

BMJ Open Co-design of family interventions in cancer: a scoping review protocol to assess key methods and processes

Cristina Alfaro-Díaz,^{1,2} Camilla S Rothausen,^{3,4,5} Maria Samuelsson ⁶

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¹Department of Nursing Care for Adult Patients, School of Nursing, Universidad de Navarra, Navarra, Spain

²IdiSNa, Navarra Institute for Health Research, Universidad de Navarra, Navarra, Spain

³Department of Oncology, Odense University Hospital, Odense, Denmark

⁴Department of Clinical Research, University of Southern Denmark, Odense, Denmark

⁵FaCe - Family focused healthcare research Center, University of Southern Denmark, Odense, Denmark

⁶Department of Care Science, Faculty of Health and Society, Malmö University, Malmö, Sweden

Correspondence to

Dr Maria Samuelsson;
maria.samuelsson@mau.se

ABSTRACT

Introduction Cancer affects not only patients but also their families, increasing the risk of stress-related illnesses among family members. Despite the development of various support interventions, family members continue to report unmet support needs, largely due to the limited implementation of these interventions into routine care or their lack of relevance to family needs. Co-design approaches, which involve stakeholders in the development process, are recommended to enhance both implementation and relevance. This scoping review aims to map the available evidence on co-design approaches in family interventions within oncology, examining key themes, methodologies and outcomes of interventions.

Methods and analysis This scoping review will be conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for Scoping Reviews checklist and the Joanna Briggs Institute framework. The review will follow five stages: identifying the research questions, retrieving relevant studies, selecting studies, charting data and collating, summarising and reporting the results. The research will focus on co-design approaches in family interventions in oncology, exploring activities involved, barriers encountered and their impact on outcomes. A comprehensive search was conducted in EMBASE, MEDLINE, Scopus, CINAHL and PsycINFO databases in August 2024, with no date restrictions, and articles will be selected based on predefined inclusion criteria. Study selection will be performed independently by two reviewers, with disagreements resolved by a third. All reviewers will carry out the data extraction. Data will be analysed using descriptive content analysis and presented through narrative summaries, tables and diagrams to highlight study characteristics and research aims. The findings will inform future research and practice, offering insights into co-design strategies in family interventions in oncology.

Ethics and dissemination Ethical approval is not needed as this scoping review does not involve collecting data from human participants. The results produced from this review will be submitted to a scientific peer-reviewed journal for publication and will be presented at scientific meetings.

Trial registration details <https://doi.org/10.17605/OSF.IO/2RWB9>.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The application of a rigorous, well-established methodological framework will ensure the production of a high-quality review.
- ⇒ Reporting adheres to the relevant EQUATOR guidelines.
- ⇒ The review will include studies published in English, Spanish, Swedish, Norwegian and Danish.
- ⇒ Focusing only on English-language terms could introduce language bias, potentially overlooking relevant research in Danish, Norwegian, Spanish and Swedish.
- ⇒ The complexity and length of the search string could make it difficult to replicate, which may impact the reproducibility of this review.

INTRODUCTION

Cancer is considered a family affair,¹ as the health and well-being of the whole family can be at risk during this time. For example, family members of persons diagnosed with cancer face a higher risk of stress-related illness, such as ischaemic and coronary heart disease, as well as stroke, compared with the general population.^{2,3} These risks persist over time. As a result, supporting family members is emphasised, and numerous support interventions have been developed.^{4,5} Nevertheless, family members continue to report unmet support needs,⁶ highlighting the ongoing need for research into effective ways to assist families affected by cancer.

Suggested reasons for the persistent unmet needs are that these support interventions are not implemented into routine cancer care⁷ or are not fully aligned with family members' needs.⁸ As a result, despite showing promising results on family members' health and well-being in research trials, support interventions may fail to reach the larger population of family members in need.⁷ To overcome implementation barriers and enhance content relevance, a co-design approach to intervention development is recommended.⁹

Co-design and participatory methods are defined as the processes in which participants and other relevant stakeholders form a partnership and take an active role in intervention development and dissemination.¹⁰ While co-design is a specific form of participatory research that emphasises shared decision-making and iterative development, participatory approaches encompass a broader spectrum of methodologies with varying degrees of stakeholder involvement. These approaches ensure that interventions are shaped by the perspectives and experiences of those directly affected. For example, Parmar *et al*¹¹ describe how a co-design process involving caregivers, healthcare providers, educators and policymakers led to the development of a caregiver education programme that fostered inclusivity and collaboration. By actively engaging caregivers in identifying key challenges and educational needs, the intervention ensured that training for healthcare providers was more relevant and impactful, ultimately improving caregiver support and well-being.

By involving end users and receivers of interventions—such as patients, caregivers and healthcare professionals—in the research processes (eg, prioritising research questions, determining strategies for data collection or refining intervention delivery),¹² co-design is suggested to lead to more relevant research and enhanced uptake of interventions.¹³ Additionally, it has been associated with improved recruitment, response and retention rates in clinical studies.¹⁴ This shift from conducting research ‘on’ people to conducting research ‘with’ people is increasingly endorsed.^{15–18} Hence, by applying co-design principles, interventions can be developed to fit the practical constraints of routine cancer care while remaining relevant to the needs of family members.⁹

Co-design encompasses a broad range of activities throughout the entire research process—from formulating the research question to dissemination of findings¹⁰—and has been associated with positive impacts on research. While previous reviews have examined family interventions in cancer care, none have specifically mapped the evidence on co-design approaches and activities within these interventions. This review seeks to address that gap by identifying and synthesising how co-design has been applied in family-focused cancer care. Additionally, this scoping review will describe the characteristics and contexts of these co-design efforts, highlighting key themes, methodologies and outcomes associated with the interventions. By offering a comprehensive overview of co-design approaches and activities, this review will serve as a foundational step toward improving our understanding and application of co-design in oncology. Ultimately, it aims to guide future research and practice in developing more effective and collaborative interventions for patients with cancer and their families. To ensure this review’s novelty, preliminary searches were conducted in PubMed, PsycINFO, CINAHL, Cochrane Library and PROSPERO to identify any comparable published or ongoing systematic or scoping reviews. No such reviews were found.

Aim

The objective of this scoping review is to systematically map the literature to provide an accessible synopsis of current co-design approaches and activities in family interventions in cancer.

METHODS AND ANALYSIS

This protocol is reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) extension for Scoping Reviews checklist.¹⁹ A scoping review method was selected as it aims to outline different types of evidence on the area of interest and the gaps for further research.²⁰ The protocol refers to an upcoming scoping review that will be undertaken iteratively following the stages first established by Arksey and O’Malley²¹ and later refined by Levac *et al*²² and Colquhoun *et al*²³ all of which are described by the Joanna Briggs Institute (JBI)²⁴: identifying the research question, retrieving relevant studies, selection of studies, charting data and collating, summarising and reporting evidence. The study protocol is registered in the Open Science Framework (<https://doi.org/10.17605/OSF.IO/2RWB9>).

Stage 1: identifying the research question

This scoping review aims to explore co-design approaches specifically in the context of family interventions in cancer. The review will answer the following main questions:

1. What approaches to research co-design exist in family interventions in oncology?
2. What activities are involved in these research co-design approaches within family interventions?
3. What is known about reported hindrances and the impact of the co-design activities on study outcomes in family interventions?

Stage 2: identifying relevant studies

The literature search will be carried out following the three-step strategy recommended by the JBI for conducting a scoping review.²⁴ In June 2024, an initial search in MEDLINE (Ovid) and EMBASE (Ovid) was carried out to identify relevant keywords found in titles, abstracts and index terms of pertinent studies. The identified keywords and index terms were used to conduct a comprehensive search. This search strategy was elaborated with the assistance of a librarian with expertise in literature review and it was informed by the Peer Review of Electronic Search Strategies Guideline Statement.²⁵ The search was conducted in August 2024 across the following databases: EMBASE, MEDLINE, Scopus, CINAHL and PsycINFO. No restrictions were placed on publication dates. Finally, a backward citation search and forward citation tracking of reference lists were performed on the sources identified during full-text screening to locate relevant articles not identified in the previous phase. The complete search strategy used in databases is described in online supplemental 1. Reviews will be retained for

hand-searching relevant references and grey literature (opinion pieces, editorials/letters, government reports and conference proceedings) will be excluded.

Inclusion criteria

The following inclusion criteria were formulated:

- ▶ *Participants*: This review will include studies involving adult patients diagnosed with any type of cancer and their adult family caregivers. The terms 'family' and 'family caregivers' are used interchangeably. 'Family' is defined as a group of two or more persons bound by strong emotional ties, a sense of belonging and a passion for being involved in one another's lives.²⁶ This inclusive definition encompasses the whole family, irrespective of blood or social relations, ensuring that the included literature is not limited to specific family members (eg, caregivers or parents). Studies that focus on family caregivers of adults with cancer, even if the patient is not included, will also be considered eligible for inclusion.
- ▶ *Exposure*: Studies will be included if they describe interventions that use co-design or participatory methods at any stage of development, implementation and dissemination.¹⁰ In this study, co-design refers to a structured, collaborative approach where patients, family members, healthcare professionals and/or researchers work together throughout different stages of the research process. This involvement can range from identifying research priorities and shaping study design to analysing data and disseminating findings.
- ▶ *Outcome*: Family interventions are defined as any approach used to promote, maintain and restore family health or the health of family members/caregivers.²⁶ This review will consider all well-defined interventions or experimental studies focusing on family members, whether or not they are physically present in the intervention.
- ▶ *Type of studies*: This scoping review will include all relevant qualitative, quantitative or mixed-method studies that used co-design to develop a new family intervention or to improve or adapt an existing one in oncology services, as well as studies that evaluated the co-design process.
- ▶ *Context*: This review will consider studies conducted in the context of any type of oncological or haematological cancer.

Stage 3: study selection

Search results collected from the electronic databases will be exported to Covidence software (available at www.covidence.org) for processing. The selection of studies will be executed in a three-step manner. First, duplicate studies will be removed. Second, two reviewers will independently review the titles and abstracts of all articles to determine eligibility. If discrepancies are present, a third reviewer will be involved. In the third step, articles will be read in their entirety and mirrored against the predefined inclusion criteria. A third reviewer will resolve

any unresolved disagreements. The final scoping review will include the reasons for excluding articles after full-text review. The study selection process will be presented in the final scoping review using the PRISMA flowchart, detailing source selection, duplicate removal, full-text retrievals, additional searches, data extraction and data presentation.

Stage 4: charting the data

A customised data extraction tool has been developed for this scoping review, based on the tool created by the JBI.²⁴ This tool will capture general data such as title, authors, year of publication, country and study type. The extraction form will be initially tested on three articles to assess its effectiveness and identify any unforeseen data that need to be recorded. All reviewers will carry out the data extraction. Additionally, the JBI Critical Appraisal Tools will be used to evaluate the quality of included studies. These tools are instrumental in evaluating the reliability, relevance and findings of the articles. However, all articles will be included in the scoping review regardless of their results, as the primary aim is to gather all available evidence on the topic. Following this, data extraction and descriptive evidence mapping will be conducted.

Stage 5: collating, summarising and reporting the results

A descriptive summary of the scoping review process and the characteristics of the included studies will be presented. In line with the methodology from JBI2,⁴ the extracted data will undergo descriptive content analysis. The results will be mapped using tables or diagrams to outline existing knowledge, emphasise key study characteristics and research aims. To ensure clarity in categorising and synthesising details concerning co-design and participatory methods, the results will be systematically classified based on the types of co-design approach, methods and stakeholders' characteristics and preparation to participate in the co-design process. A detailed narrative report will provide deeper insights into the findings, alongside a synthesis of the results and a critical discussion of their broader implications.

DISCUSSION

This scoping review protocol is a crucial first step in planning this type of review, as it provides a rigorous description of the methodology to be followed, ensuring a carefully planned and transparent review process.¹ The scoping review will systematically map the available evidence on co-design approaches and activities in family interventions in cancer. Additionally, it will describe the characteristics and contexts of these co-design efforts, identifying key themes, methodologies and outcomes associated with interventions.

The results of this scoping review will offer an overview of co-design approaches and activities in family interventions in cancer. Ultimately, this review will serve as a foundational step for enhancing our understanding

and application of co-design in oncology, guiding future research and practice in developing more effective and collaborative interventions for patients with cancer and their families.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

ETHICS AND DISSEMINATION

Ethical approval is not needed as this scoping review does not involve collecting data from human participants. The results produced from this review will be submitted to a scientific peer-reviewed journal for publication and will be presented at scientific meetings.

Contributors CA-D, MS and CSR led the design, search strategy and conceptualisation of this work. MS is the guarantor. All authors were involved in the planning and conceptualisation of the review design and the development of the search strategy. Further, all authors formulated the research questions and inclusion and exclusion criteria and drafted the form for data extraction. All authors gave their approval to the publishing of this protocol manuscript.

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ORCID iD

Maria Samuelsson <http://orcid.org/0000-0001-8700-4490>

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