ten years. Though one may argue that caregivers acquire and improve their learning by doing, it is undeniable that they can become ‘experts’ in caring, and surely they provide a unique perspective of the person with dementia and their own needs. However, besides the years of personal experience, caregivers’ knowledge of dementia and caring may also depend on other factors and may be influenced by the educational level and socio-cultural background. Similar to any complex intervention in health [47], it is important to ensure that the final version of iSupport is also adapted to the real user's experience and pre-existing abilities. An early, timely, and active involvement of caregivers is needed [48,49]. The adoption of a language register and skills training techniques that promote pre-existing abilities, rather than replace them, may enhance the acceptance and use of the intervention.

Enhancing social contacts

According to participants, iSupport could benefit from the inclusion of interactive features (e.g., chat and forum) that allow the user to communicate with other caregivers and share experiences and problem-solving strategies. This finding is consistent with a recent study [50] that found that peer support can be complementary to professional support and beneficial in reducing social isolation, and in connecting patients and caregivers to others with similar issues. Similarly, Greenwood and colleagues [51] found that, besides providing psychosocial support, peer support interactions for caregivers of people with dementia can offer practical information and guidance in managing difficult situations and gaining new perspectives on their caring role. The adoption of peer support programs for informal caregivers of people with chronic diseases and disabilities is well-established in the literature [52]. A recent scoping review [53] found that peer support was often part of multicomponent interventions that also addressed information sharing, skill development, personal coping skills and self-management. Despite the difficulty in identifying what component may or may not be beneficial for the carers, the authors concluded that peer support, particularly if delivered online, could represent a cost-effective medium and opportunity to meet caregivers' needs and preferences. Importantly, online meets between peers seem more promising, usable, and potentially effective for caregivers when embedded in online interventions [10], like iSupport.

Facilitating access to and navigation of local services

Another suggested feature to implement in the program was the inclusion of contacts of local resources for dementia, such as health care services and facilities, charities, or other relevant organizations. Consistently with what our participants reported, informal caregivers often experience a lack of information and support, especially at the beginning of the caregiver journey, when it is best to establish fruitful contacts and interactions with local health and social care services and offers in general [1]. According to the latest World Alzheimer Report [3], less than 50% of informal caregivers are advised to contact the local Alzheimer association or receive post-diagnostic support information. The navigation of the services and various offers for both people living with dementia and informal caregivers is taxing, often ineffective, and can be frustrating. The lack of information about existing services and support is associated with caregiver burden and distress [54]. A recent review on the needs of family caregivers revealed that information provided on available support services and measures was one of the main needs reported by caregivers after receiving the diagnosis [55]. Caregivers may seek support autonomously, mainly online. However, the variety of information and sources available on the Internet about dementia may contribute to creating feelings of bewilderment and difficulties in finding relevant and reliable information [56]. Hence, online interventions that also include contacts with external and local resources may help users to access and navigate the healthcare system and find the most appropriate service or information for their situation.

Limitations

We acknowledge that our study has limitations. Firstly, we included a few participants for each phase of the adaptation process. Because of their pressing needs and duties informal caregivers are a challenging population to reach and involve in research [57]. However, the number of caregivers and experts that we included in our study was adequate for the qualitative methods used and is higher than the minimum recommended by the WHO guidelines to adapt iSupport to local contexts [22]. In addition, we set up a Community Advisory Board (CAB) that included both stakeholders and caregivers, who worked with great dedication and continuity through the adaptation process of iSupport. Secondly, the discrepancy in FG size between formal and informal caregivers, and the attendance of informal caregivers in more than one group may have contributed to reaching data saturation, but it may have reduced social desirability bias thanks to both the progressive cementing of positive small group dynamics between participants and to the variety of the contents discussed. Thirdly, our study was conducted in Switzerland, a high-income country, equipped with a National Dementia Strategy that aims to improve the quality of life of people affected by dementia and to promote awareness and education on dementia [58]. Therefore, the feedback and experiences that we collected may not be easily generalized to all contexts. However, the adaptation strategies and phases described in our study may be useful for all countries interested in adapting online interventions for caregivers of people with dementia, not only iSupport. Our findings suggest that online interventions benefit from a participatory approach and the involvement of caregivers to ensure the final program meets the needs and preferences of the users [17].

Future research

The results that we collected during this study allowed us to adapt the original contents of the iSupport program to the Swiss context and to inform the development of the iSupport desktop version, mobile application and printed version. Following the Medical Research Council Guidelines for the development of complex interventions in health [59], we will proceed to assess the usability and feasibility of iSupport before its implementation. Evidence not only on the effectiveness, but also the ease of implementation and scalability of caregivers' interventions is still sparse, and nonexistent in our country. We are determined to design and conduct good quality studies to address these gaps and to promptly disseminate our findings and experience widely, through peer-reviewed publications, the WHO knowledge exchange platform [60], and the global WHO iSupport network coordinated by the Brain Health Unit at the WHO. Finally, the iSupport original program has been developed by the WHO on evidence related to carer training and support interventions and in collaboration with experts and caregivers [21]. Therefore, the program can be adapted to the extent it maintains the original aims and structure [22]. During the study, we collected recommendations and feedback that would have required a consistent change in terms of resources and digital infrastructure to be implemented. These included for instance contents based on the type of dementia and stage of the disease; a comprehensive map of all online and local resources available; consultation from professionals and legal and financial assistance. Therefore, further development of iSupport could focus on supporting specific groups of caregivers, such as young carers or caregivers of people with rare dementia, and on providing personalized support tailored to the stage of the caregiver journey and the care needs of the care recipient.

Conclusion

Despite the recognized importance of culturally adapting interventions to implement them in real-world settings, the evidence on how to conduct this process is still limited. Our study enriches this landscape by underscoring that an active engagement of the final users and stakeholders allow to adapt an intervention to their culture, values and needs. Additionally, this study provides examples of concrete strategies and methods to involve the community members and stakeholders across different phases of the intervention. Indeed, despite the emerging importance of co-constructing research together with people as collaborators, rather than simply "subjects" of traditional research, there is limited evidence regarding the modalities of this practice. Our experience confirms how the adoption of a community-based participatory approach is necessary to identify and address criticisms and potential barriers to the use and acceptance of an online educational intervention before its implementation. In conclusion, we envision this study as a potential driver for enhancing a more robust dialogue between researchers and communities. We firmly believe that community-based participatory research represents a transformative research opportunity where academics' and community members' needs can meet and find opportunity for mutual knowledge exchange and growth.

References

1. World Health Organization. Dementia. 2022. Available from: https://www.who.int/news-room/fact-sheets/detail/dementia

2. Alzheimer Schweiz. Persa l'opportunità di un programma nazionale di ricerca sull'Alzheimer. 2022. Available from: https://www.alzheimer-schweiz.ch/it/media/communicato-stampo-14032022

3. Alzheimer Disease International. World Alzheimer Report 2018. The state of the art of dementia research: New frontiers. 2018. Available from: https://www.alz.co.uk/research/world-report-2018

4. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: A systematic review of family caregivers' perceptions. BMJ Supportive and Palliative Care BMJ Publishing Group; 2020; doi: 10.1136/bmjspcare-2020-002242

5. Gilhooly KJ, Gilhooly MLM, Sullivan MP, McIntyre A, Wilson L, Harding E, Woodbridge R, Crutch S. A meta-review of stress, coping and interventions in dementia and dementia caregiving. BMC Geriatrics BioMed Central Ltd.; 2016 May;16(1). doi: 10.1186/s12877-016-0280-8

6. Kovaleva M, Spangler S, Clevenger C, Hepburn K. Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. J Psychosoc Nurs Ment Health Serv 2018 Oct;56(10):36–43. doi: 10.3928/02793695-20180329-04

7. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. International Journal of Nursing Sciences Chinese Nursing Association; 2020 Oct;7(4):438–445. doi: 10.1016/j.ijnss.2020.07.012

8. Kurasawa S, Yoshimasu K, Washio M, Fukumoto J, Takemura S, Yokoi K, Arai Y, Miyashita K. Factors influencing caregivers' burden among family caregivers and institutionalization of in-home elderly people cared for by family caregivers. doi: 10.1007/s12199-012-0276-8

9. World Health Organization. Global action plan on the public health response to dementia 2017–2025. 2017. Available from: https://www.who.int/publications/i/item/9789241513487

10. Hopwood J, Walker N, McDonagh L, Rait G, Walters K, Iliffe S, Ross J, Davies N. Internet-based interventions aimed at supporting family caregivers of people with dementia: Systematic review. Journal of Medical Internet Research Journal of Medical Internet Research; 2018 Jun;20(6). doi: 10.2196/jmir.9548

11. Parra-Vidales E, Soto-Pérez F, Victoria Perea-Bartolomé M, Franco-Martín MA, Muñoz-Sánchez JL. Online interventions for caregivers of people with dementia: a systematic review. 2017 p. 116–142.

12. Naunton Morgan B, Windle G, Sharp R, Lamers C. eHealth and Web-Based Interventions for Informal Carers of People With Dementia in the Community: Umbrella Review. J Med Internet Res 2022 Jul 22;24(7):e36727. PMID:35867388

13. Rogers MAM, Lemmen K, Kramer R, Mann J, Chopra V. Internet-delivered health interventions that work: Systematic review of meta-analyses and evaluation of website availability. Journal of Medical Internet Research JMIR Publications Inc.; 2017 Mar;19(3). doi: 10.2196/jmir.7111

14. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: Systematic review and meta-analysis. Journal of Medical Internet Research JMIR Publications Inc.; 2020 Sep;22(9). doi: 10.2196/19468

15. Guay C, Auger C, Demers L, Mortenson WB, Miller WC, Gélinas-Bronsard D, Ahmed S. Components and Outcomes of Internet-Based Interventions for Caregivers of Older Adults: Systematic Review. J Med Internet Res 2017 Sep 19;19(9):e313. doi: 10.2196/jmir.7896

16. Zhao Y, Feng H, Hu M, Hu H, Li H, Ning H, Chen H, Liao L, Peng L. Web-based interventions to improve mental health in home caregivers of people with dementia: Meta-analysis. Journal of Medical Internet Research Journal of Medical Internet Research; 2019 May;21(5). doi: 10.2196/13415

17. Goodridge D, Reis N, Neiser J, Haubrich T, Westberg B, Erickson-Lumb L, Storozinski J, Gonzales C, Michael J, Cammer A, Osgood N. An App-Based Mindfulness-Based Self-compassion Program to Support Caregivers of People With Dementia: Participatory Feasibility Study. JMIR Aging 2021 Nov 26;4(4):e28652. doi: 10.2196/28652

18. McCarron HR, Finlay JM, Sims T, Nikzad-Terhune K, Gaugler JE. Stakeholder Engagement to Enhance Interventions for Family Caregivers of People with Dementia: A Case Study of Care to Plan. Journal of Gerontological Social Work Routledge; 2019 Jan;62(1):29–47. doi: 10.1080/01634372.2018.1505797

19. Boots LMM, De Vugt ME, Van Knippenberg RJM, Kempen GIJM, Verhey FRJ. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. International Journal of Geriatric Psychiatry John Wiley and Sons Ltd; 2014;29(4):331–344. doi: 10.1002/gps.4016

20. Rathnayake S, Moyle W, Jones C, Calleja P. mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. Dementia SAGE Publications Ltd; 2019 Nov;18(7–8):3091–3112. doi: 10.1177/1471301218768903

21. Pot AM, Gallagher-Thompson D, Xiao L, Willemse B, Rosier I, M. Mehta K, Zandi D, Tarun D. iSupport: a WHO global online intervention for informal caregivers of people with dementia. World Psychiatry 2019;18:3–3. doi: 10.1002/wps.20683

22. World Health Organization. iSupport for dementia. 2019. Available from: https://www.who.int/publications/i/item/9789241515863

23. Perera C, Salamanca-Sanabria A, Caballero-Bernal J, Feldman L, Hansen M, Bird M, Hansen P, Dinesen C, Wiedemann N, Vallières F. No implementation without cultural adaptation: A process for culturally adapting low-intensity psychological interventions in humanitarian settings. Conflict and Health BioMed Central; 2020 Jul;14(1). doi: 10.1186/s13031-020-00290-0

24. Theobald S, Brandes N, Gyapong M, El-Saharty S, Proctor E, Diaz T, Wanji S, Elloker S, Raven J, Elsey H, Bharal S, Pelletier D, Peters DH. Implementation research: new imperatives and opportunities in global health. The Lancet Lancet Publishing Group; 2018 Nov;392(10160):2214–2228. doi: 10.1016/S0140-6736(18)32205-0

25. Federal Office of Public Health (FOPH). Swiss Federal Human Research Act (HRA). 2023. Available from: https://www.swissmedic.ch/dam/swissmedic/en/dokumente/bewilligungen/klv/federal_act_on_researchinvolvinghumanbeingshumanresearchacthra.pdf.download.pdf/federal_act_on_researchinvolvinghumanbeingshumanresearchacthra.pdf

26. Tremblay MC, Martin DH, McComber AM, McGregor A, Macaulay AC. Understanding community-based participatory research through a social movement framework: A case study of the Kahnawake Schools Diabetes Prevention Project. BMC Public Health BioMed Central Ltd.; 2018 Apr;18(1). doi: 10.1186/s12889-018-5412-y

27. Wallerstein N, Duran B. Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity. Am J Public Health 2010 Apr;100(S1):S40–S46. doi: 10.2105/AJPH.2009.184036

28. Bernal G, Bonilla J, Bellido C. Ecological Validity and Cultural Sensitivity for Outcome Research: Issues for the Cultural Adaptation and Development of Psychosocial Treatments with Hispanics. 1995.

29. Chen S, editor. Social support and health: theory, research, and practice with diverse populations. Hauppauge, New York: Nova Science Publishers, Inc; 2013. ISBN:978-1-62618-648-4

30. Sands MM, Meadan H, Ramos-Torres S, Fanta A. The Cultural and Linguistic Adaptation of a Caregiver-Implemented Naturalistic Communication Intervention. Early Childhood Educ J 2023 Jan;51(1):43–53. doi: 10.1007/s10643-021-01280-4

31. Xiao LD, Ye M, Zhou Y, (Rita) Chang H-C, Brodaty H, Ratcliffe J, Brijnath B, Ullah S. Cultural adaptation of World Health Organization iSupport for Dementia program for Chinese-Australian caregivers. Dementia SAGE Publications; 2022 Aug;147130122211100–147130122211100. doi: 10.1177/14713012221110003

32. Matthews AK, Anderson EE, Willis M, Castillo A, Choure W. A Community Engagement Advisory Board as a strategy to improve research engagement and build institutional capacity for community-engaged research. Journal of Clinical and Translational Science Cambridge University Press (CUP); 2018 Apr;2(2):66–72. doi: 10.1017/cts.2018.14

33. Dementia Australia. Dementia Language Guidelines. 2021. Available from: https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf

34. Teles S, Napolskij MS, Paúl C, Ferreira A, Seeher K. Training and support for caregivers of people with dementia: The process of culturally adapting the World Health Organization iSupport programme to Portugal. Dementia SAGE Publications Ltd; 2020; doi: 10.1177/1471301220910333

35. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, McLeod L, Delacqua G, Delacqua F, Kirby J, Duda SN. The REDCap consortium: Building an international community of software platform partners. Journal of Biomedical Informatics 2019 Jul 1;95:103208. doi: 10.1016/j.jbi.2019.103208

36. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. Journal of Biomedical Informatics 2009 Apr 1;42(2):377–381. doi: 10.1016/j.jbi.2008.08.010

37. IBM Corp. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp; 2017.

38. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006 Jan;3(2):77–101. doi: 10.1191/1478088706qp063oa

39. Holly C, Bugel MJ, Scuderi D, Estrada RP, Harvey J, Echevarria M, Giuliante MM, Antonio AS, Duncan KA, Shuler JB. Qualitative Descriptive Research. Scholarly Inquiry and the DNP Capstone Springer Publishing Company. New York, NY, USA; 2013. p. 69–82.

40. Messina A, Amati R, Albanese E, Fiordelli M. Help-Seeking in Informal Family Caregivers of People with Dementia: A Qualitative Study with iSupport as a Case in Point. International Journal of Environmental Research and Public Health 2022 Jun;19(12):7504–7504. doi: 10.3390/ijerph19127504

41. QSR International Pty Ltd. (2018). NVivo (Version 12). Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

42. Strategia cantonale sulle demenze. 2016. Available from: https://www4.ti.ch/dss/dsp/umc/cosa-facciamo/progetti/strategia-cantonale-sulle-demenze

43. Masterson-Algar P, Egan K, Flynn G, Hughes G, Spector A, Stott J, Windle G. iSupport for Young Carers: An Adaptation of an e-Health Intervention for Young Dementia Carers. International Journal of Environmental Research and Public Health MDPI; 2023 Jan;20(1). doi: 10.3390/ijerph20010127

44. Baruah U, Loganathan S, Shivakumar P, Pot AM, Mehta KM, Gallagher-Thompson D, Dua T, Varghese M. Adaptation of an online training and support program for caregivers of people with dementia to Indian cultural setting. Asian Journal of Psychiatry Elsevier B.V.; 2021 May;59. doi: 10.1016/j.ajp.2021.102624

45. Oliveira D, Jacinto AF, Gratao ACM, Ottaviani AC, Ferreira CR, Monteiro DQ, Barham EJ, Orlandi F de S, de Cruz KCT, Correa L, Zazzeta M, Pavarini SCI. Translation and cultural adaptation of iSupport in Brazil. Alzheimer’s & Dementia Wiley; 2020 Dec;16(S7). doi: 10.1002/alz.038917

46. Friedman EM, Shih RA, Langa KM, Hurd MD. US prevalence and predictors of informal caregiving for dementia. Health Affairs Project HOPE; 2015;34(10):1637–1641. doi: 10.1377/hlthaff.2015.0510

47. Beck C, McSweeney JC, Richards KC, Roberson PK, Tsai PF, Souder E. Challenges in tailored intervention research. Nursing Outlook 2010 Mar;58(2):104–110. doi: 10.1016/j.outlook.2009.10.004

48. Dam AEH, de Vugt ME, van Boxtel MPJ, Verhey FRJ. Effectiveness of an online social support intervention for caregivers of people with dementia: the study protocol of a randomised controlled trial. Trials 2017 Aug 29;18:1–10. doi: 10.1186/s13063-017-2097-y

49. de Beurs D, van Bruinessen I, Noordman J, Friele R, van Dulmen S. Active Involvement of End Users When Developing Web-Based Mental Health Interventions. Front Psychiatry 2017 May 3;8:72. doi: 10.3389/fpsyt.2017.00072
50. Joo JH, Bone L, Forte J, Kirley E, Lynch T, Aboumatar H. The benefits and challenges of established peer support programmes for patients, informal caregivers, and healthcare providers. Family Practice 2022 Sep 24;39(5):903–912. doi: 10.1093/fampra/cmac004

51. Greenwood N, Habibi R, MacKenzie A, Drennan V, Easton N. Peer support for carers: A qualitative investigation of the experiences of carers and peer volunteers. American Journal of Alzheimer’s Disease and other Dementias SAGE Publications Inc.; 2013;28(6):617–626. doi: 10.1177/1533317513494449

52. Solomon P. Peer Support/Peer Provided Services Underlying Processes, Benefits, and Critical Ingredients. Psychiatric Rehabilitation Journal 2004;27(4):392–401. doi: 10.2975/27.2004.392.401

53. Carter G, Monaghan C, Santin O. What is known from the existing literature about peer support interventions for carers of individuals living with dementia: A scoping review. Health and Social Care in the Community Blackwell Publishing Ltd; 2020 Jul;28(4):1134–1151. doi: 10.1111/hsc.12944

54. Putri YSE, Putra IGNE, Falahaini A, Wardani IY. Factors Associated with Caregiver Burden in Caregivers of Older Patients with Dementia in Indonesia. International Journal of Environmental Research and Public Health MDPI; 2022 Oct;19(19). doi: 10.3390/ijerph191912437

55. Steenfeldt VØ, Aagerup LC, Jacobsen AH, Skjødt U. Becoming a Family Caregiver to a Person With Dementia: A Literature Review on the Needs of Family Caregivers. SAGE Open Nursing 2021 Jan;7:237796082110290. doi: 10.1177/23779608211029073

56. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A. In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. BMC Geriatrics BioMed Central Ltd.; 2016 Sep;16(1). doi: 10.1186/s12877-016-0338-7

57. Leslie M, Khayatzadeh-Mahani A, MacKean G. Recruitment of caregivers into health services research: lessons from a user-centred design study. Res Involv Engagem 2019 Dec;5(1):17. doi: 10.1186/s40900-019-0150-6

58. National Platform Dementia. Available from: www.nationaldementiastrategy.ch

59. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, Boyd KA, Craig N, French DP, McIntosh E, Petticrew M, Rycroft-Malone J, White M, Moore L. A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. The BMJ BMJ Publishing Group; 2021 Sep;374. doi: 10.1136/bmj.n2061

60. World Health Organization. WHO launches new platform for knowledge exchange on dementia. 2021. Available from: https://www.who.int/news/item/05-05-2021-who-launches-new-platform-for-knowledge-exchange-on-dementia

Chapter 7: Discussion

The aim of this PhD project was to explore the landscape of informal caregivers of people with dementia, especially through the investigation of their mental health, needs and preferences towards support measures and interventions. iSupport is the official WHO tool for informal caregivers of people with dementia, which requires careful local adaptation. The adaptation of iSupport served as both a guide and an opportunity for a thorough exploration of caregivers’ needs and the potential solutions to support them. The following paragraphs present a summary and discussion of the main results found within and across the conducted studies, which addressed specific research questions.

Summary of findings

In chapter 3, **study 1**, we explored mental health and loneliness of caregivers of people with dementia. The burden of care provision on caregivers is notorious, but comparisons of burden levels between contexts and cultures is very limited. In line with the existing literature, our findings demonstrated that caregivers living in Ticino reported higher levels of psychological distress and loneliness compared to caregivers living in Italy. Specifically, they reported severe levels of emotional burden and anxiety. These results underscore the critical importance of providing support to this population in managing their caregiving tasks while safeguarding their psychological well-being. This first set of results of my PhD project has important and urgent implications. We believe that it is imperative for public health and local social policies to implement adequate tools and support interventions to ensure that caregivers of individuals with dementia can fulfill their roles while preserving their mental health.

In **study 2** (chapter 4), we uncovered a distinct gap between the caregivers' need for support and their actual pursuit and use of such support. Notably, several emotional (level of burden), cultural (sense of duty), relational (fear of stigma), and environmental (difficulty in reaching information) barriers seem to impede the act of seeking help. Without the intention to seek help, even highly evidence-based support tools run the risk of remaining underutilized. Recognizing these barriers, alongside the factors that facilitate help-seeking, seems crucial for developing interventions that genuinely align with caregivers' needs. The adoption of a collaborative and participatory approach that involves both formal and informal caregivers may help researchers in identifying in advance the potential barriers and make support tools more accessible. Accessibility is one key indicator of successful implementation of effective interventions. Acceptability, fidelity, and sustainability are also important and must be measured when piloting, testing, and formally assessing complex interventions. To this end, it is key to empower and actively involve in research people with lived experience.

These implications, along with the project of developing and adapting iSupport to Ticino, led us to investigate how digital interventions for caregivers are currently structured and developed in practice (**study 3,** chapter 5). Specifically, we explored the existing literature and appraised evidence about the adoption and implementation of participatory methods (PM) in the design and development of interventions, investigating the specific approaches and techniques applied. We searched, selected, and appraised existing studies and found a general lack of consistency in the application and documentation of PM across them. While few studies mentioned the application of PM with caregivers and different stakeholders, they often failed to articulate the practical implications of this involvement on the structure of the interventions. Much remains to be done.

The findings from the previous studies played a crucial role in shaping the development of iSupport, which was a core activity of this PhD. The intricate process of linguistic and cultural adaptation for iSupport is comprehensively documented in **study 4** (chapter 6). Findings from this study demonstrated the need of cultural adapting adaptation an evidence-based intervention to a specific context before implementing it in real world-conditions. Thanks to the adoption of a community based participatory approach (CBPR), we applied relevant changes to the original version of iSupport, specifically on the language, resources, contents, graphics, and interactive features. These are key prerequisites to shape interventions to the target groups needs and are features worth considering in the evaluation of the impact of interventions in research, and after their implementation. Among these insights, the adoption of a more formal yet less academic language, the emphasis on facilitating access to support tools and information, and the potential inclusion of features enabling communication with other caregivers or professionals were notable. Only by actively listening to caregivers and recognizing them as experts in their own experiences, rather than mere recipients of an intervention, we could adapt iSupport into a more familiar and useful solution in their daily lives. This work was instrumental to enable subsequent testing and evaluation of iSupport. However, it was also crucial to address an evidence gap in the field of complex interventions for caregivers. Knowledge about the modulating factors for the uptake, understanding, use, and fidelity of interventions is indispensable to inform and improve implementation and scalability after research finishes.

Lessons learnt

While this PhD project mainly focuses on key questions of access to and use of a complex intervention for caregivers of people with dementia, we devoted a time and energy to the adaptation of iSupport in Switzerland, and the informative research conducted for this thesis goes beyond this scope.

This experience provided us with a multifaceted understanding of informal care, through the adoption of multiple lenses and methods. Our journey started from obtaining an overview of caregivers' mental health and wellbeing through a cross-sectional survey. Subsequently, we explored their lived experiences and attitudes towards support measures through focus group discussions. Finally, we investigated into the domain of online interventions though a systematic review to guide the adaptation and implementation of iSupport in Switzerland.

While each study carries its own implications, that are detailed in the respective chapters, we identified two overarching and transversal topics that will be addressed in the following paragraphs: "the paradox of needing and accepting help" and "the urgency of a participatory implementation research". These lessons learnt are based on the experience of these years of research and are supported by the existing literature on the topic. This PhD has the potential to inform not only the design and conduction of future studies in caregiving, but also to formulation of hypotheses and specific research questions. These findings have the potential to contribute to advance knowledge on effective strategies for supporting caregivers and the underlying reasons for their efficacy. Moreover, these insights pave the way for policy, and practice strategies and actions in the context of informal care.

The paradox of needing and accepting help

In study 1, an in line with the existing literature (Schulz & Martire, 2004), we found severe levels of psychological distress among caregivers. However, during our research, particularly in study 2, we uncovered a significant gap between the need of caregivers to be supported and the actual use of support measures. Boots and colleagues (Boots et al., 2015) highlighted a clear paradox between the need of support and the acceptance of support, especially in caregivers at the early stages of dementia. While help-seeking is scarce in caregivers at the beginning of their caring journey, the authors found that caregivers in later stages of dementia retrospectively regret not having seeking help in the past. This finding aligns with the concept of caregiving as a process (Gaugler et al., 2004), in which not only lifestyle adjustments take place but also shifts in the acceptance and perception of the disease evolve. Similarly to our findings, the authors found that fear of stigma, not acknowledging the disease and a lack of knowledge about dementia limited the acceptance process (Boots et al., 2015). Paradoxically, feeling burdened and emotionally overwhelmed may contribute to a reluctance or hesitance in accepting help. That this finding was confirmed in our project is a crucial contribution towards the design and implementation of studies aimed at translating results of research into practice, and policy that can truly and factually address the very largely unmet needs of caregivers.

In addition to the already mentioned barriers, the social and cultural representation of dementia also plays an important role. As previously mentioned, most part of the literature in this domain has mostly focused on the challenges and negative aspects of the disease, largely overlooking the positive facets, albeit present, associated with caregiving. This has contributed to the development of a unidimensional representation of dementia, wherein the disease is believed to inevitably cause distress upon both the individuals living with dementia and their families, increasing the fear and apprehension surrounding this condition. This perspective is not only common in research but also in everyday life and language. The metaphors used in the media to refer to Alzheimer's Disease (AD) can be seen as a mirror of the fear and stigma of dementia (Zimmermann, 2017). Several authors claim that military metaphors such as "war"; "battle"; "defeat", widely used in medicine, influence the way people conceptualise and experience the diseases, included dementia (Lane et al., 2013). In line with other international studies (Alzheimer Europe, 2011), a recent cross-sectional study in Australia showed that dementia was the second most feared condition among health service consumers after cancer (Watson et al., 2023). Despite being relatively unexplored in literature, fear of dementia, also conceptualized as “dementia worry” (Kessler et al., 2012) may act as an important barrier to delayed diagnosis and support. Therefore, fear may prevent people from seeking help, consequently limiting the access to and the use of healthcare and social services and interventions, including iSupport.

A comprehensive understanding of the multitude of factors at play, encompassing not only psychological aspects but also social and cultural influences, is of paramount significance in the development of public health interventions for this specific population. This understanding extends to the initial pursuit of a diagnosis and the subsequent journey in adhering to support interventions. Without a thorough comprehension of the determinants guiding individuals' utilization or avoidance of support measures, even the most efficacious interventions risk yielding limited results. To attain a deeper understanding, the transition from a top-down intervention approach to a bottom-up approach is imperative. This transition requires an active collaboration among not only the end users but also all other stakeholders involved in the process, to collectively build the support they seek to access. In line with this perspective, iSupport is an ideal entry point to a combined top-down and bottom-up approach but requires a local adaptation that must rely on the active and informed involvement of a large variety of stakeholders, users, and other relevant actors, as this PhD project clearly demonstrated.

The urgency of a participatory implementation research

Implementation research aims at improving people’s health though well-informed policies, empowered communities and proficient program implementers and health care providers (Theobald et al., 2018). Among the key goals of implementation research are to strengthen and improve equity, efficiency, scalability, and sustainability of complex interventions.

Compared to other research approaches, implementation research holds a distinct advantage and challenge in engaging a diverse array of stakeholders, often extending beyond academic field, and encompassing various systems and organizations (Skivington et al., 2021). In this type of research, academic work invariably interacts with the complexity of the surrounding context and community. Furthermore, the iterative process of developing and evaluating complex interventions, such as iSupport, demands a multifaceted methodological approach that frequently encompasses both quantitative and qualitative techniques. It also requires different research objects, ranging from individual caregivers’ experiences to an in-depth examination of the contextual factors in which the intervention is introduced. It becomes evident that the efficacy of an intervention, intended as its ability to achieve intended clinical outcomes, loses significance when we fail to account for the intervention's adaptability, acceptability, and accessibility in diverse real-world situations and contexts.

Participatory methods (PM) are a promising approach for research designs, methods and frameworks that involve a direct collaboration and partnerships between researchers, and stakeholders, community members or others with knowledge and expertise on the topic (Vaughn & Jacquez, 2020). In line with our experience in adapting iSupport, the literature shows that PM represent an opportunity for implementation science to better understand what factors serve as barriers or facilitators to implementation within specific contexts (Tabak et al., 2012) Indeed, through the exchange of knowledge between researchers, communities, and institutions, research efforts can enhance their capacity to comprehensively evaluate and effectively respond to contextual influences (Glasgow & Emmons, 2007). Recently, some authors referred to the term “participatory implementation science” to indicate the systematic integration of PM in implementation research (Ramanadhan et al., 2018). While participatory approaches have the potential to close the gap between research and practice, they have not yet become a standard practice in public health, as also reported in our study (Ramanadhan et al., 2018). A study carried out in the United States in 2009, showed that only 0.33% of funded health interventions adopted PM (Oetzel et al., 2015). Nearly 15 years later, PM are becoming more common. Standards about PM and its applications in implementation research are though lacking. Therefore, the application instances of PM provide tangible demonstrations of both the potential and practical aspects of PM.

And yet, despite the advantages of adopting PM, this approach requires extensive efforts in information gathering, relationship monitoring, and the establishment of a common language to translate the research into a clear and comprehensible message for community members, implementers, researchers, and policy makers. To our knowledge, there are currently few methodological references and clear guidelines available to guide researchers in this specific approach, especially in the context of dementia care. Indeed, during the adaptation of iSupport, we encountered several challenges, such as determining the relevant stakeholders to engage in the process, deciding effective strategies for involvement, and defining the levels of engagement and decision making throughout the process. The scarcity of established methodological guidelines can pose a significant barrier for researchers working in implementations research. Therefore, there is a growing need to develop such resources to guide research efforts and ensure that initiatives are implemented effectively, scaled, and put in practice. We plan to devote more work into the evolution and strengthening of PM applications in various areas of public health research.

Limitations

Although each individual study has its own specific limitation, there are some overarching limitations that should be acknowledged in the present dissertation.

The main limitation is the potential heterogeneity of the studies included in our research synthesis exercises. This thesis includes four studies that differ all in terms of research questions, study designs, and methodologies, spanning from quantitative to qualitative and mixed methods. However, we believe that this variety was unavoidable and did contribute to navigate the complex landscape of dementia care. Indeed, each research question was developed upon the findings of the previous studies, and in line with the primary need of understanding the context and preventing potential barriers in the uptake and adoption of iSupport. Moreover, implementation research is naturally composed of multiple disciplines and approaches to address the complexity of its mission that include a variety of targets, from individual, to organizational, community or global levels.

Further, readers may have noticed that we didn’t provide information on the usability and feasibility of iSupport, but only on its cultural adaptation process. While we recognize that this may be perceived as an additional limitation, we purposely decided to emphasize the importance of culturally adapting an intervention before measuring its effectiveness, which may not be optimally ethical (testing the efficacy of poorly adapted interventions compromises the roots of the risk-benefits balance of research). Existing research confirms that, although cultural adaptation is considered a crucial phase in the implementation of interventions, it is often neglected and scarcely reported in literature. We know little about whether adaptation was done, and much less on how adaptation was done for most complex interventions in public health. We are glad to anticipate that the assessment of the usability and feasibility of iSupport has been already carried out as an integral part of this PhD project. We are working now on the dissemination of our findings and the associated manuscripts are currently in preparation.

Another potential limitation pertains to the specificity of the research context which might constrain the external validity of our findings. We focused on informal caregivers of people with dementia. Formal, professional caregivers were not explicitly targeted. Nor did we contemplate caregivers of people affected not by dementia. Moreover, most part of the research was conducted in Ticino, a unique cultural environment within Switzerland, and the generalizability of our results to other contexts may take this into account. Nevertheless, the experiences that we collected from the caregivers were in large part analogous with other contexts and experiences related to iSupport adaptation in different countries. This implies that, despite variations, informal caregiving encompasses aspects that are not bound by specific cultural contexts and can be applied to different cultures and settings.

Finally, we could not include people living with dementia (plwd) from iSupport adaptation, which is a potential limitation in this research. In recent years, several international organizations, including the WHO, ADI, and Alzheimer Europe, have emphasized the importance of incorporating the perspective of plwd in dementia research. This is crucial for achieving a more comprehensive understanding of the condition and promoting person-centered care approaches. However, involving people with dementia in research introduces several considerations. In our case, as iSupport primarily aims to support caregivers and their well-being, it was essential for us to gather their authentic experiences to tailor the intervention to their needs. Therefore, involving care recipients could potentially introduce social desirability bias among caregivers, limiting or distorting the expression of needs and the authenticity of their reported experiences. Furthermore, including people with dementia in research projects usually necessitates an assessment of their cognitive abilities and impairments, which could lead to the potential exclusion of certain caregiver-care recipient dyads, thus introducing a selection bias. Additionally, depending on the level of cognitive and physical impairment, the involvement of plwd requires additional resources, such as adapted spaces, activities, and tools which must be considered before starting the project. In our experience, the fact that individuals with dementia were included from the outset in the development of iSupport ensures that their voices are, at some extent, reflected in the program's content and theme (Pot et al., 2019).

In conclusion, there is a pressing need for well-defined guidelines to assist researchers in addressing the multifaceted aspects of involving plwd in dementia research. Nevertheless, this inclusion is paramount, as it holds the key to a more profound comprehension of the dyadic and relational elements, as previously discussed, that influence the well-being of both the caregiver and the care recipient.

Contributions and further directions

The research conducted within this PhD project has facilitated a valuable exchange and dissemination of findings, which subsequently evolved into international collaborations and local research projects focused on the topic of informal dementia care. Below are summarized two of the main outputs that I achieved from this experience: the international collaboration with the WHO iSupport International network, and the involvement in a new project, funded by the SNSF and carried out at the Institute of Public Health, supervised by Dr. Maddalena Fiordelli.

iSupport WHO International network

In 2020, we became members of the iSupport Network, established by the World Health Organization (WHO). The network is composed by international researchers and members of the community that are involved in adapting iSupport across different populations and cultures. The network aims at sharing knowledge and lessons learned on the adaptation and implementation processes from different cultural backgrounds and translate them into concrete implications and guidance. The decision of establishing a network originates from the needs of iSupport implementers, who sought to share their experiences and challenges encountered during the implementation process, and to receive support and strategies from fellow researchers and the WHO representatives. The ultimate goal is to collaboratively formulate best practices and recommendations to enhance the intervention and its scalability in different cultural contexts.

Our involvement entails active participation in monthly regular meetings, collaborative contributions to international grant applications, conferences, and publications. Aligned with this effort, between 2022 and 2023 we conducted a qualitative study to collect experiences and synthetize the methodologies used during the adaptation of iSupport in eleven different countries (Fiordelli et al., 2023). The study's findings underscored the importance of knowledge exchange and the sharing of best practices among nations to achieve better harmonization in the cultural adaptation and implementation process.

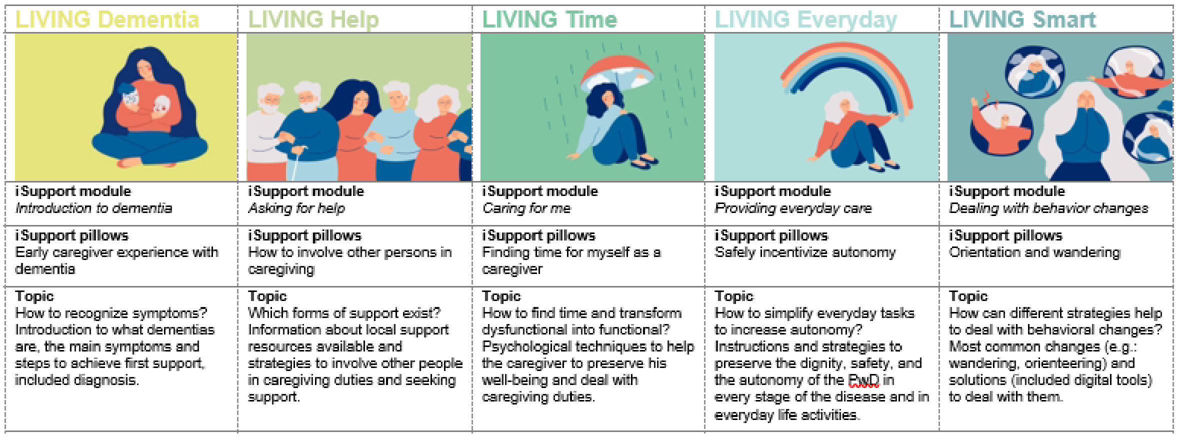
Source : Alzheimer Europe, Dementia in Europe (43), 2023.

Members of the iSupport Network presented at the 2023 International Psychogeriatric Association International Congress in Lisbon, Portugal

Free from fear. Reframing Dementia through the eyes of caregivers

In September 2023, the project “Free from fear. Reframing Dementia through the eyes of caregivers” funded by the Swiss National Science Foundation (SNSF) (Agora scheme) was officially launched. The project's roots can be traced back to the insights accumulated from caregivers over the years during the adaptation of iSupport. Specifically, it emerged as a response to the social and cultural obstacles previously mentioned, which contribute to a limited and predominantly negative perception of dementia. This perception results in increased fear and anxiety within the general population. These barriers not only impede the help-seeking behavior of existing caregivers but also hinder individuals who are not yet caregivers from accessing accurate information about dementia, thus increasing the risk of misinformation. Hence, the project aims to disseminate iSupport contents through co-designed animated videos (iSupport pillows) and open workshops (Living rooms) (Fig.1). The aim of the project is “to reframe the social meaning of dementia by promoting a trialogue on the experiential knowledge of dementia between researchers and healthcare professionals, caregivers, and citizens in Switzerland, ultimately aiming to give dignity to the complexity of dementia experience”.

Fig.1 Overview of the iSupport Pillows and Living rooms events in connection with the contents of iSupport (Fiordelli, 2022)



LIVING Dementia	LIVING Help	LIVING Time	LIVING Everyday	LIVING Smart
iSupport module *Introduction to dementia*	**iSupport module** *Asking for help*	**iSupport module** *Caring for me*	**iSupport module** *Providing everyday care*	**iSupport module** *Dealing with behavior changes*
iSupport pillows Early caregiver experience with dementia	**iSupport pillows** How to involve other persons in caregiving	**iSupport pillows** Finding time for myself as a caregiver	**iSupport pillows** Safely incentivize autonomy	**iSupport pillows** Orientation and wandering
Topic How to recognize symptoms? Introduction to what dementias are, the main symptoms and steps to achieve first support, included diagnosis.	**Topic** Which forms of support exist? Information about local support resources available and strategies to involve other people in caregiving duties and seeking support.	**Topic** How to find time and transform dysfunctional into functional? Psychological techniques to help the caregiver to preserve his well-being and deal with caregiving duties.	**Topic** How to simplify everyday tasks to increase autonomy? Instructions and strategies to preserve the dignity, safety, and the autonomy of the PwD in every stage of the disease and in everyday life activities.	**Topic** How can different strategies help to deal with behavioral changes? Most common changes (e.g.: wandering, orienteering) and solutions (included digital tools) to deal with them.

Closing remarks

The set of publications included in this PhD thesis reflects the effort to navigate the complex landscape of informal dementia care. The variety of the studies presents the attempt to explore this field from different angles, spanning from the exploration of the wellbeing of informal caregivers, to a comprehensive understanding of their support needs and preferences. The adaptation and implementation of iSupport not only served as a thread for this research project, enabling the creation of a concrete and tailored output designed to support caregivers, but also marked the beginning of a journey towards the development of additional resources, not only for the current caregivers, but also for those in the future.

This experience encapsulates, on a smaller scale, the multifaceted nature of implementation research, showcasing the intricate connection between knowledge and its practical application in real-world settings. The constant dialogue across different disciplines, methodologies, and stakeholders, ranging from community member to policy makers, represents a challenging but essential endeavor. It is through this collaborative effort that implementation research can truly serve public health, reinforcing its objectives of equity, efficiency, scalability, and sustainability, all with the aim of enhancing the well-being of all individuals.

References

Alzheimer Europe. (2011). *Who Cares? The state of dementia care in Europe. Alzheimer Europe*. http://www.alzheimer-europe.org/Publications/E-Shop/Alzheimer-Europe-Reports/Who-cares-The-state-of-dementia-care-inEurope

Boots, L. M. M., Wolfs, C. A. G., Verhey, F. R. J., Kempen, G. I. J. M., & De Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International Psychogeriatrics*, *27*(6), 927–936. https://doi.org/10.1017/s1041610214002804

Fiordelli, M., Messina, A., Magelli, A., Amati, R., & Albanese, E. (2023). Adapting iSupport program around the world: a cross-cultural study. In ALZ (Ed.), *Alzheimer's Association International Conference*.

Gaugler, J. E., Anderson, K. A., Leach, C. R., Smith, C. D., Schmitt, F. A., & Mendiondo, M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias®*, *19*(6), 369–380. https://doi.org/10.1177/153331750401900605

Glasgow, R. E., & Emmons, K. M. (2007). How Can We Increase Translation of Research into Practice? Types of Evidence Needed. *Annual Review of Public Health*, *28*(1), 413–433. https://doi.org/10.1146/annurev.publhealth.28.021406.144145

Kessler, E.-M., Bowen, C. E., Baer, M., Froelich, L., & Wahl, H.-W. (2012). Dementia worry: a psychological examination of an unexplored phenomenon. *European Journal of Ageing*, *9*(4), 275–284. https://doi.org/10.1007/s10433-012-0242-8

Lane, H. P., McLachlan, S., & Philip, J. (2013). The war against dementia: are we battle weary yet? *Age and Ageing*, *42*(3), 281–283. https://doi.org/10.1093/ageing/aft011

Oetzel, J. G., Zhou, C., Duran, B., Pearson, C., Magarati, M., Lucero, J., Wallerstein, N., & Villegas, M. (2015). Establishing the Psychometric Properties of Constructs in a Community-Based Participatory Research Conceptual Model. *American Journal of Health Promotion*, *29*(5), e188–e202. https://doi.org/10.4278/ajhp.130731-QUAN-398

Pot, A. M., Gallagher-Thompson, D., Xiao, L. D., Willemse, B. M., Rosier, I., Mehta, K. M., Z, i, D., Dua, T., Albanese, E., Batsch, N., Baruah, U., Edwards, K., Egan, K., Gallagher-Thompson, D., Guerra, M., Holroyd-Leduc, J., Kwok, T., Mehta, K., … Team, iSupport D. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. *WORLD PSYCHIATRY*, *18*(3), 365–366. https://doi.org/10.1002/wps.20684

Ramanadhan, S., Davis, M., Armstrong, R., Baquero, B., Ko, L., Leng, J., Salloum, R., Vaughn, N., & Brownson, R. (2018). Participatory implementation science to increase the impact of evidence-based cancer prevention and control. *Cancer Causes & Control*, *29*. https://doi.org/10.1007/s10552-018-1008-1

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry*, *12*(3), 240–249.

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *The BMJ*, *374*. https://doi.org/10.1136/bmj.n2061

Tabak, R. G., Khoong, E. C., Chambers, D. A., & Brownson, R. C. (2012). Bridging Research and Practice: Models for Dissemination and Implementation Research. *American Journal of Preventive Medicine*, *43*(3), 337–350. https://doi.org/https://doi.org/10.1016/j.amepre.2012.05.024

Theobald, S., Brandes, N., Gyapong, M., El-Saharty, S., Proctor, E., Diaz, T., Wanji, S., Elloker, S., Raven, J., Elsey, H., Bharal, S., Pelletier, D., & Peters, D. H. (2018). Implementation research: new imperatives and opportunities in global health. In *The Lancet* (Vol. 392, Issue 10160, pp. 2214–2228). Lancet Publishing Group. https://doi.org/10.1016/S0140-6736(18)32205-0

Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods*, *1*(1). https://doi.org/10.35844/001c.13244

Watson, R., Sanson-Fisher, R., Bryant, J., & Mansfield, E. (2023). Dementia is the second most feared condition among Australian health service consumers: results of a cross-sectional survey. *BMC Public Health*, *23*(1), 876. https://doi.org/10.1186/s12889-023-15772-y

Zimmermann, M. (2017). Alzheimer's disease metaphors as mirror and lens to the stigma of dementia. In *Literature and Medicine* (Vol. 35, Issue 1, pp. 71–97). Johns Hopkins University Press. https://doi.org/10.1353/lm.2017.0003

Chapter 8: Appendix

iSupport Swiss

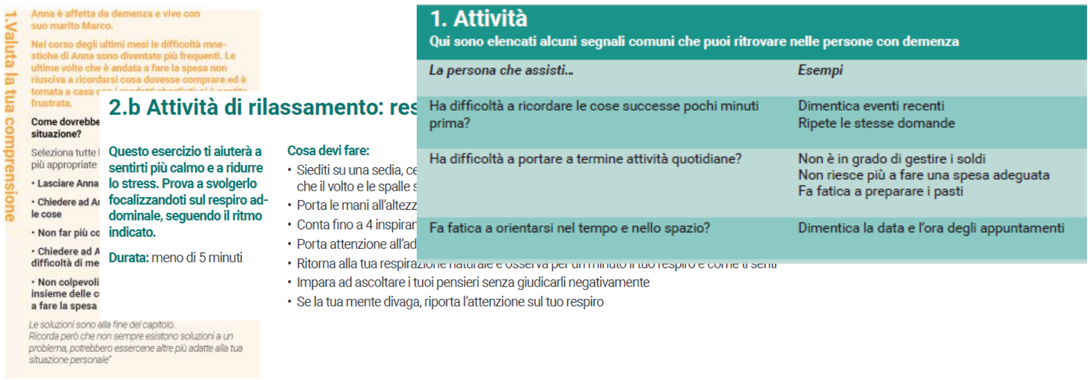
iSupport Swiss, the adapted version of iSupport in Switzerland, was officially launched in May 2023, during a press conference which was attended by the State Councilor and Director of the Department of Health and Social Affairs; the President of the Canton Commission for the Implementation of the Canton Dementia Strategy, the Director of Pro Senectute Ticino, and the Director of the Institute of the Public Health (USI). iSupport Swiss is freely available in three versions: a printed manual (Fig.1), a website (Fig. 2) and application for smartphones and tablets (Fig.3).

Each version is translated into Italian, French, and German. The online versions are supported by instructional videos, also accessible on iSupport Swiss Youtube channel, where are also available two testimonial videos (Fig.4). During the adaptation of iSupport, we also developed Pro iSupport (Fig.5), an additional guide dedicated to healthcare providers who wish to offer iSupport to informal caregivers. This guide includes a program description and addresses the main challenges related to the use of ISupport in its different formats. All graphics of iSupport Swiss, included the logo and illustrations have been specifically designed for or adapted to the program. All outputs and information on iSupport Swiss are freely available on the website of the Institute of Public Health at the following link: [iSupport Swiss]().

Fig.1 iSupport Swiss manual cover (Italian version)

iSupport
Manuale
Un programma dedicato ai familiari curanti di persone affette da demenza

Fig.1.2 iSupport Swiss manual excerpts (Italian version)



1.Valuta la tua comprensione

Anna è affetta da demenza e vive con suo marito Marco.

Nel corso degli ultimi mesi le difficoltà mnestiche di Anna sono diventate più frequenti. Le ultime volte che è andata a fare la spesa non riusciva a ricordarsi cosa dovesse comprare ed è tornata a casa c
frustrata.

Come dovrebbe
situazione?

Seleziona tutte l
più appropriate

- Lasciare Anna
- Chiedere ad A
le cose
- Non far più co
- Chiedere ad A
difficoltà di me
- Non colpevoli
insieme delle c
a fare la spesa

Le soluzioni sono alla fine del capitolo.
Ricorda però che non sempre esistono soluzioni a un problema, potrebbero essercene altre più adatte alla tua situazione personale"

2.b Attività di rilassamento: res

Questo esercizio ti aiuterà a sentirti più calmo e a ridurre lo stress. Prova a svolgerlo focalizzandoti sul respiro addominale, seguendo il ritmo indicato.

Durata: meno di 5 minuti

Cosa devi fare:

- Siediti su una sedia, ce
che il volto e le spalle s
- Porta le mani all'altezz
- Conta fino a 4 inspiran
- Porta attenzione all'ad
- Ritorna alla tua respirazione naturale e osserva per un minuto il tuo respiro e come ti senti
- Impara ad ascoltare i tuoi pensieri senza giudicarli negativamente
- Se la tua mente divaga, riporta l'attenzione sul tuo respiro

1. Attività

Qui sono elencati alcuni segnali comuni che puoi ritrovare nelle persone con demenza

La persona che assisti...	*Esempi*
Ha difficoltà a ricordare le cose successe pochi minuti prima?	Dimentica eventi recenti Ripete le stesse domande
Ha difficoltà a portare a termine attività quotidiane?	Non è in grado di gestire i soldi Non riesce più a fare una spesa adeguata Fa fatica a preparare i pasti
Fa fatica a orientarsi nel tempo e nello spazio?	Dimentica la data e l'ora degli appuntamenti

Fig.2 iSupport Swiss website login page (Italian version)

iSupport

Il browser deve avere i cookie abilitati

Version française d'iSupport

Deutsche Version von iSupport

Benvenuto/a sul sito di iSupport! Qui troverai letture, attività e consigli utili ad accompagnarti nell'assistenza a una persona con demenza.

iSupport Swiss

Un programma di formazione e supporto per familiari curanti di persone affette da demenza in Svizzera, facilmente accessibile tramite un sito web e un'applicazione per smartphone e tablet.

Disponibile anche:

Hai già un account?

anna.messina

•••••••••••

☐ Remember username

Hai dimenticato lo username o la password?

Crea un account

Fig 2.1 iSupport Swiss website excerpts (Italian version)

Ciascun capitolo contiene:

- una sezione introduttiva sull'argomento e sull'utilità del capitolo
- sezioni teoriche sul tema

1. Introduzione alla demenza

Introduzione

Perché questo capitolo è importante?

La demenza è una malattia che può avere un grande impatto sia sulla persona che ne è affetta che su chi la assiste. Circolano molte informazioni sulla demenza, conoscerla più a fondo ti aiuterà a riconoscre e salvaguardarti da equivoci comuni e false credenze.

In che modo ti sarà utile questo capitolo?

Questo capitolo ti presenterà le cause della demenza e le forme nelle quali può manifestarsi, informazioni essenziali quando ci si prende cura di una persona che ne è affetta.

Cosa imparerai?

1.Cos'è la demenza?
2.Quali sono le cause della demenza?
3.Cosa accade alla persona affetta da demenza con il progredire della malattia?
4.Cosa fare se pensi che la persona che assisti sia affetta da demenza?
5.Come chiedere aiuto?
6.Qual è l'obiettivo di questo manuale?

- sezioni "ricorda" o "suggerimenti" che riassumono i punti importanti del capitolo

Ricorda

- La demenza danneggia il cervello
- La demenza è diffusa soprattutto nelle persone anziane
- La demenza è una malattia, non fa parte del normale processo di invecchiamento
- Come primo passo è importante contattare il tuo medico di famiglia
- È importante prenderti cura di te stesso e non solo della persona che assisti
- iSupport può aiutarti nell'assistenza a una persona con demenza

1. Attività

Qui sono elencati alcuni segnali comuni che puoi ritrovare in persone affette da demenza.

Pensa alla tua esperienza personale e rifletti sulle seguenti domande

La persona che assisti...	Esempi

Le sezioni "Valuta la tua comprensione" presentano situazioni e scenari in cui un familiare curante di una persona con demenza potrebbe trovarsi. Per esempio:

"Anna, affetta da demenza, viene assistita da sua figlia Mara che abita molto vicino alla madre. Quando la va a trovare, Mara si accorge che il frigo e la credenza sono spesso vuoti, perché la madre si dimentica di andare a fare la spesa"

1. Valuta la tua comprensione

Le persone con demenza spesso dimenticano le cose o hanno problemi di memoria. Seleziona la risposta corretta

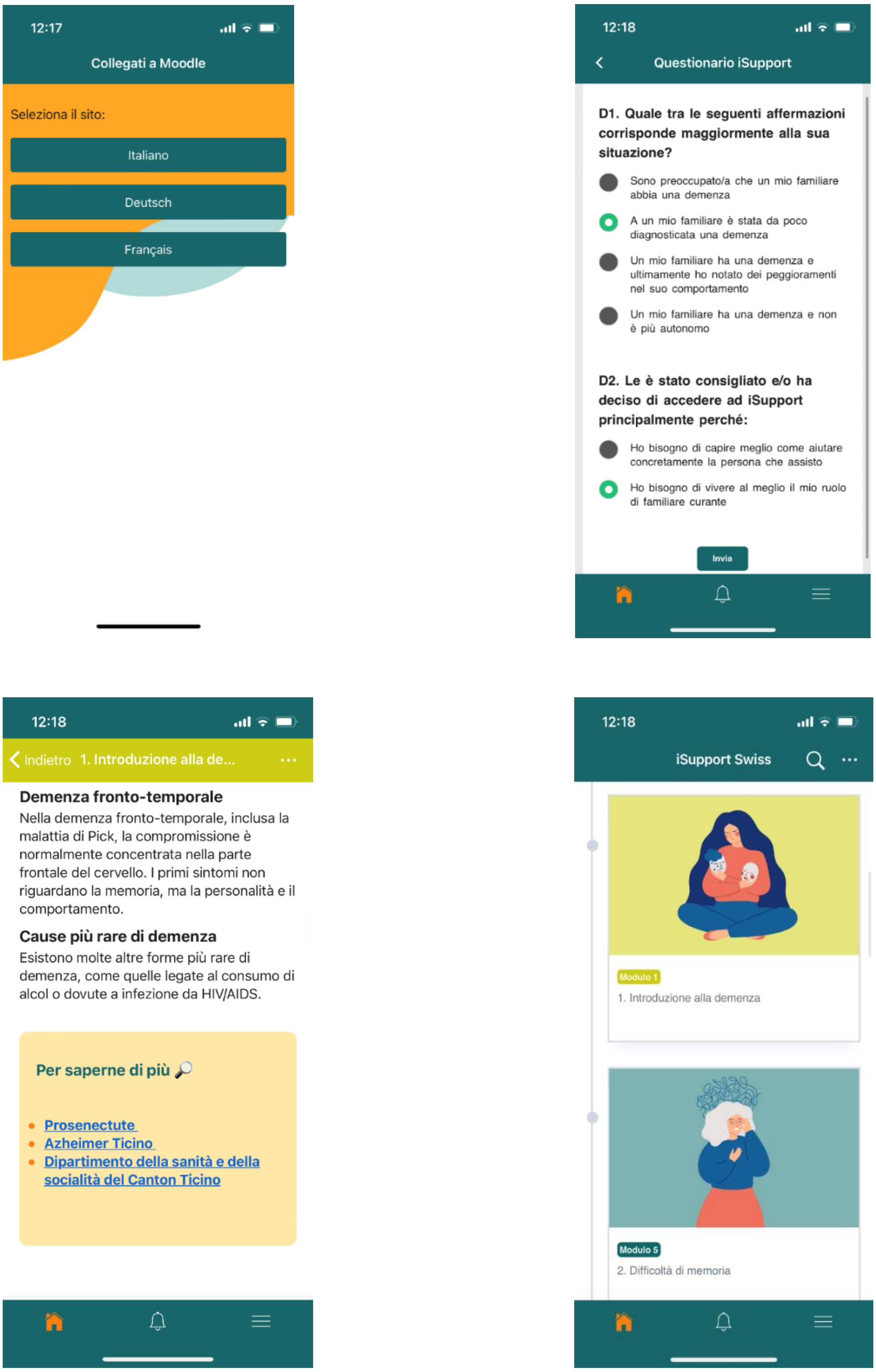
● Vero ✓ ○ Falso

Nonostante le difficoltà di memoria possano manifestarsi in stadi diversi della malattia, sono un segno comune in quasi tutte le forme di demenza.

All'utente viene chiesto di immedesimarsi nel curante descritto dallo scenario e di selezionare tra le opzioni proposte quella che più ritiene appropriata. Il programma segnala le risposte corrette e quelle non corrette fornendo una spiegazione (nel formato manuale le risposte sono riportate alla fine di ogni capitolo nell'apposita sezione).

Ogni sezione "Valuta la tua comprensione" segnala che potrebbero esserci altre soluzioni possibili, più adatte al proprio

Fig.3: iSupport Swiss mobile application excerpts (Italian version)



Seleziona il sito:

D1. Quale tra le seguenti affermazioni corrisponde maggiormente alla sua situazione?

- ● Sono preoccupato/a che un mio familiare abbia una demenza
- ◉ A un mio familiare è stata da poco diagnosticata una demenza
- ● Un mio familiare ha una demenza e ultimamente ho notato dei peggioramenti nel suo comportamento
- ● Un mio familiare ha una demenza e non è più autonomo

D2. Le è stato consigliato e/o ha deciso di accedere ad iSupport principalmente perché:

- ● Ho bisogno di capire meglio come aiutare concretamente la persona che assisto
- ◉ Ho bisogno di vivere al meglio il mio ruolo di familiare curante

Demenza fronto-temporale

Nella demenza fronto-temporale, inclusa la malattia di Pick, la compromissione è normalmente concentrata nella parte frontale del cervello. I primi sintomi non riguardano la memoria, ma la personalità e il comportamento.

Cause più rare di demenza

Esistono molte altre forme più rare di demenza, come quelle legate al consumo di alcol o dovute a infezione da HIV/AIDS.

Per saperne di più 🔎

- Prosenectute
- Azheimer Ticino
- Dipartimento della sanità e della socialità del Canton Ticino

Modulo 1
1. Introduzione alla demenza

Modulo 5
2. Difficoltà di memoria

Fig. 4: iSupport Swiss testimonial videos on Youtube

Fig.5 Pro iSupport

Pro iSupport

Una guida dedicata a operatori socio-sanitario-assistenziali per accompagnare i familiari curanti di persone con demenza all'utilizzo del programma iSupport

Fig.6 iSupport Swiss flyer

iSupport Swiss

accompagna
il familiare curante

Un programma di formazione e supporto per familiari curanti di persone affette da demenza in Svizzera, facilmente accessibile tramite un sito web e un'applicazione per smartphone e tablet.

www.
isupport.swiss

disponibile anche su:

GET IN ON Google Play

Download on the App Store

Maggiori informazioni:
isupport@usi.ch
058 666 41 30

Un progetto:
Università della Svizzera italiana

Grazie al supporto di:
Repubblica e Cantone Ticino Dipartimento della sanità e della socialità
PRO SENECTUTE

Con la collaborazione di:
alzheimer Ticino
SUPSI