PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	A Qualitative Study Assessing Organizational Readiness to Implement Caregiver Support Programs in Ontario, Canada
AUTHORS	Tseung, Victrine; Jaglal, Susan; Salbach, Nancy; Cameron, Jill

VERSION 1 – REVIEW

REVIEWER	Casey O'Brien St Vincent's Mental Health Service, Melbourne, Australia The University of Melbourne, Australia
REVIEW RETURNED	09-Dec-2019

GENERAL COMMENTS	Thank you for submitting this important paper. Implementing support programs can pose a major challenge for organisations, despite their value to carers and patients. It is very worthwhile to consider what helps and hinders integration, so we can move past these barriers. Introduction To provide a detailed context for the study the introduction, in my opinion, requires additional depth and review of past research. Specific areas that would benefit from expansion include: Impact on carer health and wellbeing – this highlights why this is an important area of research e.g. some specific figures on rates of carer depression/burnout would help set the scene. Explanation of 'multi-component' interventions as this term is vague. Please also specify how you are defining carer programs for the purposes of your study e.g., are you encouraging participants to reflect on all carer programs (practical, emotional, social, peer support etc) or limiting it to specific types of programs? Further detail on the rationale for choosing a qualitative methodology for this study is required. In my opinion, the introduction requires additional constructive commentary and review of past research in the area. You mention in the article summary that you are the first to conduct this type of study, why do you think that is so? Have there been barriers to this type of research in the past? Also, please review the statement on line 16 – I imagine there are some carer programs integrated into practice if not in the UK then internationally – perhaps clarify this statement or reference international literature to support the claim. The study objective could be operationalised to help clarify for the reader e.g., following the SPIDER tool https://journals.sagepub.com/doi/10.1177/1049732312452938 Our team published a paper in this area that might be of interest, from a healthcare provider perspective. O'Brien, C. L., Moore, G., Rolley, J. X., Ski, C. F., Thompson, D. R., Lautenschlager, N. T., ... & Castle, D. (2014). Exploring health care providers' perceptions of the needs of stroke carers: informing development of an optimal health program. Topics in stroke

rehabilitation, 21(5), 421-431.

Design
Line 41 delete ‘the used’ due to repetition
Line 44 recommend further explanation of the OSS especially for international readers. For example to what degree is this a private/public service, how many patients/catchments, and what types of care are offered.

Participants
Further details required on how participants were recruited and by whom e.g. targeted recruitment, advertisements on internal emails/intranet.

To clarify any ethical issues of dual relationships, please comment on researcher characteristics and relationship with participants e.g., were any participants also work colleagues of the researchers and if so, how was this dual relationship managed and how did this impact interpretation of results.

Data Collection
It would be helpful to add locations of focus groups/interviews, what modality (face to face, phone, Skype etc), and over what period they were conducted.
Consider including an example of a question asked in the interview, or include interview questions as an Appendix
I would recommend adding a sentence about who conducted the interviews/focus groups and their background e.g., psychology, nurse, student
It sounds like interviews and focus groups were semi-structured, with a list of questions and opportunity to be flexible depending on the responses. If this is the case, please specify that interviews were semi-structured.

Data Analysis
Please explain rationale for choosing thematic analysis.

Results
Overall, this section is well written and the inclusion of participant quotes adds depth to the theme descriptions.
Line 16 – ’29 interviews’ please specify if these were individual interviews or not.
Please comment on data saturation for this study.
It would provide added context if you included (if possible) some additional detail about the participants. For example, it would be interesting to know how many years participants had worked in the stroke care field.

A minor issue is that sometimes the longer quotes were lost in the text. To make the longer quotes stand out, consider adding a space above and below them.

There is some variation on how much explanation is provided across the themes. For example, Theme 1 has 2 paragraphs, and Theme 2 has 5-6 paragraphs of description. Is this because Theme 2 emerged with stronger consensus, had more interesting quotes, or more time was spent talking about this topic? Please reflect on this and clarify.

Discussion/Conclusion

	I acknowledge strengths and limitations have been included in the Article Summary. Please include this in the body of the discussion also. In the discussion you mention that “participant responses indicated that OTs are one of the health care professionals who would be suitable to deliver caregiver support” and in the results you indicate that “some participants provided examples of specific health care professionals they perceived to be most appropriate for this role, including OTs, social workers, nurses and other allied health professionals” It is unclear why you have chosen to focus solely on OTs in the discussion rather than the other suggested professions. I recommend reflecting on this further and amending/clarifying where necessary. Thank you once again for this interesting and important paper.

REVIEWER	Mary Khetani University of Illinois at Chicago United States
REVIEW RETURNED	21-Dec-2019

GENERAL COMMENTS	Thank you for the opportunity to review this paper. It is a well-designed and written paper that addresses the need to better understand factors for implementation of caregiver support interventions within regional stroke system institutions. My feedback is primarily intended to lend greater transparency for reproducibility. 1. Please clarify the difference between institution and program. Are there multiple programs within an institution? (p. 6) 2. comma not needed after United Kingdom (p. 6) 3. It would be helpful to have some examples of evidence-based caregiver support interventions (p. 6) 4. there is redundancy in the first sentence of study design ("and used the used") (p. 6) 5. It is unclear how exactly participants were recruited (p. 7) 6. It is unclear why data need to be collected on perceptions of availability, importance, and effectiveness of caregiver programs, if the study question is about factors impacting implementation (which assumes that implementation is not taking place). Please clarify your rationale for collecting and reporting on these data (p. 7) 7. The study question stated in the introduction is about the need to understand implementation within institutions, but #3 speaks of program level implementation considerations. It is unclear whether data were collected on program or institutional level considerations. Please clarify (p. 7) 8. Data analysis could benefit from greater detail, such as number of coders to data, inter-coder reliability checks undertaken, reflexivity considerations, and whether member-checking was used to finalize themes. (p. 8) 9. The authors are to be commended for their sample diversity. It would be helpful to provide the number and percentages for participant characteristics in Tables 1 and 2. If information was

	collected on years of experience and other relevant participant characteristics that might influence perceptions of implementation factors, this would be important to report. Otherwise, it could be commented on as a study limitation (p. 9) 10. The reporting of results is overall strong, but for areas where participants had diverse perspectives, it might be helpful to provide multiple exemplars (illustrative quotes) to lend credibility to the results (p. 12).

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Reviewer Name: Casey O'Brien
Institution and Country: St Vincent's Mental Health Service, Melbourne, Australia; The University of Melbourne, Australia Please state any competing interests or state 'None declared': None declared.

COMMENT: Thank you for submitting this important paper. Implementing support programs can pose a major challenge for organizations, despite their value to carers and patients. It is very worthwhile to consider what helps and hinders integration, so we can move past these barriers.

RESPONSE: Thank you for your comment and support of the goals of this manuscript.

COMMENT: Introduction
To provide a detailed context for the study the introduction, in my opinion, requires additional depth and review of past research. Specific areas that would benefit from expansion include:
Impact on carer health and wellbeing – this highlights why this is an important area of research e.g. some specific figures on rates of carer depression/burnout would help set the scene.

RESPONSE: Thank you for your suggestion to expand upon the literature review. We have added the following to the introduction.

Previous literature suggest that 30-33% of caregivers experience depression (3). Taking on the caregiver role can also impact other aspects of a caregiver's life, including leisure, relationships, and work. Relatives who assumed the caregiver role had increased responsibilities, decreased leisure activities and negative changes in their relationships, and the impact on their lives can still be present after a year post-stroke (4). A study conducted in the United States found that the indirect costs associated with caregiving (e.g., traveling time, out-of-pocket expenses) amounted to $5,669 per caregiver per year, and costs of total lost productivity amounted to more than $10,000 per year per employed caregiver (5). Taken together, the caregiver role affects many aspects of a caregiver's life and education and support has the potential to enhance their abilities to take on and sustain this important role.

COMMENT: Explanation of 'multi-component' interventions as this term is vague.

RESPONSE: We have added a sentence to explain 'multi-component' interventions to the introduction.

Multicomponent interventions include at least two of the following: information provision (e.g., community resources), emotional support and counseling (e.g., support groups, professional support) and skills training (physical care, problem solving) (6). For example, the 'Timing It Right' Family Stroke Family Support program is a multicomponent intervention that is delivered by a health care professional (stroke support person),who meets with the caregiver in-person in acute care and then follows up with six monthly telephone meetings to discuss caregiver's support needs and potential strategies to meet these needs (7, 8).

COMMENT: Please also specify how you are defining carer programs for the purposes of your study e.g., are you encouraging participants to reflect on all carer programs (practical, emotional, social, peer support etc) or limiting it to specific types of programs?

RESPONSE: Thank you for your comment. We have defined carer program in the introduction and provided more detail in the data collection section.

Introduction: For the purposes of this study, a caregiver education and support program is a structured, time-limited intervention with a basic protocol and program materials. A program consists of one or more of the following components: education, training and support.

Data collection: Participants were asked to reflect on all caregiver programs in general and then more specifically on caregiver programs that cross care environments using the Timing It Right Stroke Family Support Program (7, 8) as an example.

COMMENT: Further detail on the rationale for choosing a qualitative methodology for this study is required.
In my opinion, the introduction requires additional constructive commentary and review of past research in the area. You mention in the article summary that you are the first to conduct this type of study, why do you think that is so? Have there been barriers to this type of research in the past? Also, please review the statement on line 16 – I imagine there are some carer programs integrated into practice if not in the UK then internationally – perhaps clarify this statement or reference international literature to support the claim.

RESPONSE: Thank you for your suggestion to expand on the use of a qualitative methodology and the literature reviewed regarding the integration of caregiver programs into practice. We have added further details pertaining to this in the introduction and the design section.

Introduction: Caregiver program implementation has been studied in the context of dementia caregiving. Although there are more than 200 efficacious dementia caregiver programs, only 6 have been integrated into practice (13). The need to identify contextual factors that may influence implementation has emerged as an emerging research field and an important step towards effective integration into practice (13). Previous studies undertook process evaluations during caregiver program implementation (e.g., (11, 12, 14)). However, the current study aimed to identify factors that may influence implementation in real-world settings prior to developing or testing an implementation strategy (15).

Design: A qualitative approach is used when the purpose is to understand a specific phenomenon for which there has been limited research and the important variables to explore are unclear (20). There are no previous studies that have examined the implementation of caregiver education and support in standard clinical practice within the Canadian context. Specifically, a qualitative descriptive study design is particularly suited when producing a comprehensive description of participant perceptions of a specific phenomenon because data analysis and interpretation stays close to the data and participant perceptions are considered to be accurate and truthful reflections of the reality of the phenomenon (i.e., caregiver program implementation) (18).

COMMENT: The study objective could be operationalized to help clarify for the reader e.g., following the SPIDER tool https://journals.sagepub.com/doi/10.1177/1049732312452938

RESPONSE: Thank you for your comment. We have revised the study objective according to the SPIDER tool. Please see below.

Therefore, the objective of this qualitative descriptive study was to examine program level factors (i.e., within institutions) that influence local implementation of caregiver programs in the context of a regional stroke system.

COMMENT: Our team published a paper in this area that might be of interest, from a healthcare provider perspective.
O'Brien, C. L., Moore, G., Rolley, J. X., Ski, C. F., Thompson, D. R., Lautenschlager, N. T., ... & Castle, D. (2014). Exploring health care providers' perceptions of the needs of stroke carers: informing development of an optimal health program. Topics in stroke rehabilitation, 21(5), 421-431.

RESPONSE: Thank you for bringing this article to our attention. It is similar to research from our team that informed development of the Timing it Right Stroke Family Support Program (Cameron JI, Naglie G, Silver FL, Gignac MA. Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. Disabil Rehabil. 2013;35(4):315-24.)

COMMENT: Design
Line 41 delete 'the used' due to repetition

RESPONSE: Thank you for your comment. 'the used' has been deleted.

COMMENT: Line 44 recommend further explanation of the OSS especially for international readers. For example to what degree is this a private/public service, how many patients/catchments, and what types of care are offered.

RESPONSE: Thank you for your suggestion to expand on the OSS. We have added the following to design.

The OSS is publicly funded, includes 11 geographical regions, and provides specialized stroke care across the continuum. Each region includes a Regional Stroke Centre or Enhanced District Stroke Centre, community hospitals, rehabilitation hospitals, community-based providers and pre-hospital providers (21). Some of the regions are large encompassing rural areas and some are small and urban. There are 9 Regional Stroke Centres, 2 Enhanced District Stroke Centres, 16 District Stroke Centres, and 24 secondary prevention clinics (21). COMMENT: Participants
Further details required on how participants were recruited and by whom e.g. targeted recruitment, advertisements on internal emails/intranet.

RESPONSE: Thank you for your comment. We have added further details regarding recruitment in the participants section.

Regional Rehabilitation Specialists, Professional Education Coordinators, Community and Long-Term Care Specialists, and Regional/District Program Directors were invited by the corresponding author via email to participate in a focus group as part of regularly scheduled group meetings. Regional Medical Directors, health executives, and primary care leaders were invited by the corresponding author via email to participate in an interview. OSS Education Coordinators assisted with recruitment of health care professionals by emailing the study invitation to attendees of their education sessions. The primary author then coordinated and conducted all interviews and focus groups.

COMMENT: To clarify any ethical issues of dual relationships, please comment on researcher characteristics and relationship with participants e.g., were any participants also work colleagues of the researchers and if so, how was this dual relationship managed and how did this impact interpretation of results.

RESPONSE: We have added clarification regarding researcher characteristics and relationship with participants.

None of the members of the research team had any formal relationships with the participants. The corresponding author has shared their research with members of the Ontario Stroke System through invited presentations and workshops.

COMMENT: Data Collection
It would be helpful to add locations of focus groups/interviews, what modality (face to face, phone, Skype etc), and over what period they were conducted.
Consider including an example of a question asked in the interview, or include interview questions as an Appendix I would recommend adding a sentence about who conducted the interviews/focus groups and their background e.g., psychology, nurse, student It sounds like interviews and focus groups were semi-structured, with a list of questions and opportunity to be flexible depending on the responses. If this is the case, please specify that interviews were semi-structured.

RESPONSE: Thank you for your suggestions. We have added the locations for the focus group and interviews, what modality and the period when they were conducted. Focus group and Interview questions are included as an Appendix. We have added the following:

Focus groups were conducted in person at the local Heart and Stroke Foundation office and interviews were conducted by telephone. The primary author collected all data and is an occupational therapist and doctoral candidate with training in qualitative interviewing. Data collection took place over the course of four months and ended when data saturation was reached. Qualitative, semi-structured interviews and focus groups were audio-recorded, transcribed verbatim, reviewed for accuracy, and de-identified.

COMMENT: Data Analysis
Please explain rationale for choosing thematic analysis.

RESPONSE: We have added the rationale for choosing thematic analysis.

Qualitative thematic analysis is commonly used to analyze data in qualitative descriptive studies (18). Data were analyzed using inductive thematic analysis (24) and facilitated using NVivo (25).

COMMENT: Results
Overall, this section is well written and the inclusion of participant quotes adds depth to the theme descriptions.
Line 16 – ’29 interviews’ please specify if these were individual interviews or not.
Please comment on data saturation for this study.

RESPONSE: We have clarified in the methods that these were individual interviews and added comments on data saturation for this study.

Results:

Four focus groups (n=43) and 29 individual interviews yielded 72 participants (see tables 1 and 2).

Data Collection:

Data collection took place over the course of four months and ended when data saturation was reached.

COMMENT: It would provide added context if you included (if possible) some additional detail about the participants. For example, it would be interesting to know how many years participants had worked in the stroke care field.

RESPONSE: We thank the reviewer for this comment. Unfortunately, we did not routinely collect this information from participants.

COMMENT: A minor issue is that sometimes the longer quotes were lost in the text. To make the longer quotes stand out, consider adding a space above and below them.

RESPONSE: Thank you for your comment. We have increased the indent for the longer quotations to help them stand out from the main text.

COMMENT: There is some variation on how much explanation is provided across the themes. For example, Theme 1 has 2 paragraphs, and Theme 2 has 5-6 paragraphs of description. Is this because Theme 2 emerged with stronger consensus, had more interesting quotes, or more time was spent talking about this topic? Please reflect on this and clarify.

RESPONSE: Thank you for your comment. The variation on how much explanation is provided across the themes primarily depended on the participants' responses and the details provided that contribute to fully capturing the different aspects of the theme. For example, theme 1 highlights the three types of evidence that stakeholders are looking for – process, outcomes data whereas theme 2 underscores the various considerations for creating a new role to provide caregiver education and support across the continuum.

COMMENT: Discussion/Conclusion
I acknowledge strengths and limitations have been included in the Article Summary. Please include this in the body of the discussion also.

RESPONSE: We have included the strengths and limitations in the body of the discussion.

COMMENT: In the discussion you mention that "participant responses indicated that OTs are one of the health care professionals who would be suitable to deliver caregiver support" and in the results you indicate that "some participants provided examples of specific health care professionals they perceived to be most appropriate for this role, including OTs, social workers, nurses and other allied health professionals" It is unclear why you have chosen to focus solely on OTs in the discussion rather than the other suggested professions. I recommend reflecting on this further and amending/clarifying where necessary.

RESPONSE: Thank you for your comment. We have revised this section as follows:

Participant responses indicated that various health care professionals would be suitable to provide support to caregivers. One example is occupational therapists where previous literature suggests that occupational therapists can serve an important role in addressing the needs of caregivers (32). Occupational therapists are a core member of multi-disciplinary stroke teams and they contribute to caregiver training (e.g., teaching ADLs) (33, 34). Beyond training in ADLs, occupational therapists' training in mental health and meaningful occupations prepares them for addressing the psychosocial effects ofaregiving (33). There is a need to address caregivers' needs such that they are able to maintain both their own health and engagement in valued activities and provide care for their loved ones (4). This previous research (4) and our study findings highlight occupational therapists as a potential source of support for caregivers.

COMMENT: Thank you once again for this interesting and important paper.

RESPONSE: Thank you for taking the time to review our paper and provide your feedback.

Reviewer: 2
Reviewer Name: Mary Khetani
Institution and Country: University of Illinois at Chicago, United States Please state any competing interests or state 'None declared': None declared

COMMENT: Thank you for the opportunity to review this paper. It is a well-designed and written paper that addresses the need to better understand factors for implementation of caregiver support interventions within regional stroke system institutions. My feedback is primarily intended to lend greater transparency for reproducibility.

RESPONSE: Thank you for your comment and support of the goals of this manuscript.

COMMENT: 1. Please clarify the difference between institution and program. Are there multiple programs within an institution? (p. 6)

RESPONSE: Thank you for your comment. For the purposes of our study, institution refers to the organization where the caregiver program is being implemented. Program refers to the caregiver program that is being implemented.

COMMENT: 2. comma not needed after United Kingdom (p. 6)

RESPONSE: We have deleted the comma after “United Kingdom”.

COMMENT: 3. It would be helpful to have some examples of evidence-based caregiver support interventions (p. 6)

RESPONSE: Thank you for your comment. We have added in an example of an evidence-based caregiver support intervention.

For example, the ‘Timing It Right’ Family Stroke Family Support program is a multicomponent intervention that is delivered by a health care professional (stroke support person), who meets with the caregiver in-person in acute care and then follows up with six monthly telephone meetings to discuss caregiver’s support needs and potential strategies to meet these needs (7, 8).

COMMENT: 4. there is redundancy in the first sentence of study design ("and used the used") (p. 6)

RESPONSE: We deleted the repeated “the used” in the first sentence of study design.

COMMENT: 5. It is unclear how exactly participants were recruited (p. 7)

RESPONSE: We have added further details about the participant recruitment process.

Regional Rehabilitation Specialists, Professional Education Coordinators, Community and Long-Term Care Specialists, and Regional/District Program Directors were invited by the corresponding author via email to participate in a focus group as part of regularly scheduled group meetings. Regional Medical Directors, health executives, and primary care leaders were invited by the corresponding author via email to participate in an interview. OSS Education Coordinators assisted with recruitment of health care professionals by emailing the study invitation to attendees of their education sessions. The primary author then coordinated and conducted all interviews and focus groups.

COMMENT: 6. It is unclear why data need to be collected on perceptions of availability, importance, and effectiveness of caregiver programs, if the study question is about factors impacting implementation (which assumes that implementation is not taking place). Please clarify your rationale for collecting and reporting on these data (p. 7)

RESPONSE: The focus group and interview questions incorporated the domains of the Consolidated Framework for Implementation Research (CFIR) (23) to explore how individual and institution-level factors influence caregiver program implementation (see supplemental appendix). For example, individual level factors such as understanding of caregiver needs, the institution’s ability to address caregiver needs, and the evidence base for caregiver programs can all influence program implementation (23).

COMMENT: 7. The study question stated in the introduction is about the need to understand implementation within institutions, but #3 speaks of program level implementation considerations. It is unclear whether data were collected on program or institutional level considerations. Please clarify (p. 7)

RESPONSE: Within the context of this study, we have revised the objective to clarify that data were collected on institution level considerations:

Therefore, the objective of this qualitative descriptive study was to examine program level factors (i.e., within institutions) that influence local implementation of caregiver programs in the context of a regional stroke system.

COMMENT: 8. Data analysis could benefit from greater detail, such as number of coders to data, inter-coder reliability checks undertaken, reflexivity considerations, and whether member-checking was used to finalize themes. (p. 8)

RESPONSE: We have added the following detail regarding data analysis:

The first author coded all of the data and all authors reviewed the data and contributed to theme generation. Reflexive notes and field notes were taken throughout data collection and analysis to ensure the dependability and confirmability of the findings (18).

COMMENT: 9. The authors are to be commended for their sample diversity. It would be helpful to provide the number and percentages for participant characteristics in Tables 1 and 2. If information was collected on years of experience and other relevant participant characteristics that might influence perceptions of implementation factors, this would be important to report. Otherwise, it could be commented on as a study limitation (p. 9)

RESPONSE: Percentages for participant characteristics has been added to Tables 1 and 2. In addition, the following sentence was added to the limitations section “We did not systematically obtain data related to years of experience in specific roles.”

COMMENT: 10. The reporting of results is overall strong, but for areas where participants had diverse perspectives, it might be helpful to provide multiple exemplars (illustrative quotes) to lend credibility to the results (p. 12).

RESPONSE: We appreciate your comment about providing additional exemplars to the results section, given the word limit of the paper, we aimed to select quotation to represent the diverse perspectives of the different participant groups.

VERSION 2 – REVIEW

REVIEWER	Casey O'Brien Mental Health St Vincent's Hospital Melbourne, Australia
REVIEW RETURNED	12-Mar-2020

GENERAL COMMENTS	I would be pleased to accept this paper with very minor revision. Introduction paragraph 1, I think should read "relatives who assume the caregiver role have increased responsibilities..." Introduction paragraph 1 - the Berg reference used for caregiver depression is older (2005). Please add more current references (last

	5 years) and consider also including a reference for other common caregiver issues like carer burnout.

REVIEWER	Mary Khetani University of Illinois at Chicago United States
REVIEW RETURNED	25-Mar-2020

GENERAL COMMENTS	The authors are commended for responding to reviewer feedback to improve the manuscript, particularly with respect to the clarity of study scope and specificity in methodological details. This paper will make an important contribution to the literature.

VERSION 2 – AUTHOR RESPONSE

Reviewer 1 Comments:
Introduction paragraph 1, I think should read "relatives who assume the caregiver role have increased responsibilities..."
RESPONSE: Thank you. We have made this change.

Introduction paragraph 1 - the Berg reference used for caregiver depression is older (2005). Please add more current references (last 5 years) and consider also including a reference for other common caregiver issues like carer burnout.
RESPONSE: We have updated our references regarding caregiver depression and added a reference to link caregiver burden to depression.
“Previous literature suggest that 12-25% of caregivers experience depression (3, 4) and caregiver burden is positively associated with depression symptoms (5).”
References:
3. Roth DL, Haley WE, Sheehan OC, Liu C, Clay OJ, Rhodes JD, et al. Depressive Symptoms After Ischemic Stroke: Population-Based Comparisons of Patients and Caregivers With Matched Controls. Stroke. 2020;51(1):54-60.
4. Rohde D, Gaynor E, Large M, Conway O, Bennett K, Williams DJ, et al. Stroke survivor cognitive decline and psychological wellbeing of family caregivers five years post-stroke: a cross-sectional analysis. Top Stroke Rehabil. 2019;26(3):180-6.
5. Del-Pino-Casado R, Rodriguez Cardosa M, Lopez-Martinez C, Orgeta V. The association between subjective caregiver burden and depressive symptoms in carers of older relatives: A systematic review and meta-analysis. PLoS One. 2019;14(5):e0217648.