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Author/s:

Ugalde, A;Blaschke, SM;Schofield, P;Lambert, SD;Aranda, S;Boltong, A;Chambers, SK;Krishnasamy, M;Livingston, P

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Ugalde Anna (Orcid ID: 0000-0002-2473-8435)
Lambert Sylvie (Orcid ID: 0000-0002-9202-9251)
Chambers Suzanne (Orcid ID: 0000-0003-2369-6111)
Livingston Patricia (Orcid ID: 0000-0001-6616-3839)

Priorities for cancer caregiver intervention research: A three-round modified Delphi study to inform priorities for Participants, Interventions, Outcomes and Study Design Characteristics

Running Title: Caregiver Intervention Priorities Delphi Study

Authors:

Anna Ugalde¹, Sarah-May Blaschke², Penelope Schofield,^{2,3} Sylvie D Lambert⁴, Sanchia Aranda^{5,6}, Anna Boltong^{7,8}, Suzanne K Chambers⁹, Meinir Krishnasamy^{6,7,10}, Patricia Livingston¹

¹ School of Nursing & Midwifery, Faculty of Health, Deakin University, Geelong, Australia

² Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Australia

³ Department of Psychology, Swinburne University, Hawthorn, Australia

⁴ Ingram School of Nursing, McGill University, Montreal, Canada

⁵ Cancer Council Australia, Sydney, Australia

⁶ Department of Nursing, University of Melbourne, Parkville, Victoria, Australia

⁷ Victorian Comprehensive Cancer Centre, Parkville, Victoria, Australia

⁸ Melbourne School of Population and Global Health, The University of Melbourne, Parkville, Victoria, Australia

⁹ University of Technology, Sydney, New South Wales, Australia

¹⁰ Centre for Cancer Research, University of Melbourne, Parkville, Victoria, Australia

Corresponding Author

Dr Anna Ugalde

Deakin University, 1 Gheringhap Street Geelong, Victoria, Australia

a.ugalde@deakin.edu.au

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Key Points

- A three round modified Delphi study, guided by the PICO Framework, was conducted to ascertain cancer caregiver priorities in the areas of Participants, Interventions, Outcomes and Study designs.
- 25 Delphi participants, consisting of healthcare, allied health or academics with extensive clinical practice or research experience in caregiver research, completed surveys over three rounds.
- Round 1 contributions were varied and extensive and 125 codes were generated, and over Round 2 and Round 3 49 items were assessed for priority and consensus.
- High priorities included participants identified as minority groups or disadvantaged, those who are isolated and those identified as needing support; interventions that are sustainable and tailored; outcomes that are important to caregivers and studies that assess the long term impact of interventions.
- Optimising approaches to conduct these studies, complementing these findings with qualitative data and including caregiver perspectives are important avenues of future work.

Introduction

Informal caregivers are important in supporting people with cancer due to the ageing population, improvements in diagnosis and treatment, and a shift towards home-based cancer care.[1, 2] The ageing of the population, improvements in diagnosis and treatment and the shift towards home-based cancer care places significant burden on informal caregivers. Caregivers frequently experience several negative impacts associated with the care provision including psychological and physical morbidity.[3-5]

These negative impacts have informed several intervention studies aiming to improve caregiver outcomes.[6-8] The body of intervention research is diverse; for example, there is a lack of consensus on how to define caregivers,[9] leading to a significant variance in samples between studies. Interventions can also range in type, dose, format, and content [6], as well as their focus with noted categories including psychoeducational, skills training or therapeutic counselling.[7] Similarly, the range of outcomes studied and reported has also been broad, spanning categories such as quality of life, emotional support, communication and relational intimacy, and caregiving tasks.[6] Furthermore, some studies explore patient outcomes in the context of the type of caregiving they receive.[10] Overall, there have been a range of approaches trialled involving different groups, aiming to improve health outcomes.

Understanding strategic priorities for research allows investigators to determine where important resources can be allocated to make the greatest gains possible.[11] Giving researchers a voice to articulate important issues allows the development of a strong research agenda.[12] Cancer caregivers have been identified as a priority in psycho-oncology research.[13] Strategic priority setting has been conducted for cancer caregiving research. In 2016, recommendations were generated based on the literature and perspectives from over 75 invited researchers, clinicians and advocates, who attended a two-day in person meeting.[9] Recommendations were generated in four key areas, one of which included advancing the development of interventions.[9] More recently, priorities for caregiver research in cancer care was explored with a Delphi survey.[14] Four panels participated, including caregivers, clinicians, managers, and researchers, and findings identified a range of priority areas such as impact of cancer on the caregivers and integrating research into cancer care.[14] While these studies have clarified important focus areas for future cancer caregiver research, priorities for cancer caregiver interventions, specifically, are yet to be defined. This task will guide researchers to focus on intervention components such target groups or intervention content. With greater research effort now being directed towards cancer caregiver interventions, understanding these priorities will be beneficial.

The aim of this study was to solicit knowledge and consensus from cancer-specific healthcare and academic experts to develop priorities for and provide guidance on effective design and evaluation of cancer caregiver intervention research.

Methods

A study protocol has been published.[15] Briefly, this study consisted of a modified three round electronic Delphi survey; soliciting expert opinion in a series of iterative rounds. Each participant

received three surveys. Round 1 was an open ended survey with the aim to generate a wide range of perspectives, Rounds 2 and 3 were quantitative. This Delphi was structured according to the PICO framework, to allow for exploration of priority areas within cancer caregiving intervention research. Ethics was approved by Deakin University.

Participants

Delphi participants were healthcare, allied health or academics with extensive clinical practice or research experience in caregiver research.

Procedure

Participants were nominated by either the advisory committee, consisting of the authorship team, or by potential participants (snowball sampling). Potential participants were approached by email and invited to participate. If they expressed interest they were forwarded a link to an online survey in Qualtrics to complete. Written study information was provided electronically and consent was implied with return of the surveys.

The Survey

This study consisted of three survey rounds. The Round 1 survey was qualitative and responses in Round 1 informed the items for Round 2 and 3. Round 1 questions focused on Participants, Interventions, Outcomes and Methodologies. There were two additional questions for participants to identify barriers and provide further comments. Questions in Survey 1 were as follows:

- Are there specific groups of cancer caregivers that should be prioritised for intervention research? Consider relevant demographic, medical, personal or clinical factors, to identify high priority groups.
- What intervention components are important in cancer caregiver intervention research? Consider intervention content, delivery method, setting and dose, for delivery of optimal interventions.
- Cancer caregiver interventions can target various outcomes, including caregiver, patient or health service factors. Consider important outcomes for cancer caregiver interventions, including who may benefit from interventions and for which outcomes.
- Cancer caregiver interventions can be investigated using a variety of approaches. Consider which methodologies are important in understanding and evaluating the benefits of caregiver interventions.
- What are the most significant barriers to the conduct of caregiver intervention research?
- Do you have any further comments about priorities for cancer caregiver interventions?

As this was a qualitative round, analysis consisted of coding individual responses, removal of identical responses and sorting codes into categories. AU led the coding process and an interrater process was conducted with SB.

Round 1 data fed into the development of the Round 2 a survey, which was readministered in Round 3 with added, consolidated group data. Items in Round 2 and Round 3 are presented as

Supplementary Information. There were four sections in this survey: Section 1 was Priority Caregiver Groups, Section 2 was Priority Interventions, Section 3 was Priority Outcomes and Section 4 was Study Designs. Participants responded with a 4-point Likert-type Scale: 'Not important' (a score of 1), 'Somewhat important' (2), 'Important' (3) and 'Very important' (4), consistent with a previous study.[14]

The priority rating of each item was defined by the median scores. Consensus is defined as a percentage of scores that is consistent with the median. Consensus was classified as high consensus (70% or higher), moderate consensus (60% or higher), low consensus (50% or higher) or consensus not achieved (less than 50%); as classified by previous researchers[16] and as described in the protocol.[15] When median scores were not whole numbers, they were rounded up.

Adaptations from the Protocol

The Likert scale in Rounds 2 and 3 was adapted to be consistent with a previous study [14] and for this study ranged from 'Not important' to 'Very important.' Additionally, the decision was made to remove the 'no judgment' option as the eligibility criteria meant that each participant should be able to comment on each item.

While screening, it was difficult to quantify years of experience and eligibility. Consequently inclusion criteria were relaxed to allow healthcare, allied health or academics with extensive clinical practice or research experience in caregiver research to participate, as this best represented the target group. Although this study protocol stated guidelines would be developed, this was not possible due to project and methodological constraints and the aim has been realigned to provide guidance on intervention design and evaluation.

Results

Participants

A total of 92 experts were identified as being potentially eligible: 80 names were provided by the advisory committee and 12 through snowball sampling. Twenty two experts were not approached as they did not have caregiver experience, resulting in 70 participants being approached by email. Thirty-eight participants (54%) responded expressing interest and all were forwarded a survey link. Of these, 25 (66%) completed the survey. Data from non-responders were not collected.

Participants reported a mean of 25 years professional experience (range 5-45). Seventeen were academics, three held academic/clinical roles, three were in clinical roles and two were in a service management roles. Eleven were from Australia, seven were from USA, five were from United Kingdom and two were from Canada.

For Round 2, 22 participants completed the survey (12% attrition). Nineteen participants completed the Round 3 survey (14% attrition from Round 2). Delphi rounds were conducted between August 2018 and February 2019.

Round 1

Round 1 produced 125 responses to the six questions. All 25 participants answered Q1: Caregiver characteristics; 24 participants answered Q2: Interventions; all 25 participants answered Q3: Outcomes; 23 participants answered Q4: Study characteristics; 24 participants answered Q5: Barriers; and nine participants answered Q6: Other comments.

Initially, all responses were read and codes were assigned. It was common for multiple codes to be assigned to each participant's response as often several issues were generated within the same response to a given question. This analysis resulted in the development of 81 individual codes, which were linked to their original question. There were 23 codes developed in Q1: Caregiver characteristics; 23 codes for Q2: Interventions; 17 codes for Q3: Outcomes; 13 codes for Q4: Study characteristics; 2 codes for Q5: Barriers and 3 codes were classified as Other.

Next, the 81 codes were reviewed, duplicates removed and labels were reassigned to best represent the data. The codes were also assigned, as appropriate, to Participants, Interventions, Outcomes and Study Characteristics, rather than being allocated to the category in which they had been generated. During this process, all of the codes generated in Question 5: Barriers and Question 6: Other categories were removed as being not relevant to intervention priorities (e.g. comments about funding) or were repetitive with other codes and were recoded into Questions 1-4. An interrater process was conducted, which consisted of all data being reviewed and there were no changes to the coding structure as a result of the interrater process as there was agreement about the coding framework. After reviewing the codes, 32 codes were removed for being duplicates or outside of the scope of the study.

Round 1 Analysis resulted in 49 codes: 15 items for Participants, 11 items for Interventions, 12 items for Outcomes and 11 codes for Study Characteristics. These 49 codes were developed into a 49-item survey (Supporting Information).

Round 2

The 49-item survey was presented in four sections as established in Round 1.

Twenty-two people completed the survey. There were five instances of missing data across four items which were replaced with the median score.

There were no items that had a median score of not important. Eight items had a median score of somewhat important; 35 items had a median score of important (including one item that had a median score of 2.5) and seven items had a median score of very important.

Consensus varied between 23% (Item 26: Interventions that are simple and brief due to caregivers limited time) and 77% (Item 16: Interventions that are sustainable after study conclusion and Item 22: Interventions that have flexible doses to vary with caregiver need). The median consensus across all items was 50%.

Round 3

The survey was readministered with group median results presented, allowing participants to revisit their scores. Three participants did not respond to round 3, resulting in 19 responses.

Round 3 data are presented as Supporting Information with the final classification for each item, rated for priority and consensus. There were seven high priority items identified (Table 1):

Priority scores were mostly stable between Round 2 and Round 3. One item changed the priority score after Round 3. Patient physical health (Item 33) as a priority outcome went from a score of 2 (somewhat important priority) to 3 (important priority). The seven high priority items were stable between Round 2 and Round 3.

Consensus across the items is also presented as Supporting Information. The average consensus increased to 64% in Round 3, ranging from 42% (Younger caregivers, from Priority Caregiver Groups, Item 2; and Studies that include caregiver co-design, from Priority Study Designs, Item 43) to 89% (Interventions that are sustainable after study conclusion, from Priority Interventions, Item 16 and Caregiver Physical Health for Priority Outcomes, Item 34).

Table 1: High Priority Items in Cancer Caregiver Intervention Research

Category	Item
Participants	1. Marginalised, disadvantaged and minority groups
Participants	3. Socially isolated or poorly supported caregivers
Participants	8. Caregivers that are identified as needing support, rather than targeting caregivers based on demographic variables
Interventions	16. Interventions that are sustainable after study conclusion
Interventions	17. Interventions that are tailored to caregivers individual circumstances and needs
Outcomes	30. Outcomes deemed important by caregivers
Studies	44. Studies that assess the long term impact (12+ months) of interventions

The average consensus increased to 64% in Round 3, ranging from 42% (Items 2 and 43) to 89% (Items 16 and 34).

Discussion

This Delphi study was conducted over three rounds to consolidate expert views on priorities for cancer caregiver interventions. Round 1 contributions were varied and extensive and over Round 2 and Round 3 items were assessed for priority and consensus. Very important priorities included participants identified as minority groups or disadvantaged, those who are isolated and those identified as needing support; interventions that are sustainable and tailored; outcomes that are important to caregivers and studies that assess the long term impact of interventions.

The three items belonging to the Participant category focused on minority groups in need of which often have higher cancer burden and poorer outcomes. This is consistent with other priority setting work that recommends more research on vulnerable populations.[9, 14] Caregiver research generally does not focus on groups in need of intervention with very few studies screening or establishing criteria to include people who need support.[8] These findings suggest a need to move towards prioritising and targeting high risk and vulnerable groups. While these are often difficult to research, there may be need to rethink approaches to accessing these individuals. **In policy and clinical practice**, strategies to engage minority groups in accessing needed support should be developed. Further research is required to understand the diverse issues and situations affecting diverse and minority groups.

High priorities for interventions were sustainability of interventions (high consensus) and tailoring of interventions (moderate consensus). Technology based interventions may address these priority areas. A systematic review has shown these are appropriate and acceptable for caregivers,[17] however other studies suggest that interest in such interventions can vary.[18] The need for sustainable interventions has been acknowledged in psycho-oncology.[19-21] There are some cancer caregiver interventions that are implemented and in practice, [22] and further research should consider sustainability during the early stages of intervention development.

Caregiver nominated outcomes were also a high priority. This could reflect the importance of consumer driven approaches to measurement as opposed to professional assessments of functioning.[23] A priority for Study Designs was studies that have a long term follow up. Although it has been established that caregivers can experience distress in the long term, a systematic review on psychosocial interventions for couples found that follow up timing ranged from after intervention delivery to 12 months but not beyond.[24] A systematic review on psychosocial interventions for couples found that follow up timing ranged from after intervention delivery to 12 months but not beyond.[24] While this has been identified as a priority, it is important to recognise the additional study costs associated with longer follow up periods.

Consensus was not reached for four items, representing diverse or split views from participants. Three were from Participants, representing specific groups (younger caregivers, caregivers of people with rare incidence cancers, caregivers of people in palliative care settings). The other area of non-consensus was co-design of interventions (item 43). Studies of cancer caregivers that adopt co-design have noted that the process can be complex [25], and approaches to co-design can vary.[26] While there are guidelines on how to co-design which can be utilised,[27] it has been acknowledged that tailoring this process is often necessary.[28] Although this item was rated as a priority, given that consensus was not achieved may mean that some experts are not confident with the benefits of, or the methods used, for co-design of caregiver research. This may be an avenue for future work. Co-design is relevant across research, development of policy and in clinical practice interventions.

Many of the priorities identified in this study represent more methodologically challenging studies, and future research could explore optimising research approaches or methods that address these priorities. A strength of this study was the utilisation of the PICO framework. The Delphi panel were reasonably large with good retention; they were also highly experienced and a wide range of issues were generated. There are also limitations to the present study. Understanding caregivers' views about priorities through caregiver input is highly important. Another limitation was the lack of qualitative data which would have allowed us to better understand the reasoning behind scoring. Data were not collected from non-responders and consequently understanding their profile and how they compared to participants was not elucidated.

Conclusions

Cancer caregiver intervention priorities include people who are from minority groups or are disadvantaged, those who are isolated and those identified as needing support; interventions that are sustainable and tailored; outcomes that are important to caregivers and assess the long term

impact of interventions. Optimising approaches to conduct these studies and complementing these findings with qualitative work may be important avenues of future work.

Conflict of Interest Statement

The authors report no conflicts of interest.

References

1. Edwards BK, Brown ML, Wingo PA, Howe HL, Ward E, Ries LA, Schrag D, Jamison PM, Jemal A, Wu XC: Annual report to the nation on the status of cancer, 1975–2002, featuring population-based trends in cancer treatment. *Journal of the National Cancer Institute* 2005, 97(19):1407-1427.
2. Teschendorf B, Schwartz C, Ferrans CE, O'mara A, Novotny P, Sloan J: Caregiver role stress: when families become providers. *Cancer Control* 2007, 14(2):183-189.
3. Applebaum AJ, Breitbart W: Care for the cancer caregiver: a systematic review. *Palliative & supportive care* 2013, 11(3):231-252.
4. Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C: Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative medicine* 2010, 24(6):594-607.
5. Lapid MI, Atherton PJ, Kung S, Sloan JA, Shahi V, Clark MM, Rummans TA: Cancer caregiver quality of life: need for targeted intervention. *Psycho-oncology* 2016, 25(12):1400-1407.
6. Ferrell B, Wittenberg E: A review of family caregiving intervention trials in oncology. *CA: a cancer journal for clinicians* 2017, 67(4):318-325.
7. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW: Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: a cancer journal for clinicians* 2010, 60(5):317-339.
8. Ugalde A, Gaskin CJ, Rankin NM, Schofield P, Boltong A, Aranda S, Chambers S, Krishnasamy M, Livingston PM: A systematic review of cancer caregiver interventions: Appraising the potential for implementation of evidence into practice. *Psycho-oncology* 2019, 28(4):687-701.
9. Kent EE, Rowland JH, Northouse L, Litzelman K, Chou WYS, Shelburne N, Timura C, O'Mara A, Huss K: Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. *Cancer* 2016, 122(13):1987-1995.
10. Griffin JM, Meis LA, MacDonald R, Greer N, Jensen A, Rutks I, Wilt TJ: Effectiveness of family and caregiver interventions on patient outcomes in adults with cancer: A systematic review. *Journal of general internal medicine* 2014, 29(9):1274-1282.
11. Ropka ME, Guterbock TM, Krebs LU, Murphy-Ende K, Stetz KM, Summers BL, Bissonette E, Given B, Mallory G: Year 2000 Oncology Nursing Society Research Priorities Survey. In: *Oncology Nursing Forum: 2002*; 2002.
12. Nehl EJ, Blanchard CM, Stafford JS, Ainsworth S, Baker F: Research interests in the field of behavioral, psychosocial, and policy cancer research. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2003, 12(4):385-392.
13. Rankin NM, Butow PN, Price MA, Evans A: Views of psycho-oncology health professionals on priority psycho-oncology research questions. *Supportive Care in Cancer* 2011, 19(8):1133-1141.
14. Lambert SD, Brahim LO, Morrison M, Girgis A, Yaffe M, Belzile E, Clayberg K, Robinson J, Thorne S, Bottorff JL: Priorities for caregiver research in cancer care: an international Delphi survey of caregivers, clinicians, managers, and researchers. *Supportive Care in Cancer* 2019, 27(3):805-817.

15. Blaschke S-M, Lambert SD, Livingston PM, Aranda S, Boltong A, Schofield P, Chambers SK, Krishnasamy M, Ugalde A: Identifying priorities for cancer caregiver interventions: protocol for a three-round modified Delphi study. *BMJ open* 2019, 9(2):e024725.
16. Meskell P, Murphy K, Shaw DG, Casey D: Insights into the use and complexities of the Policy Delphi technique. *Nurse researcher* 2014, 21(3).
17. Heynsbergh N, Heckel L, Botti M, Livingston PM: Feasibility, useability and acceptability of technology-based interventions for informal cancer carers: a systematic review. *BMC Cancer* 2018, 18(1):244.
18. Köhle N, Drossaert CHC, Van Uden-Kraan CF, Schreurs KMG, Hagedoorn M, Verdonck-de Leeuw IM, Bohlmeijer ET: Intent to use a web-based psychological intervention for partners of cancer patients: Associated factors and preferences. *Journal of Psychosocial Oncology* 2018, 36(2):203-221.
19. Rankin NM, Butow PN, Hack TF, Shaw JM, Shepherd HL, Ugalde A, Sales AE: An implementation science primer for psycho-oncology: translating robust evidence into practice. *Journal of Psychosocial Oncology Research and Practice* 2019, 1(3):e14.
20. Rodin G: From evidence to implementation: the global challenge for psychosocial oncology. *Psycho-oncology* 2018, 27(10):2310-2316.
21. Schofield P, Chambers S: Effective, clinically feasible and sustainable: Key design features of psycho-educational and supportive care interventions to promote individualised self-management in cancer care. *Acta Oncologica* 2015, 54(5):805-812.
22. Longacre ML, Applebaum AJ, Buzaglo JS, Miller MF, Golant M, Rowland JH, Given B, Dockham B, Northouse L: Reducing informal caregiver burden in cancer: evidence-based programs in practice. *Translational Behavioral Medicine* 2018, 8(2):145-155.
23. Paul C, Sanson-Fisher R, Carey M: Measuring psychosocial outcomes: is the consumer or the professional the best judge? *European journal of cancer care* 2013, 22(3):281-288.
24. Badr H, Krebs P: A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-Oncology* 2013, 22(8):1688-1704.
25. Santin O, McShane T, Hudson P, Prue G: Using a six-step co-design model to develop and test a peer-led web-based resource (PLWR) to support informal carers of cancer patients. *Psycho-oncology* 2019, 28(3):518-524.
26. Donetto S, Pierri P, Tsianakas V, Robert G: Experience-based co-design and healthcare improvement: realizing participatory design in the public sector. *The Design Journal* 2015, 18(2):227-248.
27. Adams M, Maben J, Robert G: Improving patient-centred care through experience-based co-design (EBCD): an evaluation of the sustainability and spread of EBCD in a cancer centre. *King's College London* 2014.
28. Piper D, Iedema R, Gray J, Verma R, Holmes L, Manning N: Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study. *Health Services Management Research* 2012, 25(4):162-172.