

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	PLACE4CARERS: A MIXED-METHOD STUDY PROTOCOL FOR ENGAGING FAMILY CAREGIVERS IN MEANINGFUL ACTIONS FOR SUCCESSFUL AGEING IN PLACE
AUTHORS	GRAFFIGNA, GUENDALINA; Barello, Serena; Morelli, Niccolò; Gheduzzi, Eleonora; Corbo, Massimo; Ginex, Valeria; Ferrari, Roberta; Lascioli, Andrea; Feriti, Carolina; Masella, Cristina

VERSION 1 – REVIEW

REVIEWER	Debra Morgan University of Saskatchewan, Saskatoon, Saskatchewan, Canada
REVIEW RETURNED	02-Mar-2020

GENERAL COMMENTS	<p>Thank you for the opportunity to review this interesting paper, which addresses the important issue of understanding and addressing the needs of persons living with dementia and their caregivers in rural and remote areas.</p> <p>I will make some comments on each section, but an overall note is that 5 difference terms are used to describe the rural and remote context: “rural and remote,” “remote and rural,” “rural/remote,” “rural remote,” and “remote rural.” It might be best to choose one of these and be consistent throughout the paper and in the Figure.</p> <p>Also, the authors have done a very good job of writing the paper in English. However, a through editing is needed to correct grammatical errors throughout, that would improve the flow of the paper.</p> <p>Rationale of the study: The authors provide a social-ecological framework for the study, which is a strength. This section of the paper is quite long but thorough. Given the space devoted, the authors should make sure to thread this framework throughout the proposed studies to show how the methods are linked to the elements of the framework (uniqueness of aging in remote rural areas, opportunities and challenges of the aging-in-place</p>
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imperative, and the role of family relationship and caregiving for elderly citizens).

Methods: the term “elderlies” (pg 8, line 36) is not familiar—perhaps “older persons” could be used. “Conformation” (pg 9, line 18) also not familiar and may not be recognized by readers outside Italy. The meaning of “diffused frailty” (pg 9, line 23) is unclear to me.

WP1

Study Design: The abstract uses past tense for work packages (WP) 1 and 2 which suggests they have been completed. But on pages 9 and 10 both WP are described as future tense “will be...”. This should be clarified.

Sampling WP1: the term “dear ones” is used (pg 9, line 55). Page 10, line 55 uses the term “beloved”. For an academic paper I think the term “care receiver” which is also used in this paper is more neutral and does not make assumptions about the quality of the relationship between caregiver and receiver. Will caregivers recruited in WP1 be asked to be involved in focus groups in WP3. The description of WP3 suggests this, so perhaps note that in WP1 sampling.

Data analysis WP1: More detail is needed about the analysis. No analysis method is stated, only the aim of “taking a snapshot of the population of the family caregivers in the area in terms of needs, economic burden, and services required.”

WP2

Objective: Note tense (past tense in abstract, future tense on page 10).

Methods: search terms do not include “remote” yet this term is used throughout the paper. Is there a reason for that? If so, it is best to give a rationale for not including.

Analysis: Articles published since 2012 will be included because that was European Year of Active Aging. However, this makes quite a short period in which to identify studies. A better yield may

result from extending that period as it is unclear how much different the year of active aging would make—was there a surge in relevant research at that time?

WP3

Sampling: Line 21 says “caregivers included in the first stage of the research that have given their availability will be invited.” Assuming this is WP1, suggest adding that to WP1 description.

How many focus groups will be conducted, or expected?

Analysis: line 31, “systemizing literature review” is unclear. Is this a reference to the scoping review in WP2? Perhaps use that term as it was not a systematic review.

WP4

Line 60, “to check the consequences of services’ ideas” is unclear. Line 51 says “testing of the service ideas co-created in WP3” so perhaps use that wording.

Methods: Line 20, the plan is to check the “service’s satisfaction”. Perhaps say “satisfaction with the service”. The plan is to do this by collecting the opinions of family caregivers with one focus group at the end of the pilot. Given the rural location of the study and dispersion of caregivers, is this feasible? Getting people together will require travel etc. Would this be done by teleconference?

WP 5

Methods: Line 51 “exploratory survey for collecting their personal opinions and interests in the project.” Perhaps clarify which personal opinions are being sought (on what). Line 53 “investigating correspondence between family caregivers’ needs”. I think this should be “correspondence *with*” interest from local districts. Is the feasibility study noted on line 60 part of WP5 or another step after that?

Data Analysis: Line 15 “will be verified thanks interviews with key actors” is unclear—should some other work replace “thanks”?

	I did not see any comments on the limitations of the study, which I assume as still relevant to a protocol paper (as potential limitations).
REVIEWER	Andrea Mayrhofer University of Hertfordshire, UK
REVIEW RETURNED	12-Mar-2020
GENERAL COMMENTS	Dear authors, this is a very interesting and worthwhile study. - The reviewer provided a marked copy with additional comments. Please contact the publisher for full details.

VERSION 1 – AUTHOR RESPONSE

Answers to Dr. Debra Morgan:

- 1) Referee comment: “An overall note is that 5 difference terms are used to describe the rural and remote context: “rural and remote,” “remote and rural,” “rural/remote,” “rural remote,” and “remote rural.” It might be best to choose one of these and be consistent throughout the paper and in the Figure.”

We agree with this suggestion, and we decided to use the term “rural and remote” as it defines better a geographical and social periphery.

- 2) Referee comment: “-RATIONALE: The authors provide a social-ecological framework for the study, which is a strength. This section of the paper is quite long but thorough. Given the space devoted, the authors should make sure to thread this framework throughout the proposed studies to show how the methods are linked to the elements of the framework (uniqueness of ageing in remote rural areas, opportunities and challenges of the aging-in-place imperative, and the role of family relationship and caregiving for elderly citizens).”

Thank you very much for this comment. We significantly improved the bibliographic references in the three elements that characterize our social-ecological framework. In particular:

-Uniqueness of ageing in remote rural areas:

Vasunilashorn, S., Steinman, B. A., Liebig, P. S., & Pynoos, J. (2012). Ageing in place: Evolution of a research topic whose time has come. *Journal of Ageing Research, 2012.*

We also specified some passages in order to better connect our framework to other references:

It is interesting to note that scientific literature has less focused on ageing population in remote areas, even if these areas have more elders than urban areas. [12]. For these reasons, we can say that researches on ageing populations are urban biased. The need for health and social care related services in remote areas has not been met by service provision delivered in urban contexts [11,13,14]. Research focusing on older persons living at the geographical and social peripheries, argue that in policy and economic debates the local experiences of older persons living in remote communities have often been ignored [15,16]. The P4C project aims to address this gap.

-Opportunities and challenges of the aging-in-place imperative:

We specified in the first part of the paragraphs all the works, at best of our knowledge, that made a reflection on the necessity to invest on ageing in place:

Guo, K. L., & Castillo, R. J. (2012). The US long term care system: Development and expansion of naturally occurring retirement communities as an innovative model for ageing in place. *Ageing International*, 37(2), 210-227.

Scharlach, A., Graham, C., & Lehning, A. (2012). The "Village" model: A consumer-driven approach for ageing in place. *The Gerontologist*, 52(3), 418-427.

McDonough, K. E., & Davitt, J. K. (2011). It takes a village: Community practice, social work, and aging-in-place. *Journal of Gerontological Social Work*, 54(5), 528-541.

Mynatt, E. D., Essa, I., & Rogers, W. (2000, November). Increasing the opportunities for ageing in place. In *Proceedings on the 2000 conference on Universal Usability* (pp. 65-71).

We also rephrased the passage that cited Wiles et al., 2012. We are sorry to have been superficial about not citing the important work of Wiles, that we cited in two other different passages of the articles. We rephrased as follows:

Some researches highlighted that people prefer to age in place [1] because it has been shown that this strategy enables effectively older persons to maintain independence, autonomy, and meaningful relations in terms of connection to social support, including friends and family [22,23].

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. (2012). The meaning of "ageing in place" to older people. *The gerontologist*, 52(3), 357-366.

In the final passage of the paragraph devoted to opportunities and challenges of ageing in place, we also added a sentence related to the few interventions already done that used mainly telemedicine, neglecting the importance of a psycho-social contact:

Furthermore, in remote context, welfare and social system often results fragmented and poorly accessible, making the ageing in place a possible paradigm only with high care costs for families that have to take care alone of their elders. Few interventions devoted to ageing in place are related to digital/telemedicine intervention, without regarding the social aspect of care [26].

Satpathy, L. (2006). *Smart housing: technology to aid ageing in place-new opportunities and challenges* (Doctoral dissertation, Mississippi State University).

-The role of family relationship and caregiving for elderly citizens.

We added bibliographic references to situate in the theoretical framework our statement

Several studies have shown that caregivers are the invisible backbone of social and health care settings, particularly in remote areas, as they facilitate the integration especially in areas and communities with limited access to services[33]

Caldeira C, Bietz M, Vidauri M, et al. Senior care for aging in place: Balancing assistance and independence. In: *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*. Association for Computing Machinery 2017. 1605–17. doi:10.1145/2998181.2998206

Applebaum A. Isolated, invisible, and in-need: There should be no 'I' in caregiver HHS Public Access. *Palliat Support Care* 2015;13:415–6. doi:10.1017/S1478951515000413

Lilly MB, Laporte A, Coyte PC. Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work. *Milbank Q* 2007;85:641–90

Aronson J, Neysmith SM. The Retreat of the State and Long-Term Care Provision: Implications for Frail Elderly People, Unpaid Family Carers and Paid Home Care Workers. *Stud Polit Econ* 2016;53:37–66. doi:10.1080/19187033.1997.11675315

Moreover, in this part we did not correctly specified the scoping review that focussed on needs and interventions of support to informal caregivers. Here it is the correct reference:

Morelli N, Barello S, Mayan M, et al. Supporting family caregiver engagement in the care of old persons living in hard to reach communities: A scoping review. *Heal Soc Care Community* 2019;27:1363–74. doi:10.1111/hsc.12826

- 3) Referee comment: “Methods: the term “elderlies” (pg 8, line 36) is not familiar—perhaps “older persons” could be used. “Conformation” (pg 9, line 18) also not familiar and may not be recognized by readers outside Italy. The meaning of “diffused frailty” (pg 9, line 23) is unclear to me.”

Thank you very much. Your comment is relevant. We modified through the paper the term “elderlies” with the term “older persons”. We also modified the term conformation with dynamics and diffused frailty was removed. Moreover, we added key aspects to better characterize the social context of Vallecamonica:

In this project, we will mainly focus on the community of Vallecamonica, with 41 municipalities, and twelve hundred thousands inhabitants, 19% over 65 years old [48], to deepen the unique experiences and needs of family caregivers caring for elderly citizens located in that geographic area.

Reference: <http://dati.istat.it/Index.aspx?QueryId=18548>

WP1

- 1) Referee comment: “Study Design: The abstract uses past tense for work packages (WP) 1 and 2 which suggests they have been completed. But on pages 9 and 10 both WP are described as future tense “will be...”. This should be clarified.”

Thanks for this comment, you are right! We were unclear, and we moved the verb tense to past in WP1 and WP2 as we specified in the letter that these two work packages were already done.

- 2) Reference comment: “Sampling WP1: the term “dear ones” is used (pg 9, line 55). Page 10, line 55 uses the term “beloved”. For an academic paper I think the term “care receiver” which is also used in this paper is more neutral and does not make assumptions about the quality of the relationship between caregiver and receiver. Will caregivers recruited in WP1 be asked to be involved in focus groups in WP3. The description of WP3 suggests this, so perhaps note that in WP1 sampling.”

Yes. Thanks for these comments. We changed the dear ones or beloved to care receiver. Your impression on engagement of caregivers involved in WP1 also in WP3 is correct. We rephrased as follows:

Caregivers involved in this WP1 are invited to participate in WP3 for the co-creation of a new service.

- 3) Referee comment: “Data analysis WP1: More detail is needed about the analysis. No analysis method is stated, only the aim of “taking a snapshot of the population of the family caregivers in the area in terms of needs, economic burden, and services required.”

Thank you very much for your relevant comment that helped us to clarify the data analysis. We described in details the type of analysis that we will carry out and its objectives. We enrich the manuscript as follow:

The analysis of data was organized in four main steps. First, we performed a preliminary data analysis by computing descriptive statistics, such as mean, median, mode and standard deviation of all variables of the questionnaire. Second, we carried out a confirmatory factor analysis that aimed at confirming the theoretical relationships between factors and their related variables of tested scales used in the questionnaire. Third, we investigated the correlation between psycho-social needs, level of engagement and economic expenditures. Finally, we performed a cluster analysis to identify sub-groups of caregivers that had similarities in terms

of psycho-social needs, level of engagement and economic expenditures. Overall, this analysis helped us to understand the condition of caregivers by developing a taxonomy that cluster caregivers with similar needs, level of engagement and economic expenditures.

WP2

- 4) Referee comment: “Objective: Note tense (past tense in abstract, future tense on page 10).”

Yes, we modified it and we included dates of start and end of the WP.

The WP2 started in May 2018, mapping interventions published in scientific articles and finished in February 2019 with the acceptance of the scoping review in a scientific journal.

- 5) Referee comment: “Methods: search terms do not include “remote” yet this term is used throughout the paper. Is there a reason for that? If so, it is best to give a rationale for not including.”

We decided to rephrase, as originally, we included the term remote, but with no results. We also added a passage on the qualitative analysis of the scoping review. We rephrased as follows:

We originally included also the term remote, but the research didn't give any new result, as the notion of remote context is still not explored in literature research. We checked also qualitatively the results of the search string, reading titles, abstracts and full text.

- 6) Referee comment: “Analysis: Articles published since 2012 will be included because that was European Year of Active Aging. However, this makes quite a short period in which to identify studies. A better yield may result from extending that period as it is unclear how much different the year of active ageing would make—was there a surge in relevant research at that time?”

Thank you for your comment. We specified why we included articles starting from 2012.

We decided to start from 2012 as, considering that year as starting date, we identified 2545 articles, a consistent result. Among all the articles selected, no-one cited previously interventions.

We also better specified the inclusion criteria:

Our inclusion criteria were related to data and language of publication, accessibility of full text and focus of intervention, type of caregivers, age of care-receivers and context of intervention.

WP3

- 7) Referee comment: “Sampling: Line 21 says “caregivers included in the first stage of the research that have given their availability will be invited.” Assuming this is WP1, suggest adding that to WP1 description. How many focus groups will be conducted, or expected?”

Thank you for your comment that helped us to make some clarification of the sampling process.

First, we clarified the inclusion criteria for the focus groups of WP3:

Only family caregivers that highlighted their interest in the project during the WP1 are eligible to participate in the co-creation workshops. Thus, the selecting criteria are: family caregivers that participate in WP1 and whose elders have been living at home in Vallecannonica and assisted by one of the five home-based long-term care service's providers..

Second, we clarified the expected number of focus groups of WP3:

Based on literature suggestions and the sample dimension, we expect to organize a minimum of 3 to 6 co-creation workshops in the co-design, co-managing and co-assessment phases of the service cycle.

Guest G, Namey E, Mckenna K. How Many Focus Groups Are Enough? Building an Evidence Base for Nonprobability Sample Sizes. *Field methods* 2017;29:3–22. doi:10.1177/1525822X16639015

Third, we enriched the description of the co-creation workshops, to clarify how these workshops will be organized:

Tools and methods. We carry out co-creation workshops in three main phases of the service life cycle, i.e. design, managing and assessment. Each workshop lasts about 2 hours and is conducted by two researchers specifically trained in qualitative research. To include different point of view and enrich the discussions, the workshops involve both users (family caregivers) and service providers (ATSP). The workshops are audio recorded.

In the design phase of the service, we involved family caregivers to identify their needs and to co-design new services for supporting them. Researchers facilitate the co-design workshops using the following steps:

- Mutual acquaintance: presentation of the project, presentation of participants with their biographical info, and description of their role as informal caregiver;
- Focus on the needs: What are the difficulties of caregiving in the context of Vallecamonica, for them and for their elders;
- Insights, ideas for the new service : starting from emerged needs, what are the caregiver ideas for a new service, with a particular attention on information, educational and psycho-social help;
- Conclusions: caregivers, together with the moderator and members of the team of research, try to merge ideas for the new service in a unique project idea and to define it accurately.

In the managing and assessment phases of the service, we involve family caregivers to collect their opinions about the service's activities. While the caregivers' feedbacks in the managing phase are used to improve the service's activities currently underway, in the assessment phase they will support researchers in assessing the service after its conclusion. Researchers facilitate the co-managing and co-assessment workshops accomplishing the following steps:

- Mutual acquaintance: presentation of the results of ongoing service pilot, highlighting the number of activities, the participation and satisfaction rate of the caregivers involved;
- Opinions, feedbacks on the ongoing service: starting from service's results, what are the caregiver suggestions for improving the ongoing service (i.e. co-managing phase) or for assessing the overall service results (i.e. co-assessment phase);
- Conclusions: caregivers, together with the moderator and members of the team of research, try to make practical suggestions for improving the new service both during its implementation and after its conclusion.

- 8) Analysis: line 31, "systemizing literature review" is unclear. Is this a reference to the scoping review in WP2? Perhaps use that term as it was not a systematic review."

Thank you, we modified as suggested.

The objectives and features of the new service should be able to address caregivers' needs and expectations that emerged in WP1 and take a cue from the good practices suggested by the results of the scoping literature review in WP2.

WP4

- 9) Referee comment: "Line 60, "to check the consequences of services' ideas" is unclear. Line 51 says "testing of the service ideas co-created in WP3" so perhaps use that wording."

Thank you, we modified as suggested.

This WP is dedicated to the testing of the service ideas co-created in WP3 through a piloting action organized and delivered by ATSP.

- 10) Referee comment: "Methods: Line 20, the plan is to check the "service's satisfaction". Perhaps say "satisfaction with the service". The plan is to do this by collecting the opinions of family caregivers with one focus group at the end of the pilot. Given the rural location of the study and dispersion of caregivers, is this feasible? Getting people together will require travel etc. Would this be done by teleconference?"

Thank you for your comment. We considered the teleconference option but, in our opinion, is not the best one to promote engagement and a fruitful co-production.

WP5

- 11) Referee comment: "Methods: Line 51 "exploratory survey for collecting their personal opinions and interests in the project." Perhaps clarify which personal opinions are being sought (on what). Line 53 "investigating correspondence between family caregivers' needs". I think this should be "correspondence with" interest from local districts. Is the feasibility study noted on line 60 part of WP5 or another step after that?"

Thank you for your suggestion.

We specified the objects of the quantitative survey and we corrected "correspondence with":

In the first study, we will distribute an exploratory survey to the head of service providers in charge of social and welfare services for elders living in Valtellina. We will involve head of service providers because they know the territory and the needs of family caregivers, thus, they can give us an objective and valuable opinion on the P4C project and its implementation's effectiveness in Valtellina. The survey's aim is twofold. First, it checks the interests of the local districts in the project by investigating the correspondence with family caregivers' needs.

We also specified what is the objective of WP5 that is not to deliver the same service in another context, but to evaluate if it possible to create a service model, feasible with other contexts, and what are the changes needed in order to export this service.

Even if in this project we will not deliver a new service in another territorial context, we want to put the basements for a transferability that could be done in another action research project.

- 12) Data Analysis: Line 15 "will be verified thanks interviews with key actors" is unclear—should some other work replace "thanks"?

Yes, we modified as follows:

Results of the assessment of transferability will be verified through interviews with key actors of the local districts of Valtellina for collecting their opinions and checking the reliability of results.

Limitations

- 13) I did not see any comments on the limitations of the study, which I assume as still relevant to a protocol paper (as potential limitations).

Thank you for your suggestion. We reflect on this point and add the potential limitations of this protocol paper:

The present protocol paper presents at least two possible limitations related to the target population chosen for this study. First, we expect a small sample size in WP1, WP3 and WP4, due to the peculiarity of the remote rural context that limits the generalization of the research findings [72]. Second, the direct involvement in the design phase of the service may influence its level of innovativeness. Since the target population have medium-low level managerial or technological capabilities, we expect to identify low innovative service solution that may not involve any usage of technology. However, we believe that the investigation of the conditions of family caregivers in remote rural areas is innovative 'per se' [12] and gives new insights regarding the opinions of this marginalized population that are usually excluded from the regional and national policies [73]. By explaining this protocol research, we would like to foster the investigation of marginalized population in rural remote areas for reducing the social, economic and health discrepancies with the urban areas.

Answers to Dr. Andrea Mayrhofer

Thank you for your comments. As many comments were very specific and suggested punctual solutions, you will find our answers directly in the paper. Here we will comment some passages that need to be better clarified. You will find a connection with your specific comments through the number of comment.

Abstract

- 1) Are these social care, or social and health care services?

We specified that we are interested both on social and health care services.

- 2) WP 6 and 7 are not discussed in the abstract?

Thank you, we made a mistake and we included other 2 WP that actually were not research work packages but managerial WP for the project members.

- 3) Are services received by family caregivers or by elderly citizens?

In WP1 we were interested on services received both by family caregivers and elderly citizens. In the following steps we focused on caregivers.

- 4) What is the difference between the data gathered in these focus groups and WP3, which also aims to co-create ideas?

Thank you for these comments that enables us to better specify what are the differences between different work packages.

WP3 will build on WP1 (survey) and WP2 (scoping literature review) and aim to co-create new ideas for intervention support with and for caregivers in relation to the objectives, features and characteristics of a new service able to address the caregiver needs and expectations.

Strengths and limitations

- 5) The items discussed under this heading are not strengths or limitations. “Expected” strengths and limitations of the study might be best placed toward the end of the protocol.

Thank you for your comment. We rephrased the entire paragraph as you suggested. We also added, following the comments of the other review, our provision of a social-ecological framework.

► This study aims to use participatory methods to co-produce an accessible and sustainable service for family caregivers of elderly citizens. Participation in the planning, design and implementation of the service will include family caregivers, elderly citizens, researchers and representatives from the welfare system (as ATSP, the agency that provide home services to local community).

► To our knowledge this is the first co-produced study that uses participatory methods to enhance and sustain the role of family caregivers to make ‘ageing in place’ a sustainable reality in remote areas.

► This study is a multi-stakeholder, multi-level and self-sustainable project, which will have both short-term and long-term beneficial effects on the possibility to continue the service deployment even after the end of the project

► The study is conducted in a specific setting and we recommend that the results should be deployed in other contexts to enhance their validity.

► The study provides a social-ecological framework, analysing the uniqueness of ageing in remote rural areas, opportunities and challenges of the ageing-in-place imperative, and the role of family relationship and caregiving for elderly citizens (Figure 1)

Aims

- 6) Could you describe this agency, i.e. is it a government run agency? What are its tasks / responsibilities?

Thank you very much for this comment, we did not explain tasks and duties of the ATSP. We rephrased as follows:

To explore, understand and measure caregiver’ needs in terms of education, welfare, assistance and social inclusion and in relation to the services planned by the local home care agency, which is responsible for the delivery of basic social services and social assistance towards fragile people in the territory of Vallecamonga;

Methods and Analysis

- 7) Briefly describe their current role. Is this a home-care agency that provides live-in care, or is this a government-run welfare agency? What are their duties?

Thank you for this request of clarification. As for the previous comment, we provided a better explanation:

The ATSP is a public agency that coordinates third parties in delivering services to fragile persons as old people, families, disabled people with professional social service.

WP1

- 8) The abstract states that WP1 and WP2 were already completed. Please state the dates when the study commenced and when it will be completed. Please state when each WP began (will begin) and was (will be) completed.

Yes, you are right, we modified as requested by adding the starting and ending (or expected ending) dates in all WP.

- 9) Please state: how many service providers are in the study area? How long is “long-term”? What is meant by “household services”? How long is a “medium to long time period”?

Thank you for this request of clarification. We provided a better explanation of the inclusion criteria:

We focused on caregivers whose elders had activated home-based long-term care services from two to 12 months [49] and had been living in Vallecanyonica. Based on this constraint, the research identified five the local providers that were offering this type of services in the valley and expressly consented to participate in the project (i.e. ATSP and four rest houses). In doing so, the selecting criteria were: family caregivers, whose elders have been living at home in Vallecanyonica and assisted from 2 to 12 months by one of the five home-based long-term care service providers involved in the project.

- 10) Please state the sample size, expected rate of return of the survey (how many people you expect will complete and return the survey); inclusion criteria and exclusion criteria.

Thank you for this comment that give us the opportunity to clarify the sampling frame as follow:

The overall number of family caregivers eligible for the study was around 321. We asked the five service providers to explain the research and its objectives to all eligible family caregivers and to collect their interest in the project. Since caregivers do not usually have the time nor the interest in explaining their personal condition to unknown parties [50], the sample size of family caregivers that are both eligible and interested in the research was quite limited: 147 caregivers. To increase the response rate, a psychologist contacted by phone all the caregivers of the sample to organize with them face-to-face meetings for submitting the survey. Despite this approach required time and resources, it reduced the number of bias that may arise during the self-administration of the questionnaire. We expected that the large majority of family caregiver have medium-low health literacy and education. Thus, the presence and assistance of a psychologist supported them in understanding and filling the questionnaire correctly, by reducing the number of missing data [51]. Based on this approach, we reached a satisfactory response rate of 45% [52]. Caregivers involved in this WP1 are invited to participate in WP3 for the co-creation of a new service.

- 11) The burden of the caregiver, the elderly person, or the entire household? Please define what is meant by “economic burden” (pension incomes; care costs; loss of income of the family caregiver;.....???) Please describe how this will be measured.

Thank you for your request. We clarified that we focus on caregivers needs. We also modified the economic burden referring more generally to expenditures, as it includes all the costs that you mentioned.

The data collected in the survey were analyzed with the aim of taking a clear picture of the population of the family caregivers in the area, in terms of psycho-social needs, level of engagement, out-of-pocket expenditures for caregiving activities (e.g. drugs, private professional assistance, transportation) [53] and cost of time loss for employment, calculated as the time used by the family caregiver in caring activity multiplied by the average cost of an Italian professional caregiver [54].

- 12) The process of data analysis is unclear: The section on ‘data analysis’ in WP1 needs to be much more detailed.

Thank you for this comment. We enrich the data analysis section as follow:

We designed the questionnaire by using tested scales and clear and familiar terms. The analysis of data was organized in four main steps. First, we performed a preliminary data analysis by computing descriptive statistics, such as mean, median, mode and standard deviation of all variables of the questionnaire. Second, we carried out a confirmatory factor analysis that aimed at confirming the theoretical relationships between factors and their related variables of tested scales used in the questionnaire. Third, we investigated the correlation between psycho-social needs, level of engagement and economic expenditures. Finally, we performed a cluster analysis to identify sub-groups of caregivers that had similarities in terms of psycho-social needs, level of engagement and economic expenditures. Overall, this analysis helped us to understand the condition of caregivers by developing a taxonomy that cluster caregivers with similar needs, level of engagement and economic expenditures..

WP3

- 13) Please describe your sample before discussing the methods used. Sample selection: What is the sampling frame? Sample recruitment: How will they be selected? Data collection: describe methods used (focus groups) Data analysis: how will data generated in focus groups be analyzed.

Thank you for this comment. We moved the sampling section before Tools and Methods section and we enrich it as suggested:

Sampling. Only family caregivers that highlighted their interest in the project during the WP1 are eligible to participate in the co-creation workshops. Thus, the selecting criteria are: family caregivers that participate in WP1 and whose elders have been living at home in Vallecamaonica and assisted by one of the five home-based long-term care service's providers. A psychologist is inviting caregivers by phone by calling them on random order to arrive to an average of 8-10 participants for each workshop. To increase the participation rate, we are trying to invite 10 to 12 caregivers at each workshop, knowing that logistical difficulties often lead us to some abandonment. Based on literature suggestions and the sample dimension, we expect to organize a minimum of 3 to 6 co-creation workshops in the co-design, co-managing and co-assessment phases of the service cycle [57].

- 14) The deductive approach needs to be described in more detail. Which data is this coding frame based on? Data from WP1 or from WP2? Explain the study design. The process of data analysis is unclear: needs clarity concerning the deductive approach to content analysis.

Thank you for the comments that helped us to reflect on the data analysis process. Based on your comments, we thought that an inductive approach is more suitable for the aim of this WP than the deductive one. Indeed, the aim of the co-creative workshops and the data collection process are exploratory by moving from a specific observation to generalized theory. Thus, we modified the data analysis section as follow:

All workshops will be transcribed and analyzed using content analysis [58,59] with an inductive approach [60]. Since we investigate a specific phenomenon (i.e. aging in place) by observing the behaviors of family caregivers, we prefer to adopt an open and flexible analysis of data [61]. We will start coding the transcripts by using an open coding approach and grouping relevant concepts in categories [62]. Then, we will investigate the relationships between categories and creating higher-order themes. The coding process will continue until all the relevant insights will be coded and data saturation will be reached [63]. To ensure the reliability of the analysis, two researchers will code the transcripts in parallel, analyzing and checking any inconsistency.

Then, authors will discuss results and assemble the final set of categories in high-level themes that represent the main concepts of investigation [64]. Resulting themes and categories will be compared in term of similarities and differences with the results of WP1 and WP2 [65].

WP4

- 15) Implementation of what? Piloting and preliminary assessment needs to come before implementing and testing a new intervention more widely.

You are right. We changed the title of WP4 as follows:

Piloting and preliminary assessment

VERSION 2 – REVIEW

REVIEWER	Debra G. Morgan University of Saskatchewan, Canada
REVIEW RETURNED	07-Jun-2020

GENERAL COMMENTS	<p>Thank you for the opportunity to re-review this interesting paper. The authors have done a thorough job of revising the paper to address my comments and those of the second reviewer and explaining these changes in their response. The paper is significantly improved and I have just minor suggestions for this revision, which I outline below. I also noted quite a few small grammatical errors throughout, such as using singular when plural is needed (eg, feedbacks instead of feedback, services ideas instead of service ideas) and some issues with tense (eg, page 9, should be "We WILL carry out co-creation workshops", "we WILL involve family caregivers", "the workshops WILL BE audio recorded." These are minor and can be corrected by a good editor to improve flow and readability. I appreciate the challenges of writing academic papers in other than a first language and commend the authors on their accomplishment</p> <p>1. ABSTRACT: "elderlies" still appearing in Methods section. "Shaping caregivers' oriented services" should be "caregiver-oriented services" I believe.</p> <p>2. The term "researches" could be replaced with "research" (eg, several times on page 4).</p> <p>3. On page 7, the following sentence in the Objectives is a bit awkward and unclear: "Identify the main target of caregiver (ie, "the more needing ones) to which address the new service and to be involved in the following participatory phases...". Could this perhaps be reworded as "Identify caregivers to be involved in the participatory phases of the project, specifically those with significant caregiving difficulties." or something like that (I am not sure that I have interpreted the meaning of this objective correctly).</p> <p>4. On page 9, Objectives: "take a cure from the good practices suggested...". Did the authors mean take a "cue"?</p>
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	<p>5. On page 11, "we want to put the basements for a transferability". Rather than "put the basements" I wonder if the authors mean "develop the foundation"?</p> <p>6. On page 12, "loved ones": as noted in my first review, a more neutral term such as "care receiver" could be used.</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1

1. Please state any competing interests or state 'None declared'

Done

2. Thank you for the opportunity to re-review this interesting paper. The authors have done a thorough job of revising the paper to address my comments and those of the second reviewer and explaining these changes in their response. The paper is significantly improved and I have just minor suggestions for this revision, which I outline below. I also noted quite a few small grammatical errors throughout, such as using singular when plural is needed (eg, feedbacks instead of feedback, services ideas instead of service ideas) and some issues with tense (eg, page 9, should be "We WILL carry out co-creation workshops", "we WILL involve family caregivers", "the workshops WILL BE audio recorded." These are minor and can be corrected by a good editor to improve flow and readability. I appreciate the challenges of writing academic papers in other than a first language and commend the authors on their accomplishment

Thanks for your precious suggestions. We have revised the text accordingly.

1. ABSTRACT: "elderlies" still appearing in Methods section. "Shaping caregivers' oriented services" should be "caregiver-oriented services" I believe.

Thanks. We revised

2. The term "researches" could be replaced with "research" (eg, several times on page 4).

Thanks. We have revised according to your suggestion

3. On page 7, the following sentence in the Objectives is a bit awkward and unclear: "Identify the main target of caregiver (ie, "the more needing ones) to which address the new service and to be involved in the following participatory phases...". Could this perhaps be reworded as "Identify caregivers to be involved in the participatory phases of the project, specifically those with significant caregiving difficulties." or something like that (I am not sure that I have interpreted the meaning of this objective correctly).

Thanks. We have revised according to your suggestion

4. On page 9, Objectives: "take a cure from the good practices suggested...". Did the authors mean take a "cue"?

Thanks. We have revised according to your suggestion

5. On page 11, "we want to put the basements for a transferability". Rather than "put the basements" I wonder if the authors mean "develop the foundation"?

Thanks. We have revised according to your suggestion

6. On page 12, "loved ones": as noted in my first review, a more neutral term such as "care receiver" could be used.

Thanks. We have revised according to your suggestion