

# Virtual communities of practice improve the quality of life of family caregivers of people with alzheimer's disease: a quasi experimental study

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## ABSTRACT

Caring for someone with dementia puts a strain on family caregivers, and there's a link between that strain and their Quality Of Life (QoL). According to research, caregivers' primary requirements are disease knowledge and training, as well as support from others in similar situations, and Internet interventions show great potential in satisfying these needs. Virtual Communities of Practice (VCoPs) are Internet-based frameworks for sharing knowledge in which members cooperate and develop a sense of community trust. This paper aims to assess the influence of participation in a VCoP (created through an App) on caregivers of persons with Alzheimer's disease's quality of life. The results demonstrate a substantial difference in QoL before and after the intervention.

VCoPs allow caregivers to engage and share their knowledge, mostly by

providing them with information and assistance from peers to help them meet their needs. Furthermore, while their relative's functional status declined, caregivers' QoL did not decline, which could be attributed to their engagement in VCoP. Despite the fact that we discovered significant pre- and post-intervention variations in caregivers' health literacy, we must report the equivocal finding that this variable primarily affects QoL's physical domain. Participants also said they had a good time since the app was seen as a valuable tool, they were able to regulate their own involvement, and they met new people and felt less lonely. The findings show that participating in a VCoP improves caregivers' quality of life.

Because of the global increase in life expectancy, chronic age-related diseases are becoming more prevalent. Dementia is one of the most difficult illnesses to deal with, with Alzheimer's disease accounting for half of all dementia cases. Dementia is becoming a big public health issue. Dementia affects 47 million individuals globally, with that number estimated to rise to 75 million by 2030 and 132 million by 2050. In this situation, the function of family caregivers (hence referred to as "caregivers") becomes increasingly important.

## INTRODUCTION

Physical strain, heightened sense of burden, psychological stress, melancholy, and anxiety are all well-known symptoms of caregivers. According to the literature, there is a strong negative link between these consequences and Quality Of Life (QoL). It is undeniable that caregivers' quality of life is linked to that of the care recipient. Although there is evidence that particular aspects of caregivers' QoL, such as burden, mood, and perceived stress, are responsive to interventions, the ability to improve caregivers' overall.

QoL appears to be limited. According to research, caregivers' primary requirements are disease information and training, as well as support from others in similar situations.

Communities of Practice (CoPs) may be an alternative for providing adequate assistance to caregivers. The literature is replete with examples of how learning and knowledge exchange can take place in a communal setting. A CoP is defined as "a collection of people who do not ordinarily work together but act and learn together in order to accomplish a common goal while obtaining and negotiating suitable information". The CoP model is one way to employ a legitimate form of group working to investigate health and social care challenges and build practice, according to this description. Virtual communities of practice (VCoPs) could be a feasible Internet-based intervention in line with this concept. Virtual Communities of Practice (VCoPs) are online communities based on community of practice theory.

VCoPs are frameworks for a type of social group that shares knowledge and develops a culture of collaboration, ultimately leading to a sense of community trust. Increased engagement in them promotes knowledge sharing, rapid dissemination of ideas, and emotional support among members. Furthermore, because a virtual community is dynamic and person-centered, it may be able to help patients with chronic diseases improve their healthcare outcomes. The authors of this article want to see if there

is any proof that this concept is useful to caregivers. As a result, benefits of the health VCoP should be addressed, such as increased contact among members, knowledge production and information exchange, peer, social, and emotional support, public health monitoring, and so on.

Family caregivers of persons with Alzheimer's disease took part in the study. All of the participants were recruited in Catalonia's Osona region between July 2017 and April 2018. (Spain). Researchers first discussed the project proposal with Osona's Association of Alzheimer's Family Caregivers in order to recruit caregivers for the study (AFMADO). The information was then communicated throughout the Osona region's hospital healthcare system, as well as community health and social domains. There were a total of five (individual and group) explanation sessions with caregivers and twelve (individual and group) explanation sessions with health professionals. The researchers were able to recruit 38 caregivers from these sessions.

Caregivers who refused to engage in the study or who did not have access to an email account were excluded (as it was required to get the App installed).

In this study, a pretest-posttest quasi-experimental design was used, with a total of 38 people taking the pretest and 37 doing the posttest. The participants were randomized into two groups at random: one with 19 caregivers and an expert caregiver, and the other with 19 caregivers and three health experts. The communities were created with the use of an app created specifically for this project. Participants were the only ones who have access to the App. The communities were active from April 24, 2018 until February 20, 2019.

Each participant's caregivers' quality of life was assessed before and after the VCoP intervention. Living with someone who has Alzheimer's disease isn't always related with a reduced quality of life in all areas. QoL was thought to be a multifaceted notion. The Spanish version of WHOQOL-BREF, a self-administered questionnaire that divides QoL into four subdomains, was used to assess QoL. (Physical health, psychological health, social relationships, and environment). All of the other variables in our study were moderator variables. The subjects' preintervention demographic and caring data were

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gathered. We also used the Spanish version of the Barthel index to assess the person with dementia's functional decline.

Finally, at the last face-to-face session, caregivers were asked to complete a survey to provide feedback on the intervention. To evaluate the intervention, this survey asked two open-ended questions: "How do you rate your experience participating in the VCoP?" and "How do you rate your experience participating in the VCoP?" "Would you like to be a part of another VCoP if we decide to activate a second version?" and "Would you like to be a part of another VCoP if we decide to activate a second."

For all quantitative data analyses, we used SPSS 23.0. Because we contrasted two variables during the analysis, all of the analyses are bivariate. The level of confidence was set at 95%. To begin, we analyzed the caregivers' demographic and caring qualities to see how these influenced their QoL. Then, we compared the pre- and post-values to make conclusions on caregivers' quality of life while engaging in a VCoP, care recipients' functional decline, and caregivers' change in eHealth literacy. Finally, we established an empirical link between all variables associated with QoL in order to identify predictor and moderator variables.

The results of the survey were analyzed using both thematic and descriptive analysis. Thematic analysis is most suited for explaining a specific group's conceptualizations on a topic, and it also fits the study objectives focused on caregiver experiences. Thematic analysis was employed to find themes because the first question was open-ended. The second one was then subjected to descriptive analysis because it was a binary variable (yes or no).

The positive feedback from certain participants, as well as their desire to repeat the experience, are consistent with the study's major findings, providing qualitative support for the benefit of a VCoP. In conclusion, considering VCoP to improve family caregiver QoL may be a good idea. Improved caregiver QoL can improve caregiver well-being, which can improve the quality of care for patients with Alzheimer's disease. The findings revealed that participating in a VCoP improves caregivers' quality of life. Greater levels of participation in virtual communities, according to previous study, can help to share knowledge, spread ideas fast, and provide emotional support among members.

Nonetheless, there are several limits to our research. The recruiting for this study was tough despite the use of a variety of tactics. These issues frequently arise in Internet-based intervention trials, implying that caregiver attitudes toward these programmes may be to blame. However, caregivers' unwillingness to participate in face-to-face services is also documented in the literature. The small sample size, combined with the caregivers' characteristics, such as the fact that the majority of caregivers are women, spouses, or offspring of the dementia patient who are married, could be a stumbling block when looking for links between moderator variables and QoL. Furthermore, this research found that older caregivers were positively impacted, whereas younger caregivers were negatively impacted. Clearly, the age variable should be investigated further, as increased family responsibilities may have influenced this outcome.

In addition, there were various moderating elements from both caregivers and caring that the study did not address in our research. Caregivers' physical condition or financial positions are two factors that literature suggests may have an impact on caregivers' QoL. The degree of engagement and content of the interaction performed in the VCoP, specifically in relation to caregivers' QoL, would be a future avenue of investigation. Furthermore, there is relatively little study on caregivers' health literacy. This is an area where research is desperately needed.

Our major premise has been proven, as we've shown in earlier sections: caregivers can profit from a VCoP. VCoPs facilitate contact and knowledge exchange among caregivers, primarily by providing information and peer support to help them meet their requirements. Some of the detrimental effects of demographic and caring factors on caregivers' QoL can be mitigated by VCoP. The influence of VCoP on caregivers' overall QoL is mediated by their age and relationship with the Alzheimer's patient. In particular, those over 65 were shown to profit more, which contradicts previous research, and spouses also benefited, which is consistent with previous research.

Although we found significant pre- and post-differences in caregivers' health literacy, we must report the ambiguous result that this variable only impacts on QoL's physical domain. Participants also reported that they had a positive experience because the App was perceived to be a useful tool, because they could manage their own participation and they met peers and felt less lonely.