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Designing virtual communities of practice for informal caregivers of Alzheimer's patients: An integrative review

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Abstract

The main aim of this study is to review the literature to show how ideas around virtual communities of practice (VCoP) offer a model for supporting informal caregivers of Alzheimer's patients (caregivers) to learn how to deal with caregiving demands. 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. This review will examine the current evidence on the needs of caregivers, identify dimensions to be considered in VCoP design and suggest further directions of research. The investigation is an integrative review that builds a bridge between different areas of work. The outcome is eleven dimensions for the design of successful VCoPs for caregivers: Network Structure, Technology, Moderator, Scale, Alignment, Community Design, Sense of Trust, Knowledge Sharing, Sustainability, Ethics and Evaluation. In addition, we propose a Tree Metaphor to present our research results. Well-designed interventions based on VCoP principles have the potential of addressing caregivers' needs.

Keywords

Alzheimer's disease, communities of practice, informal caregivers, online communities, virtual communities of practice

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Introduction

Because of the ageing of the global population¹ there has been an increase in chronic disabling disorders that require a high level of care, such as dementia, including Alzheimer's disease.² Caring for a person with Dementia creates a huge burden on their family and in many ways erodes the quality of life of caregivers.³ In turn, poor informal caregiver quality of life increases the use of healthcare systems and the institutionalization of the patient. It follows, therefore, that attention to the needs of informal caregivers is a public health imperative.⁴ Interventions are required to help them learn how to deal with care giving demands and to support them emotionally.⁵

Informal 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.⁶ Informal caregivers of Alzheimer's patients (hereafter, "caregivers") are the invisible second patients.⁴ Research suggests that caregivers' main needs are information and training about the disease, and support from others experiencing the same situation.^{7,8} Caregivers are also keen to learn skills for improving the daily life management of their relative.⁹ Therefore, most interventions aim to improve information sharing, offer social support, and suggest coping strategies.¹⁰ The most common intervention for caregivers is the face to face support group.¹¹ Support groups focus on building sympathetic relations among participants to discuss problems and feelings regarding care giving.¹² The well recognized value of this intervention is the emotional support, the useful information obtained from others and its social aspects.¹² Belonging to a support group makes caregivers feel understood as they become part of a community.¹³

However, support groups differ in content, process and structure and it is unclear which groups produce a meaningful outcome for caregivers.¹¹ Furthermore, learning is not a primary focus in most models.¹⁴ Critically, one of the main support group inconveniences is the time they take up and the need to travel to meet.¹⁵

It is the argument of this paper, that some of the answers to delivering appropriate support to caregivers can be found in the literature of Communities of Practice (CoP). Originating in the field of social learning, but increasingly popular in applications within organizational studies and information systems, the literature around CoP is a fertile ground to search for evidence of how learning and information sharing can happen in a community context. "CoP 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."¹⁶ The concept captures the way that individuals' desire to learn, share knowledge and support each other can be powerfully rooted in common daily practices and a common identity.¹⁷ The health and social care fields are now showing a growing awareness of the potential of CoP as an approach to learning, identity and innovation.¹⁸

ICT-based (Information, Communication and Technology-based) interventions with caregivers appear to be able to alleviate the burden of caring and prolong community living¹⁹ as they can offer both information and social-support in scalable, convenient ways.²⁰ Moreover, Alzheimer's M-health tools have been shown to be successful in improving awareness based on providing information for both, patients and caregivers.²¹ In many senses the biggest challenge for a virtual community is the creation and sharing of knowledge.²² The concept of VCoP again rooted in the CoP literature with its learning origins offers insights into how this can be accomplished. Many of the latest ICTs are well aligned with the peer-to-peer learning processes typical of a CoP.²³ The obvious benefit of such interventions is that they can usually be accessed at the caregiver's convenience. Thus VCoPs offer a scalable way to deliver information and support from a diverse multidisciplinary team of practitioners to large groups of patients as well as their caregivers.²³

Methods

Overview

This study operates at the intersection of health and other fields of study, such as the theory of social learning, knowledge management and ICT. The researchers approached the investigation through an integrative review to build a bridge between these related areas of work.²⁴ This integrative review aims to summarize past empirical and theoretical literature to provide a more comprehensive understanding of how to address a health care problem.²⁵

The hypothesis is that a VCoP may offer an excellent model of how to help caregivers learn how to deal with caregiving demands, and to support their informational and emotional needs. Accordingly, this research was conducted to critically examine the current evidence relevant to VCoP for caregivers, identify dimensions to be considered in its design, and suggest further venues of research. A literature review of the needs of caregivers was used and a separate study of VCoPs was developed, with the aim of seeking to link the two.

Literature search and data evaluation

First, research on the community literature was gathered. We started our search in February 2017 and we included literature published from 1996 onwards, because that is when the concept in health was first used.²⁶ A conventional literature search was undertaken using the MESH terms (Medical Subject Headings): “Community Network” AND “Caregivers” AND “Alzheimer Disease” AND “Internet.” The databases searched were Scopus, PsycInfo and PubMed. The inclusion criteria were reports written in the English language on communities with informal caregivers of Alzheimer’s patients. The exclusion criteria were literature not published between 1996 and February 2017; not written in the English language; focused on the patients or on health professionals; not referencing CoP theory explicitly. More than 300 citations from the reference lists of research reports were found. After we analyzed the first 20 studies, it was found that none of the citations for “Community Network” explicitly used CoP theory. The authors chose to conduct additional searches specifying CoP which are the focus of our research.

Then a second conventional literature search was undertaken with the terms “online OR virtual OR web 2.0 based OR internet-based” AND “Community of Practice” AND “Alzheimer” AND “carer OR informal carer OR informal caregiver OR non-professional carer OR non-professional caregiver.” Again, the search was carried out through Scopus, PsycInfo, and PubMed. The same inclusion and exclusion criteria as in the first search were followed. Other relevant literature, specifically books and book chapters, were identified through an iterative process based on the journal papers found. The integrative review from this point follows the six steps of a “berrypicking” approach²⁷: footnote chasing, citation searching, journal runs, area scanning, author searching, and subject searches in bibliographies and abstracting indexing services. Through footnote chasing and citation searching several authors were identified: *Barnett, Wenger, Hara and Le May*. Regarding journal runs, two types were identified related to the project: *health sciences and information sciences journals*. Accordingly, journals of both fields were identified: *Health Informatics Journal, Journal Computer Mediated Communication, Journal of Innovation in Health Informatics, Journal of Medical Internet Research, Journal of Research in Nursing and Health and Journal Web Based Communities*. Afterwards, an area scanning which included CoP in health and VCoP in health was conducted to check all the theoretical models. The search strategy is set out in the following PRISMA flow diagram (Figure 1):

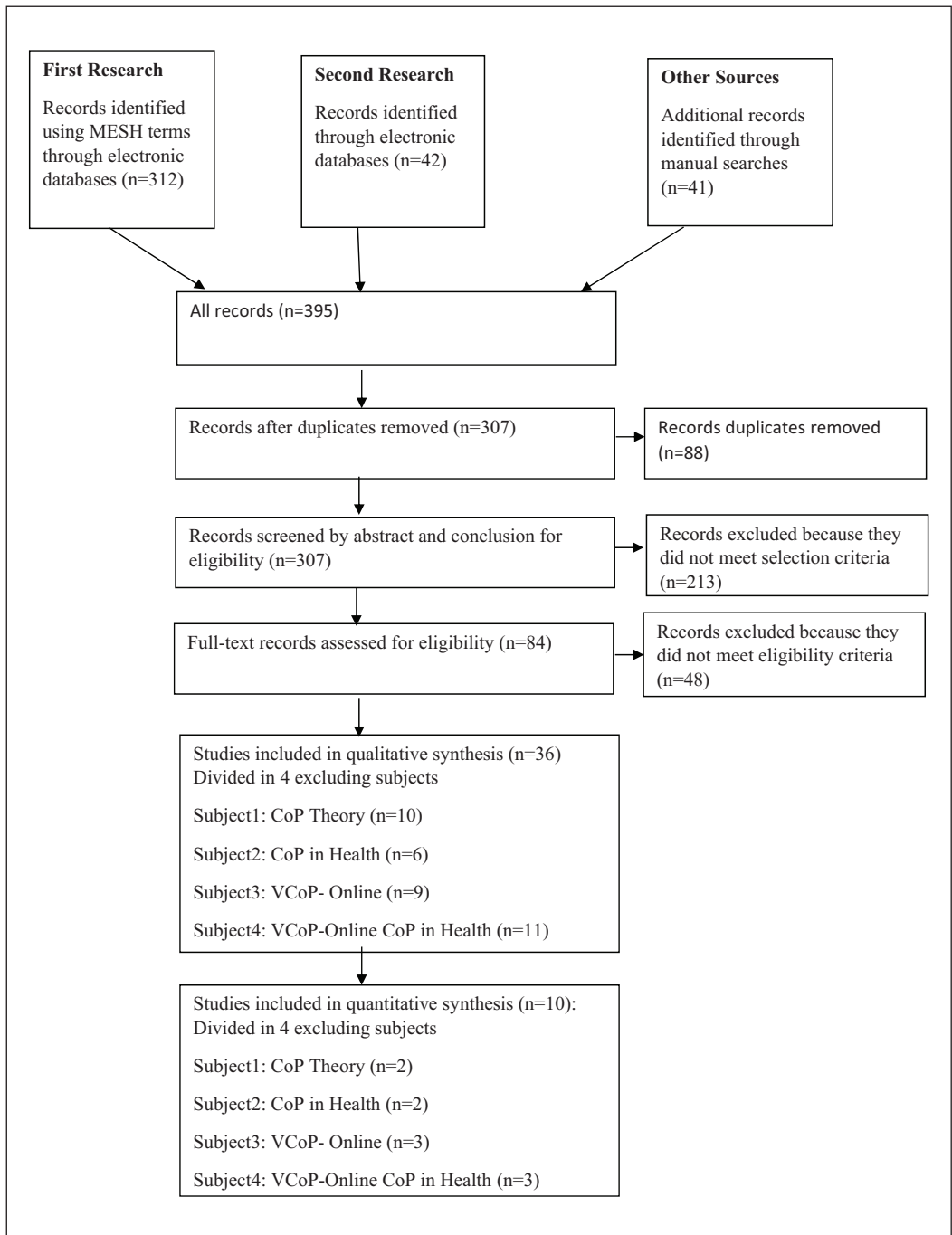


Figure 1. PRISMA Flow diagram outlining the search and review process.

With the aim of gaining a holistic understanding of the possible adequacy of the VCoP as an intervention to respond to caregivers needs, literature was divided into four main subjects: CoP theory (12 records), CoP in health (eight records), VCoP-online CoP (12 records) and Virtual-online CoP in health (14 records), (Table 1):

Separately a search on caregivers' needs was undertaken using the terms "Family caregiver" AND "Alzheimer's patient" AND "needs." The search gained 51 results of which five met the inclusion criteria which was that items had to be literature regarding the needs of Informal caregivers of Alzheimer's patients. Exclusion criteria was research focused on Alzheimer's patient own needs and formal caregivers' issues. Then, 46 results were excluded. None of the articles referred to VCoPs, indicating a gap in the literature which the study is able to fill. Results are shown in the following table (Table 2):

At that time, a search based on the terms "Intervention" AND "family caregivers" AND "Alzheimer's" was launched. We obtained 81 results, from which 66 interventions focused on patients were excluded. The most common intervention was support groups. The 15 results were divided into face to face and online interventions (Table 3):

Data analysis and presentation

All literature found in the course of the search, was critically reviewed. Through the exploration authors realised, besides the presence of several CoP definitions from 1991 to today, there are some models of VCoP in health since 1996. Researchers used Barnett's proposed framework for VCoP in health²⁸ as a starting point to identify evidence-based principles to be considered in VCoP of caregivers design. Specifically, four dimensions out of seven were taken from this author's model. Barnett's framework has been shown to be effective in improving knowledge sharing, thus reducing isolation.²⁹ However, the full research suggested that the framework for VCoP for caregivers is a process more than a normative tool that encapsulates issues.³⁰ Moreover, in a recent study related to health and social care, new concerns appeared suggesting privacy and trust,³¹ which were not mentioned in previous literature so concretely. These issues were then taken into consideration as part of the framework to achieve a successful health VCoP.

The literature of VCoP was analysed together with the information obtained caregivers' needs and current interventions. Caregivers need to have support of their peers, get information and training about the disease. Furthermore, they are keen on improving the daily life management of their relative. We read the VCoP literature through the lens of these needs to identify key features of VCoPs. At the end of this process of integrative review are eleven dimensions for successful VCoPs of caregivers: Network Structure, Technology, Moderator, Scale, Alignment, Community Design, Sense of Trust, Knowledge Sharing, Sustainability, Ethics and Evaluation.

Results

Our analysis seeks to show the ways in which the interdisciplinary literature on CoPs and VCoPs can inform the process of building communities to address caregivers' needs. The authors have identified eleven evidence-based dimensions of a VCoP which need to be considered in the caregiver context. The eleven dimensions are presented below sequentially but they should be seen as profoundly inter-related.

Network Structure is the first dimension. CoPs have a "bottom-up" social structure that facilitates learning through interactions and relationships with others who share a common practice.¹⁶ This mirrors the way that caregiving occurs in a social relational context.¹⁵ Contact with other caregivers give rise to real effects on the perception of self-efficacy and decreased stress,

Table 1. Literature obtained from the “berrypicking approach.”

Subject	Literature
CoP Theory	<p>Wenger E. <i>Communities of Practice: Learning, Meaning, and Identity</i>. Cambridge. New York; 1998.</p> <p>Collier J, Esteban R. Governance in the Participative Organisation: Freedom, Creativity and Ethics. <i>J Bus Ethics</i>. 1999;21(2/3):173–188.</p> <p>Wick C. Knowledge Management and Leadership Opportunities for Technical Communicators. <i>Tech Commun</i>. 2000;(July):515–529.</p> <p>Wenger E, Snyder W. Communities of practice: the organizational frontier. <i>Harvard Business review</i>. 2000;78(1): 139–145.</p> <p>Zane L, Berge and Mauri P, Collins. Perceptions of e-moderators about their roles and functions in moderating electronic mailing lists. <i>Distance Education</i>, 2000;21:1:81–100.</p> <p>Mcdermott BR. Knowing in community: 10 success factors in building communities of practice. <i>IHRIM J</i>. 2000;(March):19–26.</p> <p>Lesser EL, Storck J. Communities of practice and organizational performance. <i>IBM Syst J</i>. 2001;40(4):831–841.</p> <p>Wenger E, McDermott R, Dydnew W. <i>Cultivating Communities of Practice, A Guide to Managing Knowledge</i>. Harvard Bu. Boston; 2002.</p> <p>Wallace D, Saint-Onge H. Leveraging communities of practice. <i>Intranets Enterp Strateg Solut</i>. 2003.</p> <p>Probst G, Borzillo S. Why communities of practice succeed and why they fail. <i>Eur Manag J</i>. 2008;26(5):335–347.</p> <p>Nicolini D. <i>Practice theory, work, and organization: an introduction</i>. Oxford University Press; 2012.</p> <p>Omidvar, O. and Kislov R. The Evolution of the Communities of Practice Approach: Toward ty in a Landscape of practice - An interview with Etienne Wenger-Traynor. <i>J Manag Inq</i>. 2014;23(3):266–275.</p>
CoP in Health	<p>Wenger E. Communities of practice: The social fabric of a learning organization. <i>Healthc Forum</i>. 1996;39(4):20–26.</p> <p>Hara N, Kling R. Communities of practice with and without information technology. <i>Proc Am Soc Inf Sci Technol</i>. 2002;39(1):338–349.</p> <p>Gabbay J, le May A, Jefferson H, Webb D, Lovelock R, Powell J, et al. A Case Study of Knowledge Management in Multiagency Consumer-Informed ‘Communities of Practice’: Implications for Evidence-Based Policy Development in Health and Social Services. <i>Heal Interdiscip J Soc Study Heal Illn Med</i>. 2003;7(3):283–310.</p> <p>Li LC, Grimshaw JM, Nielsen C, Judd M, Coyte PC, Graham ID. Use of communities of practice in business and health care sectors: a systematic review. <i>Implement Sci</i>. 2009; 4: 27.</p> <p>Li LC, Grimshaw JM, Nielsen C, Judd M, Coyte PC, Graham ID. Evolution of Wenger’s concept of community of practice. <i>Implement Sci BioMed Cent Ltd</i>. 2009;8:1–8.</p> <p>Hara N. <i>Communities of practice: fostering peer-to-peer learning and informal knowledge sharing in the work place</i>. Springer; 2009.</p> <p>Le May A. <i>Communities of practice in health and social care</i>. Wiley-Blackwell Pub; 2009.</p> <p>Ranmuthugala G, Plumb JJ, Cunningham FC, Georgiou A, Westbrook JJ, Braithwaite J. How and why are communities of practice established in the healthcare sector? A systematic review of the literature. <i>BMC Health Serv Res</i>. 2011;11(1):273.</p>

(Continued)

Table I. (Continued)

Subject	Literature
VCoP- Online CoP	<p>Johnson CM. A survey of current research on online communities of practice. <i>Internet High Educ.</i> 2001;4: 45–60.</p> <p>Lathlean J. Communities of practice: an opportunity for interagency working. <i>J Clin Nurs.</i> 2002;394–398.</p> <p>Sharratt M, Usoro A. Understanding knowledge-sharing in online communities of practice. <i>Electron J Knowl Manag.</i> 2003;1(2):187–196.</p> <p>Schwen TM and Hara N. Community of practice: a metaphor for online design. <i>Inf Soc.</i> 2003;19(3): 257–270.</p> <p>Gray B. Informal Learning in an Online Community of Practice. <i>J Distance Educ.</i> 2004;19(1):20–35.</p> <p>Cox AM. What are communities of practice? A comparative review four seminal works. <i>Journal of Information Science.</i> 2005; 31(6):527–540.</p> <p>Bourhis A, Dubé L, Jacob R. The Success of Virtual Communities of Practice: The Leadership Factor. <i>Electron J Knowl Manag.</i> 2005;3(1):23–34.</p> <p>Dube, L., Bourhis, A, Jacob R. Towards a Typology of Virtual Communities of Practice. <i>Interdiscip J Information, Knowl Manag.</i> 2006;1:611.</p> <p>Wenger E. Communities of practice and social learning systems: the career of a concept. In: <i>Soc Learn Syst Communities Pract.</i> Chris Blackmore. 2010:225–246.</p> <p>Zhao X, Bishop MJ. Understanding and supporting online communities of practice: Lessons learned from Wikipedia. <i>Educ Technol Res Dev.</i> 2011;59(5):711–735.</p> <p>Vidgen R, Sims JM, Powell P. Do CEO bloggers build community? <i>J Commun Manag.</i> 2013;17(4):364–385.</p> <p>Rivera G, Cox AM. A Practice-Based Approach to Understanding Participation in Online Communities. <i>J Comput Commun.</i> 2016;21(1):17–32.</p>
Virtual- Online CoP in Health	<p>Winkelman WJ, Choo CW. Provider-sponsored virtual communities for chronic patients: Improving health outcomes through organizational patient-centred knowledge management. <i>Heal Expect.</i> 2003;6(4):352–358.</p> <p>Cox A, Boehm M, Summers R, Spyt T. Patient perspective - Using a virtual community to support healthcare. <i>Qual Prim Care.</i> 2003;11:143–145.</p> <p>Hara N, Foon Hew K. Knowledge-Sharing in an Online Community of Health-care Professionals. <i>Information Technology & People.</i> 2007;20(3):235–261.</p> <p>Barwick, M. <i>Developing a Community of Practice Model for Cancer and Chronic Disease Prevention.</i> Toronto, Canada; 2008.</p> <p>Falkman G, Gustafsson M, Jontell M, Torgersson O. SOMWeb: A semantic web-based system for supporting collaboration of distributed medical communities of practice. <i>J Med Internet Res.</i> 2008;10(3):1–18.</p> <p>Abidi SSR, Hussini S, Sriraj W, Thienthong S, Finley GA. Knowledge sharing for pediatric pain management via a Web 2.0 framework. <i>Stud Health Technol Inform.</i> 2009;150: 287–291.</p> <p>Curran JA, Murphy AL, Abidi SSR, Sinclair D, McGrath PJ. Bridging the gap: Knowledge seeking and sharing in a virtual community of emergency practice. <i>Eval Heal Prof.</i> 2009;32(3):314–327.</p> <p>Barnett S, Jones SC, Bennett S, Iverson D, Bonney A. General practice training and virtual communities of practice - A review of the literature. <i>BMC Fam Pract.</i> 2012; 13:1–12.</p> <p>Evans C, Yeung E, Markoulakis R, Guilcher S. An Online Community of Practice to Support Evidence-Based Physiotherapy Practice in Manual Therapy. <i>J Contin Educ Health Prof.</i> 2014; 34(4):215–223.</p> <p>Ikioda F, Kendall S, Brooks F, Reidy C. Developing an online community of practice to empower health visitors: Findings from a pilot study. <i>J Heal Visi.</i> 2014;2(8):436–440.</p>

(Continued)

Table 1. (Continued)

Subject	Literature
	Swift, L. Online communities of practice and their role in educational development: a systematic appraisal. <i>Community Practitioner: The Journal of the Community Practitioners' & Health Visitors' Association</i> . 2014;87(4):28–31.
	Jiménez-Zarco, A. I., González-González, I., Saigí- Rubió, F., Torrent-Sellens, J. The co-learning process in healthcare professionals: assessing user satisfaction in virtual CoP. <i>Computer Human Behaviour</i> . 2015;51:1303–1313.
	Ford JR, Korjonen H, Keswani A, Hughes E. Virtual communities of practice: can they support the prevention agenda in public health? <i>Online J Public Health Inform</i> . 2015;7(2):1–12.
	Barnett S, Jones SC, Bennett S, Iverson D, Robinson L. A Virtual Community of Practice for General Practice Training: A Pre-implementation Survey. <i>JMIR Med Educ</i> . 2016;2(2): e13.

Table 2. Results on search Family caregiver' AND "Alzheimer's patient" AND "needs."

Search results
Marirosa DB, Busato R, De Leo D, Zanetti O, Aleotti F, Trabucchi M, et al. Community care for patients with Alzheimer's disease and non-demented elderly people: use and satisfaction with services and unmet needs in family caregivers. <i>Int J Geriatr Psychiatry</i> . 2005;14(11):915–924.
Wackerbarth SB, Johnson MMS. Essential information and support needs of family caregivers. <i>Patient Educ Couns</i> . 2002;47(2):95–100.
Brodaty H, Donkin M. Clinical research: Family caregivers of people with dementia. <i>Dialogues Clin Neurosci</i> . 2009;11(2):217–228.
Amieva H, Rullier L, Bouisson J, Dartigues J-F, Dubois O, Salamon R. Needs and expectations of Alzheimer's disease family caregivers. <i>Rev Epidemiol Sante Publique</i> . 2012;60(3):231–238.
Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, et al. Unmet needs of caregivers of individuals referred to a dementia care program. <i>J Am Geriatr Soc</i> . 2015;63(2):282–289.

Table 3. Interventions for caregivers.

Type of intervention	Literature
Face-to-Face Support Groups	Van Den Heuvel ETP, Witte LP De, Stewart RE, Schure LM, Sanderman R, Meyboom-De Jong B. Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: Which caregivers benefit the most? <i>Patient Educ Couns</i> . 2002;47(4):291–299.
	Connor DLO. Toward Empowerment: ReVisioning Family Support Groups. <i>Soc Work Groups</i> . 2003;25(4):37–56.
	Finfgeld DL, Damianakis T, Climans R, Marziali E, Selwood A, Johnston K, et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. <i>JBI Database Syst Rev Implement Reports</i> . 2015;11(6):373.
Others	Mittelman MS, Bartels SJ. Translating research into practice: case study of a community-based dementia caregiver intervention. <i>Health Aff</i> . 2014;33(4):587–595.

(Continued)

Table 3. (Continued)

Type of intervention	Literature
On-line	<p>Perron B. Online support for caregivers of people with a mental illness. <i>Psychiatr Rehabil J</i>. 2002;26(1):70–77.</p> <p>Munn-Giddings C, McVicar A. Self-help groups as mutual support: What do carers value? <i>Heal Soc Care Community</i>. 2007;15(1): 26–34.</p> <p>Powell J, Chiu T, Eysenbach G. A systematic review of networked technologies supporting carers of people with dementia. <i>J Telemed Telecare</i>. 2008; 14(3):154–156.</p> <p>Lauriks S, Reinersmann A, van der Roest HG, Meiland F, Davies R, Moelaert F, et al. Review of ICT-based services for identified unmet needs in people with dementia. <i>Adv Inf Knowl Process</i>. 2010; 47:37–61.</p> <p>Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. The patient-doctor relationship and online social networks: Results of a national survey. <i>J Gen Intern Med</i>. 2011;26(10):1168–1174.</p> <p>Ducharme F, Dubé V, Lévesque L, Saulnier D, Giroux F. An online stress management training program as a supportive nursing intervention for family caregivers of an elderly person. <i>Can Nurs Informatics J</i>. 2011;6(2):1–26.</p> <p>Godwin KM, Mills WL, Anderson JA, Kunik ME. Technology-driven interventions for caregivers of persons with dementia: A systematic review. <i>Am J Alzheimers Dis Other Demen</i>. 2013;28(3):216–222.</p> <p>Dosani S, Harding C, Wilson S. Online Groups and Patient Forums. <i>Curr Psychiatry Rep</i>. 2014;16(11).</p> <p>Mehta N, Atreja A. Online social support networks. <i>Int Rev Psychiatry</i>. 2015;27(2):118–123.</p> <p>Gaugler JE, Reese M, Tanler R. Care to plan: An online tool that offers tailored support to dementia caregivers. <i>Gerontologist</i>. 2016;56(6):1161–1174.</p> <p>Craig D, Strivens E. Facing the times: A young onset dementia support group: Facebook™ style. <i>Australas J Ageing</i>. 2016;35(1):48–53.</p>

depression and burden on the caregiver.^{32,33} Furthermore, contact with other caregivers reduces feelings of isolation³⁴ as they meet their needs for social support and experience less stress.³⁵ Network structure may start with an already existing carer support organization in order to create the social structure of the group.³⁶

The second dimension is Technology as it plays a critical role in supporting a community. The VCoP literature attests to the importance of selecting technologies that align to the feel of a particular practice.³⁷ Virtuality frees members from constraints of time and space^{20,35,38} and it facilitates timely acquisition of information,³⁹ which caregivers need. It provides strategies promoting caregivers' health behaviour by increasing knowledge.^{20,35,40} Technology contributes to answer caregivers' demand for social support and helps them experience less stress.⁴¹ Caregivers want to share information so need quick ways to communicate (as with chat tools) and perhaps also to store and organise shared knowledge which could support quality assurance. But they also want to tell complex stories of experience and need to build trust and learn from each other. Hence, there must be functions to support some level of sharing of individual identity, like self-profiling.

The Moderator, as a community coordinator, is the third dimension. The CoP literature is replete with wisdom about defining the leadership role of a group member who helps the community focus on its domain, maintain its relationships and develop practices.¹⁶ He/she plays an integral role in enhancing the functioning of the community and facilitating learning.⁴² For caregivers, the role of moderator could be taken by health professionals or by an expert caregiver, but it could also be a peer. The moderator will have the role of facilitator of information sharing, will help to activate knowledge sharing and give support to all the members both within the caring context and the technological one.^{40,43}

The fourth dimension is Scale. In CoPs the membership size is not fixed, but it is recognised that the size of the group is a critical dimension to its success.⁴⁴ In communities for chronic patients, the smaller, more controlled size of the private community render it more sustainable as a social structure.³⁶ Scale needs to be controlled as caregivers require social support because stronger ties enable sharing difficulties about coping with the diagnosis and the day to day experience of caregiving.⁴⁵

The fifth dimension is Alignment. Within CoP theory it is recognised that a community is driven by the value members get from it.⁴⁶ 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).¹⁶ In addition, individuals' collective and organisational motivations must be aligned.⁴⁷ If these two alignments are achieved, then members gain many advantages. For caregivers, alignment provides benefits such as help with practical challenges, access to expertise,⁴³ better ability to contribute to the group, confidence in one's approach to problems, fun from being with peers, more meaningful participation to more sense of belonging.¹⁶ All these mentioned benefits would help caregivers to satisfying their needs.

The sixth dimension is Community Design. CoP as a perspective recognises the evolving nature of community. The focus of a community develops and shifts. It has cycles of energy and quietness. In the early stages trust needs to be built. Higher level functions such as successively information sharing, knowledge-sharing and creation come later. These reflections resonate with the pattern of caregiving, with its highs and lows. It is the catalyst for community growth and development as it concentrates in emerging participation.¹⁶ As the community grows, it develops a systematic body of knowledge. Caregivers, having sense of community, would realise their involvement with the community is translated into something useful as better caring for the patient, a better carer-patient relationship and better perception of their own role.⁴⁸

The seventh dimension is Sense of Trust. The most fundamental insight of CoP theory is that common experiences arising from a common context, help people to relate to each other. It is the common mundane experiences of caregiving that make them a potential community. Further, working towards a common vision for a community enables participants to build trust and relationships.⁴⁹ As a VCoP forms, it creates a sense of belonging for community members, and they develop the habit of consulting each other for help.⁵⁰ VCoP of caregivers' members would develop norms of trust, reciprocity and cooperation that support knowledge sharing. As a consequence, caregivers are encouraged to use their real names and create authentic profiles to reinforce the sense of trust.⁵¹

The eighth dimension is Knowledge Sharing. In the CoP perspective this is one of the main objectives of a community. Practice related knowledge is the specific form of knowledge the community shares, develops and maintains.⁵² In the caregiving context, this would be everyday knowledge of how to offer care, how to deal with the patients' varying condition, and other practical wisdom about living with dementia. VCoP is a very suitable framework to share and learn for caregivers where the domain, the caring of Alzheimer patients, creates the common ground and outlines the boundaries that enables them to decide what is worth sharing and how to present their ideas.¹⁶ Acquiring and sharing knowledge, caregivers will have more information about the own patient's illness, and about the use of resources and services which are the main caregivers demands.⁵³ In the case of the VCoP of caregivers including health care professionals as moderators, they would contribute mainly introducing evidence-based practice knowledge. Caregivers, from their side, would collaborate sharing their own experience and learning skills for improving daily life management of their relative which is one of their biggest concern.⁹

The ninth dimension is Sustainability. In order to sustain a CoP, members have to remain motivated in their quest to highlight and share good practice with peers.⁵⁴ If caregivers realise that they can reach their needs within the VCoP they will keep engaged. Sustainability provides caregivers

serenity, tranquility and psychological well-being and freedom helping caregivers meeting their needs.⁵⁵ Finally, VCoP of caregivers integration with an already existing patient/carer support organization may render it more effective as a social structure.³⁶

Ethics is the 10th dimension. CoP theory carries with it a particular sense of ethics of participation. Within a CoP or VCoP, everybody is viewed as an equal.⁵⁶ Furthermore, participating in a VCoP is voluntary. In respect of caregivers, this self-selection inside a non-competitive environment offered by the VCoP provides serenity and tranquillity to them matching their demands.⁵⁵ A VCoP of caregivers should prioritise patients' privacy. Moreover, the moderator has a key role in ensuring confidentiality and patient's data protection. If a moderator is a health professional, caring for patients/clients in practice reflects the ethics of the health professional and could create a motivating crucible for the renegotiation of boundaries.⁵⁷ Finally, there is a concern about a possible over reliance or even technology addiction from the caregivers perspective.⁵⁸

The 11th and last dimension is Evaluation. Communities need measures to capture and celebrate their achievements and to guide ongoing efforts to become more vibrant and effective. A CoP's value may be measured through its activity.¹⁶ Periodically, it is necessary to analyse if the results obtained by the CoP coincide with the results expected. The CoP literature proposes assessing the value of a CoP qualitatively, for example by collecting stories about its benefits. Telling stories not only helps individuals to develop an identity, but also serves to reconstruct the identity of the collective community on ongoing basis.¹⁶ Furthermore, to measure the usability of the technology is a key issue.⁵⁹ Applied to VCoP of caregivers, validation of one's practice with others who share a similar situation may affect one's own life orientation satisfying their needs.⁵² This process could be completed either by asking to members about their satisfaction with the community through surveys or suggesting them to tell stories which might help both to construct identity as an individual (caregiver) and to reconstruct the identity of the collective community of caregivers. Finally, in a VCoP evaluation by caregivers of the technology should be performed using usability tests. The results given by the different analyses should be contrasted with the expected results of caregivers.⁵⁹

Discussion

The current study suggests well-designed interventions based on VCoP principles have the potential of addressing caregivers' needs confirming the research hypothesis. Eleven dimensions have been identified to be considered in the design of this VCoP: Network Structure, Technology, Moderator, Scale, Alignment, Community Design, Sense of Trust, Knowledge Sharing, Sustainability, Ethics and Evaluation. Reflecting the organic, dynamic and living sense of the caregivers' VCoP, having in mind the analogy made between cultivating a plant and establishing a CoP¹⁶ and, acknowledging there is a growing awareness of the importance of metaphors in theory development,⁶⁰ we propose a Tree Metaphor to present our research (Figure 2). A tree has roots, trunk, branches and crown. This tree has five roots which will grow up consecutively one by one starting from Network Structure, then Technology, Moderator is the third one, later Scale and, finally, Alignment. These five roots will form a strong basis for the tree allowing it to grow a strong trunk, the Community Design. Hence, roots are the five pillars for the trunk. The trunk should develop three branches representing first, Sense of Trust, then, Knowledge Sharing and finally, Sustainability. The tree crown, which will protect and make it brighter, will be the Ethics and Evaluation concepts.

Cultivating VCoP to improve healthcare performance requires a greater understanding of how to establish and support VCoPs to maximise their potential to enhance healthcare.¹⁸ Therefore, once the tree has been grown, it needs to be watered by the institution from whom depends the community, if it is the case, and from its own moderators and members. Members of the

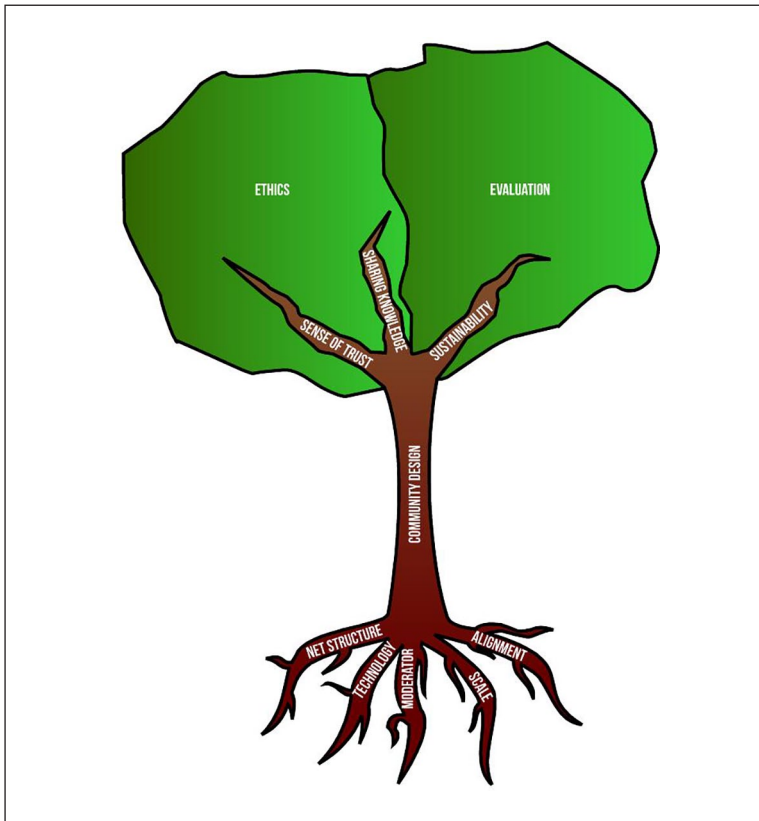


Figure 2. Tree Metaphor.

community are part of the tree and they will water it themselves giving value to the community through their own practice. Likewise, health professionals will water the VCoP prescribing it to caregivers and disseminating the VCoP of caregivers with other colleagues. In so far as the tree is duly watered, roots underpin it and the tree will continuously grow (trunk and branches) and having the crown green which means the tree is in good health. The main goal is to have a healthy and strong tree. However, not only watering the tree is important, weather may impact positive or negatively to the tree life. Community interaction with outside may be at two levels: individual or collective. Therefore, favourable and unfavourable weather may come from health and social policies, health and social institutions and professionals, non-members caregivers, caregivers' members and non-members friends or relatives, and other cases too. Weather may influence the tree differently depending on the tree's state of health.

Conclusion

Through this research we critically examined the current evidence relevant to CoP and VCoP and we identified eleven dimensions to be considered in the design for a VCoP for caregivers. We may conclude that even though the VCoP concept has not previously been used to design online interventions for caregivers, it seems that it could answer caregivers' demands.

A VCoP of caregivers can accomplish three objectives that would make them superior to face to face support groups.¹¹ First, a VCoP of caregivers would be a long-term group, which was open to new members and could be led by fellow caregivers instead of professionals. Secondly, it is an intervention focused on the personal objectives for the caregiver regarding themselves and the relative they take care of. Thirdly, the VCoP of caregivers' purpose is to create, expand, and exchange knowledge, and to develop individual capabilities. Hence, participating in a VCoP is a caregiver's own choice based on the way it provides access to expertise, help with challenges, confidence in one's approach to the problem, sense of belonging, fun of being with colleagues and more meaningful participation, covering their demands.¹¹

This analysis offers a useful contribution to the literature as several protocols and principles previously emerged regarding to VCoP^{61,50} and, specifically focused in health,²⁸ were mainly for professionals and sometimes patients, however not for caregivers. Naturally, it remains to be tested empirically how decisions about these dimensions might shape the character of a VCoP for caregivers.

Future research should consider the implementation process for a VCoP of caregivers. Furthermore, virtual reality (VR) is another technology to be explored. VR is now being used for older adults and cognitive rehabilitation.^{62,63} However, at present, informal caregivers still have many technological barriers as digital skills and bandwidth, and so these issues should be taken into account for future VR based applications. Ultimately, given that the way that caring affects caregivers' quality of life,³ the VCoP could be evaluated by its impact on their well-being.

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References

1. Chan SWC. Family caregiving in dementia: the asian perspective of a global problem. *Dement Geriatr Cogn Disord* 2011; 30(6): 469–478.
2. Avila Oliva MM, Vázquez Morales E and Gutiérrez Mora M. Deterioro cognitivo en el Adulto Mayor. *Ciencias Holguín* 2007; XIII(octubre-diciembre): 1–11.
3. Zacharopoulou G, Zacharopoulou V and Lazakidou A. Quality of life for caregivers of elderly patients with dementia and measurement tools: a review. *Int J Heal Res Innov* 2015; 3(1): 49–64.
4. Brodaty H and Donkin M. Clinical research: family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009; 11(2): 217–228.
5. López Gil MJ, Orueta R and Gómez-caro S. El rol de Cuidador de personas dependientes y sus repercusiones sobre su Calidad de Vida y su Salud. *Rev Clin Med Fam* 2009; 2(7): 332–334.
6. Plöthner M, Schmidt K, De Jong L, et al. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. *BMC Geriatr* 2019; 19(1): 1–22.
7. Fortinsky RH and Hathaway TJ. Information and service needs among active and former family caregivers of persons with alzheimer's disease. *Gerontologist* 1990; 30(5): 604–609.
8. Marirosa DB, Busato R, De Leo D, et al. Community care for patients with Alzheimer's disease and non-demented elderly people: use and satisfaction with services and unmet needs in family caregivers. *Int J Geriatr Psychiatry* 2005; 14(11): 915–924.

9. Amieva H, Rullier L, Bouisson J, Dartigues J-F, et al. Needs and expectations of Alzheimer's disease family caregivers. *Rev Epidemiol Sante Publique* 2012; 60(3): 231–238.
10. Michon A, Canuto A, Giardini U, et al. Caregiver burden in dementia: determinants and interventions. *Schweizer Arch fur Neurol und Psychiatr* 2004; 155(5): 217–224.
11. Hornillos C and Crespo M. Support groups for caregivers of Alzheimer patients: a historical review. *Dementia* 2012; 11(2): 155–169.
12. Lauritzen J, Pedersen PU, Sørensen EE, et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Database Syst Rev Implement Reports* 2015; 13(6): 373.
13. Finfgeld DL, Damianakis T, Climans R, et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Database Syst Rev Implement Reports* 2015; 11(6): 373.
14. Van Der Roest HG, Meiland FJM, Comijs HC, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatrics*. 2009;21(5):949–965.
15. Schulz R and Martire LM. Family caregiving of persons with dementia. *Am J Geriatr Psychiatry* 2004; 12(3): 240–249.
16. Wenger E, McDermott R and Dwyer W. *Cultivating communities of practice, a guide to managing knowledge*. Boston: Harvard Business School Press, 2002.
17. Vidgen R, Sims JM and Powell P. Do CEO bloggers build community? *J Commun Manag* 2013; 17(4): 364–385.
18. Le May A. *Communities of practice in health and social Care [Internet]*. Oxford, UK: Blackwell, 2009.
19. Powell J, Chiu T and Eysenbach G. A systematic review of networked technologies supporting carers of people with dementia. *J Telemed Telecare* 2008; 14(3): 154–156.
20. Godwin KM, Mills WL, Anderson JA, et al. Technology-driven interventions for caregivers of persons with dementia: a systematic review. *Am J Alzheimers Dis Other Demen* 2013; 28(3): 216–222.
21. Elfaki AO and Alotaibi M. The role of M-health applications in the fight against Alzheimer's: current and future directions. *mHealth* 2018; 4: 32–32.
22. Chiu C-M, Hsu M-H and Wang ETG. Understanding knowledge sharing in virtual communities: an integration of social capital and social cognitive theories. *Decis Support Syst* 2006; 42(3): 1872–1888.
23. Wenger E. Communities of practice and social learning systems : the career of a concept. *Soc Learn Syst Communities Pract* 2010; 225–246.
24. Russell C. An overview of the integrative research review. *Prog Transplant* 2015; 15(1): 8–13.
25. Broome ME. In concept development in nursing. In: Rodgers BL and Knafelz KA (eds) *In concept development in nursing*. 2nd ed. Philadelphia: W.B. Saunders Co., 1993, pp. 231–250.
26. Wenger E. Communities of practice : the social fabric of a learning organization. *Healthc Forum J* 1996; 39(4): 20–26.
27. Bates MJ. The design of browsing and berrypicking techniques. *On-line Rev* 1977; 13(5): 407–424.
28. Barnett S, Jones SC, Bennett S, et al. General practice training and virtual communities of practice - a review of the literature. *BMC Fam Pract* 2012; 13: 1–12.
29. Barnett S, Jones SC, Bennett S, et al. A virtual community of practice for general practice training: a preimplementation survey. *JMIR Med Educ* 2016; 2(2): e13.
30. Probst G and Borzillo S. Why communities of practice succeed and why they fail. *Eur Manag J* 2008; 26(5): 335–347.
31. McLoughlin C, Patel KD, O'Callaghan T, et al. The use of virtual communities of practice to improve interprofessional collaboration and education: findings from an integrated review. *J Interprof Care* 2018; 32(2): 136–142.
32. Cristancho-Lacroix V, Wrobel J, Cantegreil-Kallen I, et al. A web-based psychoeducational program for informal caregivers of patients with Alzheimer's disease: a pilot randomized controlled trial. *J Med Internet Res* 2015; 17(5): 1–14.
33. Marziali E and Garcia LJ. Dementia caregivers' responses to 2 internet-based intervention programs. *Am J Alzheimers Dis Other Demen* 2011; 26(1): 36–43.

34. Glueckauf RL, Ketterson TU, Loomis JS, et al. Online support and education for dementia caregivers: overview, utilization, and initial program evaluation. *Telemed J e-Health* 2005; 10(2): 223–232.
35. Ducharme F, Dubé V, Lévesque L, et al. An online stress management training program as a supportive nursing intervention for family caregivers of an elderly person. *Can Nurs Informatics J* 2011; 6(2): 1–26.
36. Winkelman WJ and Choo CW. Provider-sponsored virtual communities for chronic patients: Improving health outcomes through organizational patient-centred knowledge management. *Heal Expect* 2003; 6(4): 352–358.
37. Schwen TM and Hara N. Community of practice: a metaphor for online design. *InfSoc* 2003; 19(3): 257–270.
38. Bourhis A, Dubé L and Jacob R. The success of virtual communities of practice: the leadership factor. *Electron J Knowl Manag* 2005; 3(1): 23–34.
39. Weiser EB. The functions of internet use and their social and psychological consequences. *CyberPsychology Behav* 2002; 4(6): 723–743.
40. Boots LMM, De Vugt ME, Van Knippenberg RJM, et al. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014; 29(4): 331–344.
41. Lauriks S, Reinersmann A, van der Roest HG, et al. Review of ICT-based services for identified unmet needs in people with dementia. *Adv Inf Knowl Process* 2010; 47: 37–61.
42. Wenger E and Lave J. *Situated learning: legitimate peripheral participation*. Cambridge, UK: Cambridge, 1991.
43. Lai CKY, Wong LF, Liu K-H, et al. Online and onsite training for family caregivers of people with dementia: results from a pilot study. *Int J Geriatr Psychiatry* 2013; 28.
44. Gray B. Informal learning in an online community of practice. *J Distance Educ* 2004; 19(1): 20–35.
45. Alzheimer's Society. *Caring for a person with dementia*, https://www.alzheimers.org.uk/Caring_for_someone_with_dementia/ (2019).
46. Wenger E, Trayner B and de Laat M. *Promoting and assessing value creation in communities and networks : a conceptual framework*. The Netherlands, 2011.
47. Salido MJ. *Comunidades de Práctica: Una Metodología para Construir, Desarrollar y Fortalecer Redes de Conocimiento*. 1st. The Project Working on Solution SL, editor, 2012.
48. Molina G, Mar G and Agudelo F. Life quality among family carers. *Rev Aquichan* 2006; 6(6): 38–53.
49. Panteli N and Duncan E. Trust and temporary virtual teams: alternative explanations and dramaturgical relationships. *Inf Technol People* 2004; 17(4): 423–441.
50. Zhao X and Bishop MJ. Understanding and supporting online communities of practice: Lessons learned from Wikipedia. *Educ Technol Res Dev* 2011; 59(5): 711–735.
51. Mehta N and Atreja A. Online social support networks. *Int Rev Psychiatry* 2015; 27(2): 118–123.
52. Nicolini D. *Practice theory, work, and organization an introduction*. Oxford University Press; 2012.
53. Ford JR, Korjonen H, Keswani A, et al. Virtual communities of practice: can they support the prevention agenda in public health? *Online J Public Health Inform* 2015; 7(2): 1–12.
54. Ikioda F and Kendall S. Transformation of health visiting services in England using an Online Community of Practice. *Heal Policy Technol* 2016; 5(3): 298–306.
55. Vellone E, Piras G, Talucci C, et al. Quality of life for caregivers of people with Alzheimer's disease. *J Adv Nurs* 2008; 61(2): 222–231.
56. Brown D. Organizational learning and communities of practice: toward a unified view of working, learning, and innovation. *Organ Sci* 1991; 2: 40–57.
57. Wenger E. Social learning capability Four essays on innovation and learning in social systems Introduction: context. 2009; 1–18.
58. Mxoli A, Mostert-Phipps N and Gerber M. Risks and benefits of social computing as a healthcare tool. In: *7th Int Multi-Conference Complexity, Informatics Cybern IMCIC 2016*. 7th Int Conf Soc Inf Technol ICSIT 2016 - Proc. 2016; 2: 93–97.
59. Parra-Vidales E, Soto-Pérez F, Victoria Perea-Bartolomé M, et al. Intervenciones online para cuidadores de personas con demencia: revision sistemática. *Actas Esp Psiquiatr* 2017; 45(3): 116–126.
60. Hunt SD and Menon A. Metaphors and competitive advantage: Evaluating the use of metaphors in theories of competitive strategy. *J Bus Res* 1995; 33(2): 81–90.
61. Lathlean J. Communities of practice : an opportunity for interagency working. *J Clin Nurs* 2002; 394–398.

62. Maggio MG, Maresca G, De Luca R, et al. The growing use of virtual reality in cognitive rehabilitation: fact, fake or vision? a scoping review. *J Natl Med Assoc* 2019; 111(4): 457–463.
63. Athkins AS, Khan A, Ulshen D, et al. Assessment of instrumental activities of daily living in older adults with subjective cognitive decline using the virtual reality functional capacity assessment tool. *J Prev Alzheimer's Dis* 2018; 5(4): 216–224.