



Addressing a critical need for caregiver support in neuro-oncology: development of a caregiver navigation intervention using eSNAP social resource visualization

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Abstract

Informal caregivers are key to oncology care, but often have unmet needs, leading to poor psychological and physical health outcomes. Comprehensive, proactive caregiver support programs are needed. We describe the development of a support intervention for caregivers of persons with brain tumors. The intervention uses a caregiver navigator to help participants identify and capitalize on existing social support resources captured using a web-based tool (eSNAP) and connects participants to existing formal services. We describe the iterative development process of the manualized intervention with particular focus on the caregiver navigator sessions. The process included review of the literature and published patient navigation programs, expert and stakeholder review, and study team member review. Quantitative and qualitative data were captured from the first 15 participants randomized to receive the intervention, enrolled from February 2020 to December 2020. Four participants dropped from the study, 9 completed at least 7 modules, and 8 participants completed all 8. Quantitative and qualitative data were collected primarily from those who completed the intervention; data suggest caregivers were satisfied with the intervention and found it helpful. Our intervention is one of the first theory-based caregiver support interventions to include caregiver navigation in neuro-oncology. We use best-practice guidelines for design, including extensive stakeholder feedback. COVID-19 may have impacted recruitment and participation, but some preliminary data suggest that those able to engage with the intervention find it helpful. Data collection is ongoing in a larger trial. If effective, caregiver navigation could be a model for future interventions to ensure caregiver support.

Keywords Navigation · Caregivers · Oncology · Community health · Communication · Brain tumor

Introduction

Informal caregiving is a critical component of oncology care. Informal caregivers are family members (including “chosen family”) who provide unpaid help and support to

an individual [1]. In addition to providing patients with emotional support, assisting with medical/nursing tasks, and managing household tasks, caregivers are also often responsible for patient care coordination and advocacy [2]. Caregivers often report being unprepared and overwhelmed

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by their caregiving role; [3] unmet needs can detrimentally impact caregivers' well-being [4]. Many caregivers must therefore learn to navigate the healthcare system for the patient, but also learn what resources are available to support their own needs.

The Stress Process Model of caregiving [5, 6] (see Fig. 1) posits that caregiver well-being is impacted by context (e.g., socio-economic status, caregiving history), primary stressors related to patient care, and secondary stressors related to other roles and activities (e.g., work, parenting) or caregivers' appraisals (e.g., self-esteem, perceived competence). The relationship between caregiver role and well-being can be impacted by social support and other coping strategies. Caregiver support programs address key factors identified in the Stress Process Model [7, 8]. For instance, caregivers with more support or better access to resources may be better able to share care responsibilities. Those with more adaptive coping strategies may be able to reframe caring for the patient as an opportunity rather than an obligation. However, despite clear evidence of benefit, most oncology care settings do not offer comprehensive, proactive caregiver support programs [9–11].

To address the unmet need to support family caregivers, we developed the electronic Social Network Assessment Program (eSNAP) [12]. eSNAP is a web-based app that quickly collects and organizes social support information into visualizations of the size, quality, and function of caregivers' support networks. In addition to reminding caregivers of the availability of existing support during the cataloguing process, visualization may make the availability of support or the need to assemble additional support more salient. eSNAP also provides a tailored list of formal services (e.g., websites, community, or cancer center programs). The goal of this tool is to increase perception of caregiver support, enhance proactive support-seeking, and ultimately improve well-being.

While previous research has shown positive outcomes associated with eSNAP [13, 14], additional tailoring and engagement were needed. Thus, we developed a caregiver

navigation component to complement and augment the eSNAP intervention, based on theory, existing patient navigation interventions, and stakeholder feedback.

Patient navigation is typically used to assist patients in overcoming barriers to cancer-related care [15]. Patient navigation is commonly implemented during cancer treatment and post-treatment survivorship; having a navigation process has been required for accreditation for various cancer programs in the USA [16, 17]. Navigators often assist with problem solving, make arrangements/refer to services, and provide emotional support [18, 19]. Patient navigation is an effective tool to provide support and assistance in coordinating care, and may improve satisfaction with care, reduce distress, and increase quality of life [20, 21]. While patient navigation programs often involve caregivers in facilitating care for cancer patients and survivors, there have been few navigation interventions designed to specifically meet the supportive care needs of caregiver [22, 23]. Navigation may help caregivers—especially those with high levels of burden—identify and coordinate resources to gain support to meet their needs and better cope with the challenges of caregiving.

This paper describes the development of one of the first theory-driven navigation interventions designed specifically to support informal caregivers of cancer patients. Combined with eSNAP, the goal of our caregiver navigation program is to increase the perceived and actual social support available to family caregivers, ultimately reducing caregiver stress and improving caregiver and patient quality of life.

Methods

Overview of eSNAP and caregiver navigation intervention

The 8-week intervention, combining eSNAP and caregiver navigation, is currently being tested in a randomized controlled trial of caregivers of patients with a primary brain tumor; see [24] for study details. Neuro-oncology caregivers were chosen based on their high levels of burden [14, 25]. Caregivers and patients at Moffitt Cancer Center (MCC) are enrolled within 6 months of diagnosis of a new or recurrent primary brain tumor. After completing baseline questionnaires, caregiver participants are randomized to one of two conditions: immediate intervention initiation, or a waitlist to receive the intervention at 8 weeks. Those randomized to receive the intervention immediately are provided access to eSNAP and are contacted by a caregiver navigator to complete navigation modules weekly for 8 weeks via phone, video conferencing, and/or email. At 8 weeks, participants in both conditions complete questionnaires; caregivers randomized to immediately receive the intervention

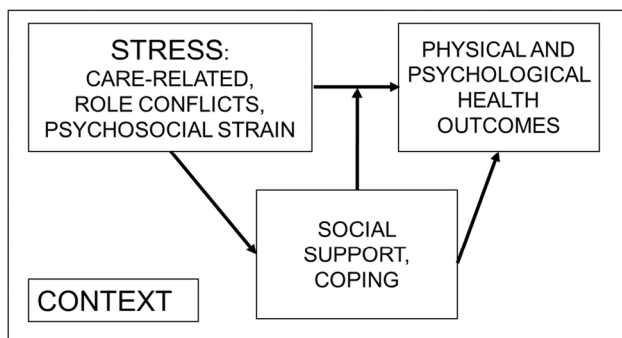


Fig. 1 Adapted Stress Process Model

also complete an additional satisfaction questionnaire and a qualitative interview. At this time, waitlisted caregivers are invited to receive the intervention.

In this manuscript, we focus on caregivers randomized to receive the intervention immediately. The study was approved by the Advarra Institutional Review Board (Pro00029204), and the procedures used adhere to the tenets of the Declaration of Helsinki. Informed consent was obtained from all participants included in the study.

A major goal of the caregiver navigation program is to provide caregivers with tools to identify and capitalize on existing support resources and integrate them with available formal services, including social work services. Each module was designed to begin with a brief assessment built around eSNAP. The caregiver navigator is able to review the visualization created by each caregiver in eSNAP [12] and can ask for additional information and context. Although flexibility is important given dynamic changes that occur with each patient's functioning, treatment, and prognosis, and caregiver resources to handle changes, we felt that intervention structure was important for fidelity purposes and evaluation within the research context.

Initial intervention development

The caregiver navigator program is a flexible, manualized intervention, and designed to be used in conjunction with eSNAP, a web-based tool to visualize existing support resources and provide targeted formal service suggestions (see [12] for additional details about eSNAP development). The intervention development process is outlined in Fig. 2. The program and associated training were based on the design of three previous patient navigation programs: the Moffitt Cancer Center Patient Navigator Research Program patient navigation intervention, [26, 27] a breast cancer survivorship navigation intervention, [28] and the PrEPárate HIV prevention patient navigation intervention [29]. All of these programs were developed with extensive involvement from patients to assist diverse and lower-resourced individuals to obtain high quality, recommended health care in a timely manner [28, 30]. Members of the study team reviewed existing program materials, including patient-facing materials and training manuals, and adapted elements of these programs based on the stress process conceptual model (Fig. 1) and the peer-reviewed caregiver literature. The lead author and members of the study team drafted eight manualized modules described in a training manual and a companion caregiver workbook, which included worksheets for each module. These materials were then iteratively refined through feedback from experts and stakeholders including clinic team members, social workers, cancer survivors, and family caregivers.

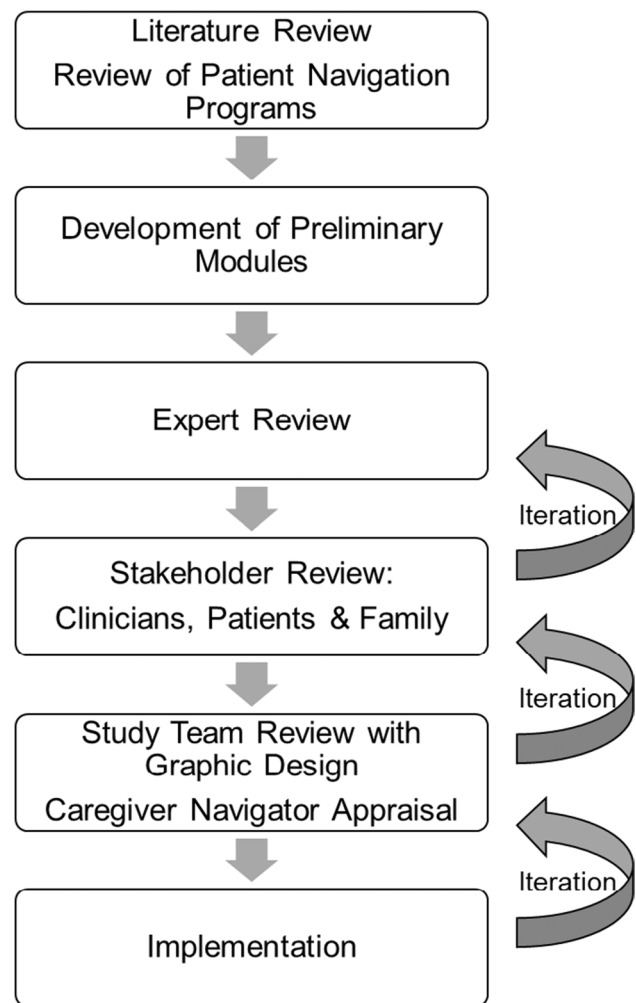


Fig. 2 Intervention development process

The initial and final structures of the intervention were very similar, with two exceptions. In the final draft: (1) a separate “Self-Care” module was included; (2) the “Overview” and “Getting Social Support” content was separated into individual modules. Stakeholder feedback primarily influenced the structure and activities within each module and the language and examples used, as described below.

Intervention refinement

Patient navigation expert review

The initial draft of the study materials was reviewed by two experts in patient navigation, who provided edits and suggestions via email and during team meetings. In addition to guidance on the structure of individual modules, incorporating specific assessment, experts also provided feedback on the navigation staffing model. Our initial plan was to utilize non-clinical/community navigators; however, experts

suggested hiring social workers given their skill-set aligned with the planned role [18]. Given the desire to increase likelihood of dissemination, we compromised; navigators were required to have some background and training in providing services in an oncology setting. Our current navigators have either social work training or have experience working with patients and families in the cancer center patient library.

Team members reviewed the two experts' feedback and made changes to the intervention to produce a draft that could be reviewed by additional stakeholders.

Stakeholder review and intervention refinement

The next iteration was reviewed by five clinical stakeholders who were members of the research team or had participated in developmental research for eSNAP; this included two oncologists, a social worker, patient navigator, and nurse. Feedback was elicited on an individual basis through emailed versions of the manual.

Two separate presentations were also concurrently made to social workers as part of a Grand Rounds and the monthly meeting of the MCC Patient-Family Advisory Council. The presentations followed a similar format. After a brief overview of the eSNAP tool and goals of caregiver navigation, we presented our planned caregiver navigation procedures and content. Feedback was elicited during 15-min discussions after each presentation, recorded by a note-taker. Stakeholders were asked to comment on their interest in the caregiver navigation program and the content, number, length, and delivery method of the modules.

Clinical staff, patients, and caregivers all expressed enthusiasm for the caregiver navigation intervention and endorsed the need for tools to support caregivers. Consensus across groups indicated that 8 weekly modules, approximately 30 min each, and starting early in the patient's cancer trajectory, was an appropriate frequency and intensity of navigation. Based on workflow issues identified by clinical staff and preferences of caregivers, we planned to offer navigation by phone. Research has indicated that telephone is a familiar technology that offers flexibility for caregivers and can even be more effective than face-to-face navigation [31]. Social workers discussed making connections between the caregiver navigators, social workers, and patient navigators to share institutional and community resources.

Caregivers and patients suggested adding a module on caregiver self-care, as they felt this was a major concern for caregivers. While self-care may be seen as somewhat outside the scope of obtaining social support, it was seen as related to effective coping within our conceptual model. Furthermore, to engage in self-care, some caregivers identified needing support in the form of encouragement, validation, and sometimes tangible support, such as someone to watch the patient.

Graphic design and caregiver navigator appraisal

We integrated feedback from stakeholders into the third draft of the intervention manual with review from the study team and worked with a graphic designer to refine the companion caregiver workbook and worksheets. The layout of the workbook and accompanying graphics was iteratively reviewed by the study team, including the caregiver navigators, as described below. We again simplified language and developed graphics to help convey our message and improve usability of the worksheets.

Concurrently, as part of training, caregiver navigators reviewed the intervention manual and caregiver-facing materials and role-played each module multiple times with different study team members, including clinical psychologists. This practice helped to further simplify language and refine module activities and worksheets to be more concrete. Feedback based on this exercise was reviewed by the study team and integrated into final drafts. For example, based on the length of the first module during these roleplays, we split the overview (module 0) from the module focused on getting social support (module 1). Separating out general overview information from the primary intervention content allowed us to maintain shorter modules, which prevented participant fatigue and fit within the time guidelines suggested by stakeholders. Furthermore, navigators identified cases in which other forms of communication with participants, such as video-conferencing or email, may be useful. Thus, email templates were drafted for each module to include content descriptions, questions for caregivers to respond to, and instructions for worksheets and practice activities.

Intervention production

The final version of module topics, brief description, and rationale for including in the intervention are outlined in Table 1. Caregiver navigators develop a caregiver-specific plan to address social support needs. The caregiver navigator may provide social support directly (e.g., emotional, informational) or may assist caregivers in obtaining support from their network or from formal resources through motivational interviewing-style communication and problem solving. Each module concludes with an activity for the caregiver to complete or topic to think about throughout the week to practice what is discussed in the module. Since finalization, the intervention has been implemented with caregivers of patients with primary brain tumor in the study described above [24].

Intervention implementation

Caregiver navigators record process data for all caregivers receiving navigation using structured encounter logs adapted

Table 1 Description of topics in the caregiver navigation intervention

Module Topic	Description	Rationale	Drawn from
0 Overview	Introduction to caregiver navigation, setting goals/expectations	Provides an introduction to navigation and helps caregiver navigator understand caregiver goals	Patient navigation—setting goals/expectations
1 Getting social support	Review of existing social support resources and needs in eSNAP, identifying facilitators and barriers to social support through caregiver navigator motivational interviewing	Helps caregiver navigator understand existing social support resources, the context in which support is provided, and what factors are contributing to the existing context. Allows caregivers to revisit and remind themselves of existing support resources and identify needs	Patient navigation—identifying facilitators and barriers
2 Problem solving	Introduction of step-wise process of identifying a problem, generating solutions, including identifying support, planning steps towards action	Provide caregivers tools to problem-solve to identify and address potential barriers in obtaining support. Problem-solving is a key skill and can enhance caregiver self-efficacy	Clinical experience—problem-solving
3 Growing your social support network	Review of potential additional/overlooked support from informal/formal sources	Caregivers may need additional support through the care trajectory and support may come from unexpected sources. Encourages caregivers to think through all potential existing avenues of support, as well as identify potential needed formal resources	Social support literature on received support; Stress Process Model
4 How to ask for help	Review best practices and rehearse asking for help	Asking for help can be difficult. Provides concrete steps and allows caregivers to practice asking for help and role-play with caregiver navigator. Also addresses potential caregiver guilt	Social support literature on enacted support; caregiving literature on hesitancy to ask for help
5 Taking care of yourself	Review importance of self-care and identify resources to facilitate self-care activities	Caregivers often focus on providing care to the patient to the exclusion of caring for themselves, yet caregiver well-being is important to maintain to ensure high quality care is provided to the patient	Caregiver suggestion; caregiving literature on self-care; Stress Process Model
6 Setting limits and dealing with unhelpful support	Review importance and rehearse strategies to implement boundaries to reduce social stress	Unwanted or unhelpful support and conflict can be detrimental to caregiver well-being. Reviews the importance of boundaries. Provides tools to help caregivers impose boundaries and allows caregiver to practice managing unhelpful support and role-play with caregiver navigator	Social support literature on unhelpful support; caregiving literature on unhelpful support; Stress Process Model
7 Positive side of caregiving	Review caregiver achievements and growth	Meaning-making is a key factor in caregiver well-being. Facilitates identification of caregiver strengths and positive experiences	Caregiving literature on meaning-making; Stress Process Model

Table 1 (continued)

Module	Topic	Description	Rationale	Drawn from
8	Review and planning for the future	Reflection on previous modules, potential gains, and identify strategies to continue practicing	Provide closure for the intervention and review caregiver gains, similar to positive side of caregiving. Creating a plan to use activities from previous modules increases the likelihood tools will be used in the future and increases potential lasting effect of intervention. Reminder of existing resources, such as social work for future needs	Patient navigation “closing” modules; caregiving literature on meaning-making; behavioral science literature on intention

from previous navigation interventions [32, 33]. For each completed encounter, caregiver navigators record (1) date/time and length of encounter; (2) mode of contact; (3) key topics addressed, including caregiver support needs and barriers; and (4) actions taken by the navigator.

Upon completion of the 8-week intervention, caregivers randomized to receive eSNAP + caregiver navigation completed a brief, purpose-driven satisfaction questionnaire assessing satisfaction and helpfulness of the intervention overall and with the caregiver navigator specifically. Items were rated on a Likert-type scale: “very,” “mostly,” “somewhat,” or “not at all.” Feedback on the intervention was also elicited through brief semi-structured qualitative interviews conducted by trained study staff over the phone (separate from navigation).

Data analysis

Descriptive statistics (e.g., means, standard deviations, frequencies) were calculated to summarize demographic data, navigation module data, and satisfaction with the intervention. Interviews were audio-recorded and transcribed. Exemplar quotes are provided.

Results

Here we present results from the preliminary evaluation of the intervention implementation.

Sessions and modules

Fifteen caregivers were randomized to the eSNAP + caregiver navigation intervention from February to December 2020. Preliminary analyses were conducted on these caregivers (see Table 2 for demographics and baseline characteristics). Of the 15, 8 caregivers completed at least 7 modules; 6 completed all 8 modules. Four caregivers withdrew from the study, all between March and April, 2020, after completing the baseline questionnaire. Two of those who dropped completed no navigation; two completed two navigator modules.

Caregivers generally completed navigation modules in manualized order, but, based on caregiver need, some modules were delivered in a different order or more than once; some modules were combined in the same discussion. Six caregivers repeated navigation modules, most commonly “Problem Solving” and “Taking Care of Yourself.” Regardless of the flexibility, the number of available sessions was fixed at 8; if a caregiver repeated a topic, they generally combined two topics into the same module during another week.

Table 2 Caregiver demographic characteristics

	All (<i>n</i> = 15)		7 + sessions (<i>n</i> = 8)		< 7 sessions (<i>n</i> = 7)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age (years)	59.27	12.256	54.75	11.24	64.43	12.04
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Relationship to patient						
Spouse or partner	14	93.33	8	100.00	6	85.71
Brother or sister	1	6.67	0	0.00	1	14.29
Gender identity						
Female	11	73.33	5	62.50	6	85.71
Male	4	26.67	3	37.50	1	14.29
Race (multiple answers permitted)						
White or Caucasian	13	86.67	8	100.00	5	71.43
Black or African American	1	6.67	0	0.00	1	14.29
Prefer not to answer	1	6.67	0	0.00	1	14.29
Ethnicity						
Non-Hispanic/Latinx	14	93.33	8	100.00	6	85.71
Prefer not to answer	1	6.67	0	0.00	1	14.29
Household income						
\$75,000 or more	10	66.67	6	75.00	4	57.14
\$50,000–\$74,999	1	6.67	1	12.50	0	0.00
\$40,000–\$59,999	0	0.00	0	0.00	0	0.00
\$25,000–\$39,999	1	6.67	0	0.00	1	14.29
Prefer not to answer	3	20.00	1	12.50	2	28.57
Comfortable using technology						
Very	6	40.00	4	50.00	2	28.57
Somewhat	3	20.00	1	12.50	2	28.57
Moderately	5	33.33	3	37.50	2	28.57
A little	1	6.67	0	0.00	1	14.29

Modality of delivery

Ninety-five percent of modules were completed by phone, but 5% were delivered by email based on caregiver preference. Phone navigation modules averaged 39 min (range: 12–92).

Satisfaction results

Nine caregivers completed the satisfaction questionnaire at the end of the 8-week intervention period. Seven of the 9 with satisfaction data had completed at least 7 navigation modules. The two caregivers who completed fewer than 7 modules did not find the intervention or the navigator to be helpful, and reported low satisfaction. Five of the 7 who completed at least 7 modules reported that the intervention overall and the navigation specifically were mostly or very helpful, and were very satisfied with both.

Qualitative feedback

The 8 participants who completed at least 7 modules all completed debrief interviews. Qualitative feedback about the caregiver navigation intervention was overwhelmingly positive. For example:

“The reflection on who could you go to for help really helped me think through and realize there might be more people that could help us than I might have thought about on my own. Thinking about those individual categories was helpful in broadening my definition of what kind of help I might want to ask people for moving forward.” (127)

“[The caregiver navigator] listened to me, validated what was going on and then she gave me the resources but also having that framework of week by week and the questions.... I really enjoyed the way it was set up on the computer, there was also a workbook, had very

good prompts. The flexibility part is so important, so I don't feel pressured." (122)

"Being able to talk to my caregiver navigator, who is there to support me and have the information to give me, brought me back to life and gave me that hope again that I needed...Knowing that it's okay to ask for help was a huge part of the program and learning how to be specific about what I need is a tremendous takeaway. Also knowing I have more support people out there by using [eSNAP]." (118)

Suggestions for improvement largely focused on needing resources sooner or more patient-focused resources. For example:

"Some of the value of [eSNAP] was not experienced by me. I had figured out most of my resources by [the time of study enrollment]." (122)

"I would have been interested to see what are tools to work with our loved ones to help them figure out their health." (124)

"Adding a chapter on living wills, advance directives, power of attorney, and other legal resources." (103)

Although we were unable to collect data systematically from caregivers who withdrew from the study or chose not to continue with navigation, anecdotally, these participants indicated that they were too busy or too overwhelmed to continue.

Discussion

This paper describes the development of a caregiver navigation intervention designed to support caregivers of patients with primary brain tumor. Following best-practice guidelines for complex health intervention development [34], we adapted elements from several patient navigation programs based on theory and existing research on caregiver needs. Using an iterative approach, we integrated feedback from multiple stakeholders to ultimately design a flexible, 8-module, primarily phone-based caregiver navigation program to be delivered with eSNAP, our online social support visualization tool. Together, the goal of the intervention is to help caregivers problem-solve and identify informal social support and formal support resources to ultimately improve well-being.

Engaged stakeholder feedback was key to several important decisions in our intervention development and implementation planning [35]. Input from caregivers and patients guided the initial decision to build a caregiver navigation program to augment our existing eSNAP intervention and informed the specific topics included. Feedback from other stakeholders during iterative development was also

invaluable. For example, developing relationships with clinic staff, obtaining feedback, and ensuring study activities did not interfere with clinic workflow helped build buy-in and integrate the study with the clinic, building trust between clinicians, patients, caregivers, and the research team. Similarly, developing relationships with social work staff helped us coordinate services, expand our available training resources, and expand resources available to provide to participants. Finally, feedback from the caregiver navigators themselves was critical in identifying changes to improve usability, such as shortening modules and simplifying language. We continue to receive feedback from caregivers and other stakeholders to capture data to support future refinements and wider implementation [36].

Although we experienced some attrition early in our initial implementation, this may be largely due to the onset of the COVID-19 pandemic and the additional stresses, uncertainty, and changes to care made during that time. For example, four participants dropped during the initial wave of March/April 2020. Although our intervention may have been helpful in problem-solving how to obtain informal support as many formal services were closed or delayed, as indicated by anecdotal responses, many caregivers may have been simply too overwhelmed to participate in research, even with mitigation techniques in place [37].

Although we currently have limited data to judge the acceptability and usability of the intervention, preliminary findings suggest participants like the intervention. Participants reported finding value in discussions with the navigators and appreciating having someone focused on their needs. Few advanced cancer caregivers report taking time for themselves or engaging in self-care practices, despite the association with improved well-being [38]. Furthermore, most communication with oncology providers is focused on the patient [39], and caregivers are often unable or unwilling to share the stress of caregiving with patients, sometimes leaving caregivers without a confidant [40]. Navigator modules may offer an important opportunity to share struggles or focus on one's self without guilt, and to obtain validation or reassurance; short, flexible, externally "required" sessions may facilitate caregiver self-care. This safe space for communication may facilitate cognitive and emotional processing, enhance coping, and ultimately improve well-being [41].

Limitations

Our focus was on a small neuro-oncology caregiver sample at one urban, NCI-designated Comprehensive Cancer Center, and our results may not be generalizable to other caregiver populations. Future work is needed for adaptations to more diverse groups of caregivers. This study was implemented early in the COVID-19 pandemic, which may have impacted

participants' experiences and willingness to participate. We saw differential response rates on feedback based on participation. Additionally, the scope of this paper is focused only on intervention development. While we present some preliminary data on caregiver satisfaction, recruitment is ongoing, and full results are not yet available on intervention efficacy. Future analysis will assess the role of navigation components in impacting caregiver and patient outcomes.

Conclusion

We used an iterative approach to design a caregiver navigation intervention based on previous patient navigation programs, theory, research, and stakeholder feedback. Preliminary findings suggest our intervention may be a useful tool to support caregivers. Efficacy testing is currently in progress; if effective, this navigator model could be implemented broadly to support families of people affected by cancer.

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Author contribution MR conceptualized and designed the study with contributions from KJW, SKS, BZ, PF, and MMB; MR and MMB were awarded funding to support the work. MR and KJW wrote the first draft of the manuscript; AO, KJW, LR, and RM contributed to later drafts. All authors read and approved the final manuscript.

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Data availability Data is available upon reasonable request from the corresponding author.

Code availability N/A.

Declarations

Ethics approval This study was approved by the Advarra Institutional Review Board (Pro00029204). The authors certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication N/A

Competing interests The authors declare no competing interests.

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