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Developing an educational resource for gynecological cancer survivors and their caregivers: A methods and experience paper

By Jacqueline Galica, Amina Silva, Kathleen Robb

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ABSTRACT

Building upon the need for greater education, identified by gynecological cancer survivors and their caregivers, the objective of this paper is to describe our patient-clinician-researcher partnership to develop an evidence- and experiential-based educational resource. We engaged in five phases using multiple research methods: 1) assembling the essential expertise, 2) reviewing the literature, 3) drafting the resource, 4) testing the resource, and 5) disseminating the resource. Our diverse partnership provided expertise toward multiple research methods that produced results useful for each successive phase. This combination – a diverse partnership and multiple research methods – resulted in a useful resource to fulfill a gap identified by knowledge users. The combined features described in our paper fill a procedural gap for clinicians and researchers intending to develop educational resources that are empirically and experientially founded.

INTRODUCTION

The number of people surviving cancer is increasing (Canadian Cancer Statistics Advisory et al., 2022). Although this is good news, cancer survivors and their informal caregivers experience a variety of concerns after completing primary treatment (Canadian Partnership Against Cancer/Partenariat canadien contre le cancer, 2018; Kent et al., 2016). These concerns may relate to physical, mental, and emotional matters (Canadian Partnership Against Cancer/Partenariat canadien contre le cancer, 2018), which can persist for years after treatment is complete. Given that unresolved concerns for cancer survivors result in greater use of healthcare resources (i.e., emergency department visits; Lebel et al., 2013), greater awareness about what to expect after treatment can help mitigate some of their concerns (Galica et al., 2020; Galica et al., 2022). Considering these points, educational resources may be helpful to prepare survivors and their caregivers for the transition out of primary cancer treatment and improve their overall well-being.

Although there has been increased attention toward developing transitional educational interventions for cancer survivors (Liska et al., 2018; Nekhlyudov et al., 2019), the development, delivery and effectiveness of these interventions can vary widely (Hawkins et al., 2017). Furthermore, the involvement of knowledge users, such as patients and/or clinicians, in the development of these educational interventions is not always apparent. Involving knowledge users throughout the process of identifying the need for and development of educational interventions increases the likelihood of their relevance and sustained use (Boden et al., 2021; Lyon & Koerner, 2016).

Despite the importance of involving knowledge users in the development of resources, there is a lack of comprehensive guidance about how to co-develop interventions to address matters relevant to cancer care. To fill this gap, our aim for this paper is to describe our patient-clinician-researcher experience developing an evidence- and experiential-informed educational resource for cancer survivors, and their caregivers, at the end of primary cancer treatment. Building upon the need for greater education identified by gynecological cancer (GC) survivors in our region (Galica et al., 2020), we developed a five-phase process (Figure 1) to develop the resource: (1) assembling the essential expertise, (2) reviewing the literature, (3) drafting the resource, (4) testing the resource, and (5) disseminating the resource. In the following sections, we describe the methods enacted in each phase of our process. We also share some of our reflections on this process for those interested in developing educational resources with and for cancer patients, survivors, and their caregivers.

Phase 1: Assembling the essential expertise

Healthcare interventions can be complex and therefore challenging to plan and implement. As such, to ensure an intervention's relevance, it is important to infuse multiple perspectives that are inclusive and pertinent to its development

AUTHOR NOTES

Jacqueline Galica, Queen's University School of Nursing; Kingston, ON; Queen's Cancer Research Institute, Division of Cancer Care and Epidemiology, Kingston, ON

Amina Silva, Brock University School of Nursing; St. Catharines, ON

Kathleen Robb, Patient Partner

Corresponding author: Jacqueline Galica, Queen's University School of Nursing, 92 Barrie Street, Kingston, Ontario, K7L 3N6

Email: **jacqueline.galica@queensu.ca**

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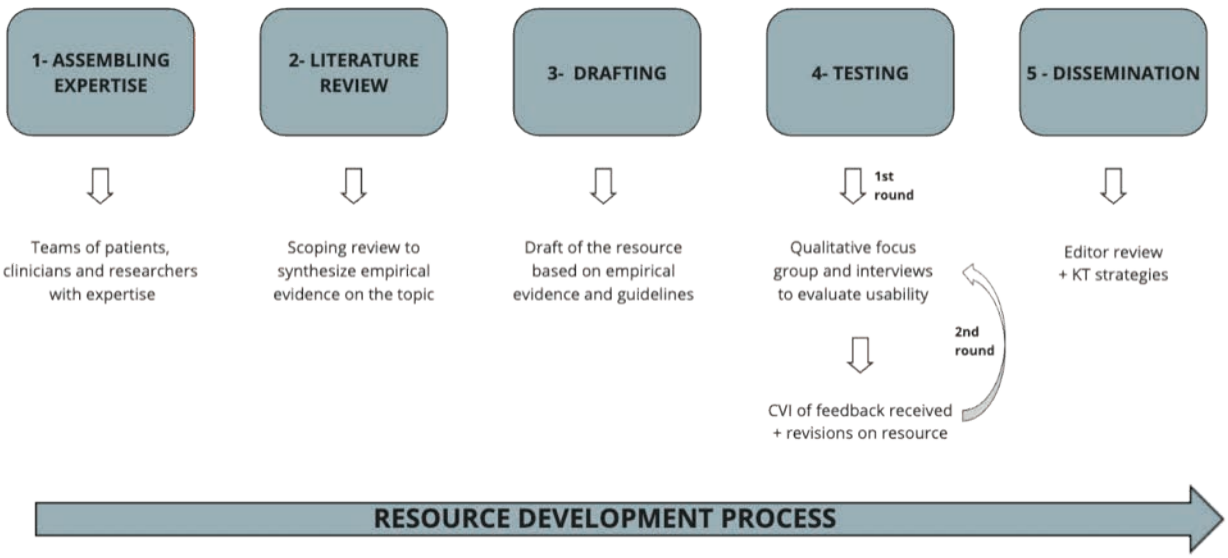
Figure 1

Stages of the Resource Development Process



(O'Cathain et al., 2019). With this in mind, we assembled two teams of patients, clinicians, and researchers with GC expertise in the planning stages of this study: a core team that was responsible for implementing the research, and an advisory team having varying backgrounds and expertise to inform the study materials and processes. The teams were both led by a GC survivor (KR) and a psychosocial oncology nurse researcher (JG) who co-led all study processes and team meetings. These co-leads oversaw and worked alongside two research assistants (one graduate student who was a registered nurse and one undergraduate nursing student) who collectively worked as the core team. The co-leads assembled an advisory team consisting of three GC survivors and four GC clinicians: two medical oncologists, a Nurse Practitioner, and a social worker with expertise in psychosocial oncology. This advisory group was assembled based upon their diverse expertise in GC care (medical, nursing and psychosocial) before conducting the following phases. In each phase, specific instructions were not provided to the advisory group; instead, the advisory group was invited to contribute any and all feedback based upon their experiential and/or clinical perspective. After a review by the core team, their feedback was incorporated into the work of each phase and used to inform the planning for the subsequent phase(s). Further details are provided within each phase.

Phase 2: Reviewing the literature

To optimally meet the needs of knowledge users, it is imperative that evidence-based information be used throughout the development process. A scoping review, which is a method useful to summarize evidence about a topic (Munn et al., 2018), was used as a second step in our development of the resource. The review synthesized empirical literature about the needs of GC survivors and their informal caregivers at the end of and following primary cancer treatment (Galica et al., 2022). The core team organized the needs identified in the included studies into seven content-specific areas: (1) physical needs, (2) sexuality-related concerns, (3) altered self-image, (4) psychological well-being, (5) social support needs, (6) supporting the return to work, and (7) healthcare preferences. These content areas were shared with our advisory team and their feedback was used to draft a model to guide clinical discussions to address GC survivors' needs at the end of primary treatment (Galica et al., 2022).

Phase 3: Drafting the resource

Our core team used the content-specific areas identified in the scoping review (Galica et al., 2022) to draft an educational resource pertaining to six[1] dimensions of recovery for GC survivors and their caregivers. Each dimension is presented as a distinct chapter in the resource beginning with general information to introduce and describe that dimension followed by content that readers can use to assess and/or self-manage what they are experiencing in relation to that dimension. Readers are assured that not all dimensions, nor all details presented within each dimension, may be relevant to them. As such, reflective questions are posed and used to identify possible topics of conversation with healthcare providers and/or caregivers. Exemplars from qualitative research papers are

1 Notably, there are seven content areas (dimensions) described in the scoping review, but only six are relevant to the resource we developed. The content included within the 'healthcare challenges and preferences' was deemed as relevant only to clinicians and not applicable to the goals of the resource intended for survivors and their caregivers.

inserted as quotes within each chapter to illuminate the experiences of other cancer survivors in relation to that dimension. Strategies and resources to self-manage each dimension were retrieved from empirical reviews and guidelines. Each chapter includes ample space for note taking and coloured illustrations exist throughout.

The drafted resource was reviewed by the advisory team who used their lived and clinical experiences to evaluate the resource's content, usability, and potential applicability for GC survivors and their caregivers. All advisory members provided feedback to improve the resource (e.g., revised wording to improve accessibility, need for more content). The core team considered the relevance of all feedback with the intended purpose of the resource; suggestions were incorporated accordingly.

Phase 4: Testing the resource

We used a qualitative approach to assess the usefulness of the resource; such methods are useful to investigate the applicability of healthcare interventions through the collection of comprehensive feedback from knowledge users (Yardley et al., 2015). Gyncological cancer survivors and their informal caregivers were purposively recruited whereby GC clinicians at our regional cancer centre identified those with diverse perspectives (e.g., a variety of GC diagnoses and representing geographic locations across our region). Individuals and/or their informal caregivers (e.g., partners, family members, etc.) who had completed primary treatment for GC within the preceding five years were invited to participate.

We completed two rounds of data collection. In Round 1, participants received the drafted resource in their preferred format (hard copy or electronic). They had two weeks to review the resource and prepare feedback and suggestions for refinement. To guide their review, participants were asked to consider their own experiences at the end of primary cancer treatment and if/how the resource would have been useful to them at that time. They were also asked to consider what content was missing from the resource based upon their experiences. We met with participants in their preferred format – either a Zoom focus group or 1:1 interview – wherein they shared their feedback and suggestions for refining the resource. Given that the resource focussed on GC survivor concerns at the end of primary treatment, data collection from GC survivors and caregivers occurred separately. This permitted us to examine the nuanced perspective of each group in relation to a resource that addressed the needs of GC survivors. This approach also allowed us to understand how to improve the resource in a way that was meaningful to both groups. The focus groups and individual interviews were audio recorded and transcribed verbatim.

The core research team reviewed participants' feedback and suggestions for relevance with the intended purpose of the resource. Relevant feedback and suggestions were grouped using a content analysis approach (Vaismoradi et al., 2013) and assembled into a list of topics to be considered for inclusion. In this way, we used a content validation process (Yusoff, 2019) wherein the core team and advisory members used a three-point scale (1 = no change needed, 2 = change could be considered, and 3 = change must be made) to evaluate the relevance of each topic considered for inclusion (Figure 2). Topics with an overall mean ranked as 2 or 3 were incorporated into a revised version of the resource.

In Round 2, the revised version of the resource was sent to Round 1 participants who again had two weeks to review and prepare their feedback and suggestions for refinement. Participants were provided with the same guidance for their second review (e.g., if/how useful, what content is missing). Thereafter, a second round of focus groups and individual interviews were conducted wherein participants provided suggestions and feedback to the revised version of the resource. Consistent with the Round 1 process, focus groups and interviews were audio recorded and transcribed verbatim and participants' feedback and suggestions were analyzed and reviewed for relevance. Although another content validation process (Yusoff, 2019) was planned, Round 2 feedback and suggestions for refinement were minor deeming the content validation process unnecessary: these minor feedback and suggestions were incorporated into the final version of the resource.

Phase 5: Dissemination

Being that the translation of evidence into clinical practice can take up to 17 years (Morris et al., 2011), engaging in carefully planned and relevant dissemination strategies are essential. Given the intent and processes used in this project, a diversity of patient, clinician, and researcher audiences were considered. The process of patient dissemination began with a plain language editor review of the resource for readability, content, grammar, cohesion, syntax, etcetera. Revisions to simplify language and ensure grammatical correctness were made while ensuring no changes to the resource's content nor meaning. Since some participants indicated a preference to receive the resource in hard copy, we identified printing options to support this mode of dissemination. The process of disseminating the resource to knowledge users occurred via academic presentations and manuscripts targeted at clinicians and researchers interested in patient education, cancer care, and survivorship.

DISCUSSION

Our patient-clinician-researcher partnership conceptualized and completed a five-phase process using multiple research methods to develop an educational resource for GC survivors and their caregivers. The diversity of members reflected on our team brought expertise needed to comprehensively inform and implement each phase. These included the lived experiences of cancer survivors and/or caregivers, the perspectives of clinicians working in a cancer care system, and researchers with expertise to plan and oversee the methods used. The methods used in our process were also diverse (e.g., review and qualitative methods) and informed the implementation of each successive phase. This combined approach – diverse membership and multiple research methods – presents in an original process to develop an educational resource for cancer survivors and their caregivers.

Figure 2

Content Validation Example

Dear ,

We have received suggestions from focus group participants on the draft Guide intended to support survivors and their caregivers for life following primary treatment for gynecological cancer. Given your personal and/or clinical and research expertise in gynecological cancer survivorship care, we would like to ask you for your opinion about the relevance of each suggestion received. We have attached the most current draft of the Guide for your reference.

Please review each of the following suggestions/feedback and rate the relevance of each suggestion using instruction provided below. Space is provided for you to add comments and/or context that will assist us to revise the Guide as appropriate.

We ask that you provide your responses by .

Rating scale:	
1 =	the suggestion does not apply to the intent of the Guide; no change or addition is required
2 =	the suggestion has some relevancy to the intent of the Guide but is not critical; a change, addition or reference could be considered
3 =	the suggestion is critical to the intent of the Guide; a change or addition should be made

Rationale/Comments:
Please provide the rationale for your relevance rating and your recommendation about where the item, if relevant, could be included. Please suggest the level of detail that should be included (e.g., just acknowledge the item as an issue, or include it with its strategy and resources, or just enhance an existing reference to the item, etc.). If you are aware of any useful resources that could be helpful, please provide these details.

Suggestion		**Relevance**		
1	Some participants (survivors) suggested that 'end-of-life' issues should be included along with strategies and resources to plan for death (e.g., information about MAID, palliative and hospice care options, etc.). Considering the intent of the guide, how do you rate the level of importance of this suggestion?	1 ( )	2 ( )	3 ( )
	RATIONALE/COMMENTS			

Although collaborations between knowledge users and researchers can improve clinical outcomes and research uptake (Boden et al., 2021; Lyon & Koerner, 2016), there is a lack of comprehensive guidance about how to co-develop interventions to address the informational needs of cancer patients, survivors and/or their caregivers. Our five-phase, multiple-research-methods approach provides cancer clinicians and/or researchers, particularly within gynecology oncology, with a process that addresses this gap. This process is innovative in that it integrates and prioritizes a patient-clinician-researcher partnership within a series of phases that involve multiple research methods. Furthermore, the research methods used in each phase produced results that were used within subsequent phases. Indeed, involving stakeholders in a multiple phase and multiple-methods-research process is recommended to develop interventions (O'Cathain et al., 2019). Our process builds upon this recommendation (O'Cathain et al., 2019) to integrate pertinent experiential and empirical knowledge to develop highly relevant educational resources for cancer patients, survivors, and/or their caregivers.

Process insights, strengths and limitations

When we completed the process of co-developing the resource, we reflected on our time of working together. In our reflections, we believe there are two noteworthy features of our collaboration that were essential to developing a relevant resource while maintaining a successful and rewarding research partnership. We believe that these features fueled our team's determination to persist through the lengthy process, nearly four years in our case, to complete the five phases described above. Below we describe our reflections of these features that can be useful for other patient-researcher partnerships planning to – or in the process of – working together.

The first noteworthy feature is our team's unwavering commitment to achieving the mutually defined goal of this project: to develop the resource. This commitment largely stemmed from the lived and clinical experiences of enduring the gap in cancer care that the resource intended to fill. However, due to the diversity of perspectives and availabilities of our team, it was useful to set clear and realistic timelines in order to keep the team engaged and motivated. This was particularly helpful as we faced adversities (e.g., recruitment challenges) that

resulted in revised project timelines. Such revisions were determined collaboratively, which sometimes proved challenging since our team included a core and advisory team who had various levels of involvement in project processes. In such instances, it was useful to refer to the role descriptions and expectations developed at the beginning of our partnership.

The second noteworthy feature of our team's success relates to our communication. Establishing spaces for thoughtful and respectful dialogue and clear role expectations was essential given the diversity of backgrounds reflected among team members. For instance, differences in perspectives stemmed from our lived experiences, either as a patient or clinician, which resulted in language differences to describe our perspectives and approaches to achieve the goal. Furthermore, our patient partner's disciplinary background was in executive-level strategic change management wherein projects were developed using rigorous project management methodology and change management frameworks. In this discipline, common terms and approaches used to develop projects varied greatly from those in the disciplinary backgrounds of our team's health researchers. One such example is the varied understanding of the term "*dissemination*". For our health researchers, this term broadly refers to knowledge translation strategies to promote the resource (e.g., via conference presentations). However, for our patient-partner with a business background, dissemination refers to the broad distribution of the resource (e.g., circulated printed copies). These language differences resulted in initial tensions whereby team members felt left behind or misunderstood in the process of developing the resource. Admittedly, the ensuing conversations required careful listening, respectful tones, and ample time to truly understand each other's stance in relation to the conversation being had and the overall project goal. Notably, as we neared the end of the project, we more easily recognized such language differences and were able to expediently discuss these.

CONCLUSION

Clinical guidelines and practice standards provide little-to-no guidance about supporting GC survivors and their caregivers through the transition from primary treatments; our process was intended to fill this gap using a combination of empirical and experiential evidence completed by a patient-clinician-researcher partnership. Although our process was completed to meet a need within our local cancer survivor community, our processes can be used by knowledge user-researcher partnerships within other geographical settings and population groups to develop relevant educational resources. Our reflections and learnings can be used to facilitate processes used by other teams.

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