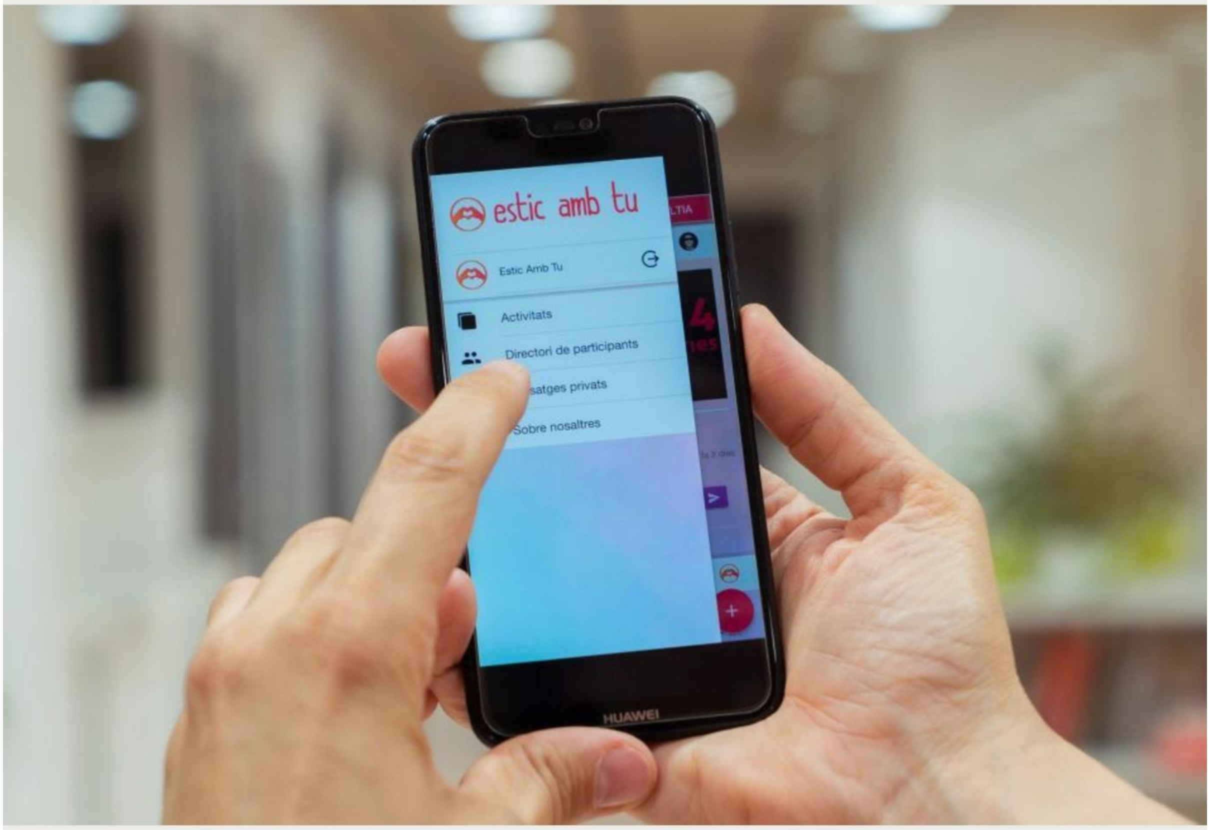
DOCTORAL THESIS

Virtual Communities of Practice for Family Caregivers of People with Alzheimer's: Knowledge Sharing and Quality of Life

Montse Romero Mas



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Montse Romero Mas

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Doctoral Programme: **Comprehensive Care and Health Services**

2021

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Building so that caring can take place.

Carmen De la Cuesta-Benjumea

When I walk along with two others,

from at least one I will be able to learn.

Confucius (Kongzi)

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Acknowledgements

Diuen que si una cosa t'apassiona, treballes i et lleves ben d'hora, ben d'hora, et sortiràs amb la teva. Diuen que així neixen els projectes. Diuen que persones que amb esforç i constància fan néixer projectes fent equip amb altres persones. Així va néixer aquest projecte, aquesta tesi que vaig iniciar el febrer del 2016 i que m'ha permès fer equip amb moltes persones a qui voldria mostrar el meu agraïment.

En primer lloc, voldria agrair a la Universitat de Vic-Universitat Central de Catalunya l'oportunitat i el recolzament que m'ha donat en tot moment per portar a terme aquesta tesi. En especial, a la Facultat de Ciències de la Salut i el Benestar i, sobretot, a les deganes de la Facultat de Ciències de la Salut i el Benestar: la Dra. Margarida Pla, la Dra. Mireia Subirana, la Dra. Paola Galbany i la Dra. Míriam Torres. Agrair també al Dr. Raimon Milà que m'encoratgés a començar aquesta tesi quan tan sols era idea.

Molt especialment, voldria agrair l'interès i la col·laboració de les persones cuidadores familiars que van decidir participar en l'estudi, sobretot a la moderadora. També agrair el bon fer dels tres professionals de salut que van acceptar moderar una comunitat i formar part d'aquest projecte. Sense vosaltres, no m'hagués estat possible realitzar aquest estudi.

A continuació, agrair la predisposició de l'Associació de Familiars i Malalts d'Alzheimer d'Osona per col·laborar en la recerca. També als professionals de salut de la comarca que van contribuir de manera activa a difondre el meu projecte per arribar a les persones cuidadores familiars, sobretot a les professionals de l'Hospital de la Santa Creu de Vic.

El dia que vaig conèixer en Pere Martínez de Confluència va ser un dia clau per mi i pel projecte ja que va posar a la meva disposició recursos humans i tècnics per tal que l'app "EsticAmbTu" fos una realitat. Gràcies Pere per col·laborar de forma altruista en diferents projectes socials i gràcies per creure amb mi.

L'app necessitava un nom i els alumnes de l'Escola Sant Genís i Santa Agnès que en aquell moment cursaven segon, amb la professora Carme Cuní al capdavant, van aprendre què era l'Alzheimer i què comportava per les persones cuidadores. Els nens i nenes van batejar l'app amb "EsticAmbTu", un nom que va encantar a les persones cuidadores. Gràcies per obrir-me les portes i acceptar de col·laborar en aquesta tesi amb la il·lusió que ho vau fer. Gràcies també al dissenyador Guillem Lluch, qui va donar forma al logo de l'app.

El meu perfil i la meva trajectòria em demanaven una tesi amb menció internacional. Aquesta menció internacional no hagués estat possible sense la generositat del Dr. Andrew M. Cox i de la "University of Sheffield". L'Andrew és un expert en comunitats de pràctica i des que va conèixer la recerca va acceptar formar-ne part i acompanyar-me, no només en les meves estades a Sheffield, sinó durant tota la tesi. Thanks a lot Andrew.

Al llarg d'aquests cinc anys de tesi he tingut oportunitat de comptar amb companys que m'han ajudat en la realització de tasques concretes. Voldria esmentar la Cindy Voltas, en Dr. Dyego Leandro Bezerra de Sousa i la Sophie Lagesse. Gràcies a tots tres.

Gràcies també als companys i amics de la UVic-UCC que m'han ajudat a avançar en el dia a dia. Gràcies a tots i a totes. Gràcies Olga Isern, Dr. Jordi Naudó i Mercè Prat. Gràcies Aina Roca, et penso. I "gràcies moltes" Núria Gorchs pel teu suport incondicional i pels moments compartits.

Gràcies a les meves amigues Gemma Camps i Susanna Salvans. Sé que hi sou i em reconforta.

Aquesta tesi no hagués estat possible sense la col·laboració de les meves directores: la Dra. Anna Ramon i la Dra. Beni Gómez. Unes directores, com diuen els valencians, "DE CATEGORIA". Gràcies a les dues per creure en mi i per l'acompanyament que m'heu fet durant tota la tesi. Gràcies pel vostre suport en aquest procés d'aprenentatge. Gràcies per ensenyar-me a escriure amb rigor, claredat i coherència.

Vull acabar els agraïments donant les gràcies a LA MEVA FAMÍLIA. Gràcies FERRAN i NÚRIA per la paciència que heu tingut, per posar-m'ho molt fàcil i per tot el suport que m'heu donat en tot moment. Gràcies a la meva mare (de qui vaig aprendre el significat de cuidar), als meus sogres, als meus germans i als meus cunyats. Gràcies a tots i a totes per ser-hi sempre. I un record molt especial pel meu pare qui sempre em deia: "si una cosa t'apassiona, treballes i et lleves ben d'hora, ben d'hora, et sortiràs amb la teva". Us estimo molt!

Taradell, Març del 2021

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List of Abreviations

AFMADO: "Associació Familiars i Malalts d'Alzheimer d'Osona" (Osona Association of People with Alzheimer's and their Relatives)

App: Mobile Application

CoP: Community of Practice

EHEALS: eHealth Literacy Scale

EHealth: digital health

ICT: Information, Communication and Technology

LINKS: Leveraging Internet based Knowledge Sharing

QoL: Quality of Life

M-health: Mobile Health

QoL: Quality of Life

VCoP: Virtual Community of Practice

WHOQOL- BREF: World Health Organization Quality of Life short version

Abstract

Caring for a person with Alzheimer's places a burden on family caregivers of people with Alzheimer's and there is a strong negative correlation between this burden and their quality of life (QoL). The main needs of family caregivers are to have the support of their peers, to have access to information, to receive training about the disease and to care oneself. Therefore, meeting the needs of the caregivers is a public health imperative. Virtual Communities of Practice (VCoPs) are defined as Internet frameworks for sharing knowledge, where members collaborate with each other and gain a sense of trust in the community. The aim of this research is to provide resources, specifically VCoPs, to help family caregivers of people with Alzheimer's cope with their role. This study was undertaken through an intervention which consisted of designing and establishing two VCoPs for family caregivers of people with Alzheimer's: one moderated by an expert caregiver and the other by health professionals. The VCoPs were developed through an app. The VCoPs were designed and established by following the eleven dimensions proposed in this thesis, as a conceptual framework to help caregivers learn how to deal with the demands of caregiving and to meet their needs. VCoPs helped to improve the QoL of family caregivers of people with Alzheimer's, particularly if they included health professionals. Age and the relationship with the person with Alzheimer's were moderator variables. Social knowledge and social support were priorities for the family caregivers. The differences between the VCoP moderated by health professionals and that moderated by an expert caregiver reaffirmed the importance of the moderator profile. The analysis of the exchange of knowledge, interactions and participation presented clues to conclude that a VCoP with only family caregivers of people with Alzheimer's was more like a support group, whilst the inclusion of health professionals tailored the VCoP to a more information giving place. This study shows that the benefit of VCoPs lies in the ongoing social interaction, which is rooted in the reality of community.

Keywords: *virtual community of practice, knowledge sharing, quality of life, family caregiver, Alzheimer's disease*

Introduction

Over the past decades, life expectancy has increased considerably, impacting on chronic age-related conditions. One of these disabling chronic disorders that requires a high level of care is dementia. 47 million people worldwide live with dementia, and this statistic is expected to increase to 75 million by 2030 and to 132 million by 2050 (Ministerio de Sanidad - Consumo y Bienestar, 2019). 80% of dementia cases are the result of Alzheimer's disease (Crous-Bou et al., 2017). The initial and characteristic symptom of Alzheimer's is the loss of memory of recent events, while the memories that are part of the most remote memory, such as the memories of youth and childhood, are preserved for longer. As the disease progresses, problems with language, attention, recognition, comprehension, and performing actions appear (Alzheimer's Association, 2018). Behavioural disorders are varied in terms of type and frequency in the evolution and development of the disease (Weller & Budson, 2018). The resources of research to fight Alzheimer's disease are, first and foremost, invested in the disease itself and the person suffering from it (Liggins et al., 2014).

Alzheimer's not only affects those who suffer from it, but also their care environment. Carers often suffer from physical, psychological or economic problems, among others, arising from the care of their relative. Caring for a person with dementia impacts directly on the caregiver's family, creating a huge burden and, in many ways, eroding their quality of life (QoL) (Zacharopoulou et al., 2015). In this context, the role of family caregivers is of major importance as they become the invisible second patients (Gallagher et al., 2011).

Caregivers are individuals who have a significant personal relationship with, and provide a broad range of unpaid assistance to, an older person or an adult with a chronic or disabling condition outside of a professional or formal framework (Plöthner et al., 2019). In Spain, the health system covers 20% of the total time devoted to long-term care and the remaining 80% is performed within the informal care system (Masana, 2017).

Family caregivers are people who usually have a strong emotional link with the person with Alzheimer's and who feel, therefore, a huge sense of responsibility for that person (Masana, 2017).

They must cope with both the diagnosis itself and the impact of the disease on the family. Family caregivers need to incorporate the care of the person with Alzheimer's into their own life, with little or no preparation for this new role. They require information about the disease and about the resources available to them (Plöthner et al., 2019). In addition, they need emotional support, as the act of caring may burden them (Bruvik et al., 2012). They are, in some way or another, in urgent need of knowledge. As a consequence of the care they give, the family caregivers' own health may even be compromised and their QoL could deteriorate (Farina et al., 2017). Yet, for the health and social care system the focus of the disease is the person with Alzheimer's. Therefore, interventions for family caregivers of people with Alzheimer's are required. Giving answers to caregivers' needs is a public health imperative as, otherwise, they are at risk of social exclusion.

Literature indicates that interventions for family caregivers already exist (Parra-Vidales et al., 2017). One of the most widespread means of intervention is the support group. The information society, with the Internet, gives an overview of health with a more user-centred focus and within which several interventions have been developed for family caregivers, such as creating forums and providing training. However, more interventions for family caregivers of people with Alzheimer's are essential. The fact that life expectancy is growing, together with statistics showing that the average duration of Alzheimer's disease is 8-10 years (Burns & Iliffe, 2009), will increase the number of family caregivers required.

Family caregivers can feel better by sharing their experiences and knowing that there are other people facing the same kind of problems (Zloty et al., 2011). Within the support groups, they share the experiences acquired day by day and get emotional support. These facts open a door to the idea that somehow the support group could go a step further and turn into a Community of Practice (CoP). The CoP theory was first developed for the field of business but, over time, it has been used in the health sector. The main aim of a CoP is to enable those people within it, who have the same concerns, to share their knowledge. These communities build knowledge through the exchange of ideas and the fostering of relationships. They are characterised by the domain (area of knowledge that unites the community), the community (the group of people for whom the domain is relevant) and the practice (the body of knowledge, methods, tools, stories, cases, documents that the participants share and develop together) (Wenger et al., 2002). When the CoP is Internet-based, it is called the Virtual Community of Practice (VCoP).

The Internet could contribute much more to supporting the needs of caregivers as it offers the possibility of uniting people and providing them with the tools to share their knowledge. The use of the Internet and related technologies is potentially very important among caregivers.

Literature about the CoP offers several models for designing and establishing CoPs and VCoPs, mainly in the field of business (Probst & Borzillo, 2008). More recently, some authors have offered suggestions and proposed models for designing VCoPs in the health sector. These proposals were not specifically for family caregivers, none of them were for family caregivers of people with Alzheimer's and they usually included health professionals (Barnett et al., 2012).

The general aim of this research is to provide resources, specifically VCoPs, to help family caregivers of people with Alzheimer's cope with their role. The specific objectives are:

1.- To propose a conceptual framework which shapes the design of the VCoPs, so as to help family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to support their needs.

2.- To analyse how membership of a VCoP impacts on the QoL of family caregivers of people with Alzheimer's.

3.- To study the knowledge shared among family caregivers of people with Alzheimer's in VCoPs, the interaction between them and their participation in the community, as well as how these factors are related to the caregivers' QoL.

Based on the framework proposed which shapes the design of the VCoPs, an intervention was designed to help family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to support their needs. Through this intervention, two VCoPs were created for this research, based in Osona, a region of Catalonia, Spain. The membership of the VCoPs was expected to contribute to the improvement of family caregivers' QoL. Moreover, this research studied the knowledge shared among the caregivers in the VCoPs.

The **Conceptual Framework** chapter details the family caregivers' context and their needs, together with the impact that caring for a family member has on their QoL. The chapter then introduces existing interventions and, afterwards, it reviews the concept of CoPs and the exchange of knowledge with its progression to VCoPs. It then presents the VCoP in health and its models for establishing VCoPs in health. The chapter justifies the need for this study and introduces the general and specific objectives. Finally, it proposes a conceptual framework for designing VCoPs, which benefits family caregivers of people with Alzheimer's in order to reach the first goal of this study.

The **Methodology chapter** is focused on the methodology of the current research. First, it explains the methodological approach. Then, the target population, variables and the instruments for data handling and data analysis tools, are presented, followed by a precise description of the intervention. Finally, data collection and data analysis are described.

The **Results chapter** is centred on the findings coming from the analysis. It provides the findings coming from the analysis through six sections broken down according to the methodological approach.

The **Discussion chapter** introduces the discussion of the research results. It offers a dialogue between the findings of this research and the existing literature.

The **Conclusion** summarises the conclusions of the previous chapters and of this thesis. In addition, the author introduces strengths and limitations of the study. Finally, it reflects on the implications for research of this study and it suggests new lines of related research.

Conceptual Framework

Family Caregivers of People with Alzheimer's Disease

This first part of the conceptual framework chapter is focused on the family caregivers of people with Alzheimer's. First, it introduces both the concept and context of Alzheimer's. Secondly, it defines family caregivers and their context in Spain, as this is the country where the intervention for this research took place. Then, it shows the deterioration of caregivers' QoL due to the act of caring for a person with Alzheimer's. The next step is to introduce the caregivers' needs and see the existing interventions and, specifically, the intervention proposed by this study.

Concept and Context of Alzheimer's

Due to the global rise in life expectancy, the impact of chronic conditions associated with age is growing (Ministerio de Sanidad - Consumo y Bienestar, 2019). One of the most significant chronic diseases among the elderly is dementia (Weller & Budson, 2018). Dementia mainly affects older people over the age of 65 and causes progressive, irreversible cognitive deterioration with disturbances in behaviour, impaired judgment, disorientation, loss of memory and language and the ability to perform basic activities of daily living (Alzheimer's disease international & WHO, 2012). 47 million people worldwide live with dementia, and this statistic is expected to increase to 75 million by 2030 and to 132 million by 2050 (Ministerio de Sanidad - Consumo y Bienestar, 2019). Therefore, at present, dementia is a major public health problem.

Alzheimer's disease is the most common cause of dementia (Weller & Budson, 2018). Alzheimer's is defined as "a syndrome due to brain disease, generally of a chronic or progressive nature, in which there are deficits of multiple upper cortical functions that affect the daily activity of the patient" (Díaz et al., 2014). It is characterised by three primary groups of symptoms (Burns & Iliffe, 2009). The first group (cognitive dysfunction) includes memory loss, language difficulties and executive dysfunction, which is the loss of higher-level planning and intellectual coordination skills. The second group comprises psychiatric symptoms and behavioural disturbances, collectively termed non-cognitive symptoms. The third group comprises difficulties with performing activities of daily living. The symptoms of Alzheimer's disease progress from mild symptoms of memory loss to very severe dementia within an average of 9 years (Burns & Iliffe, 2009).

Given the symptoms, it is fair to assume that people with Alzheimer's become dependent. This dependency is a referential situation in which one person needs others. There are, therefore, two subjects involved in the relationship: the one who needs and the one who is needed (Durán, 2006).

In Spain, it is estimated that the number of people affected by dementia exceeds 700,000 and it is expected that by the year 2050 the number will have more than doubled to nearly two million (Ministerio de Sanidad - Consumo y Bienestar, 2019). The prevalence of Alzheimer's is around 6% in people over the age of 70 and it accounts for 70% of all types of dementia (Ministerio de Sanidad - Consumo y Bienestar, 2019). Despite these statistics, the Spanish health system only covers 20% of the total time devoted to long-term care, while the remaining 80% is covered by the informal or family care system (Masana, 2017). Within this context, the role of family caregivers has become increasingly important.

Family Caregivers of People with Alzheimer's

Family caregivers are individuals who have a significant personal relationship with and provide a broad range of unpaid assistance to an older person or an adult with a chronic or disabling condition outside of a professional or formal framework (Plöthner et al., 2019). So, being a family caregiver is a very demanding task. The amount of time needed for caregiving increases as the severity of the dementia worsens until the caregiving can become a full-time job (Alzheimer's Association, 2018). Consequently, caring for a relative with dementia poses an especially high risk of other negative outcomes, such as social exclusion, family conflicts or financial stress. Hence, family caregivers are the invisible second patients.

In Spain, the family caregiver role is mainly represented by the female gender (80%), even though more and more men are taking on care and the responsibilities of caring for their dependent family members (CEAFA & Sanitas, 2016). Yet, most social protection systems continue to be marked by ideological connotations rooted in family models based on the old social concept of the sexual division of labour. In contrast with the traditional family in which up to three different generations with clearly differentiated roles often coexisted, at present, the family adopts other models, sometimes far removed from that traditional structure. The social status of women (the main supporters of the traditional family model) has changed. The woman has gone from simply being a housewife to managing both an active work life as well as domestic obligations.

Thus, the State continues to disadvantage women and the recent reforms do not take the needs of family and women into account. In the European context, the Mediterranean countries are still an example of the "familist" welfare model, according to which public policies assume that families should lead the provision of welfare for their members (Esping-Andersen et al., 2003). Previous studies show that the profile of a Spanish family caregiver is a female between 45 and 64 years of age (Ministerio de Sanidad Consumo y Bienestar Social, 2018). The 25% of caregivers who do have a paid work activity make this activity compatible with the caring. Hence, the "potential caregiver" is the group of women between the ages of 45 and 65 who are mostly spouses and daughters of the dependent (not external). They share a home with the cared-for person, carry out their care work on a daily basis, do not have a paid job or receive help from other people. They must also manage the care work, as well as the running of the household (CEAFA & Sanitas, 2016). Therefore, this woman is a middle-aged person who is going to spend most of her active life taking care of her family member, and who, once the cause of dependency (death of the family member) has been overcome, will lack opportunities to reintegrate into "normal life".

Quality of Life of Family Caregivers of People with Alzheimer's

The World Health Organization defines QoL as "the individual perception of a human being's position on life, cultural background, considering his value in relation to his objectives, goals and standards" (Li et al., 2004). The concept goes beyond the presence or absence of illness. It integrates, in a complex manner, four domains of QoL: physical health, psychological, social relationships and the environment (World Health Organization. Division of Mental Health. , 1996). Family caregivers of people with Alzheimer's associate good QoL with serenity, tranquillity, psychological well-being, freedom, general health and good financial status. From the caregiver's perspective, factors which improve their QoL are the good health of the person with Alzheimer's, independence from the person with Alzheimer's, and more help to deliver the care. Conversely, worries about the future, the prognosis of the person with Alzheimer's disease and stress are the factors that, from their point of view, worsen their QoL (Farina et al., 2017; Takai et al., 2011). Then, the progression of functional disability in people with Alzheimer's should also be considered.

Family caregivers reveal that the adverse effects caused by the task of caring for a family member with Alzheimer's are, in particular, the amount of their own time that care takes up, decreased activities, social problems, deteriorating health, feelings of discomfort, work problems and imbalances in family dynamics (Ministerio de Sanidad - Consumo y Bienestar Social, 2005). They report a lack of information on how to treat the illness of the person they care for; they feel unprepared for the changes and losses that result from that illness and often feel isolated, alone, and unsupported (Northouse et al., 2010). A person with information and knowledge about the disease is more likely to feel integrated into society. Hence, each person should be aware of the importance that self-care can have for their health and well-being.

Caring for a dependent person is often considered a stressful situation, causing attrition. Research supports this argument as it states that family caregivers suffer from physical strain, an increased sense of burden, psychological stress, depression and anxiety (Bruvik et al., 2012). There are several factors, such as social, economic, demographic, environmental, the existence of social support networks, limited access to and use of health services, severity of the disease, behavioural disorders, hours of care, social isolation and family cohesion, which possibly affect the health of dementia caregivers (Zacharopoulou et al., 2015).

Needs of Family Caregivers of People with Alzheimer's

Even though caring for someone with Alzheimer can be rewarding, it is also challenging, as it is associated with high levels of burden, causing stress, and reduced QoL (Adelman et al., 2014). Hence, understanding the needs of caregivers is vital to developing and delivering the kinds of services and resources that will alleviate burden and improve quality of life (Queluz et al., 2020).

The early literature shows that the initial focus of the caregivers' needs was to get information about the disease and the resources and services to help with caregiving (Fortinsky & Hathaway, 1990). Then, the need for legal protection, planning assistance and assistance with the constant supervision of the person with Alzheimer's (mainly from the health professionals) was identified (Francis & Munjas, 1992). Later, significantly, the education and social support were considered by the caregivers to be more important than task-oriented assistance (Bowd & Loos, 1996).

At this point, the needs perceived of the caregivers evolved and aligned themselves with the healthcare systems which offered a more holistic perspective focused on the person-centred approach. Family caregivers of people with Alzheimer's had the need to learn skills for improving the daily life management of their relative (Amieva et al., 2012). Furthermore, caregivers raised the importance of the care of oneself (Swartz & Collins, 2019). Access to information is still a primary need but attention to personal health (emotional health and physical health) and receiving help from others are also required (Queluz et al., 2020). In addition, family caregivers of people with Alzheimer's have the need for social recognition (Plöthner et al., 2019). Finally, support and anticipatory guidance for the caregivers is especially helpful during care transitions and at the care recipient's end of life (Swartz & Collins, 2019).

Along this line, there are two more aspects which should be pointed out. Firstly, literature shows that an unmet need is a lack of quality information about support strategies or services that can help to alleviate the challenges of their care situations (Gaugler et al., 2016). "Quality information" in this context represents information, guidance, or consultation that is effectively tailored to meet the needs of individual dementia caregivers in ways that are helpful and feasible. Secondly, research shows that support needs are significantly more important for female caregivers than for male caregivers (Wackerbarth & Johnson, 2002).

After overviewing the needs of family caregivers of people with Alzheimer's, it is worth mentioning that health systems should provide family caregivers with better information about the disease, appropriate cognitive and behavioural disorder management skills and, finally, psychological support (Ferré-Grau et al., 2011). Hence, interventions are required to help them learn how to deal with the demands of care giving and to support them emotionally (López Gil et al., 2009).

Meaningfully, comprehensive management of the person with Alzheimer's includes building a partnership between health professionals and family caregivers, referral to Alzheimer's Associations and psychosocial interventions (Brodaty & Donkin, 2009). Practitioners should then realise that caregivers may have different information and support needs and that those needs may change throughout the caregiving experience (Wackerbarth & Johnson, 2002). In addition, professionals should help family caregivers by introducing them to local support groups, which is best done through local Alzheimer's associations. Alzheimer's associations provide family caregivers with information, emotional support, practical advice, support groups, training programmes, help sheets, free-to-call helplines and useful websites (Alzheimer's Association, 2014).

Interventions for Family Caregivers of People with Alzheimer's

Attention to the needs of family caregivers is a public health imperative because poor QoL of the caregiver increases the use of healthcare systems and the institutionalisation of the person with Alzheimer's. Interventions must therefore be carried out to improve the quality of the services provided and to prevent anything that could negatively affect carers (Alzheimer's Association, 2018). Currently, there are several types of interventions focused on the needs of the family caregivers of people with Alzheimer's: case management, psychoeducational therapy, counselling, support groups, respite, training of the person with dementia, psychotherapeutic approaches and multicomponent approaches (Alzheimer's Association, 2014). Although the ability to enhance the general QoL of caregivers appears to be limited, there is evidence that specific components of QoL, such as burden, mood, and perceived stress, are responsive to interventions (Fazio et al., 2018).

Literature agrees that one of the most effective resources for the creation and sharing of knowledge is the community-based approach (Brown & Duguid, 1991). A wide range of programmes are rooted in this approach which emphasises dialogue through social networks (Swan et al., 2000) and helps to informally share knowledge obtained from experienced and skilled people (Jordan & Jones, 1997). People mainly participate in communities for the value they get from those communities, for personal connections and for the opportunity to improve their skills (Wenger et al., 2002).

Social support interventions provide a venue for family caregivers to share their caregiving experience, build social relationships and receive emotional comfort and informational material (Lee et al., 2020). One of the most widespread and well-recognised interventions for family caregivers of people with Alzheimer’s is the support group, which is rooted in this community-based approach.

Support groups are supportive and rarely standardised interventions, which can be both professionally-led or peer-led (Lauritzen et al., 2015). They help family caregivers to deal with their own needs, providing emotional support, useful information from others and the social aspects that belonging to a group offers (Bank et al., 2006). Support groups help caregivers to release their frustration and to develop coping strategies (Simpson et al., 2018). They have a long history of offering an effective and economical way of improving health outcomes (Mehta & Atreja, 2015). Meaningfully, the health and social system encourages caregivers of people with Alzheimer’s to participate in this kind of group. Peer support is beneficial for caregivers as it provides a source of positive emotional support, a means of airing negative feelings and the opportunity to get help to address problems that arise in the everyday life care of people with dementia (Lauritzen et al., 2015).

However, support groups differ in content, process and structure and it is unclear which groups produce a meaningful outcome for caregivers (Hornillos & Crespo, 2012). In addition, despite the interest in this kind of intervention and the many changes in methodology, the actual level of knowledge regarding the effects and mechanisms of support groups is more or less the same as it was about twenty years ago (Hornillos & Crespo, 2012). Furthermore, geographic and time constraints, combined with a lack of substitute caregivers may preclude attendance at traditional support groups.

Internet-based interventions hold considerable promise for meeting the educational and support needs of dementia caregivers (Boots et al., 2014). Nevertheless, most of the studies are heterogeneous and involve different participant groups, interventions, comparison conditions, and outcomes. The most common formats of Internet-based supportive interventions are based on websites. Offering support via the Internet is an innovative intervention that reaches caregivers. However, despite prolific effectiveness and efficacy research on eHealth interventions for caregivers of people with dementia, there is a critical shortage of implementation research. Furthermore, there is a mismatch between eHealth intervention research and implementation frameworks (Christie et al., 2018).

Specifically, virtual communities are consequences of the Internet framework, which, by definition, is a network itself. It is a network of networks, allowing communication. Literature offers the first definition of online communities: "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace" (Rheingold, 1993, p. 6). Then, the idea that they are useful to leverage knowledge was introduced (McDermott, 1999) and that virtual communities use networked technology to establish collaboration across geographical barriers and time zones (Johnson, 2001). The evolution of the concept offered a new definition of virtual communities as "online social networks where people with common Internet interests, goals or practices interact or exchange information and knowledge, and engage in social interactions" (Chiu et al., 2006, p. 1873). These virtual communities may offer family caregivers the opportunity to interact with peers for guidance, information and encouragement.

Online support groups are a type of virtual community whose primary purpose is to provide a forum in which individuals with similar concerns can support each other. They may or may not be facilitated by a trained leader, who would mostly be a health professional. Specifically, online support groups appear to be a viable option of support for families and friends of people with a mental illness, including Alzheimer's (Perron, 2002). One of the benefits of the online support groups is the convenience of sending and receiving messages 24 hours a day from around almost the whole world. Consequently, users can be geographically and temporally separated (Godwin et al., 2013). Also, caregivers in an online support group may need to consider their thoughts before sending messages. Using the Internet gives them a chance to reflect and there is a record of interactions between caregivers (Chung, 2014; Dosani et al., 2014). These groups are valuable because they have the advantages of mutual aid and the accessibility of computer technology (Finn, 1999). Furthermore, an online support group provides support communication and, by being a valuable peer support, lessens isolation (Craig & Strivens, 2016).

On the other hand, online support groups have limitations, which must be considered. Firstly, demographic factors, such as gender, age, race or socio-economic status are neutralised (Dosani et al., 2014). Secondly, the members of virtual communities take longer to develop interpersonal impressions of each other than members who interact face to face. There are also doubts about the accuracy of the information being shared. Still, research has indicated that caregivers of people with Alzheimer's find respite in online communities for solutions and emotional support (Scharett et al., 2017). So, virtual communities look promising for keeping the support for caregivers accessible and affordable.

The benefits of eHealth use, defined as the usage of health services and information disseminated through the Internet and related technologies (Eysenbach, 2001), is potentially very important among the population of caregivers (Sarkar et al., 2016). This Internet-related health concept is even more promising because future generations of family caregivers will be more familiar with the Internet (Blom et al., 2015). Furthermore, the enormous potential of smart mobile devices led to increased activity in developing and providing mobile health (m-health) solutions for Alzheimer's (Elfaki & Alotaibi, 2018). Alzheimer's m-health tools have been shown to be successful in improving awareness of the disease based on providing information for both people with Alzheimer's and caregivers (Elfaki & Alotaibi, 2018). Moreover, recent research has found a link between eHealth literacy and health literacy levels and the carers' perceptions of their caregiving role, self-efficacy, and coping (Efthymiou et al., 2017). EHealth literacy has been defined as "the ability to seek, find, understand, and appraise health information from electronic sources and the extent to which individuals have context-specific and analytical skills needed to successfully navigate online health information" (Norman & Skinner, 2006, p. 2).

One of the most challenging aspects of virtual communities is their dependency on users for the generation of content, as any user can act as a producer of the content consumed on the sites (Baumer et al., 2011; Velasquez et al., 2014). Research indicates that virtual communities evolve over time when people become aware of themselves as group members, feel ownership of the content, feel attachment to the group and see helping others as their responsibility (Dennen, 2014; Rodgers & Chen, 2005). Encouraging participation and building thriving communities are frequently cited central challenges for any virtual community. However, "a theoretical and conceptual framework for user participation remains undefined, as most of the research has approached participation in terms of its quantity" (Malinen, 2015, p. 228). Empirical studies of online participation have typically focused on the most visible and dominant participants who, in reality, represent a minority among community members (Malinen, 2015). Still, in many ways, the biggest challenge for a virtual community is the creation and sharing of knowledge (Chiu et al., 2006). This challenge leads us to the concept of CoPs and, furthermore, to VCoPs. These communities (already used in the field of health) are informal social entities, which have arisen from shared identities, concerns and interests and which build knowledge through the exchange of ideas and the fostering of relationships. Therefore, a health VCoP is another intervention based on the community approach, which could give a response to the needs of family caregivers of people with Alzheimer's.

Virtual Communities of Practice in Health

This section first studies the background of CoPs in order to introduce the concept and see its functionality. Secondly, it introduces the evolution of CoPs to VCoPs, which emerge with the information society. Then, it overviews the itinerary of CoPs and VCoPs through the field of health. Finally, it summarises the models for VCoPs in health.

Background of Communities of Practice

The earliest attempt to define CoPs was "professional communities". It was defined as a community in whose members are bound by their identity, rarely leave the community, share common values and have defined, acknowledged roles that are understood by members and non-members (Goode, 1957). In professional communities, members share a common language, only partially understood by non-members, and the community itself exert power over them. Nevertheless, the concept was not further developed until the creation of knowledge was integrated into the definition (Brown & Duguid, 1991; Wenger & Lave, 1991). CoPs were seen to be of interest to organisations as a means of solving problems (Wenger & Lave, 1991). Furthermore, the concept of the community of communities where everybody involved is viewed as equal was introduced (Wenger & Lave, 1991). CoPs were centred on interaction between novices and experts, and the process by which newcomers create a professional identity. It was a matter of people from the same field improving their skills by working alongside experts and being involved in increasingly complicated tasks.

The CoP concept evolved becoming a type of informal learning organisation (Wenger, 1996). A new perspective, that of learning in the context of our lived experience of participation in the world was introduced. In line with this perspective, the first documented CoP appeared. It was an ethnographic study among the Xerox technicians' group where it could be seen that specific of machine malfunctions were solved by informal discussions and storytelling (Orr, 1996). Moreover, the term 'occupational community', which suggests a focus on the worker's ability to meet the company's goals rather than individual goals, was raised (Orr, 1996).

The CoP concept kept growing. In 1998 learning was seen as being integrated into the experience of participation (Wenger, 1998). Thus, in a CoP knowing, belonging and doing are not separable. Then, a CoP was defined as a shared professional identity which is the glue that binds the members of a community together (Wenger, 1998). At this point, the social learning theory integrated with meaning, practice, community and identity was introduced. Moreover, these four traits were turned into three interrelated dimensions: mutual engagement, joint enterprise and shared repertoire (Wenger, 1998). Concretely, a CoP was viewed as a way of emphasising that every practice is dependent on social processes through which it is sustained and perpetuated, and that learning takes place through the engagement in that practice (Gherardi et al., 1998). The term community within the CoP context is understood as the participation in an activity system about which participants share an understanding of what they are doing and what that means for their lives and for their communities.

Making progress in the evolution of the CoP concept, another definition of CoPs was raised. It was described to use active participation and decision-making by individuals, as opposed to separate decision-making that is present in traditional organisations (Collier & Esteban, 1999). This approach acquires creative and effective solutions from the communities' participants that are essential for organisations, if they are to survive in environments of continuous change. CoPs are the sum of both stakeholder interest and the development of individuals within the community. Authoritarian management is replaced by self-management and ownership of work (Collier & Esteban, 1999). So, the learning that evolves from these communities is collaborative and that collaborative knowledge of the community is greater than any individual knowledge.

Knowledge is often seen as a rich form of information. It is about know-how and know-why. The construct "knowledge sharing" implies the giving and receiving of information framed within a context by the knowledge of the source. What is received is the information framed by the knowledge of the recipient (Sharratt & Usoro, 2003). Then, resource sharing is recognised as being a major reason for collaboration between partners (Ahuja, 2000). Between network partners and within organisations, knowledge is shared through both formal and informal relationships (Caimo & Lomi, 2015). The objective of knowledge sharing may span from organisational learning to collaborative problem solving, to peer support or to capacity building (Sibte & Abidi, 2006).

As seen in the previous section, these objectives entail the explanation of knowledge and the facilitation of its flow throughout a CoP. The concept captures the way that individuals desire to learn, share knowledge and support each other, which can be powerfully rooted in common daily practices and a common identity (Vidgen et al., 2013). CoPs build knowledge through the exchange of ideas and the encouragement of relationships. Among the main reasons why CoPs are effective tools for knowledge sharing is the fact that much of an individual's knowledge is intangible and tacit in character (Ardichvili et al., 2003). Tacit knowledge (also called experiential), defined as knowledge that is understood without being stated, has a personal quality which makes it hard to formalise (Biggam, 2001). CoPs offer the framework for sharing tacit knowledge.

In line with this, collaborative teams and CoPs were defined as entities that help solve authentic problems (Wick, 2000). In addition, a more concrete definition of CoPs appeared, that is, as groups of professionals with similar task responsibilities (Wick, 2000). This definition enables interdisciplinary knowledge and practice. CoPs exist to promote learning via communication among their members. Furthermore, the concept of communities of interest, defined by their collective concern with the resolution of a problem which brings together stakeholders from different communities of practice, was introduced (Fischer, 2001).

Also in the same year, components of CoPs which distinguish them from traditional organisations and learning situations, believing that the main function of a CoP is to help establish discussion were identified (Johnson, 2001). It was then that the concept of facilitation, a concept borrowed from constructivism which also applies to CoPs, was integrated (Johnson, 2001). In fact, from the very beginning of the CoPs, there is evidence that the facilitator or moderator role is a key factor in the development of the CoP (Ranmuthugala et al., 2011) .

Later, a CoP was defined as “a group of people who may not normally work together but who are acting and learning together in order to achieve a common task whilst acquiring and negotiating appropriate knowledge” (Lathlean, 2002, p.396). This definition paves the way for offering the key factors that influence the development, functioning and maintenance of each CoP: membership, commitment, relevance, enthusiasm, infrastructure, skills and resources. With this definition many opportunities for CoPs in health could be seen. Moreover, the CoP theory is one way in which a legitimate and highly contemporary form of group work may be used to explore health and social care issues and develop practice, as they may increase social, human, organisational, professional and patient capital (Lathlean, 2002).

In line with the creation of knowledge, another definition appeared: “informal networks that support professional practitioners to develop a shared meaning and engage in knowledge building among the members” (Hara & Kling, 2002, p. 339). Each CoP has unique attributes. However, there are several common elements in all CoPs: practice, professional identity, autonomy, shared vision, supportive culture, shared meaning, and collective knowledge building (Hara & Kling, 2002).

More or less in line with the last two definitions, dated 2002, another description of CoPs was presented “groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis” (Wenger et al., 2002, p. 10). These communities build knowledge through the exchange of ideas and the encouragement of relationships. So, CoPs were characterised by the domain (the area of knowledge which joins the community), the community (the group of people for whom the domain is relevant) and the practice (the body of knowledge, methods, tools, stories, cases, documents that the participants share and develop together). Then, three components were identified in CoPs: people, practice and capabilities (Wallace & Saint-Onge, 2003) which resemble the practice, domain and community (Wenger et al., 2002). Later, three levels of CoPs based on organisational structure and governance were introduced (Wallace & Saint-Onge, 2003): informal groups, supported groups and structured groups.

It is through mutual engagement that the group develops a shared repertoire of stories and cases that function as a dynamic knowledge source on which to base future practice (Gray, 2004; Wenger, 1998). CoPs are proposed as collaborative, informal networks that support professional practitioners in their efforts to develop shared understanding and engage in work-relevant knowledge building (Cox, 2005). In addition to this, the organisational environments where a CoP develops and operates were identified, defining four typologies of CoPs (Bourhis et al., 2005): demographics, organisational context, membership characteristics and technological environment.

From another perspective, CoPs help to foster an environment in which knowledge can be created and shared to improve the effectiveness of existing practices used in organisations (Probst & Borzillo, 2008). When building CoPs for business, six terms should be considered: leadership, sponsorship, objectives and goals, boundary spanning, risk-free environment and measures (Probst & Borzillo, 2008).

Later, very much in line with the previous idea of mutual engagement, developing shared understanding and engaging in work-relevant knowledge building (Cox, 2005; Gray, 2004), but taking into account the concept of identity (Wenger, 1998), four characteristics of the CoPs groups were identified (Li et al., 2009a): members interact with each other in formal and informal setting, members share knowledge with each other, members collaborate with each other to create new knowledge and CoPs foster the development of a shared identity among members. Moreover, these characteristics are somehow connected with the three dimensions later introduced: personal membership, koinonia and society (Gobbi, 2009).

After all these years of CoP theory growth, the concept was taken back to its origins of learning but the term was examined more thoroughly (Wenger, 2010). A CoP was viewed as a simple social system whereas a complex social system could be viewed as interrelated CoPs. The CoP concept does not exist by itself. It is part of a broader conceptual framework for thinking about learning in its social dimensions. It is a perspective that locates learning, not in the head or outside it, but in the relationship between the person and the world, which for human beings is a social person in a social world. In this relationship of participation, the social and the individual constitute each other.

A CoP entails a shared domain that becomes a source of identification. This identity creates a sense of commitment to the community as a whole, not just connections to a few linking nodes. A community usually involves a network of relationships. A network is the set of relationships, personal interactions and connections among participants, viewed as a set of nodes and links, with allowances for the flow of information and helpful linkages. Still, many networks exist because participants are all committed to some kind of joint enterprise. CoPs are networks in the sense that they involve connections among members, but not all networks are CoPs (Wenger et al., 2011). A CoP is "the simplest social structure that has all the elements of the perspective: learning interaction between social structure and the person, and the mutual constitution of the two" (Omidvar & Kislov, 2014, p. 4).

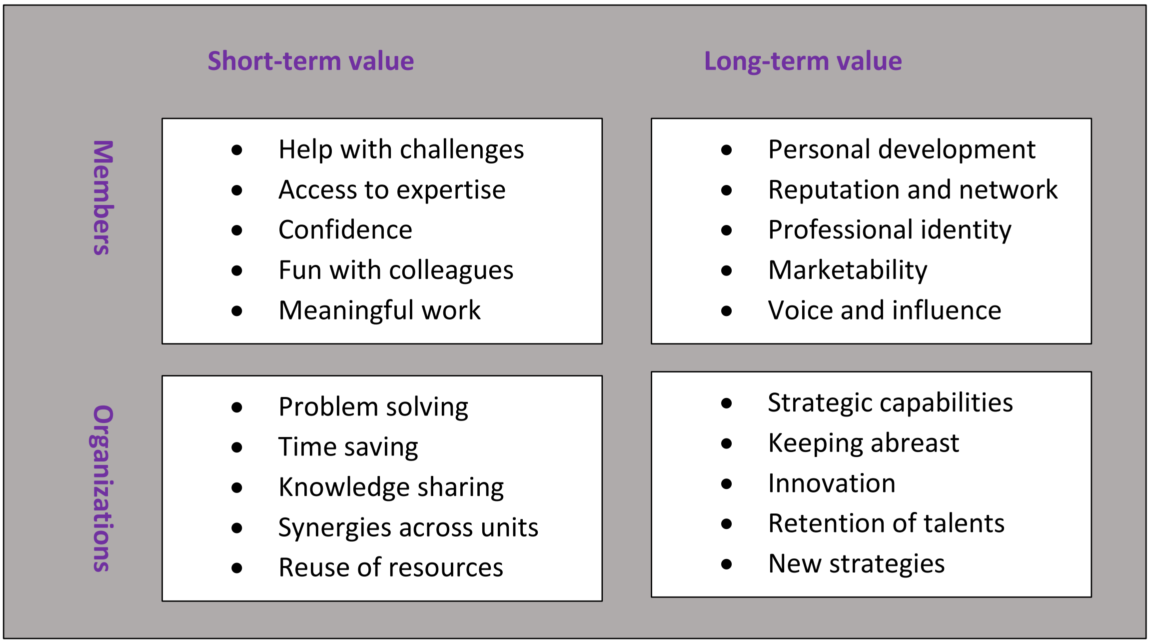
Through this section, reviewing the CoP concept it has been seen that CoPs are resources to focus on in order to create value (Figure 1):

Figure 1. *Communities of practice as strategy of value creation*

Note. Adapted from https://jennymackness.wordpress.com/2011/07/12/value-creation-in-communities-of-practice/ (Wenger et al., 2011)

The creation of value of this CoP is based on the dimensions presented in Figure 2:

Figure 2. *Dimensions of CoPs' Value Creation*



	Short-term value	Long-term value
Members	• Help with challenges • Access to expertise • Confidence • Fun with colleagues • Meaningful work	• Personal development • Reputation and network • Professional identity • Marketability • Voice and influence
Organizations	• Problem solving • Time saving • Knowledge sharing • Synergies across units • Reuse of resources	• Strategic capabilities • Keeping abreast • Innovation • Retention of talents • New strategies

Note. Adapted from https://wenger-trayner.com/project/why-focus-on-communities-of-practice/ (Wenger & Trayner, 2021)

Furthermore, this CoP theory, rooted in the concept of knowledge sharing, the first example being in the company Xerox, evidenced that sharing advances at individual and collective levels opens many doors in a wide range of fields, including healthcare. CoPs in the field of healthcare will be presented later in this chapter. However, at this point, an explanation of how the Internet influences CoPs should be provided.

Background of Virtual Communities of Practice

With the influence of the Internet in all aspects of society and the emergence of virtual communities (as has been shown in *Interventions for family caregivers of people with Alzheimer's*), the notion of VCoPs flourished. Online communities, dating from 1993 (Rheingold, 1993), were soon seen as a useful resource to leverage knowledge (McDermott, 1999) and cyberspace classrooms were the first attempt to develop VCoPs (Palloff & Pratt, 2001).

Knowledge sharing was the main concept of CoPs and introducing virtuality does not change the goal. A VCoP shares the characteristics of a CoP, but their members interact primarily in a virtual environment using online communication technologies (Dube et al., 2006). VCoPs consist of individuals with a shared passion who communicate via virtual media to advance their own learning and that of others (Thoma et al., 2018).

When the concept of VCoPs emerged, the debate was about whether relationships and trust could be built online, and whether tacit knowledge and practice could be also shared online. With regard to trust, some authors initially pointed out that it is difficult to form a VCoP, as online communication can only strengthen existing face-to-face CoPs (Nichani & Hung, 2002). Then, the concept evolved to the point where although, at some point, face-to-face contact in the community-building process can be useful and facilitate community development, it is possible to build community without it (Palloff & Pratt, 2001). It was essential to clearly define the community's purpose and create a gathering place for the group. In addition, the group should promote internal leadership and define norms. Trust is the glue that binds and encourages the members of a community to act in a sharing and flexible manner. If these factors converge, the Internet immediately benefits by establishing collaboration across geographical barriers and time zone (Godwin et al., 2013).

The other concern about VCoPs was whether tacit knowledge and practice could be shared online. Herrington & Oliver (2000) argued that ICT can provide the essential authentic context required by situated learning. They designed a multimedia learning environment to support authentic learning situations and their study concluded that situated learning and knowledge sharing could be successfully supported in this environment. Technologies are well aligned with the peer-to-peer learning processes typical of CoPs (Wenger, 2010). VCoPs foster communication, personal development and the exchange of resources (Li et al., 2009a). They are frameworks for a form of social group who share knowledge, where members establish a culture of collaboration and they ultimately come to have a sense of trust in the community. This definition gave positive answers to both issues (Abidi et al., 2009).

Having seen that, in general, VCoPs share similar characteristics with CoPs, it is time to evidence the several aspects in which they differ (Lai et al., 2006):

1. Design: VCoPs, by nature, involve more design than face-to-face CoPs as technological infrastructures have to be built to support the functioning of the CoP.
2. Membership: VCoPs may be open while CoPs are usually closed. In VCoPs, members do not necessarily know each other before becoming CoP members. CoPs are mainly sub-groups.
3. Leadership: leaders and moderators of VCoPs are recruited, while in CoPs they may emerge from the community considering that CoPs emerge mostly from existing grouping and organisation based.
4. Form of communication: in VCoPs communication is primarily computer-mediated, while in CoPs it is primarily face-to-face.
5. Time to develop the community: it usually takes longer to develop a VCoP than a CoP.
6. Technological support: this is essential for VCoPs but not for CoPs.

Literature provides a range of several advantages of VCoPs over CoPs. Being online, a VCoP frees its members from time constraints (availability is 24 hours a day) and space constraints (it can be accessed from anywhere) (Godwin et al., 2013). Moreover, it facilitates a learning room to create and share knowledge, promoting interaction. VCoPs offer a broad spectrum of cost-effective advantages versus face-to face interactions (Ardichvili et al., 2003). When the motivating factor of online use is the acquisition of information, then psychological well-being and social integration of the participant increases (Winkelman & Choo, 2003). In addition, greater levels of participation in

VCoPs help to share knowledge, disseminate ideas quickly and provide emotional support among members (Koh & Kim, 2004).

For a CoP, the virtual environment facilitates a space for the learning and enculturation of newcomers, as well as an opportunity for more experienced practitioners to gain new insights into various aspects of the practice and of their own professional identities as coordinators (Gray, 2004). Sharing ideas not only helps to develop and construct identity as an individual practitioner, but also serves to reconstruct the identity of the collective community of moderators on an ongoing basis. Moreover, there is a need for exploring how technology in general could become integrated into their practices (Cox, 2005).

Over the years, research has offered various classifications of VCoPs. Depending on their structural characteristics, they could be classified as demographics, organisational context, membership characteristics or the technological environment (Dube et al., 2006). Hara and Hew (2007) identified different shared knowledge: tacit, explicit, book knowledge, practical knowledge or cultural knowledge. Moreover, they identified six factors for a sustainable knowledge sharing VCoP: self-selection, validation of one's practice by others who share a similar working situation, a need to gain a better understanding of current knowledge and best practices in the field, a non-competitive environment, the asynchronous nature of the online communication medium and the role of the community moderator. Later, Zhao & Bishop (2011) offer a model, different from Hara and Hew's (2007), which highlights six elements relevant for VCoPs: individuals, practice, content, interaction, community and technology. Based on this model, it is believed that a key to the success of a VCoP may be for both the practice and the outcomes of practice to somehow be accessible online.

According to Lave and Wenger's (1991) theory of situated learning, a new member in a VCoP transitions, over time, from peripheral participation in the community towards becoming a masterful member. By sharing and developing ideas, by discussing, by problem solving, and generally striving to become a more competent member, the community members are able to engage in the mutual development of both their own knowledge and the community's pool of expertise (Usoro et al., 2007). Although thriving, VCoPs depend on active members and lurking can be the vital first step for individuals who are wary of Internet communications and technology, or who lack confidence in their knowledge base (Macphee et al., 2009). Literature pointed out the importance of peripheral members (Wenger et al., 2002). Peripheral members may not be a passive first thought and may still gain value and enhance their practice from this type of membership. Users can engage with the sites in different ways (Malinen, 2015).

Hence, in line with the suggestion of CoPs as an option to deliver appropriate support to caregivers, VCoPs could be a potential Internet-based intervention for family caregivers of people with Alzheimer’s.

Use of Communities of Practice and Virtual Communities of Practice in Health

In the previous sections of this chapter (*Background of Communities of Practice* and *Background of Virtual Communities*), by reviewing the literature on CoPs and VCoPs, the evolution and characteristics of face-to-face CoPs and VCoPs have been presented. The aim of this section is to get an overview of the use of these communities in health.

The history of health and social care is rooted in the formation of CoPs (Wenger, 2009). However, the first documented CoP related to health is from 1996 (Wenger, 1996). Since then, the CoP concept has been applied to health and it is gaining in popularity. The two existing systematic reviews of CoPs in health concluded that CoPs are promoted in the healthcare sector as a means of generating and sharing knowledge improving organisational performance (Li et al., 2009b; Ranmuthugala et al., 2010).

Health and social care CoPs highlight the possibility of finding learning partners regardless of title or affiliation (Wenger, 2009). The focus should be on learning what is necessary for the benefit of users. Recognising the user as a participant, the community is especially important when everyone has multiple sources of knowledgeability about their conditions (the state of a person with respect to a landscape, not with respect to a specific practice). Furthermore, considering that CoPs may contribute to the introduction of new methods of informal learning, health VCoPs can identify and address unmet patients’ needs (Van Oerle et al., 2018). As users, learning in such communities, patients/clients become increasingly active participants in the world of health and social care practices (Wenger, 2009). It is therefore essential to include the patient's perspective explicitly within the social learning process in health and social care.

Literature states that the main benefits of health VCoPs are increased interaction among the members, the process of creating and sharing knowledge, the peer, social and emotional support, public health surveillance and the potential to influence health policy (Jiménez-Zarco et al., 2015). Focusing on a chronic disease, such as Alzheimer’s, previous research has already suggested that healthcare organisations can promote the creation and use of knowledge by chronic patients through the introduction of a virtual, private, disease-specific patient community (Winkelman & Choo, 2003). This virtual socialisation alters the role of chronic disease patients from external consumers of healthcare services to a VCoP of external customers.

Tacit knowledge is acquired by a patient with a chronic disease experientially through the activities of daily living with that disease. Introducing a virtual, private, disease-specific patient community operationalises the principles of patient-centred care by validating the needs, preferences, contributions and experiences of chronic patients as high-quality sources of knowledge (Winkelman & Choo, 2003). Then, person-centred healthcare organisations may use the VCoP to direct and support the empowerment of chronic patients in their care. An innovative challenge would be the use of a health VCoP to help caregivers meet their needs.

Having seen the theoretical part of CoPs and VCoPs and their potential use in health, it is time to see how these communities have been implemented in health. Below, are the most relevant experiences that appear in the two systematic reviews of CoPs, as well as other more recent examples of VCoPs (Li et al., 2009b; Ranmuthugala et al., 2010):

1. A CoP in a hospital cafeteria (Memorial Hospital): a nurse was concerned about a diabetic patient turned blind’s ability to take his medication properly. An informal conversation

between this nurse, a medical student, an occupational therapist and a nurse from another section led to a solution for the user, as pooling their own previous experiences helped to find it. In addition, these health professionals of the hospital shared ideas and solutions with thirty other users. This kind of informal problem solving happens in every organisation, but in a learning organisation it is the norm. In a fundamental way, healthcare is about learning (Wenger, 1996).

2. A CoP considering learning could address the barriers encountered in traditional medical further education (Parboosingh, 2002).
3. A CoP initiative at the University Hospital of Leicester: www.yourheart.org.uk . The aim was to support patients through acute and chronic heart conditions and in life after treatment. The platform was set up to inform patients about the facts of their condition and to allow direct access to healthcare professionals via email and an "ask the expert" forum. It was based on asking patients what they wanted (Cox et al., 2003).
4. A VCoP as an intervention for patient empowerment. Chronic disease patients, with the tacit support of their health-care organisation, have a forum supporting the integration of knowledge gained from the experiences of living with chronic disease in their self-management (Winkelman & Choo, 2003).
5. A CoP for enhancing the process of evidence-based policy development in health and social care. It facilitated and evaluated two multiagency CoPs working on improving specific aspects of health and social services for older people and analysed how they processed and applied knowledge (Gabbay et al., 2003).
6. A VCoP of nurses, the purpose of which was twofold: firstly, to examine the types of activity that nurses undertake in a virtual community, as well as the types of knowledge that nurses share with one another; secondly, to examine the factors that sustain knowledge sharing among the nurses from their personal perspectives (Hara & Hew, 2007).

7. A project which intended to develop recommendations for the design and implementation of a CoP model to support shared priorities for the prevention of cancer and chronic disease. The project provided a forum for practitioners to interact and share knowledge and experiences pertinent to their tasks, to solve problems and to address gaps in knowledge, research and practice (Barwick, 2008).
8. A study of the communication between distributed health care professionals in oral medicine through the Swedish Oral Medicine Web (SOMWeb), centred on user-contributed case descriptions and meetings. It was focused on and exclusive to practitioners (Falkman et al., 2008).
9. A practitioners' VCoP to analyse the exchange of knowledge for the management of paediatric pain (Abidi et al., 2009). This analysis was developed through the model “Leveraging Internet Networks for Knowledge Sharing" (LINKS). LINKS is a model grounded in the CoP concept (Sibte & Abidi, 2006). It provides a conceptual framework to help establishing VCoPs to share knowledge, specialising in health, through 2.0 tools. It is a model, which incorporates different methods of analysis, depending on the knowledge that is used. Health knowledge sharing operates between three elements: healthcare knowledge, knowledge-sharing context, and knowledge-sharing medium (Sibte & Abidi, 2006). All three elements are covered in the conceptual level.
10. A VCoP to support innovation in primary care in the Basque Public Health Service (HOBE) (Abos-Mendizabal et al., 2013). It was aimed at all primary care professionals in the Basque Public Health Service (Osakidetza) in the provinces of Biscay and Araba.
11. A VCoP for general practitioner training (ConnectGPR) (Barnett et al., 2014) implementing the health VCoP framework proposed by Barnett et al. (2012).
12. A VCoP to support evidence-based physiotherapy practice in manual therapy. The purpose of this study was to explore how a CoP promoted the creation and sharing of new knowledge in evidence-based manual therapy, using Wenger's constructs of mutual

engagement, joint enterprise and shared repertoire as a theoretical framework. Participants applied research evidence to the contexts in which they worked through reflective comparison of what they were reading with its applicability in their everyday practice. The participants’ shared goals contributed to the common ground established in developing collective knowledge about different study designs, how to answer research questions and the difficulties of conducting sound research (Evans et al., 2014).

13. A VCoP in simulation: the simulation education community is the Society for Simulation in Healthcare's Sim Connect Web site (Thoma et al., 2018).

CoPs in the healthcare sector vary in form and purpose (Ranmuthugala et al., 2010). There is no dominant trend in how the CoP concept is operationalized (Li et al., 2009b). While researchers are increasing the efforts to examine the impact of CoPs in healthcare, a greater understanding of how to establish and support CoPs to maximise their potential to improve healthcare is probably required. Furthermore, these interventions evidence that almost all the existing CoPs and VCoPs are directed at health professionals. Only Winkelman and Choo (2003) and Barnett et al. (2014) applied their study to patients but no study, representative of CoPs, was directed at family caregivers.

Models for Virtual Communities of Practice in Health

Literature provides a few sources to address this need for understanding how to establish and support VCoPs in health. Firstly, as was presented in the section *Use of Communities of Practice and Virtual Communities of Practice in Health*, Sibte and Abidi (2006) presented a model called Leveraging Internet Networks for Knowledge Sharing (LINKS). According to this model, health knowledge sharing operates between three elements: healthcare knowledge, knowledge-sharing context, and knowledge-sharing medium (Sibte & Abidi, 2006). All three elements are covered in the conceptual level. The conceptual level has three dimensions: knowledge modalities (type of knowledge shared), knowledge sharing context (topics and motivations in knowledge sharing) and knowledge sharing medium (the digital media outlets used). The operational level of the model highlights the culture of collaboration among knowledge stakeholders from varying backgrounds and with varying roles. The model addresses the trust the users have in online communities on the compliance level (Stewart & Abidi, 2012).

Secondly, Hara and Hew (2007) identified six factors for sustainable VCoPs in health: self-selection, the validation of one's practice by others who share a similar working situation, a need to gain a better understanding of current knowledge and best practices in the field, the non-competitive environment, the asynchronous nature of the online communication medium and the role of the community moderator.

Finally, Barnett et al. (2012) contributed to the VCoP theory by taking the Probst and Borzillo (2008) model from the business field and adapting it to the health framework. These authors suggested a seven-step framework model:

1. Facilitation: to promote engagement and to ensure community standards.
2. Champion and support: to start the network with a stakeholder champion and support.
3. Objectives and goals: to establish clear objectives, which provide members with responsibilities and motivate them to contribute more actively.
4. A broad church: to consider involving people from different backgrounds.
5. A supportive environment: to promote a supportive and positive culture.
6. Measurement, benchmarking and feedback: to include measurement as a factor in the design of VCoPs, including benchmarking and feedback.
7. Technology and community: to ensure ease of use and access. Communities are more likely to share knowledge when there is a mixture of online and face-to-face meetings, members self-select and both passive and active users are encouraged.

The first model is mainly focused on the analysis of the knowledge shared within the community (Sibte & Abidi, 2006). The second one emphasises the sustainability of the community (Hara & Hew, 2007). The third model, being rooted in the business field and adapted to the health framework, makes use of the health VCoP establishment consistently (Barnett et al., 2012). However, the three models were implemented through VCoPs of health professionals, not of patients or family caregivers.

Lessons Learned and Research Proposal

After reviewing the literature, it was understood that the impact of chronic conditions associated with age is growing, and that one of these disabling chronic disorders which requires a high level of care is Alzheimer's disease. Here, the role of family or informal caregivers is crucial. Their QoL is diminished by their situation. The primary needs of family caregivers are to have the support of their peers, access information, training about the disease and caring oneself. Therefore, meeting caregivers' needs is a public health imperative, as otherwise, their health and QoL could be severely impaired. Most of the interventions for caregivers are focused on improving the sharing of information, offering social support and suggesting coping strategies. Moreover, the existing research shows virtual environments seem to be a means for fulfilling these needs.

Considering the CoPs theory, and furthermore, integrating it into the current information society, it has been seen that VCoPs may be a resource to help family caregivers of people with Alzheimer's meet their needs.

Demographic factors and all that caregiving entails, may possibly affect the health of caregivers and may influence their QoL. Care-recipient functional deterioration is another factor which could impact on family caregivers' QoL. EHealth literacy of the caregivers may dictate their participation in a virtual community, as well as their caregiving role, self-efficacy and coping.

However, it was realised there were no specific guidelines or models for designing VCoPs for either family caregivers or caregivers of people with Alzheimer's.

Therefore, there is a need for:

1. Designing interventions and resources for caregivers as well as exploring whether VCoPs could be a resource for caregivers.

2. Having a framework to design and analyse VCoPs of family caregivers of people with Alzheimer's to help them learn how to deal with the demands of caregiving.
3. Improving family caregivers' QoL through these interventions and resources.

The general aim of this research is to provide resources, specifically VCoPs, to help family caregivers of people with Alzheimer's cope with their role. There are three specific objectives:

1. To propose a conceptual framework which shapes the design of the VCoPs, so as to help family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to meet their needs.
2. To analyse how membership of a VCoP impacts on the QoL of family caregivers of people with Alzheimer's.
3. To study the knowledge shared among family caregivers of people with Alzheimer's in VCoPs, the interaction between them and their participation in the community, as well as how these factors are related to the caregivers' QoL.

With the aforementioned aims in mind, two hypotheses are to be considered:

1. A VCoP offers the possibility of helping family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to meet their needs.
2. VCoPs in health are beneficial for improving the QoL of family caregivers of people with Alzheimer's. The shared knowledge, the interaction between members and their participation in VCoPs influence the QoL of family caregivers of people with Alzheimer's.

A Conceptual Framework of Virtual Communities of Practice for Family Caregivers of People with Alzheimer's

In the previous sections of this chapter, the literature on VCoPs, the caregivers' needs and current interventions have been presented. On one hand, it has been noticed that caregivers need to have the support of their peers, receive information and training about the disease. Moreover, caregivers are keen on improving the daily life management of their relative. On the other hand, the literature showed the presence of several CoP definitions from 1991 to today, and the existence of some models and frameworks of VCoPs in health since 1996. However, a gap has been identified, as there is no implementation of VCoPs for either family caregivers or family caregivers of people with Alzheimer's. Here, the interdisciplinary literature on CoPs and VCoPs can inform the process of building communities to address caregivers' needs.

This section presents a framework to design VCoPs to help caregivers learn how to deal with the demands of caregiving and to support their informational and emotional needs. All the information in this section comes from the work of Romero-Mas et al. (2020) who undertook the study to design VCoPs for family caregivers of people with Alzheimer's through an integrative review. Eleven dimensions were identified within the literature for successful VCoPs of caregivers: Network Structure, Technology, Moderator, Scale, Alignment, Community Design, Sense of Trust, Knowledge Sharing, Sustainability, Ethics and Evaluation. The salient points of the eleven dimensions are presented below:

1. Network Structure:

Literature about VCoPs evidences that a VCoP facilitates learning through interaction and relationships with others who share a common practice (Wenger et al., 2002). This somehow mirrors the way that caregiving manifests itself in a social relational context (Schulz & Martire, 2004). On one hand, contact with other caregivers can adversely affect the caregiver's own feelings of self-efficacy, thereby increasing anxiety, symptoms of depression and a sense of carrying a heavy burden (Cristancho-Lacroix et al., 2015; Marziali & Garcia, 2011). On the other hand, contact with other caregivers can reduce feelings of isolation (Glueckauf et al., 2005) as their needs for social support are met and they experience less stress (Ducharme et al., 2011).

2. Technology

Technology plays a critical role in supporting a community. Virtuality frees members from the constraints of time and space (Godwin et al., 2013), and it facilitates timely acquisition of information (Weiser, 2002). These two characteristics are aligned with the needs of family caregivers of people with Alzheimer's. Technology provides strategies for promoting caregivers' health behaviour by increasing knowledge (Boots et al., 2014). Consequently, technology contributes to meeting the demands of family caregivers for social support and helps them experience less stress (Lauriks et al., 2007).

3. Moderator

The moderator is the community coordinator (Gray, 2004) who plays an integral role in enhancing the functioning of the community and facilitating learning (Wenger & Lave, 1991). For family caregivers of people with Alzheimer's, the role of the moderator could be undertaken by health professionals, but also by a peer. The moderator will have the role of facilitator of the sharing of information and will help to activate knowledge sharing and give support to all the members, both within the caring context and the technological one (Boots et al., 2014; Lai et al., 2013).

4. Scale

In CoPs, the number of members is not fixed, but it is recognised that the size of the group is critical to its success (Gray, 2004). In communities for people with a chronic disease, the smaller, more controlled size of the private community makes it more sustainable as a social structure (Winkelman & Choo, 2003). The parallel with family caregivers of people with a chronic disease should be drawn. Scale needs to be controlled as family caregivers require social support and because stronger ties enable the sharing of difficulties coping with the diagnosis and the day to day experience of caregiving (Alzheimer's Society, 2019).

5. Alignment

Within CoP theory it is recognised that a community is driven by the value members get from it (Etienne Wenger et al., 2011). This value comes from the alignment of three related concepts: domain (common ground), community (social structure) and practice (specific knowledge the community shares, develops and maintains) (Wenger et al., 2002). In addition, the collective and organisational motivation of each individual must be aligned (Salido, 2012). If these two alignments are achieved then, specifically, family caregivers of people with Alzheimer's benefit from help with practical challenges, access to expertise, having more ability to contribute to the group, confidence in their approach to problems, fun from being with peers, more meaningful participation and a stronger sense of belonging (Lai et al., 2013; Wenger et al., 2002).

6. Community Design

As the community grows, it develops a systematic body of knowledge. Therefore, family caregivers of people with Alzheimer's, who have a sense of community, would realise that their involvement with the community translates into something useful: better care for the person with Alzheimer's, a better carer-care recipient relationship and the carers' better perception of their own role (Molina et al., 2006).

7. Sense of Trust

The most fundamental insight into the theory of CoPs is that common experiences arising from a common situation help people to relate to each other. It is the common, mundane experiences of caregiving that make caregivers a potential community. As a VCoP forms, it creates a sense of belonging for community members, who develop the habit of consulting each other for advice (Zhao & Bishop, 2011). A VCoP of family caregivers would develop norms of trust, reciprocity and cooperation that support knowledge sharing.

8. Knowledge Sharing

Practice related knowledge is the specific form of knowledge the community shares, develops and maintains (Nicolini, 2012). In the context of caregiving, this would be the everyday knowledge of how to offer care, how to deal with the ever-changing condition of the person with Alzheimer's and other practical wisdom about living with Alzheimer's. A VCoP is a suitable framework within which family caregivers can share and learn and where the domain creates the common ground and outlines the boundaries that enable them to decide what is worth sharing and how to present their ideas (Wenger et al., 2002). Having acquired and shared knowledge, caregivers will have more information about their own relative's illness and about the use of resources and services, which are the caregivers' main demands (Ford et al., 2015).

9. Sustainability

In order to sustain a CoP, members have to remain motivated to share good practice with their peers (Ikioda & Kendall, 2016). If family caregivers realise that their needs can be met within the VCoP, they will remain engaged. Sustainability gives caregivers serenity, tranquillity and psychological well-being, as well as the freedom to help them meet their needs (Vellone et al., 2008). Finally, a VCoP of family caregivers of people with Alzheimer's that is integrated into an already existing patient/carer support organisation, may make it more effective as a social structure (Winkelman & Choo, 2003).

10. Ethics

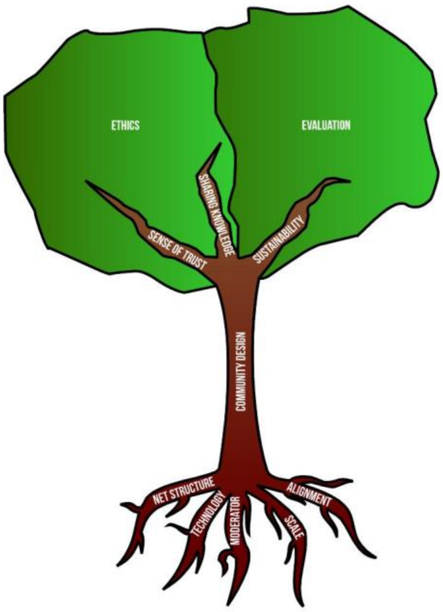
The CoP theory carries with it a particular sense of the ethics of participation. Within a CoP or a VCoP, members are treated as equals (Brown & Duguid, 1991). Furthermore, participating in a VCoP is voluntary. With regard to family caregivers, this self-selection within the non-competitive environment that the VCoP offers, affords the carers the calm and tranquillity to meet their needs (Vellone et al., 2008). A VCoP of family caregivers of people with Alzheimer's should prioritise the privacy of those with Alzheimer's. Moreover, the moderator has a key role in ensuring confidentiality and the protection of the Alzheimer's patients' personal data.

11. Evaluation

CoP literature evidenced that communities need measures to capture and celebrate their achievements, as well as to ensure continued efforts to become more active and effective. Wenger et al. (2002) pointed out the value of a CoP could be measured through its activity. Then, periodically, the results obtained should be contrasted with the expected ones. Furthermore, measuring the usability of technology is a key issue. When applied to VCoPs of family caregivers of people with Alzheimer's, the validation of their practice by others who share a similar situation, may affect their own life orientation by meeting their needs (Nicolini, 2012). This process could be completed, either by asking members about their satisfaction with the community through surveys, or suggesting they tell stories which might help them, both to construct an identity as an individual (family caregiver) and to reconstruct the identity of the collective community of family caregivers of people with Alzheimer's. The results obtained by the different analyses should be contrasted with the expected results of the caregivers (Parra-Vidales et al., 2017).

Wenger et al. (2002) suggested an analogy between cultivating a plant and establishing a CoP. Romero-Mas et al. (2020) saw this parallel with the organic and living environment of a VCoP of family caregivers and they suggested a tree metaphor to represent their framework, which was also used for this study (Figure 3).

Figure 3. *Tree Metaphor*



Note. Adapted from "Designing virtual communities of practice for informal caregivers of Alzheimer's patients: An integrative review" (p. 2987), by Romero-Mas, et al., 2020, Health Informatics Journal, 26 (4).

The main goal when designing a VCoP for family caregivers of people with Alzheimer's is to have a healthy, strong tree (Romero-Mas et al., 2020). Therefore, the tree should be duly watered in order to let the roots underpin it. Then, the tree will grow (trunk and branches) and the crown will turn green, which means the tree is in good health. The institution upon which the community depends, its moderators and members, will water it. However, whilst watering the tree is important, the weather (community interaction) may also impact, both positively and negatively on the tree's life. Community interaction with the outside world may be on two levels: individual or collective.

Therefore, favourable and unfavourable weather may come from, among others, health and social policies, health and social institutions and professionals, non-family member caregivers, family member caregivers, non-member friends or relatives. Furthermore, the weather may influence the tree differently, depending on the tree's state of health (Romero-Mas et al., 2020). Cultivating VCoPs to improve healthcare performance requires a greater understanding of how to establish and support VCoPs, so as to maximise their potential to enhance healthcare (Le May, 2009).

The framework presented in this section offers a contribution to the literature, as the protocols and principles regarding VCoPs that focus specifically on health were mainly aimed at professionals and sometimes patients, but not on at family caregivers or at family caregivers of people with Alzheimer’s (Barnett et al., 2012).

The main focus of the following chapters is to empirically test how decisions about these dimensions of the framework presented might shape the character of a VCoP for family caregivers of people with Alzheimer’s.

Methodology

Methodological approach

This study operates at the intersection of health and other fields of study, such as knowledge management and the Internet, communications and technology. With the main objective of this study in mind, the positivist paradigm was the first one to be considered for conducting this research as, initially, the researcher was focused on the second objective. The positivist paradigm tries to write and explain the events, processes and phenomena of the social world, so that generalisations that exist objectively can be formulated (Jason & Glenwick, 2016). The search for these generalisations or systematic explanations must be based on empirical evidence. It is these evidences that lead to the analysis of the empirical relations, the basis for all systematic explanation. The positivist paradigm insists on systematic, verifiable and comparable knowledge, measurable and replicable (Jason & Glenwick, 2016). However, delving into the first and third specific objectives, a more interpretative perspective seemed to be more helpful. So, the constructivism paradigm was contemplated. Constructivism is based on the basic assumption that the social world is one constructed with meanings and symbols, which implies the search for this construction and its meanings (Ruiz-Olabuénaga, 2012). Both paradigms could be considered but, from the researcher's perspective, neither of them covered the needs of this research. Therefore, the paradigm considered for this study was pragmatism. Pragmatism can integrate the use of multiple research methods such as qualitative, quantitative and action research methods (Hoshmand, 2003), as it is problem-oriented.

An integrative coexistence reasoning was followed where the possibilities of each methodology were valued equally and where it was also recognized that its complementary combination was a good way to study many of the social phenomena (Bericat, 1998).

The methodology of this thesis followed a mixed approach (Johnson et al., 2013), in such a way that it allowed the researcher to combine quantitative and qualitative methods during the course of the research. This approach is fully consistent with the objective of this thesis which aims to provide resources, specifically VCoPs, to help family caregivers of people with Alzheimer's cope with their role.

In order to engender a desirable outcome for family caregivers in need, the researcher proceeded with an intervention research. The intervention sought a change of behaviour of the caregivers which could lead them to meet their needs. It consisted in developing two VCoPs. The lack of tools and resources to carry out the intervention made the researcher think of designing her own. First, an app had to be designed and developed in order to host and permit the development of the VCoP. Then, the two VCoPs with all the participants had to be established. The intervention design of the thesis followed the eleven dimensions proposed in this conceptual framework to design two VCoPs for family caregivers of people with Alzheimer's. The observational process, analysed mainly from an interpretative description, allowed the researcher to conduct the study into the first objective of this thesis.

The intervention offered the chance to develop a longitudinal study of the caregivers' QoL to reach the second objective of the current research. This part was conducted from a quantitative approach which was mostly based on the bivariate statistical analysis. Furthermore, the intervention permitted the study of the knowledge shared, the interaction and the participation among caregivers, which was the third objective of this thesis. This study was managed through both qualitative and quantitative approaches.

Target population

Family caregivers of people with Alzheimer's living in Osona, a region of Catalonia (Spain), were being studied. Furthermore, health professionals working in Osona, a region of Catalonia (Spain), contributed as moderators of a VCoP.

Variables, Instruments, Tools and Analysis

Hypotheses relate two or more variables that will serve as the basic argument throughout the research. The step from defining the hypotheses and specifying the objectives to determine the variables is a very important process. In order for the researcher to conduct the research, one of the tasks which must be performed is to measure the study variables with appropriate instruments. In addition, depending on the kind of variables studied, several tools should be used for their specific analysis.

The variables, data handling instruments, data analysis tools and types of analysis which determined the actual research are detailed in Table 1:

Table 1. *Relation* of *variables, data handling instruments, data analysis tools and types of analysis for each specific aim*

Specific Aim (SP)	Variables	Data handling Instruments	Data analysis tools	Analysis
SP1	- Caregivers' needs - The eleven dimensions of the VCoPs: Network Structure, Technology, Moderator, Scale, Alignment, Community Design, Sense of Trust, Knowledge Sharing, Sustainability, Ethics and Evaluation.	- Literature Review	---	-Descriptive Analysis
SP2	- Membership of VCoP - QoL (*overall, physical, psychological & social*) and QoL_change (*overall, physical, psychological and social*)	- Spanish validated version of WHOQOL-BREF (*from 0 to 100*) – self admin - Spanish validated version of BARTHEL (*from100 to 0*) – self admin - Spanish validated version of eHEALS (from 0 to 60)– self admin	-SPSS 23.0	-Descriptive Statistical Analysis -Bivariate Statistical Analysis
SP3	- Knowledge sharing (overall & moderators): modality (*explicit, experiential and social*), topics (*disease information, social support – seeks support, gives support, gratitude - skills with the person with Alzheimer's, caring yourself & functionality of the research*), purpose (*information – about disease, about sender, about app& Internet link - & interactivity – seek answer, do not seek answer*) - Interaction (overall & moderators): #text, #photo, #event, #poll, #like, #comment, #direct message, #mentions, centrality indicators, betweenness centrality - Participation (overall & moderators): time (*dawn, morning, noon, afternoon, evening and night*), month (*M1-M11*), label (*"caring for others", "caring for yourself" and "disease"*), needs (*Alzheimer's information, support in care, social contact & caring for yourself"*), motivations (*"to instigate the resolution of problems in collaboration", "to inform and educate peers through personal-professional experiences, points of view and know-how", "to be informed and educated", "to negotiate and validate what one thinks", "to exchange ideas", "to build capacity", "to serve as a knowledge agent", "to form a viable community on a specific subject" and "considerations related to the communities"*), type of participation (*contributing, troublemaker, not contributing and lurker*), interest in the community and sense of trust (*0-5*) - QoL_Change (*overall, physical, psychological and social*)	- App Content - Oral open questions - Tailored Survey – self admin	-SPSS 23.0 -UCInet6 -LINKS Model	-Content Analysis – Inter-coder Reliability -Social Network Analysis -Bivariate Statistical Analysis -Thematic Analysis

Intervention description

The intervention allowed to implement two VCoPs for family caregivers of people with Alzheimer's ("I'mWithYou" VCoP and "I'mWithYouPlus" VCoP). The design and development of the intervention followed the conceptual framework presented in section *A conceptual framework of virtual communities of practice for family caregivers of people with Alzheimer's*:

1. Network Structure

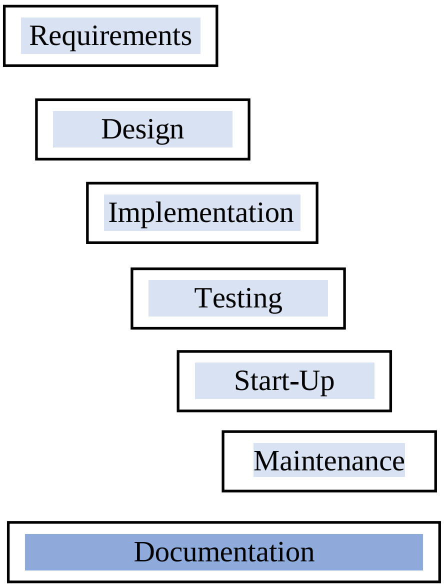
Network Structure started from an already existing carer support organisation in order to create the social structure of the group. First, the research idea was shared with the Osona Association of People with Alzheimer's and their Relatives (AFMADO), which understood the aim and the need of research for their members. It was then distributed to the hospital healthcare system and community health and social care services of the whole Osona region of Catalonia (Spain). In total, eight explanatory sessions with caregivers and twelve sessions with health professionals were held. From these sessions, 38 caregivers were recruited. All participants were recruited between July 2017 and April 2018. The inclusion criteria for family caregivers were as follows: being a family caregiver of a person with Alzheimer's; having Internet access; being able to use a smartphone, tablet or computer to download the app; and having their relative living in Osona. The exclusion criteria were family caregivers who did not want to participate in the investigation, and family caregivers who did not have an email address (at this was required to get the app installed). The participants were randomly divided into two groups of 19 caregivers.

2. Technology

As technology plays a critical role in supporting a community, a lot of attention was paid to this dimension. As Wenger points out (Wenger & Trayner, 2015), there is no specific Internet-based solution in the market to establish VCoPs. As a result, a VCoP was designed and tailored specifically for family caregivers of people with Alzheimer's. Considering the recent boom in m-health in the global and the Spanish market and the range of challenges involved, an app was chosen to set up the VCoP. This app was co-designed by the researcher together with *Confluència*[1] (a company dedicated to the development of mobile applications, digital identity, web design, online marketing and web analytics, among other services) who were in charge of the technical development.

The design of the app was developed using the classical Waterfall method (Weisert, 2003), in which each phase follows the previous phase in a linear fashion (Figure 4). This approach is inflexible, as once a phase is completed it moves on to the next, with the idea of not addressing it again later. This methodology was chosen instead of a more flexible one because the requirements and scope were very clear and the technology to be used was well known by the development team. During the whole process, the recommendations of *the Guia bàsica de recomenacions per el desenvolupament d'apps de salut i atenció social* (The basic guide of recommendations for developing health and social care apps) / (Fundació TIC Salut Social, 2018) were considered.

Figure 4. *Waterfall methodology*



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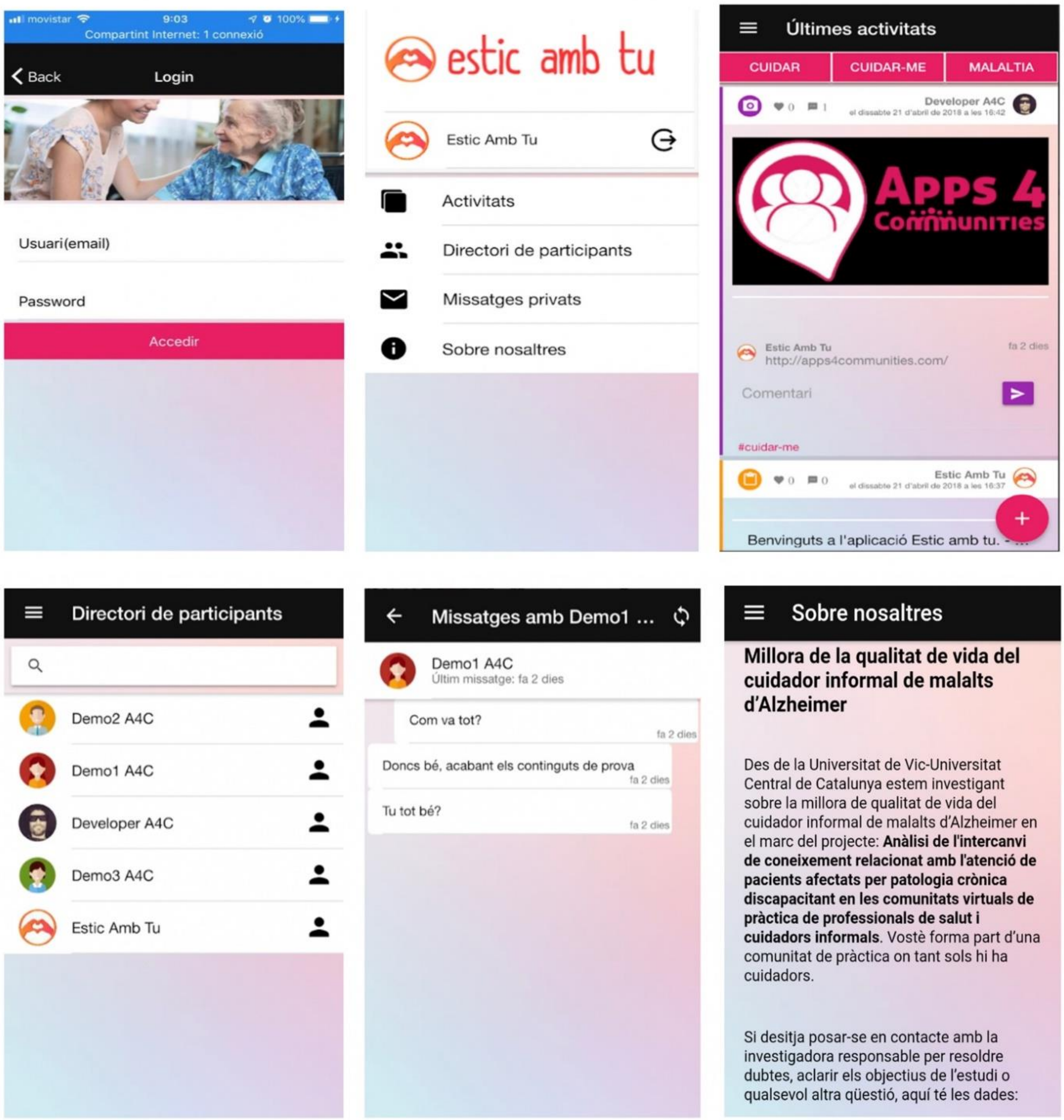
[1] http://confluencia.eu/

All the details regarding to the app development can be seen in *Annex A*. However, Figure 5 shows the main screens.

Figure 5. *Samples of the app "Estic amb tu-I'mWithYou" screenshots*



Estic Amb Tu fa 2 dies
http://apps4communities.com/

Benvinguts a l'aplicació Estic amb tu. - ...

Demo1 A4C
Últim missatge: fa 2 dies

Com va tot? fa 2 dies

Doncs bé, acabant els continguts de prova fa 2 dies

Tu tot bé? fa 2 dies

Millora de la qualitat de vida del cuidador informal de malalts d'Alzheimer

Des de la Universitat de Vic-Universitat Central de Catalunya estem investigant sobre la millora de qualitat de vida del cuidador informal de malalts d'Alzheimer en el marc del projecte: **Anàlisi de l'intercanvi de coneixement relacionat amb l'atenció de pacients afectats per patologia crònica discapacitant en les comunitats virtuals de pràctica de professionals de salut i cuidadors informals**. Vostè forma part d'una comunitat de pràctica on tant sols hi ha cuidadors.

Si desitja posar-se en contacte amb la investigadora responsable per resoldre dubtes, aclarir els objectius de l'estudi o qualsevol altra qüestió, aquí té les dades:

The first screen which appears when the app is initiated shows the logo. Then, the username and the password are required (Figure 5– on top left). Once the participant information is validated, the main screen with all the available options is shown (Figure 5– on top centre): the timeline activities (Figure 5 – on top right), the directory of participants (Figure 5 – below left), the direct messages (Figure 5 – below centre) and the contact information appears (Figure 5 – below right).

3. Moderators

The main reason for setting up two VCoPs instead of one was to see the difference between the communities according to their moderators' profile. In the "I'mWithYou" VCoP the moderator was an expert caregiver, whereas the "I'mWithYouPlus" VCoP included three health professionals. The inclusion criteria for the health professionals were as follows: being a professional in health and/or social care; working with people with Alzheimer's and/or caregivers; having Internet access; being skilled in using a smartphone, tablet or computer to enter the virtual community; and living in Osona. Health professionals who had no email or were not eager to participate in the study were ruled out. In our case, a nurse, a psychologist and a geriatric physician participated, all with more than 10 years of experience working with people with Alzheimer's and their informal caregivers. As to the expert caregiver, she had been taking care of her spouse for 8 years, and fulfilled the same inclusion criteria as all the other caregivers (regular participants).

Since all messages were labelled, as it has been explained at the deployment of the app (*Annex A*), the researcher sought a geriatric physician to moderate the "disease" label, a nurse to moderate the "caring others" label, and a psychologist to moderate the "caring for yourself" label. However, this initial decision was changed during the session that tested version 0 of the app with the moderators, because by then, the health professionals chosen to be the moderators said that they would rather prefer to moderate the whole community together rather than having it split into labels. It was agreed that the health professionals would moderate all the messages of the "I'mWithYouPlus" VCoP in a collaborative way, while the "I'mWithYou" VCoP would be moderated by an expert caregiver from the local AFMADO association, thinking about the sustainability of the study. In addition, another expert caregiver was identified within the community so that s/he could replace the moderator if necessary. As this moderator substitute was not required during the intervention, s/he was a regular participant and was not even aware of his/her selection.

Following the suggestion of Berge and Collins (2000), our moderators were supposed to take the roles of a filter, firefighter, facilitator, editor, manager, discussion leader, content expert, helper, and marketer. However, the researcher leading the intervention assumed the role of manager and marketer, releasing the moderators from the following tasks: controlling access of the participants; communicating to the rest of the community the role of the moderators and their goal by explicitly mentioning that this tool is not a medical consultation; maintaining communication with users by phone or email (for technical questions, comments, suggestions); organising a face-to-face session for each group a few months after the community had started; organising a final session preparing for the closing and evaluation; and working for the sustainability of the VCoP.

All moderators were invited to attend the three face-to-face meetings with all the regular participants. In addition, moderators attended three more meetings alone with the researcher in order to solve their doubts, to remind them of the VCoP goals, to motivate them and encourage their activity in the VCoPs. In other words, the meetings with the moderators were set up to create a space for dialogue with them to move forward with the practice of the VCoP.

4. Scale

This dimension is about community scale. In the intervention, the scale is the sample of the study. The research involved 38 caregivers and 4 moderators. CoP literature does not agree on the scale, but it does suggest that with fewer members, over time, interactions may become stale, and with a larger number of members, interactions will not be so strong. Furthermore, the health professional moderators, from their experience in previous interventions, suggested avoiding a huge group so that peers could strengthen their bonds. However, the caregivers promoted the VCoPs and in the final part of the study the researcher started receiving requests to add members to the communities.

5. Alignment

Researcher explained the purpose of the study during the explanatory sessions. For the proper functioning of the communities, it was crucial to understand that the "I'mWithYouPlus" VCoP was not a health consultation. The health professional moderators were in the community to help with the knowledge sharing, but not to replace the health care professional of the community members. Thus, the participants and researcher' motivations were aligned. The alignment of the participants was acquired through the practice of the VCoP which was defined during all the process of its development.

6. Community design

Since the literature does not agree on the time a VCoP takes to develop (Boots et al., 2014), and because the duration of effective interventions ranged between 5 weeks and 2 years (Lee et al., 2020), it was decided that the communities would last a maximum of 12 months depending on its maturity. The main community development was done virtually through the app. Participants could communicate to all the VCoP members at the same time, or they could choose one-to-one interaction. However, three face-to-face sessions, lasting 90 minutes, were facilitated between the researcher and the participants. The first support session was conducted once the app was available to download. It mainly dealt with the download and use of the app, together with the introduction of participants and with filling out the informed consents and pre-tests (Spanish validated version of WHOQOL-BREF – self-administered, Spanish validated version of BARTHEL – self-administered Spanish validated version of eHEALS – self-administered). The goals of the second meeting were socialising, provoking debates that would continue later in the virtual forum and discussing any difficulties that might hinder the work of the community. The final face-to-face meeting was for evaluation, completing the post-tests tests (Spanish validated version of WHOQOL-BREF – self-administered, Spanish validated version of BARTHEL – self-administered Spanish validated version of eHEALS – self-administered), the tailored self-administered survey giving feedback and closing the app. If any participant was unable to attend the meeting, the researcher provided them with individual feedback and with the post-tests and tailored survey. All face-to-face pre-established meetings were recorded by the researchers. In addition, other face-to-face meetings (mainly sporadic and involving two people, or organised by the moderators for a specific task) took place throughout the process.

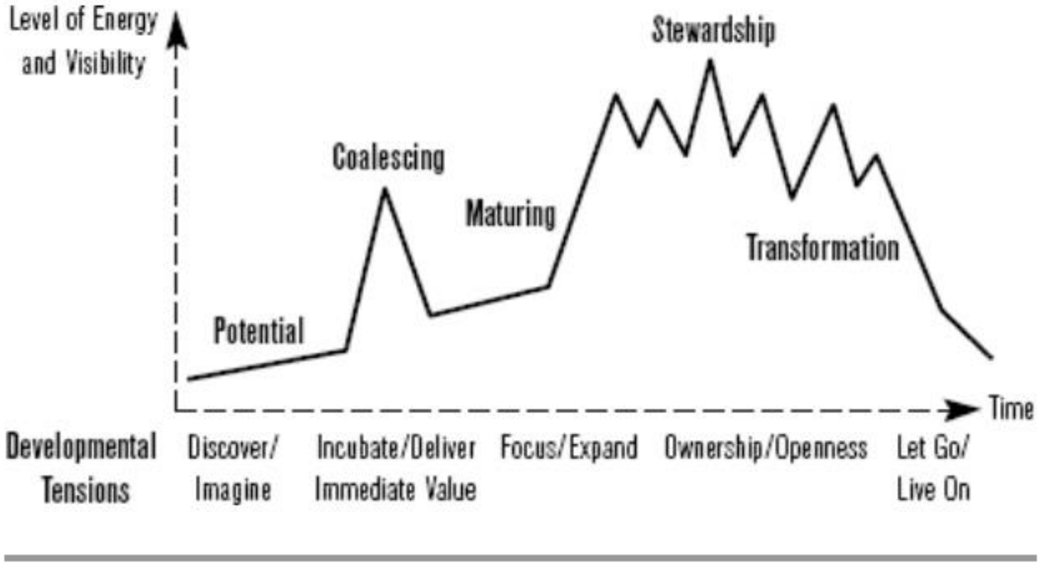
7. Sense of trust

The app was exclusively for members chosen for this research. The main quality of the app was robustness, as ICT engineers and researcher considered this would be crucial in helping participants to trust the community. There were suggestions to improve the app in a later version (*Annex A Table A3*) but participants were aware that this version was solid. Moreover, having two research groups – the M_3O (Methodology, Methods, Models and Outcomes of Health and Social Sciences), linked to University of Vic-Central University of Catalonia (UVic-UCC); and the PSiNET (Psychology, Health and Internet), linked to Universitat Oberta de Catalunya (UOC) – supporting the research was important for the participants. The face-to-face sessions were held at the UVic-UCC, led by the researcher of the study, with tasks of coordination within the two VCoPs. In addition, the app included a directory of participants where all the members were required to upload a photo and a small description (profile). During the face-to-face meetings, they verbalised the usefulness of this section for them. They also mentioned the suitability of the app's name and logo, the origin of which was explained by the researcher (*Annex A Table A2)*, who also gave them a picture drawn by the children. During the final face-to-face meeting, a video recorded by the children for the family caregivers was projected.

8. Knowledge sharing

The common domain, which was the caring of people with Alzheimer's, facilitated the ground that enabled the sharing of information, experiences and ideas. In addition, community development evolved through the five stages literature suggests: potential, coalescing, maturing, stewardship, and transformation (Wenger et al., 2002) (Figure 6). These communities started as networks of members that hold the potential of becoming connected. As members build connections, they coalesced into communities. Then, the communities grown. When mature, communities when through cycles of high and low activity. During this stage, communities often take active stewardship of the knowledge which lead to a stage of transformation. This transformation may either change the practice of the community or even though causing its death. The communities of this research stopped when they were mature and they started taking active stewardship.

Figure 6. *Community Life Cycles Related to Time and Level of Energy and Visibility*



Note. Adapted from Stages of Community Development, Cultivating Communities of Practice: A guide to Manage Knowledge, (p. 61), by Wenger et al., 2002, Harvard Business School Press

Knowledge sharing was one of the main foci of the study as one of the specific goals of this research was to understand the knowledge shared within the communities. Moderators were encouraged to persuade participants to share knowledge. It was presumed that the professionals as moderators would introduce evidence-based practice knowledge and that the family caregivers would share their own experience and learning skills for improving the daily life management of their relative, which is one of their biggest concerns.

9. Sustainability

These previous eight dimensions were designed to guarantee the sustainability of the VCoPs. The initial idea of linking the VCoPs to AFMADO was to ensure the sustainability of the communities but AFMADO stated they were too small to integrate the research in their structure. Currently, the researcher and the ICT company are exploring the possibility of collaborating with the *Fundació Pasqual Maragall*[2] (a private non-profit foundation dedicated to scientific research on Alzheimer's disease). In addition, an agreement between the researchers (and the institutions they represent) and *Confluència* was signed to explore and support possibilities for sustainability, exploitation and further research.

10. Ethics

All participants received a written explanation of the study and signed an informed consent form (*Annex B* and *Annex C*), and family caregivers committed themselves to privacy of their relative's data. In addition, ethics approval was obtained from the University of Vic-Central University of Catalonia Ethics Committee, on 9 January 2017 (*Annex D*). Furthermore, since the literature consulted regarding ethical aspects within virtual communities of patients states that moderators must be informed if the research observer interferes within the process of the

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[2] https://fpmaragall.org/en/

investigation (Eysenbach & Till, 2001), all participants, including the moderators, were made aware of the process of observation research.

Finally, the literature states that users' rights must be ensured: clear and explicit consent, right of access, right to be informed, and right to erasure (https://www.freeprivacypolicy.com/blog/8-user-rights-gdpr/). Thus, once the user enters the app, he/she receives a legal message. There is also a menu where you can edit your profile or enter activities, directory of participants, private messages, and "about us". It also gives you the option to exit. You can enter and exit the app without having to log in each time. If you want to log out completely, it informs you that you are doing so, and that you will need to log in to enter again.

11. Evaluation

Before implementation several testing sessions were conducted between the ICT engineers and the researcher and also with moderators. Most of the corrections were included in the latest version of the app. Other issues regarding technology which appeared during the study, most of them suggested by the participants, were collected for the implementation of a potentially improved version of the app. In addition, during the last face-to-face session, we requested feedback during from the participants about their experience within the VCoPs. It was an oral open question during the last meeting.

Data Handling

First, with the aim of analysing how membership of the family caregivers in a VCoP affects their QoL, the researcher measured caregivers' QoL shortly before starting the VCoP intervention and shortly after it was ended. Caregiver membership in the community was the independent variable, while caregiver QoL was the dependent variable. To measure caregiver QoL, the Spanish validated version of WHOQOL-BREF was used (Servicio Andaluz de Salud, 2010), a self-administered questionnaire to assess QoL which sub-divides QoL into four sub-domains: physical health, psychological health, social relationships and environment.

Then it was considered how the moderator variables impact family caregivers' QoL. Demographic factors (such as age, gender, number of offspring, level of education and marital status) and caring variables (the familial relation with the person with Alzheimer's and length of caring) were collected about the participants pre-intervention. In addition, more variables were used: functional deterioration of the person with Alzheimer's and caregiver eHealth literacy. With the aim of isolating the impact of care-recipient deterioration, the functional deterioration of the person with dementia was measured with the Spanish version of the Barthel Index (Artaso et al., 2002). This test was answered by the caregivers regarding their care-recipient, pre- and post-intervention. EHealth literacy was then measured with the eHealth Literacy Scale (eHEALS), again pre- and post-intervention, to evaluate the effect of this control variable (Norman & Skinner, 2006).

Later, in order to study the knowledge shared and the interaction between the participants in each community, all the messages sent, while the two VCoPs, were active were duly monitored. All the messages of the two communities were registered at the communities' web server (each VCoPs independently). At the end of the intervention, all messages were retrieved and registered in individual arrays of messages, including the following information:

- **Activity ID**: unique activity identifier.
- **Sub-activity ID**: unique sub-activity identifier. For the message type, it equals the activity ID detailed above.
- **Type**: text, photo, event, poll, comment, like and direct message.
- **Label**: activity label. It could be: “disease”, “caring for others” or “caring for yourself”.
- **Day**: post-publication day.
- **Time**: post-publication time.

- **Content**: content of the post. It could be a text or a photo link to the user's photo in case it was uploaded. “Like” did not include content.
- **User ID**: unique identifier of the user who made the post.
- **Recipient ID**: the person the publication is aimed at. It is usually set to "all"; it only varies in the case of direct messages indicating the destination user ID.

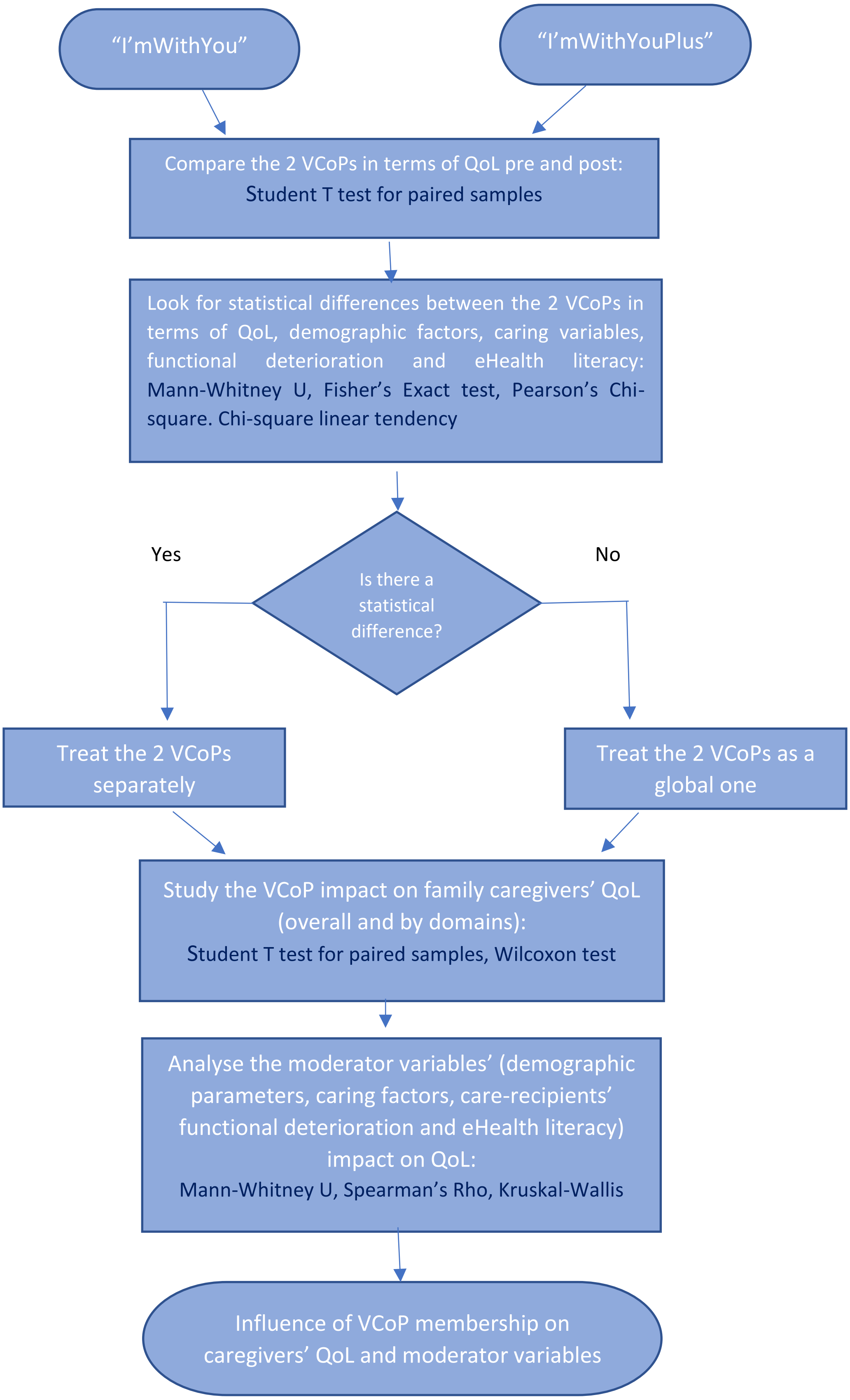
At this point, with the goal of gaining a better understanding of members’ participation in the community, a tailored survey was designed for this research in order to be filled out shortly post-intervention (*Annex E*). The survey was based in the existing literature looking for answers to complete the LINKS model. Due to the opportunity cost, it was not piloted. Considering that to get another group of caregivers to whom the survey could be piloted required to recruit more caregivers outside the communities, the researcher decided not to pilot them. In case the caregivers had any difficulty when answering it, the researcher would guide them. The survey was distributed to participants in paper form or delivered in an electronic format via email. It included questions about caregiver needs, their motivation for participating in the community, the way they participated, the influential members, their trust in the community and their interest in participating again in a VCoP, if there were the possibility of setting up a new one.

Finally, in order to complete the needed information regarding participants evaluation, during the last face-to-face meeting all the members were asked orally and openly to evaluate their experience: ““How do you assess the experience of participating in the VCoP?”.

Data Analysis

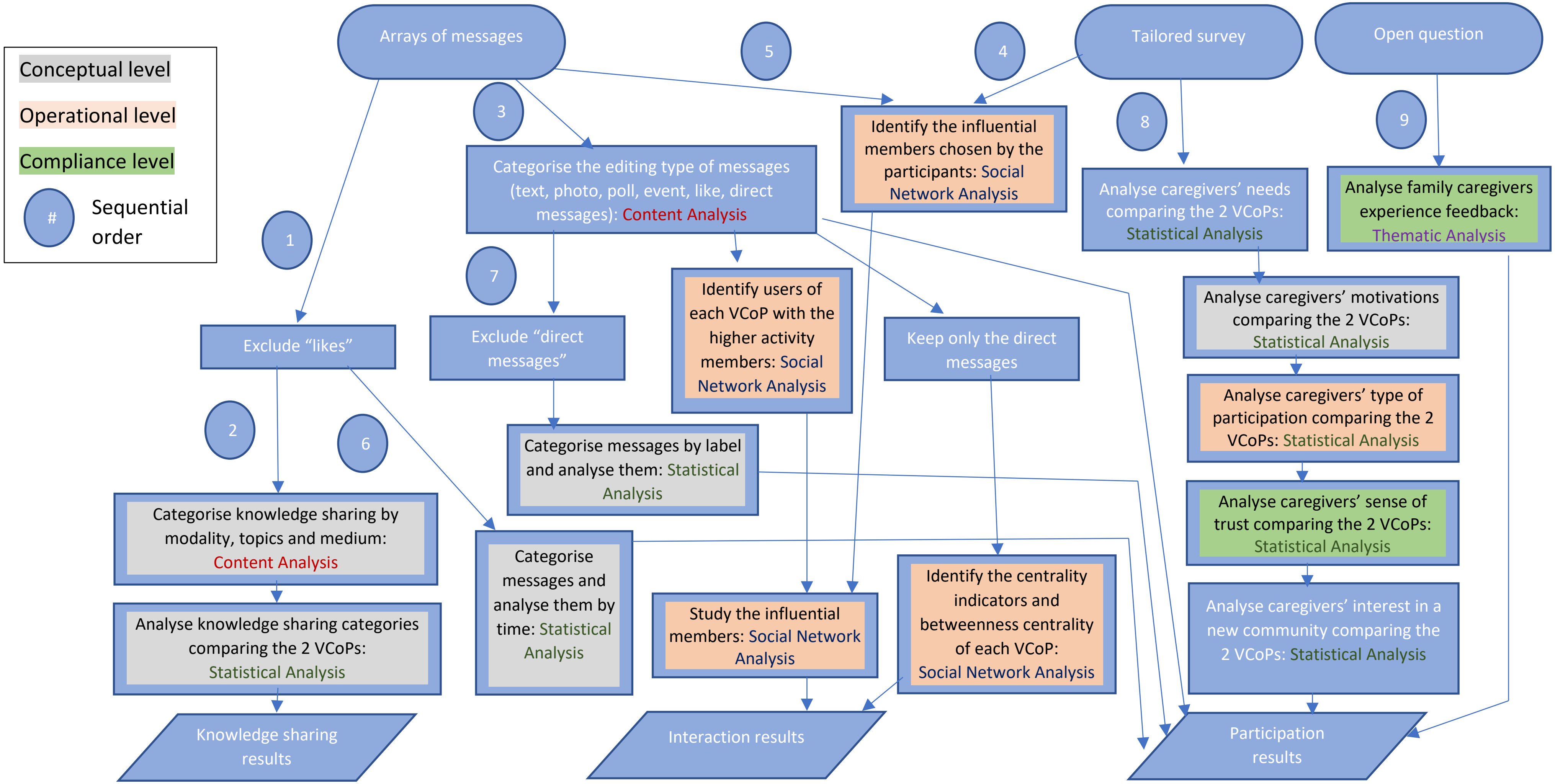
The data analysis started by studying the influence of VCoP membership on the caregivers' QoL, followed by the exploration of the moderator variables' impact on their QoL. SPSS 23.0 was used for all the quantitative data analysis. All the analysis was bivariate, as two variables were contrasted during the analysis. When comparing two variables, first each variable needed to be categorised. Then, the standard distribution of each variable had to be measured. The next step was to analyse if the data was impaired. In case the comparison was between a qualitative and a quantitative variable, the number of groups in the qualitative variable had to be considered. Finally, depending on the type of variable, if the data followed a standard distribution, whether it was impaired data, and the number of groups (if applicable), the researcher proceed with the suitable statistic test. When data followed a standard distribution, then the analysis proceed with parametric tests. Otherwise, nonparametric tests were applied. The confidence level was established at 95%. The normality tests were Shapiro-Wilk and Kolmogorov-Smirnov. The flux diagram underneath details the process of this part (Figure 7):

Figure 7. *Flux diagram of the influence of VCoP membership on the family caregivers' QoL*



The next step was to analyse the exchange of knowledge, interactions and participation of users in each community. This analysis was rooted in the Leveraging Internet Networks for Knowledge Sharing (LINKS), which incorporates different methods of analysis depending on the knowledge that is used (*Models for virtual communities of practice in health)*. All the message arrays, the answers of the tailored survey and the feedback of the final open question given, were examined separately for each VCoP. This part of the analysis included content analysis, statistical bivariate analysis, social network analysis and thematic analysis. The flux diagram underneath details the process (Figure 8):

Figure 8. *Flux diagram of the knowledge sharing, interaction and participation analysis in each VCoP*



First, "like" messages were excluded as they do not include any discussion data. The messages were then analysed through a content analysis, which was conducted to categorise the discussion data and determine the frequencies of each of the identified categories. The content analysis was mostly focused on the conceptual level (healthcare knowledge modality, knowledge sharing context and knowledge sharing medium), which concerns the knowledge sharing activity that took place in each community. The process of categorisation was determined by searching the existing literature of both VCoPs and caregivers' needs (*Conceptual Framework* chapter*)*, and in the inter-coder reliability. To start with, all the categories were established, as a deductive approach was followed. The first categorisation concerned the knowledge modality (*Annex F Table F1*), the second related to the topics shared according to the caregivers' needs (*Annex F Table F2*), and the third and final one was regarding the message medium (*Annex F Table F3*).

In order to proceed with the inter-coder reliability for the categorisation of the messages, the study used all the messages from the two VCoPs together reaching a total number of 1925. Moreover, there were two researchers involved (the author of this thesis and a second researcher). Considering the number of messages to be categorised was between 1,000 and 5,000, a level of agreement in population of 85% was assumed (Lacy & Riffe, 1996). The two researchers then categorised separately 139 messages randomly chosen (Lacy & Riffe, 1996). The standard error was 5%. The level of agreement achieved was of 0.787 Kappa coefficient accepted as 0.80% agreement (Lacy & Riffe, 1996; Landis & Koch, 1977). The two researchers then proceeded with the categorisation of the remaining messages.

Once all the categorisations regarding knowledge "modality", "topic" and "purpose" were completed, the study proceeded with the statistical analysis of this data. Again, all the analysis was bivariate as two variables were contrasted all the time. This analysis followed the same rationale as the one considered for comparing the QoL of the two communities explained at the beginning of this section. The confidence level was established at 95%. Next, the interactions were analysed through some parts of the social network analysis (Figure 8). Within the global network including all messages, interaction (which mainly concerns the operational level) was analysed through the role of the participants in the VCoP and the influential members of each community were identified. With regards to their role in the VCoP, initially participants could be community moderators or regular participants. The moderators performed the role of facilitating information, helping to activate the knowledge sharing and giving both care and technological support to all the members of the community. The regular participants could be involved in the VCoP according to their needs and motivation.

When analysing the influential members, the first task was to identify a seed set of k users in the VCoP that caused a maximum spread of information to the remaining users of the community - i.e. influencers (Kaple et al., 2017). These influencers are more active in voicing their opinions. Consequently, the opinions and behaviour of the rest of the participants in that network are influenced by such influencers. However, their positive comments and writing motivate people. Through a descriptive statistical analysis, the researcher searched for the users of each community who started more conversations, wrote more “comment”, clicked more “like” and sent more “direct message”. In addition, the tailored survey included a question in which caregivers had to mention three participants who were important to them (*Annex E*).

Still within the interaction (Figure 8), the next step was to analyse the networks coming from the direct messages of both communities. The focus was on directed conversations because their interactive nature and directedness are what underlies the community component in CoPs. Descriptive statistics together with UCInet were used for visualisation and measurement.

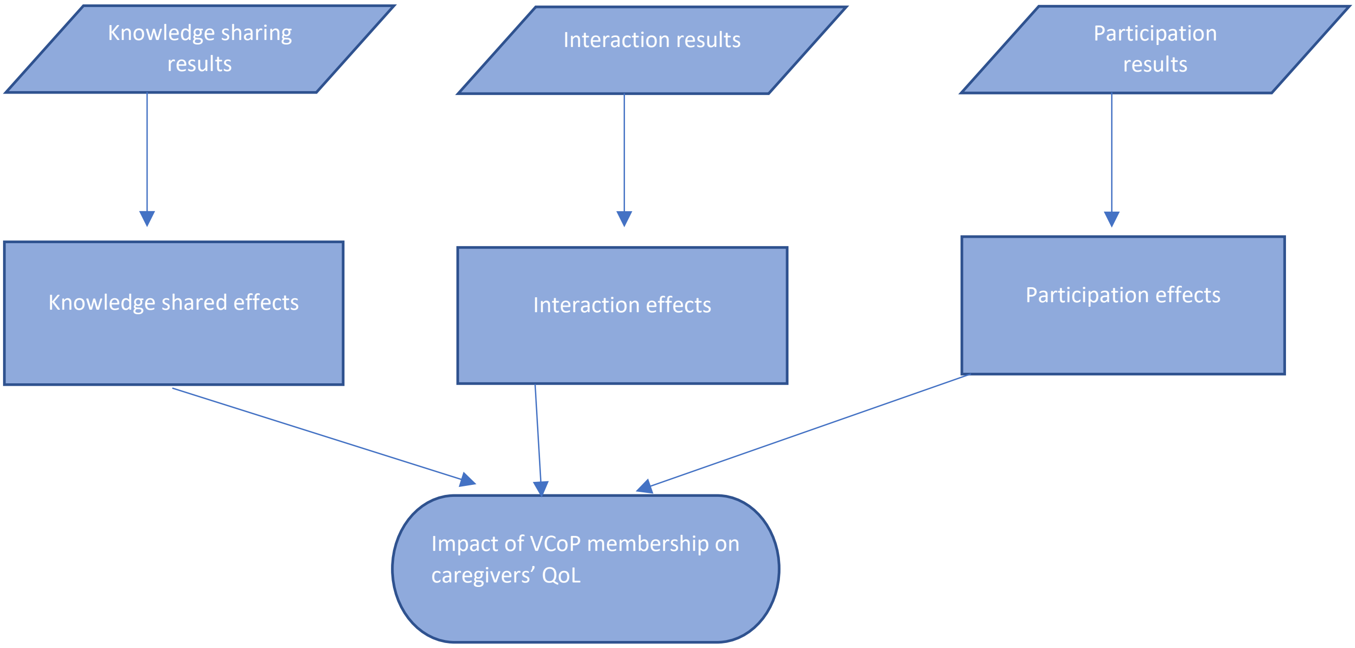
Then, a study of the family caregivers’ participation in the two VCoPs was carried out (Figure 8). Messages were categorised by time: daily (“dawn”, “morning”, “noon”, “afternoon”, “evening” and “night”) and monthly (month 1 April 2017- “M1” to month 11 February 2018- “M11”). In addition, a categorisation by label was conducted (“caring for others", "caring for yourself" or "disease"). The data obtained was statistically analysed through a bivariate analysis following the same rationale as the one considered for comparing the QoL of the two communities explained at the beginning of this section. The confidence level was established at 95%.

The rest of this information comes from the tailored self-administered survey answered by the family caregivers (*Annex E*). The outcomes from the survey were studied using bivariate statistics. Specifically, the parameters examined were: users' needs ("Alzheimer's information", "support in care", "social contact" and "caring for yourself") (Marirosa et al., 1999; Plöthner et al., 2019); users' motivations ("to instigate the resolution of problems in collaboration", "to inform and educate peers through personal-professional experiences, points of view and know-how", "to be informed and educated", "to negotiate and validate what one thinks", "to exchange ideas", "to build capacity", "to serve as a knowledge agent", "to form a viable community on a specific subject" and "considerations related to the communities") (Sibte & Abidi, 2006); and type of participation ("troublemaker", "not contributing", "lurker" and "contributing") (Wang & Yu, 2012). The caregivers' trust in the communities was then measured asking the participants to rate their trust in their VCoP from 0 to 5. For an online community to succeed, members need to have a sense of trust that they will be treated with respect and care by the community, that their problems and concerns will be heard, and that others will provide information and support for them. Moreover, all the members were asked about their interest in participating again in a VCoP, in case there was the possibility of setting up a new one (dichotomic variable). All this data gathered through the surveys was statistically analysed. This analysis followed the same rationale as the one considered for comparing the QoL of the two communities explained at the beginning of this section.

Finally, during the last face-to-face meeting, all participants were asked to answer an open question evaluating their experience, the data from which was analysed through thematic analysis. Thematic analysis is best suited to elucidating the conceptualisations that a given group holds on a topic, and also fits the research questions focused on exploring the caregivers' experiences (Joffe, 2011). Specifically, thematic analysis was used to identify themes (Braun & Clarke, 2006).

At the end, in order to close the cycle, the researcher looked for empirical relationships between the knowledge sharing variables, interaction and participation parameters with caregivers' QoL (Figure 9). Relations were analysed through Spearman correlation tests and U of Mann-Whitney tests.

Figure 9. *Flux diagram of the VCoP's impact on family caregivers' QoL*



Results

This section discusses and displays results with regards to whether VCoP membership affected family caregivers' QoL; which moderator variables had an impact on caregivers' QoL; the interaction between members; the participation in the communities according to members' roles; and, finally, how the knowledge shared, the interactions and participation affected caregivers' QoL.

The Impact of Virtual Communities of Practice Membership on Family Caregivers' Quality of Life

Initially, there were two VCoPs, each with 19 family caregivers of people with Alzheimer's. The descriptive statistics of the demographic variables and caring characteristics are presented below in Table 2:

Table 2. *Comparison of demographic and caring values of the two VCoPs*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Gender, n (%)		
Male	3 (15.78)	5 (26.32)
Female	16 (84.22)	14 (73.68)
Marital status, n (%)		
Married	15 (78.94)	13 (68.42)
Single	2 (10.55)	2 (10.53)
Divorced	2 (10.55)	4 (21.05)
Level of studies, n (%)		
Primary	4 (21.05)	3 (15.78)
Secondary	10 (52.63)	8 (42.11)
University	5 (26.32)	8 (42.11)
Relation with the PWA, n (%)		
Descendant	12 (63.17)	18 (94.74)
Spouse	4 (21.05)	1 (5.26)
Other relation	3 (15.78)	0 (0)
Age, M (SD)	56.31 (12.06)	55.15 (9.22)
Descendant number, n (SD)	1.71 (0.99)	1.36 (1.01)
Length of caring, n (SD)	3.26 (2.21)	4.78 (2.63)
Barthel pre, n (R)	19 (22.26)	19 (16.74)
eHEALS pre, n (R)	19 (19.24)	19 (19.76)

With the aim of evaluating the impact of participation in a VCoP on the QoL of caregivers of people with Alzheimer's disease, the means of WHOQOL-BREF questionnaires pre and post intervention of both VCoPs were compared. A participant of "I'mWithYouPlus" dropped during the intervention. So, this user did not fulfill the post-intervention questionnaires. Paired sample t- test indicates that the caregivers' QoL before and after the intervention had changed significantly only in the "I'mWithYouPlus" VCoP (Table 3). This means that caregivers belonging to the "I'mWithYouPlus"

VCoP increased their overall QoL participating in the VCoPs. There were no differences when focusing on physical, psychological, social or environmental domains individually.

Table 3. *Comparison of caregivers’ WHOQOL-BREF pre and post intervention of the two VCoPs*

		“I’mWithYou”				“I’mWithYouPlus”		
Variable	**n**	**Mean**	**SD**	***p-value***	**n**	**Mean**	**SD**	***p-value***
WHQOL-BREF								
Overall-Pre	19	69.37	14.72	*0.920*	19	63.8	14.3	*0.038**
Overall-Post	19	69.78	14.33		18	69.2	13.8	
Physical-Pre	19	72.16	17.03	*0.954*	19	67.3	17.9	*0.771*
Physical-Post	19	72.42	14.07		18	68.8	22.5	
Psychological-Pre	19	66.05	18.26	*0.686*	19	61.6	19.7	*0.929*
Psychological-Post	19	68.47	19.40		18	61.0	23.2	
Social-Pre	19	70.00	15.37	*0.685*	19	66.0	19.6	*0.896*
Social-Post	19	71.68	16.96		18	65.1	24.0	
Environmental-Pre	19	67.32	15.45	*0.752*	19	63.9	15.4	*0.675*
Environmental-Post	19	68.26	15.36		18	61.3	19.3	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Then, with the aim of reaching a bigger sample, the researcher tested whether the variable of being part of one or the other community had any impact on caregivers’ QoL. The differences between the overall QoL values pre-intervention of the two VCoPs was therefore explored. Mann-Whitney U test indicates there was no significant statistical differences (Table 4).

Table 4. *Comparison of caregivers’ WHOQOL-BREF pre- intervention of the two VCoPs*

Variable	“I’mWithYou”	“I’mWithYouPlus”	*p-value*
WHOQOL-BREF pre, n (R)	19 (21.32)	19 (17.68)	*0.313*

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Next, the demographic variables, caring characteristics, functional deterioration of the person with Alzheimer’s, and eHealth literacy in the two VCoPs were studied in order to identify significant differences. No significant statistical differences between them were identified (Mann-Whitney U). Consequently, the two groups can be considered homogeneous and statistically comparable, and results can be presented about all participants as a whole.

In total, there were 38 regular caregivers in the VCoPs. The youngest participant was 28 years old, while the oldest was 81, and they had an average age of 56 years. 29 (79%) were female and 8 (21%) male. 27 (73.7%) were married, 6 (15.8%) divorced and 4 (10.5%) single. 29 (78.9%) were offspring of the recipient of care, 5 (13.2%) spouses and others 3 (7.9%). These findings are consistent with results from other national studies involving caregivers for elderly people (IMSERSO/ GFK, 2005). They had a mean of 1.5 offspring. In terms of educational attainment, 7 (18.4%) had reached primary studies, 17 (47.4%) secondary and 13 (34.2%) university studies. Whereas the mean of length of caregiving was 4 years, the length of time varied from 2 to 8 years.

In order to evaluate the impact of participation in a VCoP on the QoL of caregivers of people with Alzheimer’s disease, the means of WHOQOL-BREF questionnaires pre and post intervention were compared. The initial mean of QoL was 66.65 (out of 100), while after the caregivers had participated in the VCoP, this rate increased to 69.50. Paired sample t- test suggests that caregivers’ QoL before and after the intervention had changed significantly (Table 5). This means that family caregivers increased their overall QoL participating in the VCoPs, although there were no differences when we focused on physical, psychological, social or environmental domains individually.

Table 5. *Comparison of all caregivers' WHOQOL-BREF pre and post intervention*

Variable	**n**	**Mean**	**SD**	***p-value***
WHOQOL-BREF				
Overall-Pre	38	66.60	14.60	*0.002**
Overall-Post	37	69.50	13.90	
Physical-Pre	38	69.78	17.37	*0.307*
Physical-Post	37	70.67	18.48	
Psychological-Pre	38	63.86	18.84	*0.426*
Psychological-Post	37	64.83	21.38	
Social-Pre	38	68.05	17.41	*0.364*
Social-Post	37	68.48	20.64	
Environmental-Pre	38	65.64	15.32	*0.615*
Environmental-Post	37	64.86	17.49	

* Significant statistical differences $p<0.05$

** Highly significant statistical differences $p<0.001$

Then, the variable "QoL_change" for all the participants was introduced. In fact, there were five variables as the change of overall QoL together was studied with the change of its four domains for each participant. These variables represented the change between pre and post intervention. Hereafter, when mentioning QoL, the researcher will refer to it as "QoL_change".

The Impact of Moderator Variables on Family Caregivers' Quality of Life

For the analysis of the impact of moderator variables on family caregivers' QoL, the researcher also considered the two VCoPs together as a whole one. Initially, this study explored the influence of caregivers' demographic variables on their QoL: age, gender, level of education and marital status. Age parameter was turned to a binary variable having a value of 0 to 65 years of age or over 65. From these four demographic variables, a significant difference in age was found with caregivers' QoL. Mann-Whitney U test showed there was a significant difference between age groups in terms of their overall rate of QoL. The participants who improved their QoL more were those over 65 as their overall QoL mean increased from 66.30 to 74.64. Participants under 65 years of age increased their QoL from 66.70 to 67.85. Specifically, an age association was found with the psychological domain of QoL (Table 6). None of the other demographic variables offered statistically significant differences.

Table 6. *Relation between demographic variables and family caregivers' QoL*

Variable	n	Mean Diff. Overall QoL	SD Overall QoL	Overall QoL *p-value*	Physical QoL *p-value*	Psychological QoL *p-value*	Social QoL *p-value*	Environ. QoL *p-value*
Age	**37**			*0.025**	*0.566*	*0.008**	*0.270*	*0.270*
<=64	28	1.08	15.84					
>65	9	8.33	6.48					
Gender	**37**			*0.479*	*0.148*	*0.094*	*0.0957*	*0.871*
Male	8	7.53	13.60					
Female	29	1.54	14.57					
Level Education	**37**			*0.760*	*0.119*	*0.153*	*0.907*	*0.999*
Primary	7	6.14	8.83					
Secondary	17	4.39	14.54					
University	13	-0.94	16.62					
Marital Status	**37**			*0.092*	*0.440*	*0.633*	*0.285*	*0.225*
Married	27	4.06	11.63					
Single	4	-14.02	26.11					
Divorced	6	8.70	10.08					

*Significant statistical differences $p<0.05$

** Highly significant statistical differences $p<0.001$

With regards to caring characteristics, the variables studied were the familial relationship with the person with Alzheimer's, length of caring and number of offspring (Table 7*)*. With respect to the relationship with the person with Alzheimer's (spouse, offspring and others), the Kruskal-Wallis test showed there was a statistically significant difference in the overall QoL rate (Table 7). Specifically, if the carer was a spouse, their QoL improved more as the mean went from 69.75 to

75.68. Offspring, however, increased their overall QoL less, and "other relation" decreased their overall QoL from 90.75 to 87.50. A relation with the psychological domain was found again, with more influence on caregivers who were spouses of the care recipient (Table 7). There was a significant negative correlation between length of caring and caregivers' QoL in the psychological and social domains (Table 7). Caregivers taking care of the person with Alzheimer's for less time were the ones who increased their QoL the most. Nevertheless, the Spearman correlation test found that there was no correlation between care-recipients' functional deterioration and caregivers' QoL (Table 7). Even though the Barthel index decreased, caregivers' QoL did not. Finally, the Spearman correlation test demonstrated a positive correlation between eHEALS and the physical domain of QoL (Table 7). These results denote that family caregivers with a higher eHealth literacy increased their physical domain of QoL more.

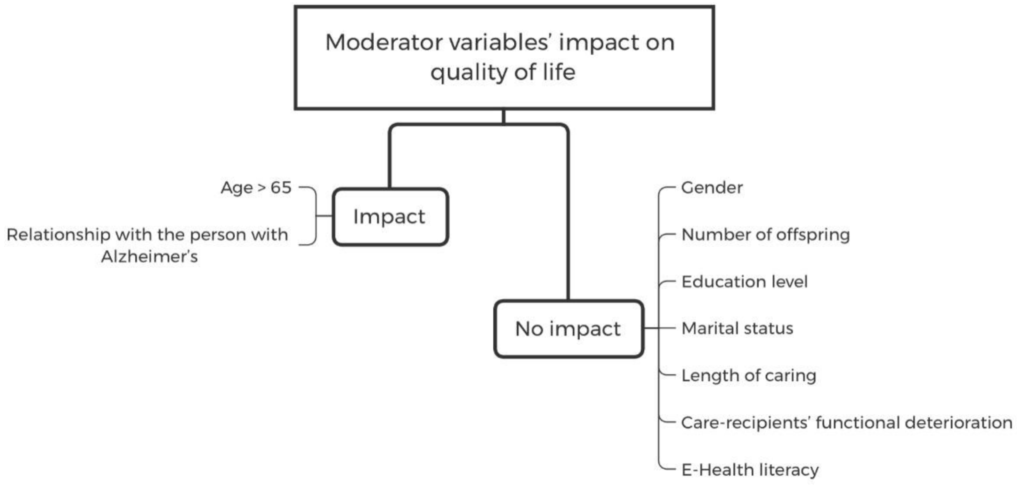
Table 7. *Relation between caring factors, Barthel and eHEALS variables and family caregivers' QoL*

Variable	**n**	**Mean Diff. Overall QoL**	**SD Overall QoL**	**Overall QoL Correlation Coefficient (p-value)**	**Physical QoL Correlation Coefficient (p-value)**	**Psychological QoL Correlation Coefficient (p-value)**	**Social QoL Correlation Coefficient (p-value)**	**Environ. QoL Correlation Coefficient (p-value)**
Relationship person with Alzheimer's	**37**			*(0.045*)*	*(0.132)*	*(0.042*)*	*(0.918)*	*(0.292)*
Offspring	29	2.98	15.69					
Spouse	5	7.80	4.78					
Other relation	3	-6.75	6.24					
Number of offspring	37	1.45	1.03	*(0.492)*	*(0.305)*	*(0.345)*	*(0.558)*	*(0.788)*
Length of caring (years)	**37**	4.19	2.60	-0.237	-0.176	-0.372*	-0.446*	-0.171
Change_ Barthel	**35**	-9.67	13.22	-0.750	-0.328	-0.069	-0.282	0.123
Change_ eHEALS	**35**	4.45	7.58	0.256	0.431*	0.148	0.134	-0.082

* Significant statistical differences p<0.05
** Highly significant statistical differences p<0.001

Figure 10 below provides a visual perspective of the impact of VCoPs on caregivers' overall QoL:

Figure 10. *Impact of moderator variables on family caregivers' QoL*



Knowledge Shared within the Two Virtual Communities of Practice

A total of 1925 messages were exchanged within the two communities: 933 messages were shared in the "I'mWithYou" VCoP and 992 in the "I'mWithYouPlus"VCoP. In this section and all the following ones, the messages of the two VCoPs were analysed separately as this study intends to see differences between the two kinds of VCoPs.

With the aim of analysing the knowledge shared (mainly the conceptual LINKS level), first, the "like" messages were removed, as they do not include any content. In total there were 865 messages in the "I'mWithYou" VCoP and in 839 messages the "I'mWithYouPlus"VCoP. The findings of this study coming from the content analysis of the knowledge shared show that the most common modality in both communities was social knowledge, coinciding with the main topic "social support" (Table 8). The second kind of knowledge shared was" experiential". Furthermore, both VCoPs were mainly concerned about "give support". The results indicated that participants shared knowledge regarding caring for the people with Alzheimer's. In both communities, most of the messages' main purpose was "interactivity". Comparing both VCoPs, Pearson's Chi-Square test suggested that there are statistically significant differences in all the variables apart from "functionality of the research" (a subcategory of "topic") and "interactivity" (a subcategory of "purpose"), although there was a difference in the number of posts (Table 8). This means that the knowledge shared is different in the modality variable and in most of the elements of the topic and purpose variables, but is similar in "functionality of the research" (topic) and "interactivity" (purpose).

Table 8. *Comparison of knowledge shared by all participants within the two VCoPs*

Variable	**"I'mWithYou"**	**"I'mWithYouPlus"**	***p-value***
Modality, n (%)	856	839	
Explicit	75 (8.76)	177 (21.09)	*<0.001***
Experiential	249 (29.09)	200 (23.84)	*0.014**
Social	794 (92.75)	807 (94.28)	*0.004**
Topic, n (%)	856	839	
Disease information	110 (12.85)	172 (20.09)	*<0.001***
Social support	788 (92.06)	810 (96.54)	*<0.001***
- Seeks support	167 (19.51)	92 (10.97)	
- Gives support	492 (57.48)	540 (64.36)	
- Gratitude	129 (15.07)	178 (21.21)	
Skills w/PWA	200 (23.36)	141(1.,81)	*<0.001***
Caring yourself	76 (8.88)	113 (14.47)	*0.003**
Functionality of the research	95 (11.09)	79 (9.42)	*0.201*
Purpose, n (%)	856	839	
Information	314 (36.68)	296 (35.28)	*<0.001***
- About disease	35 (4.09)	89 (10.61)	
- About sender	238 (27.80)	160 (19.07)	
- About app	27 (3.15)	13 (1.55)	
- Internet Link	14 (1.64)	34 (4.05)	
Interactivity	819 (95.68)	813 (96.9)	*0.162*
- Seeks answer	266 (31.07)	246 (29.32)	
- Does not seek answer	553 (64.61)	567 (67.58)	

* Significant statistical differences p<0.05
** Highly significant statistical differences p<0.001

The main differences between the two VCoPs in knowledge sharing activity are summarised in Table 9:

Table 9. *Differences between the two VCoPs in knowledge sharing activity*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Modality	-Few messages of "explicit" knowledge.	-Similar numbers of messages regarding "explicit" and "experiential".
Topic	-Priority for "seeks support" over "gratitude". -After "social support", the second topic is "skills in relation to the person with Alzheimer's" before "disease information". -Last priority for "caring for yourself".	-Priority for "gratitude" over "seeks support". -After "social support", the second topic is "disease information" before "skills in relation to the person with Alzheimer's". - Last priority for "functionality of the research".
Purpose	-Huge "informative messages "about sender". -More informative messages "about the app" than providing "an Internet link".	-Informative messages quite split between "about sender" and "about disease". -More informative messages providing "an Internet link" than "about the app".

As the literature points out that moderators are key when considering the knowledge of a VCoP (Ranmuthugala et al., 2011), the main goal of having two VCoPs was to compare the presence/absence of health professionals. The researcher therefore examined the detail of the knowledge shared by the two kinds of moderators, a total of 552 messages: 163 in the "I'mWithYou" VCoP, and 389 in the "I'mWithYouPlus" VCoP. Again, the "like" messages were excluded, ending up with a total of 513 messages: 162 in the "I'mWithYou" VCoP, and 351 in the "I'mWithYouPlus" VCoP. These messages were categorised according to modality, topic and purpose of the knowledge (Table 10).

Table 10. *Comparison of knowledge shared by moderators within the two VCoPs*

Variable	**"I'mWithYou"**	**"I'mWithYouPlus"**	***p-value***
Modality, n (%)	162	351	
Explicit	16 (9.87)	130 (37.04)	*<0.001***
Experiential	49 (30.25)	68 (19.37)	*0.006 **
Social	156 (96.30)	341 (97.15)	*0.480*
Topic, n (%)	162	351	
Disease information	21 (12.96)	115 (32.76)	*<0.001***
Social support	149 (91.98)	343 (97.72)	*<0.001***
- Seeks support	33 (20.38)	28 (7.98)	
- Gives support	95 (58.64)	254 (72.36)	
- Gratitude	21 (12.96)	61 (17.38)	
Skills w/PWA	34 (19.14)	34 (9.69)	*<0.001***
Caring yourself	12 (7.41)	59 (16.81)	*0.004**
Functionality of the research	28 (17.28)	26 (7.41)	*0.014**
Purpose, n (%)	162	351	
Information	59 (36.42)	137 (39.03)	*<0.001***
- About disease	6 (3.70)	61 (17.38)	
- About sender	40 (24.69)	38 (10.83)	
- About app	11 (6.79)	11 (3.13)	
- Internet Link	2 (1.24)	27 (7.69)	
Interactivity	159 (98.15)	345 (98.29)	*0.248*
- Seeks answer	82 (50.62)	151 (43.02)	
- Does not seek answer	77 (47.53)	194 (55.27)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Moderators of both groups shared mainly social knowledge. Moderators coincide in the main topic: "social support" and specifically, "give support". The results indicated that moderators shared knowledge regarding caring for the people with Alzheimer's. Considering the purpose of the messages, even though moderators gave information, in both groups the main purpose was "interactivity". Comparing the knowledge shared by moderators, Pearson's Chi-Square test indicated significant statistical differences in all the variables apart from "social knowledge" (a subcategory of modality) and "interactivity" (a subcategory of "interaction"), although there was a difference in the number of messages (Table 10).

The main differences brought to light between the two moderators' groups are summarised in Table 11:

Table 11. *Differences between the two kinds of moderators' knowledge sharing*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Modality	-Few messages of "explicit" knowledge.	-More messages with "explicit" than "experiential" knowledge.
Topic	-Priority for "seeks support" over "shows gratitude". -The last topic is "caring for yourself", while they are more concerned about "skills in relation to the person with Alzheimer's".	-Priority for "gratitude" over "seeks support". -The last topic is "skills in relation to the person with Alzheimer's", while they are more concerned about "caring for yourself".
Purpose	-Huge informative messages "about sender". -More informative messages "about the app" than providing "an Internet link". -More messages about "functionality of the research" than about "caring for yourself". -Interactivity "seeks answer".	-Huge informative messages "about disease". -More informative messages providing "an Internet link" than "about the app". -More messages about "caring for yourself" than "skills in relation with the person with Alzheimer's". -Interactivity "does not seek answer".

Interaction between Members of the Virtual Communities of Practice

Once the knowledge sharing activity had been studied, the interaction within each VCoP were analysed (mainly operational LINKS level). The list of participants with their users’ ID may be seen in Table 12:

Table 12. *List of participants – Users’ ID*

Type of participant	“I’mWithYou” VCoP	“I’mWithYouPlus” VCoP
Regular	user1 - user2 - user3 - user4 - user5 - user6 - user7 - user8 - user9 - user10 - user11 - user12 - user13 - user14 - user15 - user17 - user18 - user19 - user20	user21 - user22 - user23 - user24 - user25 - user26 - user27 - user28 - user29 - user30 - user31 - user32 - user36 - user37 - user38 - user39 - user40 - user41- user42
Moderator	user16	user33 - user34 - user35

As an interaction is a mutual or reciprocal action or influence over the Internet (Gray, 2004; Turoff et al., 1993), the first aim was to identify the influential members of each VCoP. Since these were the more active members in the VCoP, those users in both communities who started more conversations, wrote more “comments”, clicked more “likes”, and sent more “direct messages” were identified. In addition, in the self-administered survey distributed to all participants, there was a question where individuals were required to mention three users who they thought were influential in the community. The most influential users can be seen in Table 13:

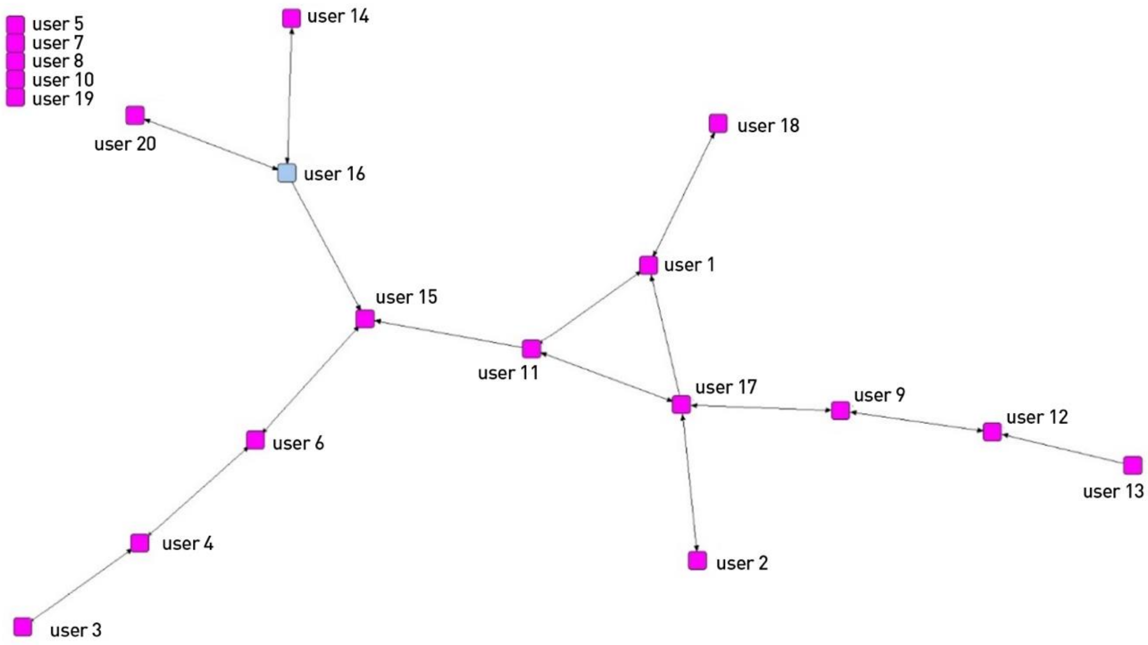
Table 13. *The most influential users of the two VCoPs*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Starting more conversations, #messages (user)	51 (user16)	35 (user35)
	24 (user 13)	23 (user33)
	19 (user15)	13 (user34)
More "like", #likes (user)	30 (user2)	88 (user35)
	15 (user15)	63 (user 33)
	6 (user18)	40 (user 34)
More "comment", #comments(user)	116 (user15)	88 (user35)
	105 (user16)	63 (user33)
	75 (user17)	50 (user34)
More "direct messages", #direct messages (user)	19 (user17)	58 (user35)
	17 (user18)	23 (user42)
	10 (user2)	20 (user36)
Most mentioned, #mentions (user)	6 (user16)	12 (User35)
	5 (user15)	11 (user34)
	3 (user2)	9 (user33)

In the "I'mWithYouPlus" VCoP the moderators were the most influential members, forming its core group. In the "I'mWithYou" VCoP, even though the moderator (*user16*) was considered influential, *user15* appeared very influential too, together with *user2*, *user17* and *user18*. These users grouped with the moderator to form the core group of this VCoP.

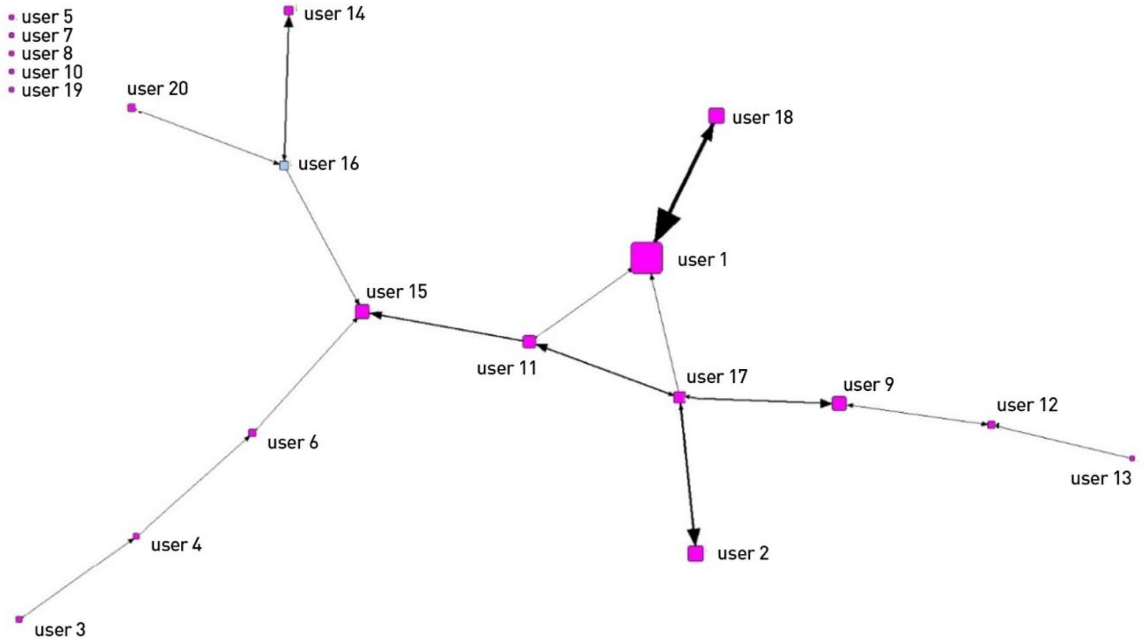
Then, with the aim of completing the research on the interactions of the two VCoP, both networks of "direct message" were analysed. Focusing on the "I'mWithYou" VCoP, first the representation with moderator attribute is included (Figure 11). Examining the density indicators, the network exchanged a total of 70 messages with an average value of 3.043 and a deviation of 3.641. Hence, the direct messages network of the "I'mWithYou" VCoP showed low activity and contained 25% of isolated participants.

Figure 11. *The "I'mWithYou" VCoP basic representation with moderator attribute (blue) UCInet*



After examining the centrality indicators, the most active actors, in the sense that they were the ones who mobilised and contacted, were *user17* (1st), *user18* (2nd) and *user1* (3rd). The most contacted actor was *user1* (10 outdegree and 19 indegree) with a lot of difference with respect to the rest of the network. The main reason was, basically, the relationship between *user18* and *user1*. The moderator (*user16*) did not play a very relevant or visible role, according to these indicators (Figure 12).

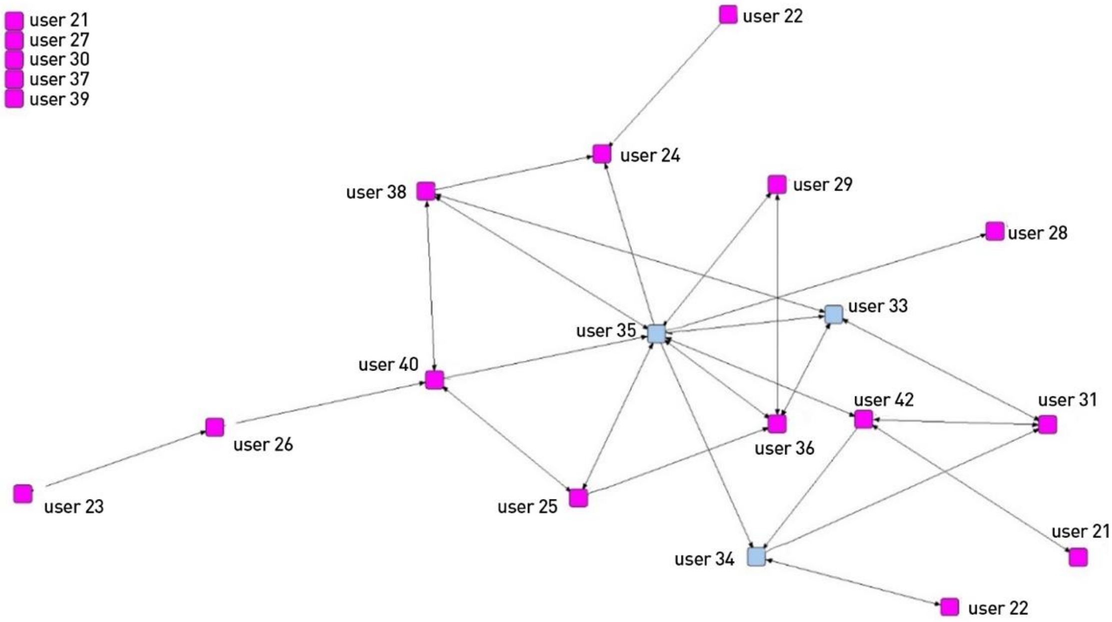
Figure 12. *Centrality indicators represented (indegree node size, outdegree arrow size) UCInet*



The mean of the betweenness centrality was 5.85. Specifically, *user17* (34), *user11* (22), *user9* (19) and *user15* (11) were key to keeping the network together, since if these intermediaries had been missing, the network would have been disconnected. Again, the moderator (user16) did not play a very relevant role according to these indicators. These outcomes reaffirm the results of the "I'mWithYou" VCoP main activity network, where it was observed that there was another key user different than the moderator (*user16*), and that the VCoP counted on a core group helping and pushing the activity.

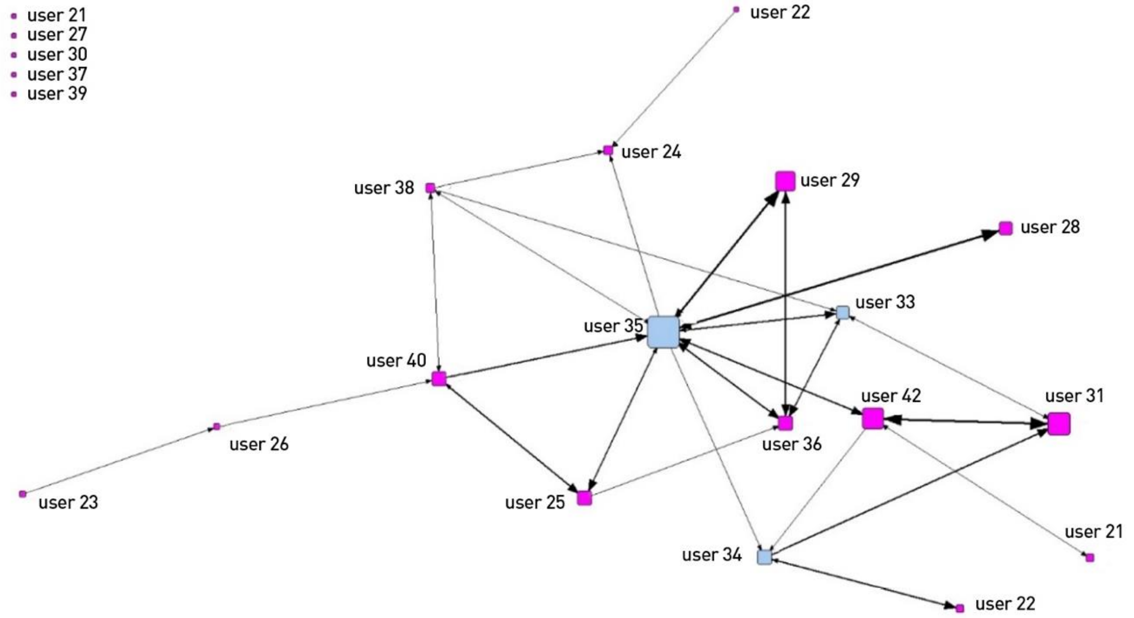
Focusing on the "I'mWithYouPlus" VCoP, the researcher first presents the representation with moderator attribute (Figure 13). Examining the density indicators, the network exchanged a total of 189 messages with an average value of 4.109 and a deviation of 3.252. Hence, the direct messages network of the "I'mWithYouPlus" VCoP showed low activity and contained 22.7% of isolated participants. Still, it was more active than the "I'mWithYou" VCoP.

Figure 13. *The "I'mWithYouPlus" VCoP basic representation with moderator attribute (blue) UCInet*



After examining the centrality indicators, the most active actors, in the sense that they were the ones who mobilised and contacted, were first *user35*, who is the nurse moderator, then *user42*, and third, *user31*. In addition, the actors who were most contacted were again *user35*, *user31*, and *user42* (Figure 14). Comparing the two direct messages networks, there was more activity in the "I'mWithYouPlus" VCoP than in the "I'mWithYou" VCoP.

Figure 14. *"I'mWithYouPlus" centrality indicators represented (indegree node size, outdegree arrow size) UCInet*



The mean of the betweenness centrality was 12.00. *User35*, *user42*, and *user40* were key to keeping the network together; they were the intermediaries that if they had been missing the network would have disconnected as the largest amount of information passed through them. The moderator (*user35*) stood out above the rest, due to his role as intermediary. The other two moderators (*user33* and *user34*) were on the list of key players in maintaining the network, although they were not the most important. Hence, these findings, together with the ones coming from the "I'mWithYouPlus" VCoP main network, show that the moderators led the network.

Participation in the Virtual Communities of Practice According to Participants' Role

Participation Medium

In order to analyse the users' participation medium, first, the "like" messages were excluded. Then, the messages were categorised according to the type of interaction sent, time of day and month of year (Table 14). Again, Pearson's Chi-Square test suggests that there are significant statistical differences between the two VCoPs with regards to all these variables, although there was a difference in the number of messages (Table 14).

Table 14. *Comparison of all participants' message times within the two VCoPs*

Variable	**"I'mWithYou"**	**"I'mWithYouPlus"**	***p-value***
Time, n (%)	856	839	*<0.001***
Dawn (from 1am to 6 am)	6 (0.70)	30 (3.58)	
Morning (from 6am to 12pm)	281 (32.83)	233 (27.77)	
Noon (from 12pm to 15pm)	120 (14.02)	82 (9.77)	
Afternoon (from 15pm to 20pm)	238 (27.80)	256 (30.51)	
Evening (from 20pm to 23pm)	197 (23.01)	208 (24.79)	
Night (from 23pm to 1am)	14 (1.64)	30 (3.58)	
Month, n (%)	856	839	*<0.001***
M1 (VCoP face-to-face meeting)	67 (7.83)	42 (5.00)	
M2 (Researchers meeting with moderators)	206 (24.07)	200 (23.84)	
M3 (Researchers meeting with moderators)	127 (14.84)	64 (7.63)	
M4	81 (9.46)	56 (6.67)	
M5	59 (6.90)	63 (7.51)	
M6 (Researchers meeting with moderators)	103 (12.03)	33 (3.93)	
M7	27 (3.15)	49 (5.84)	
M8 (VCoP face-to-face meeting)	103 (12.03)	131 (15.62)	
M9	45 (5.26)	133 (15.85)	
M10	5 (0.58)	45 (15.36)	
M11 (VCoP face-to-face meeting)	33 (3.85)	23 (2.75)	

*Significant statistical differences $p<0.05$

** Highly significant statisticas differences $p>0.001$

Members of the VCoPs could participate in the community at any time during the day, although the most active participation was either in the morning or afternoon (Table 14). The daily message average was 3.1 in the “I’mWithYou” VCoP and 3.2 in the “I’mWithYouPlus” VCoP. Monthly, the mean was 56.54 in the “I’mWithYou” VCoP and 70.91 in the “I’mWithYouPlus” VCoP. The face-to-face meetings organised by the researcher took place in “M1”, “M8” and “M11”, and the moderators’ meetings in “M2”, “M3” and “M6”.

The development of both communities was different: the “I’mWithYou” VCoP was quicker than the “I’mWithYou” VCoP (Table 14). In addition, the “I’mWithYou” VCoP had four months in which the number of messages were over the mean, whereas the “I’mWithYouPlus” VCoP had only three. However, in both of them the positive impact of the face-to-face meetings in terms of number of messages can be seen.

Conversations could be started with: “text”, “photo”, “poll” or “event”. Then, these messages could be “like” or “comment”. The “like” messages were then included again in order to categorise the type of messages, in editing terms (Table 15). “Comments” was the most common message in both groups (Table 15), while “event” and “poll” were hardly used. Both communities shared mainly “texts”, and they interacted using “like”, “comment” and “direct message”.

Table 15. *Comparison of the type of messages and labels within the two VCoPs*

Variable	**"I'mWithYou"**	**"I'mWithYouPlus"**	***p-value***
Messages, n (%)	933	992	*<0.001***
Text	95 (0.18)	106 (10.68)	
Photo	57 (6.11)	8 (0.81)	
Event	3 (0.32)	0	
Poll	1 (0.11)	0	
Likes	77 (8.25)	153 (15.42)	
Comment	625 (66.99)	536 (54.03)	
Direct Message	75 (8.04)	189 (19.06)	
Label, n (%)	858	803	*<0.001***
Caring for others	596 (69.46)	465 (57.91)	
Caring for yourself	115 (13.40)	193 (24.03)	
Disease	147 (17.14)	145 (18.06)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

The "direct message" were then excluded in order to analyse the variable "label", as the "direct message" could not be labelled. Again, Pearson's Chi-Square test suggests that there are significant statistical differences between the two VCoPs with regards to the "label" messages, although there was a difference in the number of messages (Table 15).

The main differences in the participation medium between the two VCoPs are summarised in Table 16:

Table 16. *Differences in the participation medium between the two VCoPs of all participants*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Time	-Messages are sent in the "morning". -Most messages in "M3", "M6", "M8": quicker community development.	-Messages mostly sent in the "afternoon". -Most messages in "M2", "M8", "M9": slower community development.
Messages	-High quantity of "comment". -Considerable quantity of "photos".	-High quantity of "like" messages. -High number of "direct message".
Label	-Priority for "disease" over "caring for yourself".	-Priority for "caring for yourself" over "disease".

The participation medium of the moderators was then examined, and the "like" messages again excluded. The messages were then categorised according to type of interaction sent, time of day and month of year (Table 17).

Table 17. *Comparison of the moderators' message times within the two VCoPs*

Variable	"I'mWithYou"	"I'mWithYouPlus"	*p-value*
Time, n (%)			*<0.001***
Dawn	1 (0.62)	16 (4.56)	
Morning	93 (57.41)	78 (22.22)	
Noon	15 (9.26)	23 (6.55)	
Afternoon	38 (23.46)	141 (40.17)	
Evening	15 (9.26)	91 (25.92)	
Night	0 (0.0)	2 (0.58)	
Month, n (%)			*<0.001***
M1 (VCoP face-to-face meeting)	9 (5.55)	11 (3.13)	
M2 (Researchers meeting with moderators)	29 (17.90)	63 (17.95)	
M3 (Researchers meeting with moderators)	15 (9.26)	30 (8.55)	
M4	11 (6.79)	34 (9.69)	
M5	15 (9.26)	37 (10.54)	
M6 (Researchers meeting with moderators)	34 (20.99)	20 (5.70)	
M7	9 (5.55)	29 (8.26)	
M8 (VCoP face-to-face meeting)	18 (11.11)	39 (11.11)	
M9	14 (8.64)	54 (15.38)	
M10	3 (1.86)	22 (6.27)	
M11(VCoP face-to-face meeting)	5 (3.09)	12 (3.42)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

In the "I'mWithYou" VCoP, moderator was mostly active during the "morning", followed by the "afternoon". The moderators increased their activity after the face-to-face meetings. The daily message average was 0.39 for the "I'mWithYou" VCoP moderator and 0.99 for the "I'mWithYouPlus" VCoP moderators. Monthly, the mean of messages for the "I'mWithYou" VCoP moderator was

11.82, while for the "I'mWithYouPlus" VCoP the mean was 29.82. Pearson's Chi-Square test indicated significant statistical differences in all these variables, although there was a difference in the number of posts (Table 17). In this case, the main difference may have come from the fact that the "I'mWithYou" VCoP included only one moderator, whereas the "I'mWithYouPlus" VCoP had three.

The "like" messages were then included again in order to categorise the type of messages, in editing terms. Moderators started most of the conversations. The "I'mWithYouPlus" VCoP moderators were more active in all kinds of messages, apart from "photos" (Table 18).

Table 18. *Comparison of moderators' type of messages and labels within the two VCoPs*

Variable	**"I'mWithYou"**	**"I'mWithYouPlus"**	***p-value***
Messages, n (%)	163	389	*<0.001***
Text	43 (26.38)	69 (17.74)	
Photo	8 (4.91)	2 (0.511)	
Like	1 (0.61)	38 (9.77)	
Comment	103 (63.19)	201 (51.67)	
Direct Message	8 (4.91)	79 (20.31)	
Label, n (%)	155	310	*<0.001***
Caring others	136 (87.74)	155 (50.0)	
Caring yourself	6 (3.87)	85 (27.42)	
Disease	13 (8.39)	70 (22.58)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

With the aim of analysing the variable "label", here the "direct message" were excluded again. Pearson's Chi-Square test suggests that there are significant statistical differences between the moderators of the two communities with regards to the label messages, although there was a difference in the number of messages (Table 18).

To summarise, the Table 19 shows the main differences between the two VCoP moderators:

Table 19. *Differences in participation medium between the two VCoP moderators*

Variable	"I'mWithYou"	"I'mWithYouPlus"
Time	-Messages mostly sent in the "morning". -Most messages in "M3", "M5", "M6", "M8".	-Messages mostly sent in the "afternoon". -Most messages in "M4", "M6", "M8".
Messages	-High quantity of "like". -Very few "direct message".	-High quantity of "comment". -High number of "direct message".
Label	-Priority for "disease" over "caring for yourself".	-Priority for "caring for yourself" over "disease".

Participants Evaluation of the Virtual Communities of Practice

Having explored the participation medium, the focus was turned onto the participants feedback from the tailored self-administered survey (*Annex E*), as the researcher needed to study the members participation in the communities according to their role. The items considered from the tailored self-administered survey for this section were needs, motivations, type of participation, sense of trust and interest in participating in a new VCoP. All regular participants answered the tailored self-administered survey a part from a participant of the "I'mWithYouPlus" VCoP who dropped out before the end of the study.

The initial parameter to be studied was family caregivers' needs. Pearson's Chi-Square test indicates that no statistically significant differences were found between the needs of the two groups (Table 20). For the caregivers of both VCoPs, the most important need was the "information about the disease", whereas their least important one was "social support".

Table 20. *Comparison of the needs of regular participants of the two VCoPs*

Variable	“I’mWithYou”	“I’mWithYouPlus”	*p-value*
Alzheimer's information, n (%)			*0.641*
No	5 (26.31)	6 (31.57)	
Yes	14 (73.69)	12 (68.43)	
Support in care			*0.886*
No	8 (42.10)	8 (44.44)	
Yes	11(57.90)	10 (55.56)	
Social support			*0.641*
No	14 (73.69)	12 (68.43)	
Yes	5 (26.31)	6 (31.57)	
Caring for yourself			*0.886*
No	11 (57.90)	10 (55.56)	
Yes	8 (42.10)	8 (44.44)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

The motivation question included nine items. Participants rated 9 questions from 0 to 10. Their main motivation to participate in the VCoPs was "To be informed and trained ". The rest of answers were very similarly (Table 21). The only aspects that stand out are that in the “I’mWithYou” VCoP, "instigate the resolution of problems in collaboration" is the second motivation, while for the “I’mWithYouPlus” VCoP it is the sixth; and that in the “I’mWithYouPlus” VCoP, “to form a viable community on a specific subject” is the third motivation, while for the “I’mWithYou”VCoP it is the sixth. Still, no statistically significant differences were found between the motivations of the two groups (Table 21).

Table 21. *Comparison of motivation of the regular participant of the two VCoPs*

	n	Mean	SD	*p-value*
To instigate the resolution of problems in collaboration				*0.097*
"I'mWithYou"	19	7.89	2.56	
"I'mWithYouPlus"	18	6.61	1.88	
To inform and educate the peers through personal-professional experiences, points of view and know how				*0.167*
"I'mWithYou"	19	7.83	3.05	
"I'mWithYouPlus"	18	6.72	2.95	
To be informed and educated				*0.469*
"I'mWithYou"	19	8.61	2.12	
"I'mWithYouPlus"	18	8,22	1,93	
To negotiate and validate what one thinks				*0.073*
"I'mWithYou"	19	6.78	2.88	
"I'mWithYouPlus"	18	5.11	2.52	
To exchange ideas				*0.937*
"I'mWithYou"	19	7.84	2.46	
"I'mWithYouPlus"	18	7.94	2.18	
To build capacity				*0.563*
"I'mWithYou"	19	7.50	2.57	
"I'mWithYouPlus"	18	7.00	2.57	
To serve as a knowledge agent				*0.080*
"I'mWithYou"	19	6.44	3.58	
"I'mWithYouPlus"	18	4.44	3.03	
To form a viable community on a specific subject				*0.857*
"I'mWithYou"	19	6.89	2.76	
"I'mWithYouPlus"	18	7.06	2.73	
Considerations related to the communities				*0.765*
"I'mWithYou"	19	5.88	3.18	
"I'mWithYouPlus"	18	4.78	2.96	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

With respect to how they contributed to the community, none of the users responded that they participated as “troublemaker” or “not contributing”. Again, Pearson’s Chi-Square test showed there were no statistically significant differences between the two groups. A participant from the “I’mWithYouPlus” VCoP, who filled survey, did not answer this question. In the “I’mWithYou” VCoP there were 11 lurkers and 8 contributors, whereas in the “I’mWithYouPlus” VCoP there were 11 lurkers and 6 contributors (Table 22).

Table 22. *Type of participation and interest in continuing: A comparison between the two VCoPs*

Variable	**“I’mWithYou”**	**“I’mWithYouPlus”**	***p-value***
Type of participation n (%)			*0.676*
Lurker	11 (57.90)	11 (64.7)	
Contributor	8 (42.10)	6 (35.3)	
Interest in a new VCoP n (%)			*0.717*
No	6 (31.60)	5 (26.3)	
Yes	12 (63.20)	13 (68.4)	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

With respect to participants’ sense of trust in the community (compliance LINKS level), the “I’mWithYou” VCoP had a mean of 4.05 (out of 5), and the “I’mWithYouPlus” VCoP 3.94. Two participants from the “I’mWithYouPlus” VCoP,who filled the survey, did not answer this question. The Mann-Whitney U Test indicated there were no statistically significant differences between the two VCoPs (Table 23).

Table 23. *Comparison of the sense of trust between the two VCoPs*

Variable	n	Mean	SD	*p-value*
Sense of trust				*0.756*
"I'mWithYou"	19	4.05	1.08	
"I'mWithYouPlus"	16	3.94	1.12	

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

The last question of the survey asked whether the family caregivers would be interested in participating in a potentially new VCoP. A participant of the "I'mWithYou" VCoP, who filled the survey, did not answer this question. Out of the 36 regular participants who answered the question, 25 gave an affirmative answer, whereas 11 rejected the possibility. There were no statistical differences between the two communities regarding this question (Table 22).

Finally, 19 of the 42 participants in the two VCoPs gave feedback evaluating the intervention through an open oral question during the last face-to-face meeting: "How do you assess the experience of participating in the VCoP?". Participants reported that they had a positive experience because the app was perceived to be a useful tool, they could manage their own participation, they met peers and felt less lonely. Moreover, they reflected that the stage of their care-recipient illness could sometimes reduce their possibility of sharing information (Table 24).

Table 24. *Themes and quotations from the two questions survey*

Theme	Quotation
Positive experience	"The group is positive, for me it has been very good" *user16* "I really enjoyed the app" *user15*
A useful tool	"This app is another option within the spectrum that existed" *user13* "One more tool to look for support apart from professional care which is very good" *user42*
Managing own participation	"I am not active. When there were no messages, I missed it" *user41* "The key is that if you feel like speaking, you speak and if you don't, you don't speak" *user3*
Peers	"Being able to talk to people who have the same situation as you, the same problem as you and you see that we can't do anything about it because the disease advances" *user29* "Because of all I read I realise what's to come, this has accelerated me and told me to make the most of things, make the most of now that you can do all these things" *user9*
App continuity	"I wish the app could continue; it shouldn't be over" *user18* "I'd like to know if there was a chance to keep the app alive and that people could be added" *user16*
Availability	"You can enter whenever you want" *user15* "The advantage of doing it when you want" *user11*
Different phases	"Having caregivers going through different emotional and disease points is an advantage and a disadvantage" *user4* "We are all at different phases, emotionally and with regards to the disease" *user12*
No loneliness	"With this app you have people around you who listen to you and love you" *user20* "You don't feel alone anymore" *user22*

The Effects of Knowledge Shared, Interactions and Participation on Quality of Life

Having studied the knowledge that family caregivers shared, their interactions and their participation in the two VCoPs, the researcher analysed their relation with caregivers' QoL.

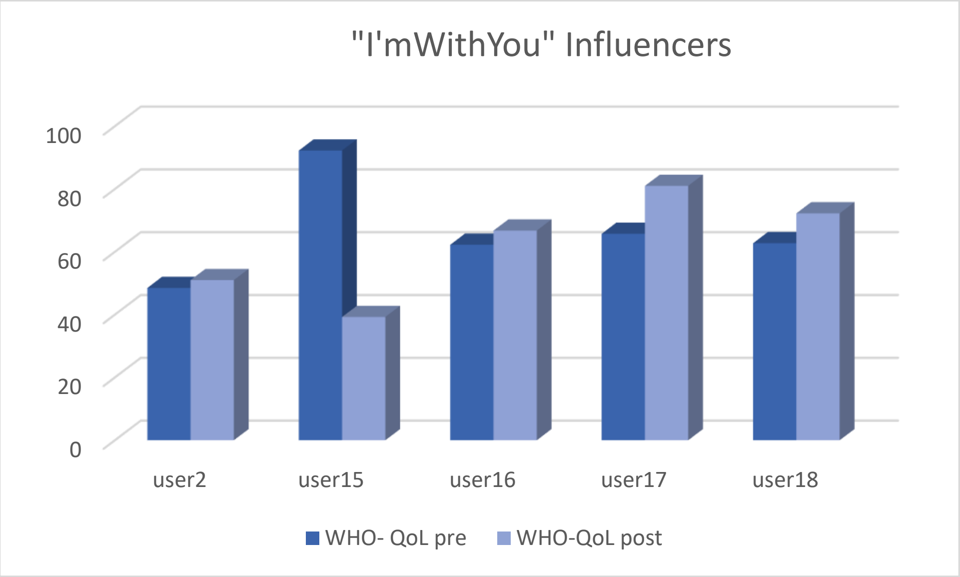
The Effects of Knowledge Shared on Quality of Life

The study started exploring the knowledge shared. The Spearman correlation test indicated that with regards to the type of knowledge shared, the topics shared and the purpose of the message, there was no correlation with QoL in either of the VCoPs, either with global QoL or by domain (*Annex G Table G1 and Table G2*).

The Effects of Interaction on Quality of Life

The QoL change of the "I'mWithYou" VCoP core group was then checked, which, as can be seen in section *Interaction between Members of the Virtual Communities of Practice*, is comprised of *users 2, 15*, *16*, 17 and *18* (Figure 15). Four out of five increased their QoL. Considering the involvement of *user15* in the community, his/her results were surprisingly negative. A conversation between researchers and *user15* revealed that *user15* was facing a difficult personal situation in addition to having his/her relative with Alzheimer's.

Figure 15. *"I'mWithYou" influencers QoL pre and post intervention*



In the "I'mWithYouPlus" VCoP the most influential users were the moderators. As they are health professionals, this study did not measure their QoL.

The Effects of Participation on Quality of Life

Finally, the relations between family caregivers' participation in the VCoP and their QoL were examined.

The researcher started by analysing the relation between the family caregivers' participation medium within each VCoP and their QoL. The Spearman correlation test indicated that there was a significant negative correlation between the clicks on "like" and the caregivers' QoL with regards to the social relationship domain in the "I'mWithYou" VCoP. No other correlation could be found with regard to the type of message in either of the two VCoPs (*Annex H Table H1 and Table H2*).

Then, the family caregivers' needs were studied. The Mann-Withney U test indicated that there were only significant statistical differences in the "I'mWithYou" VCoP between the need "support in care" and social domain QoL (Table 25).

Table 25. *Statistical differences between needs and QoL of "I'mWithYou" and "I'mWithYouPlus"*

Variable	**n**	**Overall QoL** ***p-value***	**Physical QoL** ***p-value***	**Psychological QoL** ***p-value***	**Social QoL** ***p-value***	**Environ. QoL** ***p-value***
Alzheimer's information						
"I'mWithYou"	19	*0.298*	*0.823*	*0.343*	*0.823*	*0.816*
"I'mWithYouPlus"	18	*0.494*	*0.553*	*0.553*	*0.616*	*0.616*
Support in care						
"I'mWithYou"	19	*0.351*	*0.657*	*0.152*	*0.012**	*0.310*
"I'mWithYouPlus"	18	*0.146*	*0.408*	*0.274*	*0.965*	*0.515*
Social support						
"I'mWithYou"	19	*0.754*	*0.964*	*0.893*	*0.559*	*0.754*
"I'mWithYouPlus"	18	*0.820*	*0.892*	*0.437*	*0.213*	*0.682*
Caring for yourself						
"I'mWithYou"	19	*0.442*	*0.778*	*0.657*	*0.840*	*0.395*
"I'mWithYouPlus"	18	*0.122*	*0.408*	*0.460*	*0.360*	*0.829*

* Significant statistical differences $p<0.05$

** Highly significant statistical differences $p<0.001$

The next variable studied was the family caregivers' motivation. No correlations were found in the "I'mWithYou" VCoP. The Spearman's correlation test indicated that there was a positive correlation between the motivation "To negotiate and validate what one thinks" and "To build capacity" with family caregivers' overall QoL when studying the "I'mWithYouPlus" VCoP. Focusing on domains, a positive correlation was found between "To negotiate and validate what one thinks" and the psychological domain, again in "I'mWithYouPlus" (Table 26).

Table 26. *Correlations between motivations and caregivers' QoL of "I'mWithYou" and "I'mWithYouPlus"*

Variable	n	Overall QoL Correlation Coefficient	Physical QoL Correlation Coefficient	Psychological QoL Correlation Coefficient	Correlation Coefficient Social QoL Correlation	Environ. QoL Correlation Coefficient
To instigate the resolution of problems in collaboration						
"I'mWithYou"	19	-0.023	0.031	-0.715	-0.078	-0.442
"I'mWithYouPlus"	18	-0.372	0.157	0.141	-0.337	-0.034
To inform and educate the peers						
"I'mWithYou"	19	0.154	0.175	-0.033	0.119	-0.233
"I'mWithYouPlus"	18	-0.176	-0.287	-0.231	-0.345	-0.254
To be informed and educated						
"I'mWithYou"	19	0.122	-0.040	-0.022	-0.458	-0.215
"I'mWithYouPlus"	18	0.342	0.332	0.208	0.430	0.278
To negotiate and validate what one thinks						
"I'mWithYou"	19	0.010	-0.176	-0.013	-0.303	-0.284
"I'mWithYouPlus"	18	0.508*	0.442	0.616*	0.199	-0.072
To exchange ideas						
"I'mWithYou"	19	0.094	-0.113	0.110	-0.216	-0.200
"I'mWithYouPlus"	18	0.369	0.173	0.177	-0.001	0.032
To build capacity						
"I'mWithYou"	19	0.298	0.074	0.194	-0.016	0.002
"I'mWithYouPlus"	18	0.502*	0.441	0.312	0.207	0.030
To serve as a knowledge agent						
"I'mWithYou"	19	0.054	0.005	*0.000*	-0.168	-0.213
"I'mWithYouPlus"	18	0.087	0.257	0.050	*-0.306*	-0.059
To form a viable community on a specific subject						
"I'mWithYou"	19	-0.137	-0.176	-0.213	-0.211	-0.301
"I'mWithYouPlus"	18	0.172	0.197	0.261*)*	0.060	*-0.225*
Considerations related to the communities						
"I'mWithYou"	19	-0.116	-0.231	-0.223	-0.465	-0.202
"I'mWithYouPlus"	18	0.004	0.265	0.093	-0.234	-0.021

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

The next variable analysed was the type of participation. The Mann-Whitney U test indicated that there were no differences in any of the communities between the type of participation and family caregivers' change of QoL, either in overall QoL or in any domain (*Annex H Table H3*).

The following variable analysed was the sense of trust. The Spearman correlation test denoted there was no significant correlation between level of trust and the QoL, be it overall or by domain in either of the two communities (*Annex H Table H4*).

Finally, the variable interest in a new VCoP was analysed with regards to its relation with family caregivers' QoL (*Annex H Table H5*). There were no significant statistical differences between the users who were interested in a new VCoP and the ones who were not, either in their overall change of QoL or by domain in either of the two VCoPs (Spearman correlation test).

Discussion

The aim of this research was to provide resources, specifically VCoPs, to help family caregivers of people with Alzheimer's cope with their role. The first specific objective was to propose a conceptual framework which shaped the design of the VCoPs, so as to help family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to support their needs.

A Conceptual Framework of Virtual Communities of Practice for Family Caregivers of People with Alzheimer's

Through a literature review the researcher presented a conceptual framework to guide the design and establishment of VCoPs for family caregivers of people with Alzheimer's (Romero-Mas et al., 2020). Despite there is a critical shortage of implementation research on eHealth interventions for family caregivers of people with Alzheimer (Christie et al., 2018), the intervention's design of the thesis followed the eleven dimensions proposed in this conceptual framework to establish two VCoPs for family caregivers of people with Alzheimer's. The process proves the first hypothesis of this study which is that a VCoP offers the possibility of helping family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to meet their needs.

The Impact of Virtual Communities of Practice Membership on Family Caregivers' Quality of Life

The second specific aim of this study was to analyse how membership of a VCoP impacts on the QoL of family caregivers of people with Alzheimer's. It investigated both the impact of the VCoPs on global QoL scores and on specific domains. Family caregivers of people with Alzheimer's improve their global QoL whilst participating in a VCoP, which opens a door to considering VCoPs as a means of enhancing the QoL of family caregivers. Previous research indicates that the ability to enhance the general QoL of caregivers appears to be limited, having more evidence that specific components of QoL could be responsive to interventions (Fazio et al., 2018). Studying the two VCoPs separately, only the "I'mWithYouPlus" VCoP shows significant statistical differences in pre and post overall QoL.

These results are aligned with the literature, which indicates that, currently, the majority of the most effective interventions for health-related QoL among family caregivers of people with dementia include health professional facilitators (Lee et al., 2020). However, VCoPs without health professionals but with an expert caregiver could be a more cost-effective intervention.

The Impact of Moderator Variables on Family Caregivers' Quality of Life

In prior research on family caregivers of people with a chronic disease, demographic parameters were associated with caregivers' QoL. Specifically, the most common related factors were gender, age, and level of education (Farzi et al., 2019; Nogueira et al., 2019; Sücüllüoğlu et al., 2019). Female caregivers, who are typically the majority of caregivers, appear to face a greater adverse impact on their QoL (Andreakou et al., 2016). In this study, probably due to the lack of variability as 79% were female caregivers, no significant difference was found between males and females with regards to their QoL. Neither did level of education act as moderator variable in this research. Age was the only demographic parameter studied that impacted caregivers' QoL. Interestingly, even though the literature states that older people may be more vulnerable to a deterioration in their QoL while caring (Brodaty & Donkin, 2009), this study indicates that the oldest caregivers were the ones whose QoL improved most; specifically, their psychological QoL. Erickson and Johnson (2011) suggest that it may be possible for older adults to perceive themselves as more efficacious as a result of using the Internet as a tool to lead an independent life, remain in contact with family and friends, and make informed decisions. Even though there was a concern about ageism, because of the caregivers' age, this research shows virtuality is not a handicap for them. Furthermore, the eHealth literacy was a moderator of caregivers' QoL from the perspective of the physical domain. This result is difficult to interpret as in this study participants' mean age was over 55 years and, among this population, eHealth literacy is a rather under-researched concept (Sarkar et al., 2016). Nevertheless, previous investigations have pointed to an association between eHealth use and poorer levels of social functioning, communication, worry, and family relationship but did not mention the physical domain.

Regarding to the caring variables, there was a difference between the relationship with the person with Alzheimer's (spouse, offspring and other relation) and overall QoL. Existing investigations have already found a significant association between the relationship with the person with Alzheimer's variable and caregivers' QoL (Farzi et al., 2019). Therefore, the findings are in line with the literature. No other caring variable was a moderator of caregivers' overall QoL. However, caring variables moderated caregivers' QoL in specific domains. As in previous investigations (Farzi et al., 2019), there was an association between the relationship with the person with Alzheimer's and the psychological domain of QoL, again with more influence in spouses. In addition, this study noted a negative correlation between length of caring and the psychological and social domains of QoL. These results are in line with existing research, which indicates that the longer a caregiver remains in his or her role, the more likely negative outcomes are to occur (McLennon et al., 2011). Furthermore, literature suggests that the hours spent offering care have a significant relationship with the QoL of chronic illness caregivers (Nogueira et al., 2019). The spouses of people with Alzheimer's are the ones who spend more time with them as they live together. These two caring variables are thus somehow linked and it makes sense that both of them act as moderator variables.

Previous publications evidence that the caregivers' QoL gets worse when the functional capacity of the elderly person with Alzheimer's disease declines (Pinto et al., 2009). Additionally, when care recipients have moderate/severe dementia symptoms, such as frequent distressed behaviours, there seems to be more potential opportunities to improve the caregiver's QoL (Laver et al., 2017). In the current study, no correlation between the functional deterioration of the person with Alzheimer's and caregivers' QoL was found. Nevertheless, caregivers' QoL did not decrease when their relative had deteriorated functionally. Hence, the neutralisation of this relation between the functional deterioration of the person with Alzheimer's and caregivers' QoL could be due to their participation in a VCoP.

Knowledge Shared, Interaction and Participation in the Two Virtual Communities of Practice and their effects on Caregivers' Quality of Life

The third specific aim of this thesis was to study the knowledge shared among family caregivers of people with Alzheimer's in VCoPs, the interaction between them and their participation in the community, as well as how these factors are related to the caregivers' QoL.

Knowledge Shared within the Two Virtual Communities of Practice

The findings of this research show that the most common modality of knowledge shared in both VCoPs was social knowledge, coinciding with the main topic which was social support. Existing literature shows that a high level of social support is related to a lower burden on the caregiver, since it is an important source of help for caregivers when dealing with these situations (Esandi & Canga, 2011). Therefore, the practices carried out within the VCoPs agree with previous research.

The second kind of knowledge most shared was experiential. VCoPs offer the framework to share experiential knowledge (Chen et al., 2006). These results show that even though VCoPs are explicitly designed to share experiential knowledge, family caregivers use the VCoPs according to their needs. The VCoP with health professionals shared a similar number of experiential and explicit knowledge, which means that in the "I'mWithYouPlus" VCoP there was more evidence-based knowledge. Considering that CoP theory seeks to turn explicit knowledge into experiential knowledge, in addition to encouraging the sharing of explicit knowledge (as was discussed in the section on the *Background of Communities of Practice*), the community with health professionals follows the common pattern of a VCoP more closely.

In line with previous research which states that family caregivers need support from others experiencing the same situation (Marirosa et al., 1999), most of the messages were seeking interaction. Nevertheless, they were more concerned about acquiring knowledge related to caring for the person with Alzheimer's than to caring for themselves.

However, there were statistical differences between the two VCoPs in all the variables studied except the functionality of research and the interaction variables. In the "I'mWithYou" VCoP, there was a huge quantity of informative messages about the sender looking for social support, while in the "I'mWithYouPlus" VCoP the informative messages were split fairly evenly between sender and disease. Probably, this is because health professionals share more knowledge related to the disease.

Focusing on the moderators' exchange of knowledge, the results were very similar to the overall results of the VCoP they moderated. These findings aligned perfectly with the literature, which states that the moderator plays a key role in the community (Ranmuthugala et al., 2011). On exploring the modalities shared by the moderators, it was seen that the expert caregiver shared very few explicit knowledge messages, whereas the health professionals shared more explicit than experiential knowledge. This is coherent because health professionals provide mainly evidence-based knowledge.

Caregivers reporting stronger self-efficacy and taking time for themselves reduced the burden and reported greater QoL (Coen et al., 2002; Gonyea et al., 2005). In this study, as is also reported in the literature, the health professional moderators insisted on the fact that caregivers need to take care of themselves as they have the tendency to prioritise the care-recipient and all the other factors, ignoring their own health. Furthermore, the literature indicates that caregivers would like to receive more information and support from their general practitioner, which confirms the importance of this figure in the management of this pathology (Marirosa et al., 1999).

With regard to the relation between the exchange of knowledge and caregivers' QoL – focusing on the type of knowledge shared, the topics shared, label and the purpose of the message – no correlation could be found with either global QoL or QoL by domains. These results indicate that the benefit of VCoPs lies not in the content but in the ongoing social interaction which is rooted in the reality of community. However, as has already been seen, interactions through social networks on the Internet facilitate the transmission of both explicit and tacit knowledge (Fadul, 2014).

Interaction between Members of the Virtual Communities of Practice

This study confirmed the influencer role of the moderators in both VCoPs. The fact that in one VCoP there were three moderators while in the other only one may account for the presence of a core group with five participants in the “I’mWithYou” VCoP (including the moderator). Wenger et al. (2002) already pointed out that lively communities have a moderator who organises events and connects the community, but others in the community also take on leadership roles. These actors together end up modelling the core group, which is the heart of the community. Wenger et al. (2002) suggested that the core group is around 10-15 per cent of the whole community. With respect to our study, in the “I’mWithYou” VCoP it consisted of nearly 20% and in the “I’mWithYouPlus” VCoP 13%. These differences in percentages are probably due to the fact that the “I’mWithYou” VCoP had only one moderator while the “I’mWithYouPlus” VCoP had three. The VCoP with only an expert caregiver as moderator built a larger core group. In addition, four out of five caregivers of this core group increased their QoL.

At this point, it was necessary to consider the community’s interaction with the outside world, which may be on two levels: individual or collective. Favourable and unfavourable circumstances may come to the VCoPs from health and social policies, health and social institutions and professionals, non-member caregivers, the friends or relatives of member and non-member caregivers, among other cases. Outside factors may influence the VCoP differently, depending on its state of health.

Participation in the Virtual Communities of Practice According to Participants' Role

Finally, the LINKS model considers participation. Starting with the relevance of time in the VCoP, in this study there were differences between the two VCoPs with regards to the time at which messages were sent between the two VCoPs. In the "I'mWithYou" VCoP, activity was mainly in the morning, while in the "I'mWithYouPlus" VCoP it was split between morning and afternoon. This difference may be because the health professional moderators worked in the morning.

It is also important to mention that the "I'mWithYou" VCoP developed more quickly than the "I'mWithYouPlus" VCoP as they had a lot of social interaction. Moreover, face-to-face meetings had a positive impact on the number of messages of the two groups, which is perfectly in line with the literature, where studies suggest that face-to-face meetings contribute to the strengthening of the bonds between the members (Salido, 2012). Finally, the stages of the disease itself may influence caregivers' participation within the community. Previous research already recommended offering training programmes at the onset of caregiving to help caregivers learn, as soon as possible, how to deal with the demands of caregiving and to promote their health (Ducharme et al., 2011).

When caregivers were asked about their needs, they answered that what was most important for them was the need for information about the disease, whereas the least important was social support. These results agree with the literature, which indicates that one of the most important needs for the caregivers is information about the disease (Plöthner et al., 2019). However, this study showed that even though the perception of the caregivers was in line with the theory, in practice the most important need for caregivers was social support.

The family caregivers of this study chose to be part of the VCoP and were therefore looking forward to participating in the communities. Their main motivation to participate in the communities was to be informed and trained. In some way, these results are related to the caregivers' needs and to the family caregivers' motivations to play the role of caregiver. The literature demonstrates that family caregivers who identify more beneficial components of their role experience less burden, better health and relationships, and greater social support (Brodaty & Donkin, 2009). In fact, caregivers may be motivated to provide care for a number of reasons: a sense of love or reciprocity, spiritual fulfilment, a sense of duty, guilt, social pressures, or, in rare instances, greed (Brodaty & Donkin, 2009). Family caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations (Brodaty & Donkin, 2009).

In this research, none of the participants considered they did not contribute or that they caused trouble. The members that Wenger et al. (2002) called peripheral in this research were called lurkers. In both communities, lurkers represented around 50% of the participants. During the face-to-face meetings, they reported that they followed the conversations as they were receiving notifications of all the interactions. In addition, they considered they learnt through the VCoP. It was their own decision to play the role of lurker. Wenger et al. (2002) already pointed out that peripheral members may not be as passive as first thought and may still gain value and enhance their practice from this type of membership. Being a lurker could be helpful for novice family caregivers. On the top of that, lurking can be a vital first step for individuals who are wary of ICT or lack confidence in their knowledge.

Moreover, the findings indicate that members trusted their VCoP. In the early stages, trust needs to be built and higher-level functions such as information sharing, knowledge-sharing and creation come later. These reflections resonate with the pattern of caregiving, with its highs and lows. As the community grows, it develops a systematic body of knowledge. Family caregivers, having a sense of community, would realise their involvement with the VCoPs is translated into something useful, such as better caring for the patient, a better carer-patient relationship and better perception of their own role (Molina et al., 2006).

Finally, it is worth mentioning that this research is in line with the existing literature, which states that the presence of health professionals in the online intervention leads to an increase in the caregivers' commitment to the intervention and reinforces their confidence to implement the strategies learnt (Boots et al., 2014) - which will help to improve care and the QoL of the person with dementia (Ducharme et al., 2011; Lai et al., 2013).

The Effects of Knowledge Shared, Interactions and Participation on Quality of Life

The only correlation found between the type of messages and caregivers' QoL was a significant negative one between the number of "like" messages and their QoL in the social relationship domain in the "I'mWithYou" VCoP. These findings may suggest that lurkers took more advantage of the community, which was contrasted with previous literature that links greater levels of participation with helping them to share knowledge, disseminating ideas quickly and providing emotional support among members (Koh & Kim, 2004). However, no other differences were found with respect to the type of messages.

Regarding the caregivers' needs, the results of this study shows that there were significant statistical differences in the "I'mWithYou" VCoP between the support in care need and QoL in the social domain. These results are in line with the existing literature, which suggests that social isolation and family cohesion may affect the health of dementia caregivers (Zacharopoulou et al., 2015).

There was a positive correlation between the motivations to negotiate and validate what one thinks and to build capacity, and caregivers' overall QoL in the "I'mWithYouPlus" VCoP. These two motivations are aligned with the needs of information about the disease and support in care highlighted by the caregivers. Furthermore, these findings fit with the CoP definition of Wenger et al. (2002, p. 10): "CoPs are groups of people who share a concern, a set of problems or a passion about a topic, and who deepen their knowledge and expertise in this area through interacting on an ongoing basis". In addition, in the same VCoP, there was a positive correlation between negotiation and validation of what one thinks and QoL in the psychological domain. This relation has been seen in previous studies where the caregivers' perception of their own role impacts their QoL (Molina et al., 2006).

Considering this study proposed an Internet-based intervention, it is interesting to see that this experience improved participants' digital skills. Additionally, participants who enhanced their eHealth literacy the most were the ones who improved their QoL the most.

Finally, participants evaluated the VCoPs, providing encouraging feedback. They reported that they had a positive experience citing a number of reasons: the app was perceived to be a useful tool; members could manage their own participation; and they met peers and so felt less lonely. Furthermore, they showed interest in repeating the experience. Even though no correlation was found between the interest in a new VCoP and family caregivers' QoL, it is consistent with the main findings of this study, which provides qualitative support to the value of a VCoP.

This study therefore proves the second hypothesis that was posed which was that VCoPs in health are beneficial for improving the QoL of family caregivers of people with Alzheimer's. The shared knowledge, the interaction between members and their participation in VCoPs influence the QoL of family caregivers of people with Alzheimer's.

Conclusions

VCoPs are resources to help family caregivers of people with Alzheimer's cope with their role. Firstly, VCoPs for family caregivers of people with Alzheimer's may be designed and established by following the eleven dimensions proposed in this thesis, as a conceptual framework to help caregivers learn how to deal with the demands of caregiving and to meet their needs.

Secondly, VCoPs help to improve the QoL of family caregivers of people with Alzheimer's, particularly if they include health professionals. The age of the carer and their relationship with the person with Alzheimer's are moderator variables. Furthermore, VCoPs may break the relationship between the deterioration of the person with Alzheimer's and their caregiver's QoL. VCoPs may also improve caregivers' eHealth literacy. In this research, caregivers with greater eHealth literacy saw the greatest improvement in their QoL.

Thirdly, social knowledge and social support are priorities for family caregivers of people with Alzheimer's and VCoPs do provide supportive relationships. Therefore, supportive relationships are found within the VCoPs. VCoPs facilitate the transmission of both explicit and experiential knowledge, which is one of the essential elements of VCoPs. Moreover, this study shows that the benefit of VCoPs lies not in the content of the knowledge shared or in the type of message but rather in the ongoing social interaction, which is rooted in the reality of community.

All members of a VCoP have their own role inside the community to establish their own practice, which highlights collaborative work where everybody counts (core group, active members and lurkers). The VCoPs also highlight the significance of health professionals for family caregivers and their management of Alzheimer's.

VCoPs where peers count on each other function more as a support group, whereas those moderated by health professionals, function more as a place to go to acquire information.

The VCoPs were a positive experience for the caregivers and they perceived the VCoP as a useful resource. In addition, most of the participants showed interest in participating in another similar VCoP.

Strengths, Limitations and Future Research

The research work presented in this thesis has several strengths, as well as some limitations. Moreover, it brings useful and hopeful advances for further work.

With regards to the strengths of the research, it contributes to addressing a public health problem. Over the past decades, life expectancy has increased considerably, having an impact on chronic age-related conditions. One of these disabling chronic disorders that requires a high level of care is dementia and, specifically, Alzheimer's disease. Caring for a person with Alzheimer's burdens family caregivers, and there is a close negative relationship between this burden and their QoL. Family caregivers of people with Alzheimer's need more resources to help them cope with their role and improve their QoL.

In order to address this problem, this thesis proposes a framework which shapes the design of the VCoPs so as to help family caregivers of people with Alzheimer's learn how to deal with caregiving demands and to meet their needs. Moreover, it is an outcome which could provide guidance and help to continue to build evidence on interventions for family caregivers of people with other chronic diseases.

An app was developed from the initial stage to the implementation stage with the sole aim of conducting our study. The app was grounded in a consistent theory, CoP theory (Wenger, 1998). The existing literature has already evidenced that technology including an app is a proven tool for improving the QoL of family caregivers of people with dementia (Cahill et al., 2007). These two considerations together, with the current high use of apps in health (49,809 healthcare apps are available in Google Play worldwide), leads to a strong evidence-based basis for this study (Statista, 2021).

Furthermore, this investigation observed that family caregivers of people with Alzheimer’s improved their global QoL whilst participating in a VCoP, which opens a door to considering VCoPs as a means of enhancing the QoL of family caregivers of people with Alzheimer’s. The moderators profile has a direct impact on the caregivers’ QoL**,** which was seen when this study analysed the two VCoPs separately: the VCoP including health professionals as moderators was the one in which the family caregivers increased their QoL significantly. Having better results when including health professionals in the interventions with family caregivers of people with Alzheimer’s is a recognised pattern. This study shows the importance of counting on health professionals in the VCoPs, but it also considers the inclusion of expert caregivers. Family caregivers count on health professionals for the management of the situation, but having VCoPs moderated by expert caregivers could be more cost effective.

In addition to offering a longitudinal study of the caregivers’ QoL, this research aimed to identify the moderator factors that impact their QoL. Age and relationship with the person with Alzheimer’s may be considered as moderator variables when family caregivers participate in VCoPs.

Moreover, this intervention had an impact on the participants’ digital skills. It helped to improve their digital skills, and improved the QoL of the caregivers with a higher level of eHealth literacy. In the current Information Society, these results are a strength of the research as it opens up inclusion opportunities for participants.

Another strength of this thesis that should be highlighted is the novel application of the LINKS model to the analysis of the two VCoPs for family caregivers. This model has been considered before to analyse the knowledge exchange between health professionals first (Abidi et al., 2009) and, later on, to study health related knowledge on Twitter (Xu et al., 2014). However, no previous literature shows the potential of using the LINKS model to analysing the exchange of knowledge between family caregivers.

In addition, this study offers a holistic perspective of the model while previous studies developed only part of the model. Deployment of the whole model provides evidence of most aspects related to the knowledge shared between the participants, the interaction between them and their participation in the VCoPs. Furthermore, it analyses the knowledge shared in the VCoPs, which was identified as a gap as there was a lack of this kind of information in previous studies. Participants use the VCoP according to their current needs, which, considering the different stages of the Alzheimer's disease, is an advantage.

This study points out the sense of community behind the CoP concept. The connection between the knowledge shared, the interaction and participation and QoL shows that it is not just the knowledge content but also the community itself that is valuable.

Finally, this thesis presents a complete study that includes all the phases of a piece of research, thus providing a comprehensive review. It starts with an exhaustive literature review followed by an outline of the design of the VCoPs (including the conceptual framework). It then brings the technological implementation together with the pre and post intervention tests, and concludes with the quantitative and qualitative analysis.

With regards to its limitations, the sample could have been larger. Despite using a range of strategies, recruitment for this study was difficult. Nevertheless, there are online interventions for caregivers with fewer participants than in this study (Lai et al., 2013). A larger sample would have allowed for the integration of a control group in our study, which would have made the findings more robust. In addition, it should be mentioned that the caregivers' age, together with their eHealth literacy, excluded a lot of caregivers from the study.

Moreover, this study introduces evidence that older caregivers experienced a positive impact, while younger caregivers experienced a less positive one. Clearly, the age variable should be further explored as additional family burdens could have influenced this effect. Furthermore, in this research there were several potential moderating factors related to the caregivers' demographics and the caring itself that were not considered. The caregivers' physical condition or their financial situation are aspects which the literature points to as having a potential influence on caregivers' QoL (ZamZam et al., 2011).

Finally, this thesis only could register when members participated actively. It would have been interesting to have full traceability of the participants in the app in order to obtain more details about the exchange of knowledge, especially with regards to the lurkers.

Considering the implications for future research, this thesis, with the conceptual framework presented to guide the design and development of VCoPs, provides a useful contribution to the literature, since several protocols and principles that previously emerged (Lathlean, 2002; Zhao & Bishop, 2011) and that were specifically focused on health (Barnett et al., 2016) were aimed mainly at health care professionals and sometimes at users, but not family caregivers. This conceptual framework could be considered for future research in this field.

The knowledge family caregivers share, their interaction with each other and their participation as members of a VCoP provide policy makers with ideas about designing future interventions for family caregivers, which should be more user-centred. VCoPs could be considered to be another resource for family caregivers that health care professionals could prescribe. This study showed the potential of apps based on VCoP theory, specifically for family caregivers of people with Alzheimer's. However, more research along these lines should be considered.

Moreover, with the aim of obtaining a more user-centred app, rooted in VCoP theory, suggestions and recommendations from family caregivers should be considered. Furthermore, collaboration with ICT engineers is essential for reaching the expected results. Hence, exploring the collaborative methodologies of co-creation could be a new line of research. In fact, there is already evidence of interest in this line of research, as a project led by the University of Vic-Central University of Catalonia – "Co-created ICT solutions for Alzheimer's Informal Caregiving" (Co-Care) – has been funded by the European Commission (2020-2022). Co-Care (https://co-care.eu/) is a new project which aims to stimulate user-led design in the development of ICT-based Alzheimer’s care solutions.

In addition, the potential of a VCoP for family caregivers of people with other chronic diseases could also be explored. This line of research would give another dimension to the current study, as it could involve a wide range of collectives.

Furthermore, these achievements may open doors to the family associations of people with Alzheimer’s and their caregivers, which, as this research has shown, play an important role in the context of the family caregivers. These associations could consider offering VCoPs to their caregiver members as another service or resource.

Finally, a reflection on the impact of this study in light of the current Covid-19 health emergency is carried out. People with Alzheimer's and their caregivers, as well as society as a whole, are having to cope with an unprecedented situation that may have a significant impact on them. Breaking the routines that people with Alzheimer's had, such as receiving home care, visiting relatives, attending a day centre and keeping medical appointments, will have a direct impact on their well-being, increasing their anxiety and confusion whilst making the situation much more difficult for the caregiver, who has also become much more isolated as a result of the lockdown. The opportunity for caregivers to have access to a community of people who are experiencing circumstances similar to their own is very valuable. It means they can feel understood, gain strength from the experience of others, avoid isolation, share their concerns, find creative or alternative strategies and solutions and enhance the bonds of support and help in the family caregiver community. Therefore, in a situation such as the current global pandemic, VCoPs would enable caregivers to become connected and unite to overcome the loneliness of being unable to seek support, help or advice when caring for people with Alzheimer's.

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Annexes

Annex A: Deployment of Waterfall Methodology

The deployment of the Waterfall methodology is outlined below:

a. Requirements

The requirements were based on the foundations and theory of CoP and VCoP. The focus was on the requisites mentioned by Wenger (Etienne Wenger, 2010): a home page to assert its existence and describe its domain and activities; a conversation space for online discussions; a repository for its documents, including research reports, best practices, and standards; a good search engine to find things in its their knowledge base; a directory of membership with some information about areas of expertise and domain; in some cases, a shared work space for synchronous electronic collaboration, or to enhance teleconferences with visuals; and community management tools, mostly for the moderator but sometimes for the community at large. Finally, the researcher and ICT engineers agreed that our requirements would be the ones presented in Table A1:

Table A1. *List of app requirements*

ID	Requirement
REQ 1.	An initial screen to identify the user.
REQ 2.	A timeline for discussions with all participants.
REQ 3.	All messages should be labelled to help members find the information more easily.
REQ 4.	A directory of participants.
REQ 5.	A direct message's option. Each participant should be able to send individual messages to any of the other participants in order to have private messages.
REQ 6.	A main repository.
REQ 7.	Notifications to all the participants regarding the community activity in real time.
REQ 8.	An icon and a name: The application icon is the first thing users see. It should stand out, be pleasant and be related to family caregivers of people with Alzheimer's.
REQ 9.	An interface explaining the research.
REQ 10.	Suitable usability for the "potential caregiver" (group of women between the ages of 45 and 70, housewives, daughters of the dependent person and without external employment).
REQ 11.	It should foster a good user experience.
REQ 12.	It should be robust so as to allow users to feel safe sharing within the app.
REQ 13.	Possibility to retrieve all the message arrays in order to let researchers analyse the knowledge shared within each community.

b. Design

During the stage design, a functional and technical analysis was performed to determine what requirements previously listed were to be implemented and how it would be done. Hence, the list of decisions taken regarding the requirements considering the resources available for this research can be seen in Table A2:

Table A2. *List of decisions considering available resources*

ID	Decision
DEC 1.	The app will include an initial screen to introduce the username and password.
DEC 2.	We will have a wall for discussions with all participants. Within this wall, members will be able to introduce messages in the format of text, photo, poll and event. In addition, members should be able to comment or like a previous message. As text, links to other pages could be introduced.
DEC 3.	All messages will be labelled according to: “disease”, “caring for others” or “caring for yourself”. In this way, each label will allow all the messages related to it to be shown. It will help members to find the information more easily.
DEC 4.	A directory of participants. All members will be required to host a photo and a small description (profile). Each participant will be able to edit his/her profile and will be able to check the profile of all the others.
DEC 5.	A direct message’ option. Each participant will be able to send individual messages to any of the other participants in order to have private messages (not labelled).
DEC 6.	A main repository. As the ICT engineers were aware of the memory space of users’ cell phone, we decided that if users require repositories they could be external. We will have to persuade members sharing links to introduce evidence-based knowledge in the community. The Internet itself was considered a huge repository.
DEC 7.	Notifications to all the participants regarding the community activity in real time. Users could check the m-App any time, but they were notified if there was activity within the community.
DEC 8.	An icon and a name. The name of the app was sought to be significant for the family caregivers. The name was given by the second-year pupils (7-8 years old) of the *Sant Genís i Santa Agnès* primary school in Taradell, a town of Osona County. The researcher got involved with the group of the students and, together with the educational team of the school, they led the students’ learning about the situation that family caregivers of people with Alzheimer’s have to face, together with their needs. Once the students were aware of the issue, they came up with “I’mWithYou” (“EsticAmbTu”) and the idea of the logo, which a professional designer later gave shape to. The designer also gave an orange colour for the community with the expert caregiver and blue for the community including health professionals.
DEC 9.	An interface about the research with the contact details (telephone and email) of the researcher in case the members needed to contact her for any query or problem.
DEC 10.	Suitable usability for the “potential caregiver”. As the users had to be from Osona, a region of Catalonia, the language of the app was Catalan.
DEC 11.	Foster a good user experience. It was possible to view the interface both horizontally and vertically. In addition, we made sure all buttons and interfaces were familiar. The app included an integrated guide explaining the main functions on the first use of each option and it incorporated confirmation messages. Finally, the design of the interfaces was simple and practical. The app incorporated aspects related to the caregivers’ emotions or preferences, such as a photo related to caregiving on the identification screen of the app. Unless users exited explicitly from the app, they did not have to pass the security step every time they clicked on the icon.
DEC 12.	Robustness so as to allow users to feel safe sharing within the app. The ICT engineers had experience with the language used and they knew it was the right one. In addition, *Confluència* hired an Amazon hosting service in order to ensure the security and capacity of the app.
DEC 13.	The m-App would be settled in a web platform in order to let the ICT engineers to manage the information shared.

c. Implementation

The implementation of the app was done by *Confluència’s* ICT engineers. All the functions decided during the design stage were implemented duly. The technological environment was IONIC

Platform; the languages used were HTML, Javascript, and CSS; and the API version was Cordova. Finally, an Amazon AWS was contracted for the hosting.

d. Testing

Confluència's ICT engineers tested the app after the implementation, and the researchers then tested the app again, giving feedback to the ICT engineers. The "I'mWithYou" version 0 was then launched. This version 0 was tested together in a meeting session by the ICT engineers, the researchers and the moderators of the two communities. Once the feasible updates regarding the time and funding were agreed upon, the ICT engineers worked on the latest "I'mWithYou" version 1. In addition, *Confluència* committed to not misusing the mails of the users. The data was only used for this study and would not be used for anything other than this study, such as selling addresses to a laboratory, making them public or not sending them spam.

e. Start-Up

The development of the app was done between September 2017 and March 2018, and the app was finally launched on 24 April 2018. In fact, two versions were launched: "I'mWithYou" (orange logo) and "I'mWithYouPlus" (blue logo). The two apps were exactly the same, but for our research we required two separate VCoPs, with both apps being available in Google Play and App Store. In order to launch an app in the Google Play Store, it is essential to abide by all the company policies and to accept the distribution agreement for developers. Besides, all apps published in the app Store are pre-reviewed by an Apple expert, but the requirements are quite similar to those listed for publication in the Google Play Store. Our two apps (same app with two names in order to establish 2 VCoPs) passed all these requirements. Finally, during the first face-to-face meeting, or by sending an email to each participant who could not attend it, we made sure all participants (both regular participants and moderators) downloaded the appropriate app.

f. Maintenance

Suggestions coming from participants throughout the study were considered for a second version of the app, but in the end were not implemented. They could be summarised as Table A3 indicates:

Table A3. *Participants' suggestions for "I'mWithYou" Version 2*

ID	Suggestion
SUG 1.	To allow enlargement of the profile photo.
SUG 2.	To remove the character limit in the user profile description.
SUG 3.	To allow all the latest activity of the timeline to appear at the top (even though they are comments or likes).
SUG 4.	To allow links in the comments.
SUG 5.	To ensure manual or automatic version updates.
SUG 6.	To insert the informed consent inside the app and include General Data Protection Regulation Acceptance of terms and conditions. "I declare that I upload the images to the app and I make them lawful and that it is what I call a responsible statement".

Annex B: Information about the Research for Participants

Informació per als participants

Els membres de l'equip d'investigació Grup M_3O "Methodology, Methods, Models and Health and Social Outcomes" estem duent a terme el projecte d'investigació:

«Anàlisi de l'intercanvi de coneixement relacionat amb l'atenció de pacients afectats per patologia crònica discapacitant en les comunitats virtuals de pràctica de professionals de salut i cuidadors informals»

El projecte ha d'analitzar com la participació dels Cuidadors Informals de Malalts d'Alzheimer (CIMA) en una comunitat virtual de pràctica afecta la qualitat de vida del cuidador a partir del coneixement que comparteixen, els mitjans que utilitzen i el rol dels participants.

Es crearan dues comunitats de pràctica virtuals amb els CIMA que participin a l'estudi (un dels dos grups inclourà els professionals de la salut) i a continuació s'analitzarà la participació dels CIMA en aquests. En el projecte participen els següents centres de recerca: Grup M_3O de la UVic-UCC PSiNET de la UOC i AFMADO.

En el context d'aquesta investigació li demanem la seva col·laboració formant part de l'estudi ja que vostè compleix els següents criteris d'inclusió:

1. Ser cuidador informal d'un malalt d'Alzheimer (CIMA), cuidador principal o secundari.
2. Tenir disponibilitat d'accés a Internet.
3. Poder utilitzar un smartphone, tablet o dispositiu mòbil.
4. Viure a Osona.

Aquesta col·laboració implica participar en:

Fase 1: Pre-intervenció

a) Contestar un qüestionari sobre la qualitat de vida (WHOQOL-BREF).

b) Respondre el test sobre el Barem de Valoració de la Dependència del malalt (BVD).

c) Passar l'escala eHEALS sobre habilitats digitals.

Fase 2: Intervenció

Formar part de les dues comunitats de pràctica de CIMA, una de les quals inclourà professionals de la salut i l'altra no.

Fase 3: Post-intervenció

a) Contestar un qüestionari sobre la qualitat de vida (WHOQOL-BREF).

b) Respondre el test BARTHEL sobre el deteriorament funcional del familiar amb Alzheimer.

c) Passar l'escala eHEALS sobre les seves habilitats digitals.

d) Respondre un qüestionari sobre la seva participació a les comunitats.

Tots els participants tindran assignat un codi que no permetrà vincular directament al participant amb les respostes donades, com a garantia de confidencialitat. Les dades que s'obtindran de la seva participació no s'utilitzaran amb un altre fi diferent de l'explicitat en aquesta investigació. Es custodiaran de forma segura sota la responsabilitat directa de l'investigador principal. Aquestes dades quedarien protegides mitjançant un sistema de codificació, i únicament hi podran accedir les investigadores del projecte: Montse Romero Mas, Anna Ramon Aribau i Beni Gómez-Zúñiga. Es conservaran vinculades al codi del participant únicament durant el temps que sigui imprescindible.

El fitxer de dades de l'estudi estarà sota la responsabilitat de la investigadora principal davant del qual es podrà exercir en tot moment els drets que estableix la Llei 15/1999 de protecció de dades personals.

Estem a la seva disposició per a resoldre qualsevol dubte que li sorgeixi. Pot contactar amb nosaltres a través d'AFMADO (afmado@afmado.com o 663486415) o bé directament: montse.romero@uvic.cat o 619459296.

Annex C: Informed Consent for Participants

Consentiment informat

Jo, ____, major d’edat, amb DNI ___________________________, correu electrònic ____ i número de telèfon _____________________ , actuant en nom i interès propi

DECLARO QUE:

He rebut informació sobre el projecte **«Anàlisi de l'intercanvi de coneixement relacionat amb l'atenció de pacients afectats per patologia crònica discapacitant en les comunitats virtuals de pràctica de professionals de salut i cuidadors informals»** del que se m’ha lliurat el full informatiu annex a aquest consentiment i pel qual es sol·licita la meva participació. He entès el seu significat, se m’han aclarit els dubtes i m’han estat exposades les accions que es deriven del mateix. Se m’ha informat de tots els aspectes relacionats amb la confidencialitat i protecció de les dades dels participants en el projecte.

La meva col·laboració en el projecte és totalment voluntària i tinc dret a retirar-me del mateix en qualsevol moment, revocant el present consentiment, sense que aquesta retirada pugui influir negativament en la meva persona en cap cas. En cas de retirada, tinc dret a què les meves dades identificatives siguin cancel·lades del fitxer de l’estudi.

Així mateix, renuncio a qualsevol benefici econòmic, acadèmic o de qualsevol altra naturalesa que pogués derivar-se del projecte o dels seus resultats.

Per tot això,

DONO EL MEU CONSENTIMENT A:

1. Participar en el projecte «Anàlisi de l'intercanvi de coneixement relacionat amb l'atenció de pacients afectats per patologia crònica discapacitant en les comunitats virtuals de pràctica de professionals de salut i cuidadors informals»

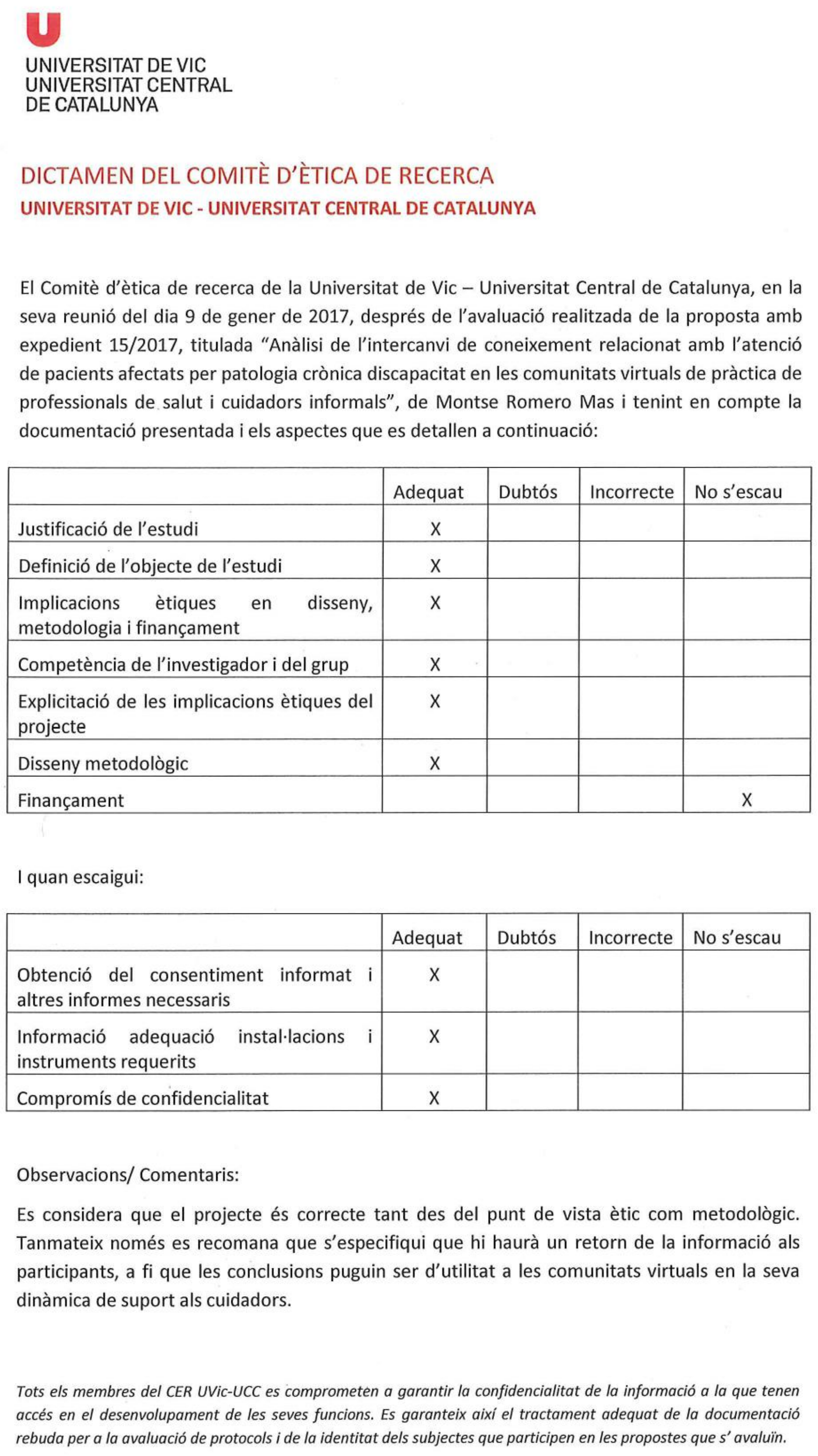
2. Que l’equip d’investigació Grup M_3O “Methodology, Methods, Models and Health and Social Outcomes” i la Montse Romero Mas com investigadora principal, puguin tractar les meves dades en els termes i abast necessari per la recerca, entenent que en cap cas es difondran de manera que es puguin vincular a les meves dades identificatives i que únicament es conservaran durant el temps que sigui necessari per complir les funcions del projecte.

3. Formar part d'una de les dues comunitats virtuals de pràctica del projecte (una exclusivament de cuidadors de malalts d'Alzheimer i l'altre incloent-hi professionals) de forma aleatòria. En el cas que formi part d'un grup de suport, pot ser que en la comunitat on se m'assigni no hi hagi la resta del grup.

Vic, a 18 juny 2017

Signatura Participant   Signatura IP

Annex D: UVic-UCC Ethics Committee Approval



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UNIVERSITAT CENTRAL
DE CATALUNYA

DICTAMEN DEL COMITÈ D'ÈTICA DE RECERCA
UNIVERSITAT DE VIC - UNIVERSITAT CENTRAL DE CATALUNYA

El Comitè d'ètica de recerca de la Universitat de Vic – Universitat Central de Catalunya, en la seva reunió del dia 9 de gener de 2017, després de l'avaluació realitzada de la proposta amb expedient 15/2017, titulada "Anàlisi de l'intercanvi de coneixement relacionat amb l'atenció de pacients afectats per patologia crònica discapacitat en les comunitats virtuals de pràctica de professionals de salut i cuidadors informals", de Montse Romero Mas i tenint en compte la documentació presentada i els aspectes que es detallen a continuació:

	Adequat	Dubtós	Incorrecte	No s'escau
Justificació de l'estudi	X			
Definició de l'objecte de l'estudi	X			
Implicacions ètiques en disseny, metodologia i finançament	X			
Competència de l'investigador i del grup	X			
Explicitació de les implicacions ètiques del projecte	X			
Disseny metodològic	X			
Finançament				X

I quan escaigui:

	Adequat	Dubtós	Incorrecte	No s'escau
Obtenció del consentiment informat i altres informes necessaris	X			
Informació adequació instal·lacions i instruments requerits	X			
Compromís de confidencialitat	X			

Observacions/ Comentaris:

Es considera que el projecte és correcte tant des del punt de vista ètic com metodològic. Tanmateix només es recomana que s'especifiqui que hi haurà un retorn de la informació als participants, a fi que les conclusions puguin ser d'utilitat a les comunitats virtuals en la seva dinàmica de suport als cuidadors.

Tots els membres del CER UVic-UCC es comprometen a garantir la confidencialitat de la informació a la que tenen accés en el desenvolupament de les seves funcions. Es garanteix així el tractament adequat de la documentació rebuda per a la avaluació de protocols i de la identitat dels subjectes que participen en les propostes que s' avaluïn.

Es resol emetre el següent dictamen com a:[1]

Favorable[2] __X__ Favorable condicionat ___ Desfavorable ___

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DE CATALUNYA
Vicerectorat de Recerca
i Professorat

Data: 09/01/2017
Firma president del Comitè:

---

[1] Qualsevol modificació o incidència que afecti al desenvolupament del projecte (finalitat, persones de l’equip, etc.), s’haurà de notificar al CER UVic-UCC per tal de tornar a valorar el projecte.

[2] Un dictamen favorable comporta per l’investigador principal les següents obligacions:

a) Presentar, si escau, el projecte a convocatòries externes (competitives o no) amb els mateixos elements essencials que han estat avaluats favorablement pel CER.
b) Desenvolupar, si escau, el projecte amb els mateixos elements essencials que han estat avaluats favorablement pel CER.
c) Presentar una memòria justificativa de compleció del projecte a la seva finalització, incloent un resum de màxim 5000 caràcters i tots els documents que es consideri necessari fer arribar al CER. Aquest material es conservarà als arxius de la UVic-UCC per a futures revisions.

Tots els membres del CER UVic-UCC es comprometen a garantir la confidencialitat de la informació a la que tenen accés en el desenvolupament de les seves funcions. Es garanteix així el tractament adequat de la documentació rebuda per a la avaluació de protocols i de la identitat dels subjectes que participen en les propostes que s’ avaluïn.

Annex E: The Tailored Self-Administered Survey

The tailored self-administered survey in Catalan can be seen in Figure E1.

Figure E1. *Tailored self-administered survey in Catalan*

estic amb tu

DATA:

1. Nom i cognoms:

2. Com contribueixes a la comunitat: (Marca una de les respostes)

a) Creant problemes

b) Observant

c) Contribuint

d) No contribuint

3. Quines de les següents necessitats són importants per tu?

a) La necessitat d'informació i educació sobre l'Alzheimer

b) La necessitat de suport en la cura del familiar

c) La necessitat de contacte social

d) La necessitat de cuidar-se un mateix

4. Què t'ha motivat a formar part d'aquesta comunitat? (0 menys, 10 més)	0	1	2	3	4	5	6	7	8	9	10
a) Promoure la resolució de problemes en col·laboració											
b) Informar i educar persones que estan en la mateixa situació que tu iguals a través d'experiències, punts de vista i saber fer											
c) Ser informat i educat											
d) Negociar i validar el que penses											
e) Intercanviar idees											
f) Construir capacitat											
g) Servir com a agent de coneixement											
h) Formar una comunitat viable sobre un tema concret											
i) Consideracions relacionades amb les comunitats											

5. Valora el nivell de confiança que tens en la comunitat: (0 menys i 5 més)

0-1-2-3-4-5

6. Menciona a 3 usuaris de la comunitat importants per tu:

______________________, ____________________________, ______________________________

7. T'interessaria participar si comença un nou «EsticAmbTu»? Sí No

The tailored self-administered survey in English can be seen in Figure E2.

Figure E2. *Tailored self-administered survey in English*

estic amb tu

DATE:

1. Name and Surname:

2. How do you contribute to the community? (Mark one of the answers)

a) Making trouble

b) Lurker

c) Contributing

d) Not contributing

3. Which of the following needs are important to you?

a) The need for information and education about Alzheimer's

b) The need for support in the care of the relative

c) The need for social contact

d) The need to take care of oneself

4. What motivated you to be part of this community? (0 least, 10 most)	0	1	2	3	4	5	6	7	8	9	10
a) To instigate the resolution of problems in collaboration											
b) To inform and educate the peers through personal-professional experiences, points of view and know how											
c) To be informed and educated											
d) To negotiate and validate what one thinks											
e) To exchange of ideas											
f) To build capacity											
g) To serve as a knowledge agent											
h) To form a viable on a specific subject											
i) Considerations related to the communities											

5. Assess the level of trust you have in the community: (0 least, 5 most)

0-1-2-3-4-5

6. Mention 3 community users important to you:

____________________, ___________________________, ____________________________

7. Would you be interested in participating in a new "I'mWithYou"? Yes No

Annex F: Knowledge Shared Categorisation

The categorisation concerned to the knowledge modality can be seen in Table F1. The categorisation concerned to the knowledge shared context can be seen in Table F2. The categorisation concerned to the message medium can be seen in Table F3.

Table F1. *Knowledge shared modality (content analysis)*

Type	Meaning	
Modality	Types of knowledge shared. Diversity of the healthcare knowledge that exists and needs to be shared between the stakeholders. They are not mutually exclusive.	
Categories	Meaning	Example
Explicit	Explicit knowledge is codified knowledge represented by information in journals, clinical pathways, protocols, and procedures (McAdam & McCreedy, 2000), and it describes how things should work. When the health professional shares his/her professional experience, we considered it as explicit and non-experiential, unless at some point he speaks of a particular case. All information about AFMADO was considered explicit.	*"You see that patience cannot leave you .... Caring for a person to whom you tell things they now understand and now don't understand, can be exhausting. And sometimes we can do nothing but contradict them, because as caregivers we can't cope any more. As much as possible, it is important not to contradict them, or make them do things without shouting. There are many things that if they are not done now can be done later, of course, this is the complete opposite of what we have been told, that we must have everything under control when it is not controlled it is good that you go to the doctor because sometimes, as you said, other diseases or infections come out"* User35
Experiential	This is also called tacit healthcare knowledge. It is the non-formalised innate knowledge of participants and embodies their experiential know-how, skills, and intuitive judgment about what really works and how to make it work (Sibte & Abidi, 2006). For example, when a participant shared a real story; or if the health professional shared a specific case.	*"With my mother tomorrow, we will go to the doctor because we notice that she gets very angry when there is something she does not like and this is quite often, and yet she had never shown this bad character like she does now, nothing distracts her, she just wants to lay on the sofa. It happened to us some time ago and we thought it was due to a low mood and urine infection. We thought it was because of the disease. Good night everyone"* User32
Social	This is for a society what personal knowledge is for a person. Social knowledge is developed from contact with the minds of other people through communication, which sets in motion a process of thought and sentiment similar to theirs, and enables us to understand them by sharing their states of mind (Cooley, 1926).	*"Good morning thanks for the information. They always teach you some trick to cope with it better"* User31 *"Good morning, those of you who are in the hospital and care home I hope you are able to move forward with strength, for the rest of us who have a lot of patience and also strength to move forward as it is a difficult burden to bear. Merry Christmas to all and a hug for everyone"* User14

Table F2. *Knowledge shared context (content analysis)*

<table>
<tr><td>Type</td><td colspan="4">Meaning</td></tr>
<tr><td>Context</td><td colspan="4">Caring for a person with Alzheimer's</td></tr>
<tr><td>Categories</td><td colspan="4">Meaning</td></tr>
<tr><td rowspan="12">Topics</td><td colspan="4">Related to the caregivers' needs obtained from existing literature</td></tr>
<tr><td>Subcategories</td><td colspan="3">Meaning</td></tr>
<tr><td rowspan="5">Social support (Fortinsky & Hathaway, 1990) (Marirosa et al., 1999)</td><td colspan="3">Having friends and other people, including family, to turn to in times of need or crisis to give you a broader focus and positive self-image.</td></tr>
<tr><td>Subcategories</td><td>Meaning</td><td>Example</td></tr>
<tr><td>Seeks support</td><td>Research suggests that social support is sought to such an extent because it is an effective method of coping with stress and may protect against potential adverse mental health consequences.</td><td><i>"Hi! I'm user4, user6's sister. Our mother is still quite independent, but we see that this is coming to an end. We wanted to ask you if any of you have experience in using any GPS-type device? Do you think they are effective? Do you advise it? Our mother can still go out alone to walk for a while.</i>
<i>Thank you"</i> User 4</td></tr>
<tr><td>Gives support</td><td>To provide social support. All messages where there is information about AFMADO.</td><td><i>"I'm so glad you shared your situation. I understand that since you are still at the initial phase, you need time to deal with it. Very nice that your mother likes to do "homework" so much. That sure helps a lot. Lots of encouragement and keep talking"</i> User16</td></tr>
<tr><td>Gratitude</td><td>An expression of appreciation for what one has or has received.</td><td><i>"Thanks for all your comments"</i> User4</td></tr>
<tr><td rowspan="2">Skills with the person with Alzheimer's (Amieva et al., 2012)</td><td colspan="2">Meaning</td><td>Example</td></tr>
<tr><td colspan="2">When the content has to do directly with the person with Alzheimer's. When it has to do with the person you are caring for.</td><td><i>"FADO (Osona healthcare foundation- homecare and day care) used to come with my grandfather to do hygiene and medication control and we were happy. He was a very difficult man and really all the girls who came had enough patience to win him over. However, I found there was a lack of information transfer and lack of communication between FADO and relatives"</i> User11</td></tr>
<tr><td>Disease information (Fortinsky & Hathaway, 1990; Marirosa et al., 1999)</td><td colspan="2">Information about Alzheimer</td><td><i>"We haven't communicated in days. I wanted to let you know that I am very happy since xxx has started to attend the Crommia day centre in Torelló. He is very happy and I think he has improved in the sense that he is more connected as they make him do memory exercises, gymnastics, etc. And also they have helped with the issue of diapers that a few days ago I told you I was worried about. And above all they are very careful in dealing with the person with Alzheimer's and communicating with the family. And you? User15, how is your mother? And the others, do you have any news? I hope you are well!"</i> User16</td></tr>
<tr><td>Caring for oneself (Michon et al., 2004)</td><td colspan="2">Any activity that we do deliberately in order to take care of our mental, emotional and physical health.</td><td><i>"Thanks user35. Just reading this already makes me smile. And it makes me more attentive to what I see especially in HOW I look at it. Be it on the subway inside or at home in a corner or ... Thank you very much"</i> User40</td></tr>
<tr><td>Functionality of the research</td><td colspan="2">When users share information about the app and/or how the study works</td><td><i>"One comment about this programme: I get on the screen that there are new messages and I look and nothing at all. The other mistake is that it can't be enlarged. Well, I guess they'll fix it. A hug"</i> User1</td></tr>
</table>

Table F3. *Knowledge shared medium (content analysis)*

Type	Meaning			
Medium	The family caregivers and health professionals share their knowledge through the app.			
Category	Meaning			
Purpose	In a previous study applying the LINKS model (Xu et al., 2014), the classification used was “Information, Action, Interaction” (Lovejoy & Saxton, 2012). The reason for “action” is the intention to have followers. However, in our communities we do not have followers. In addition, in other studies (Waters et al., 2009), organisations seem to employ new media for at least two primary purposes: information and sharing, and dialogic relationship-building (interactivity). These findings made the researchers take the decision to adopt Waters et al.’s constructs: information and interactivity (quality of interaction).			
	Subcategories	Meaning		
	Information	The primary purpose of the messages is solely to inform, to provide information relevant to the stakeholders.		
		Subcategories	Meaning	Example
		No information	Primary goal is not to provide information relevant to the others.	*Bon dia””* User 16
		About the disease	Information about Alzheimer’s.	*“I really liked the two TV3 programmes. The first was very sweet and very close to seeing patients and interacting with students and reacting to music. I loved it and it moved me. The one in "A Monster in the Head" makes us realise that there is a lot of research ahead and a lot of uncertainty in general about who can suffer from it. What is clear is that eating and physical habits are very important. We already know, good nutrition and basic exercise. Good night!!!”* User15
		About the sender	We classify photos of people with the purpose of proving information about the sender. Information about the sender and/or the person who s/he is caring for.	*“Last week's stroke did a lot of harm”* User20
		About the research	When content about the research is provided.	*“User38 the message is not repeated. Only unintentionally, you clicked “intro” but it can be read every time you type”* User15
		Internet link	All messages that include a link.	*“As President of AFMADO and on behalf of its Board, we would like to invite you to participate in the AFMADO Assembly. The association was created in 2013 to support caregivers, spread the disease and provide tools and guidance. Non-professional caregivers, if you join us, we’ll help you to face your situation. We will support each other. We are family, professionals and affected like you. Are you motivated to?????? See our website www.alzheimerosona.com”* User13
	Interactivity	Meaning		
		Regarding "interactivity", we started from the premise that the mere fact of writing in the app is already an interaction, so we differentiated whether the message “seeks an answer” or “does not seek an answer”.		
		Subcategories	Meaning	Example
		Seeks an answer	When it is a text note and a greeting it is considered to seek an answer as the goal is interactivity. When the user13 makes an intervention in which s/he offers the services of AFMDO (he/she leads the association), the aim of the message is to look for interactivity, because s/he expects action from the rest of the group.	*“In several posts we have talked about the benefits of music in people diagnosed with Alzheimer's ... I want to share with you this link of 10 tips to enjoy music at home with our family. It is an activity that can be done in any phase of the disease as long as it is rewarding for the person and adapted to their abilities. What do you think? Do you already do it? Will you try it? http://blog.fpmaragall.org/ca/consells-per-gaudir-de-laudicio-de-m%C3%BAsica-amb-una-persona-amb-demencia-a-casa” User33*
		Does not seek an answer	When it is a comment, we consider that it is giving an answer and not looking for one.	*“Rest user31 and take the opportunity to do what you like”* User36

Annex G: Correlations between the Knowledge Shared Variable and Quality of Life of the Two Communities

Table G1. *Correlations between the knowledge shared variable and caregivers' QoL: "I'mWithYou"*

Variable	**n**	**Overall QoL Correlation Coefficient**	**Physical QoL Correlation Coefficient**	**Psychological QoL Correlation Coefficient**	**Social QoL Correlation Coefficient**	**Environ. QoL Correlation Coefficient**
Modality						
Explicit	19	0.009	-0.255	0.071	-0.336	-0.264
Experiential	19	*0.076*	-0.190	0.104	-0.280	-0.187
Social	19	0.422	0.341	0.474	0.019	-0.042
Topic						
Disease information	19	0.036	0.246	0.095	-0.324	-0.241
Social support						
Seeks support	19	0.062	-0.160	0.081	-0.194	-0.171
Gives support	19	0.051	-0.254	0.109	-0.256	0.106
Gratitude	19	-0.108	-0.266	-0.090	-0.404	-0.406
Skills w/PWA	19	0.067	-0.185	0.109	-0.314	-0.217
Caring for yourself	19	0.035	-0.254	0.075	-0.345	-0.241
Functionality of the research	19	0.067	-0.185	0.108	-0.314	-0.217
Purpose						
Information						
About disease	19	-0.107	0.362	*0.098*	-0.117	0.016
About sender	19	-0.076	-0.408	0.041	-0.347	-0.234
About app	19	0.110	-0.264	-0.015	-0.338	-0.004
Internet link	19	0.097	*-0.061*	0.025	0.012	0.277
Interactivity						
Seeks answer	19	-0.023	-0.198	0.429	-0.001	-0.079
Does not seek answer	19	0.009	-0.266	0.056	-0.339	-0.213

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Table G2. *Correlations between the knowledge shared variable and caregivers' QoL: "I'mWithYouPlus"*

Variable	**n**	**Overall QoL Correlation Coefficient**	**Physical QoL Correlation Coefficient**	**Psychological QoL Correlation Coefficient**	**Social QoL Correlation Coefficient**	**Environ. QoL Correlation Coefficient**
Modality	18					
Explicit		*0.050*	0.002	-0.065	-0.219	*0.097*
Experiential		-0.003	-0.030	-0.118	-0.152	0.152
Social		*-0.124*	-0.288	-0.377	-0.167	-0.088
Topic	18					
Disease information		0.069	-0.042	-0.139	-0.180	0.156
Social support						
Seeks support		0.370	0.082	0.088	0.013	0.123
Gives support		-0.124	-0.058	*-0.065*	-0.234	*0.048*
Gratitude		*0.236*	0.095	-0.055	0.011	0.042
Skills w/PWA		0.050	-0.043	-0.167	*-0.185*	*0.175*
Caring for yourself		0.011	0.012	-0.036	-0.199	0.057
Functionality of the research		0.050	-0.043	-0.167	-0.185	0.175
Purpose	18					
Information						
About disease		0.192	-0.124	-0.132	-0.236	-0.186
About sender		0.133	-0.021	-0.040	-0.107	*0.181*
About app		0.000	*-0.189*	-0.446	-0.435	-0.139
Internet link		0.011	0.163	0.166	0.039	0.029
Interactivity						
Seeks answer		0.152	-0.111	-0.158	-0.137	0.201
Does not seek answer		0.039	0.086	0.003	-0.181	0.093

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Annex H: Correlations and Statistical Differences between Participation and Caregivers' Quality of Life of the Two Communities

Table H1. Correlations between participation medium and caregivers' QoL: "I'mWithYou"

Variable	n	Overall QoL Correlation Coefficient	Physical QoL Correlation Coefficient	Psychological QoL C Correlation Coefficient	Social QoL Correlation Coefficient	Environmental QoL Correlation Coefficient
Messages	19	0.045	-0.236	0.086	-0.274	-0.157
Text	19	-0.439	-0.402	-0.353	-0.151	-0.273
Photo	19	-0.080	-0.384	-0.042	0.260	-0.021
Like	19	-0.229	-0.316	-0.223	-0.601*	-0.258
Comment	19	0.029	-0.263	0.083	-0.318	-0.178
Direct Message	19	0.374	0.243	0.285	0.078	-0.146
Label						
Caring for others	19	-0.039	-0.383	0.005	-0.326	-0.193
Caring for yourself	19	-0.004	-0.250	0.061	-0.244	0.017
Disease	19	-0.024	0.220	0.034	-0.233	-0.103
Time						
Dawn	19	-0.398	-0.403	-0.398	-0.426)	-0.410
Morning	19	0.169	-0.380	0.780	-0.119	0.800
Noon	19	-0.127	-0.364	-0.069	-0.159	-0.158
Afternoon	19	0.007	-0.186	0.082	-0.226	-0.283
Evening	19	0.020	-0.241	0.124	-0.154	-0.252
Night	19	-0.162	-0.284	-0.260	-0.220	0.135

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Table H2. *Correlations between participation medium and caregivers' QoL: "I'mWithYouPlus"*

Variable	**n**	**Overall QoL Correlation Coefficient**	**Physical QoL Correlation Coefficient**	**Psychological QoL Correlation Coefficient**	**Social QoL Correlation Coefficient**	**Environmental QoL Correlation Coefficient**
Messages	18	0.023	-0.085	-0.128	-0.281	*0.009*
Text	18	0.459	0.115	0.221	0.188	0.268
Photo	18	-0.210	0.100	-0.220	-0.328	0.293
Like	18	-0.054	-0.017	-0.080*	-0.156	*0.152*
Comment	18	-0.021	-0.013	-0.098	-0.204	0.012
Direct Message	18	0.018	-0.017	0.080	-0.156	0.152
Label						
Caring others	18	0.023	-0.037	-0.025	-0.258	0.074
Caring yourself	18	0.032	-0.055	-0.139	-0.348	-0.160
Disease	18	-0.168	-0.127	-0.224	-0.344	-0.116
Time						
Dawn	18	0.316	0.289	0.130	0.249	0.445
Morning	18	0.171	0.144	-0.207	0.318	-0.138
Noon	18	0.372	0.072	0.069	-0.029	0.173
Afternoon	18	0.041	-0.044	-0.021	-0.322	0.127
Evening	18	0.008	0.068	0.001	-0.212	0.051
Night	18	-0.080	0.025	0.062	0.090	0.036

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Table H3. *Statistical differences between type of participation and caregivers' QoL of "I'mWithYou" and "I'mWithYouPlus"*

Variable	**n**	**Overall QoL *p-p-value***	**Physical QoL *p-value***	**Psychological QoL p-value**	**Social QoL *p-value***	**Environ. QoL *p-value***
Lurker						
"I'mWithYou"	19	*0.840*	*0.492*	*0.904*	*0.968*	*0.492*
"I'mWithYouPlus"	17	*0.350*	*0.301*	*0.808*	*0.530*	*0.404*
Contributor						
"I'mWithYou"	19	*0.812*	*0.494*	*0.874*	*0.966*	*0.486*
"I'mWithYouPlus"	17	*0.356*	*0.281*	*0.773*	*0.319*	*0.399*

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Table H4. *Correlations between sense of trust and family caregivers' QoL of "I'mWithYou" and "I'mWithYouPlus"*

Variable	**n**	**Overall QoL Correlation Coefficient**	**Physical QoL Correlation Coefficient**	**Psychological QoL Correlation Coefficient**	**Social QoL Correlation Coefficient**	**Environ. QoL Correlation Coefficient**
Sense of trust						
"I'mWithYou"	19	-0.115	-0.295	-0.029	-0.060	0.410
"I'mWithYouPlus"	16	0.198	0.235	0.185	0.217	0.044

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001

Table H5. *Statistical differences between interest in new VCoP and family caregivers' QoL of "I'mWithYou" and "I'mWithYouPlus"*

Variable	**n**	**Overall QoL *p-p-value***	**Physical QoL *p-value***	**Psychological QoL *p-value***	**Social QoL *p-value***	**Environ. QoL *p-value***
Interest in new VCoP (Cont.)						
"I'mWithYou"	18	*0.682*	*0.820*	*0.494*	*0.335*	*0.820*
"I'mWithYouPlus"	18	*0.336*	*0.336*	*0.999*	*0.924*	*0.336*

* Significant statistical differences p<0.05

** Highly significant statistical differences p<0.001