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Feasibility of implementing an electronic social support and resource visualization tool for caregivers in a neuro-oncology clinic

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Abstract

Purpose—The goals of this study were to assess the feasibility of a web-based application – electronic Social Network Assessment Program (eSNAP) – to automate the capture and visualization of family caregiver social network data of neuro-oncology patients.

Methods—Caregivers were recruited from a neuro-oncology clinic at an NCI-designated comprehensive cancer center. Participants completed baseline questionnaires on a laptop in clinic assessing demographic characteristics. After baseline, participants were randomly assigned to either create a social network visualization using eSNAP (intervention) or to usual care (control) condition. Those who used eSNAP provided likeability/usability data. All participants were asked to complete follow-up questionnaires at 3 weeks and 6 weeks after baseline to determine feasibility of longitudinal study.

Results—We recruited 40 caregivers of patients with primary malignant brain tumor to participate in this study. Participants rated eSNAP usability and likeability highly, indicating that eSNAP would help them consider their available social support. At 3 weeks, 90% of participants completed questionnaires and 82.5% completed questionnaires at 6 weeks.

Conclusions—There is a need to encourage family caregivers of patients with primary malignant brain tumor to engage their existing social network resources to help alleviate caregiver burden. Our findings suggest that our web-based application to address this issue is feasible to implement with high usability and likeability. This pilot study identified minor changes to the intervention to improve effectiveness and has implications for future research in this understudied population.

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Conflict of Interest

The authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest in the funding of this research.

The authors have full control of the primary data and will allow review of data if requested.

Keywords

caregiving; social support; feasibility study; neuro-oncology

Introduction

Although the incidence of primary malignant brain tumor is relatively rare, representing less than 2% of all new cancer cases [1], the disease often has a profound impact on patients and those who provide care. Patients often experience physical debilitation and changes in cognitive function, personality and behavior [2–5]. Because of the severity of symptoms and how quickly patients may decline, most caregivers of these patients indicate they are overwhelmed and underprepared [6]. Many caregivers also report feeling a sense of guilt and total responsibility for care and fear about the patient's impending death, as well as a sense of isolation [7–10]. Caregivers for patients with primary brain tumor are often at risk for high levels of burden, [11] as well as fatigue, health problems and depression [2].

Despite this high level of need, there has been little prospective systematic longitudinal research with caregivers of patients with a malignant primary brain tumor [12, 13] and few interventions designed for or tested within the population [7, 12]. The high level of burden can serve as a barrier to recruitment and retention; participation in research is often viewed as an additional burden to an already stressful situation without any personal benefit [14]. This creates a catch-22 in that high burden can be an obstacle to conducting the type of research needed to develop and test interventions to reduce burden. As such, ensuring that researchers conducting foundational intervention research are able to recruit and retain participants is key. Because previous work has shown that lack of benefit can often influence participation in research, it is also important to ensure that participants are able to use and like the intervention [15, 16].

Objectives

Our primary goal was to test the feasibility of recruiting and retaining family caregivers of neuro-oncology patients in a pilot trial of a psychosocial intervention, with longitudinal follow-ups. Our secondary goal was to determine the usability and likeability of eSNAP for those who were randomized to the intervention group.

Methods

Intervention

Our team developed the web-based electronic Social Network Assessment Program (eSNAP) with the goal of encouraging caregivers of patients with primary brain tumors to engage their existing social network resources, with the intent of ultimately reducing caregiving burden. There is strong evidence that high quality social support is a vital component to caregiver wellbeing [12], and is associated with better caregiver coping, and improved caregiver psychological and physical health, especially when available early in the cancer care trajectory [17–19]. Social support can include informational (e.g. information or help problem-solving), emotional (e.g. “being there” or validation), and/or instrumental

support (e.g. assistance with household tasks). However, in a time when support is critical, caregivers may distance themselves from available support as they become immersed in caregiving tasks, opting to spend all available time with the patient [20]. Caregivers also report that they find it stressful to identify and organize available resources, and instead try to handle everything themselves [21–23].

eSNAP is based on a clinical interview process used in supportive care called ecomapping. Ecomaps are visualizations that depict the size, strength, quality and function of a person's social network and are a valuable tool for highlighting barriers to support, such as social isolation, or failure to take advantage of existing support. Visualization of complex information can organize data, reduce cognitive load, and provide new insights and knowledge [24]. Social network visualization can prime, or create implicit associations to, the availability of these resources. Having organized one's support network and creating the visualization, individuals can refer back to this image during times of stress to identify those who could provide support. For example, ecomapping has been shown to improve caregiver's understanding of their social networks, help identify unrealized potential social resources, and facilitate discussions with health care providers in other populations experiencing illness [21, 22]. eSNAP automates the ecomapping process to make it more user-friendly and more flexible [25].

eSNAP users are asked to list social network resources that they either have approached or could approach for help in the following six areas: (1) hands on support, (2) informational support, (3) communication support, (4) financial support, (5) emotional support, and (6) self-care support. After listing resources in each relevant area, the user is then presented with a visualization of their existing social network resources (see Figure 1; note this is a visualization of the social network only and users do not interact with their support resources through the app). If a participant listed two or fewer resources in any of the six sections, they were prompted to review a resource list within the app (e.g. Hope Lodge housing; reputable websites). These resource lists were also available for any participant who wished to learn more information; lists included the name of the organization, a brief description, and contact information. A PDF of the completed visualization and selected resource list were emailed to participants. (For more details on the development of eSNAP, please see Reblin, Wu [25]).

Study design

To determine the feasibility of recruiting and retaining family caregivers of neuro-oncology patients in a longitudinal study of eSNAP, we conducted a pilot study using a two-group randomized design. Feasibility here is defined using guidelines from the National Institute for Health Research (<https://www.nihr.ac.uk/glossary>) which aims to answer the question, "Can the study be done?". That includes assessing items such as participant willingness, intervention acceptance in clinic, and follow-up rates. Our a priori goal was to recruit 40 participants and to obtain feedback about the likeability and usability of the eSNAP app from those who were randomized to the intervention group. After consent and completion of baseline questionnaires, described as time point 1 (T1) in clinic, participants were randomly assigned to receive eSNAP or usual care (questionnaires only) in a 3:1 ratio. The

intervention condition was oversampled in order to gather more feedback; those who received eSNAP were asked to evaluate it immediately afterwards. All participants were asked to complete follow-up questionnaires at 3 weeks (T2) and 6 weeks (T3) to test the feasibility of collecting longitudinal data electronically. Participants in the intervention condition were also asked whether they had used or thought about the eSNAP information after baseline. Neuro-oncology clinic staff were informed and closely included over the duration of the research project and all study activities were conducted with approval by the Institutional Review Board. Informed consent was obtained from all individual participants included in the study. Our pilot study was registered to clinicaltrials.gov, protocol number NCT03026699.

Study participants and recruitment

Participants were recruited from a neuro-oncology clinic at an NCI-designated comprehensive cancer center. Inclusion criteria were identifying as the individual who provided the most care for an adult patient diagnosed with primary malignant brain tumor, English-speaking and -reading, having access to email, and being over age 18.

Potential participants were identified through clinic schedules. Scheduled patients were screened for diagnosis. The majority of patients with primary brain tumor are accompanied to appointments by their primary caregiver. Patients who had a caregiver at the appointment were approached in-person by the researcher after they had checked in for their appointment, either right after they had been placed in their exam room or in a quiet, private space in the waiting room. The researcher explained the study to the caregiver and patient, invited caregiver participation, and obtained written informed consent from caregivers wishing to participate.

Measures

Recruitment and enrollment data were recorded. Demographic data, self-reported health characteristics, and use of internet/web-based apps were collected at baseline, and at baseline, T2, and T3 we also collected a short collection of self-report and observational psychosocial assessments to determine feasibility of questionnaire completion. Study data were collected and managed using REDCap electronic data capture tools [26] hosted at Moffitt Cancer Center.

Study procedure

Participants completed the T1 baseline questionnaire on a laptop in a quiet area of the clinic or exam room. Participants were then randomized to either the intervention group or the control group using the institutional Subject Registration and Randomization System, an online tool which automates blinded random assignment. Those assigned to the intervention group were given a laptop with the eSNAP website, and upon completion, were asked to assess the eSNAP user experience.

Since there was usually sufficient downtime between provider encounters (e.g. between nurse and MD), all intervention participants were able to complete the questionnaire and eSNAP during their clinic appointment. On average, participants spent 15–20 minutes on the

questionnaires and 10–15 minutes on eSNAP. Participants in the control condition were simply thanked and reminded about the follow up questionnaires. For all participants, T2 and T3 questionnaires were completed online at home by email invitation through REDCap. Participants received \$25 compensation for each completed questionnaire.

Analysis

Descriptive statistics were used to calculate recruitment and retention for all participants as well as usability and likeability of the intervention for those participants who received it.

Results

Participant Characteristics

As shown in Table 1, most participants were white (n=36, 94.7%) non-Hispanic (35, 92.1%), female (30, 79.6%), and were on average 57.8 years old (range 29–80 years). Participants had known the patient for an average of 33.7 years (range 3–57 years) and were mostly spouses (25, 64.1%) of the patient. Patients were on average 51.3 years old (range 22–76 years) and most were male (22, 57.9%).

The majority (90%) of participants used their smartphone on a regular basis, followed by laptops (66.7%), then desktops and tablets (both 46%). Email (92%) and social networking apps/websites (77%) were used on a regular basis, with most participants (85%) indicating they used the internet multiple times a day.

Recruitment and retention

Recruitment took place from May to August 2017. Figure 2 shows the enrollment flow chart. While study participants were caregivers, we recruited based on clinic patient lists. In total, 160 patients were assessed for initial eligibility of their caregivers. Because we wanted to avoid interruption of clinic workflow and to determine the feasibility of recruitment with one part-time research assistant, 85 patients were not approached due to time constraints (e.g. research assistant not available; insufficient time between consultations to approach caregivers) or cancelled/no show to their appointment (n=21). Two caregivers were approached to introduce the study but were lost to follow-up after interruption by clinic staff and before consent. Twenty-three patients were not eligible, mostly due to absence of a caregiver/primary caregiver at the time of the appointment (n=21). Only 10 caregivers refused participation, with most stating they were too busy or they did not want to have to stay in clinic any longer than they needed to. Forty caregivers enrolled and were randomized to either receive eSNAP at baseline and complete questionnaires over time (n=30) or receive usual care (questionnaires only; n=10). At three weeks 92.5% (n=37) of participants completed questionnaires, and 80% (n=32) completed questionnaires at six weeks.

Intervention usability and likeability

Out of 30 participants enrolled into the intervention group, 29 completed the eSNAP user experience and likeability questionnaire at baseline (Table 2). Participants indicated they felt that eSNAP is easy to understand (M=6.3), the app would make them more confident about support if they needed it (M=5.8), could help them understand what their support network

looks like ($M=6$), and that they understood the information presented in the app ($M=6.4$). Participants strongly disagree that they would resist using the app ($M=1.8$) or that it was frustrating to use ($M=2.1$).

Participants also had an opportunity to respond to open-ended questions regarding features they liked or didn't like about eSNAP. Comments provided valuable feedback and tended to be positive, with participants reported that the app "Made me think about my support network" or "Gave me some ideas I hadn't thought of before". Some participants indicated that the app would be more helpful if it was available earlier in the patient's diagnosis, or if they were able to revisit the app as their needs changed. Moreover, many participants liked being able to start using eSNAP in clinic but wanted/needed more time than available to use all features.

Participants in the intervention group were asked in follow up questionnaires how often they had referred to the eSNAP print-out, and if they had used it, how useful it was, and how much they liked it. The majority (over 70%) of the intervention participants indicated that they had not referred back to the eSNAP social network PDF at either the three (T2) or six week (T3) follow up time points. While most participants did not refer back or use eSNAP, there is a slight increase in perceived use and usefulness of eSNAP at the six-week time point with some participants.

Discussion

The need for comprehensive cancer care must address the needs of both the patient and their caregiver [7]. The burden associated with caregiving may present a barrier to recruitment and retention in the very studies that seek to help alleviate these caregiving challenges. In this study, our goal was to identify caregiver interest, participation, usability, and likeability of a psychosocial intervention for this specific, underserved population. The eSNAP intervention attempts to provide an accurate assessment and reminder of existing social network resources which may ensure more positive caregiving experiences [27].

Previous research has identified barriers in recruiting advanced cancer caregivers for research [28–30]. Specifically, caregivers of neuro-oncology patients are an understudied group and sample sizes of studies that are done are often small [12]. Despite these potential barriers, our study suggests that this population is very willing to participate in research, even those who endorse high levels of distress. Despite having only one part-time staff member, we were able to enroll 40 participants in less than 4 months. Additionally, we found that recruiting caregivers through patients in the clinic waiting room was an effective strategy. We found that over 70% of patients were accompanied by a primary caregiver and of those eligible, less than 5% refused participation and 80% of all participants completed the 6-week assessment. It was helpful that caregivers could complete the baseline during downtime in the clinic and complete follow-ups online. A systematic review of psychosocial interventions for cancer caregivers suggests that mode of delivery is one major barrier to recruitment and retention and recommends more flexibility to allow a broader reach [7].

A key aspect to keeping participants engaged in interventions is increasing usability and likeability [15, 16]. The majority of participants in the intervention condition liked eSNAP and found it useful. Several participants mentioned in the open-ended responses that it served as a good reminder of their existing support networks and helped their organization by having all their resources located in one spot. Most found eSNAP easy to use; however, the two participants who had the most difficulty were also among the oldest and self-identified as the least tech-savvy. Older adults have traditionally trailed younger adults in technology adoption. However, more and more older adults are becoming more familiar with technology and the age gap is closing [31]. Until gaps in technological literacy are addressed, it is important to offer technology interventions with human support available to offer training, oversee the process, and answer questions [32].

Although completing the baseline during downtime helped recruitment, cooperation and constant communication with clinic staff was vital for successful implementation without interruption to clinic workflow. Because the priority was (and should be) patient care, some research sessions were interrupted, leading to several participants lost to follow up when they left before the research assistant was able to return, and some missing data when participants were interrupted while completing questionnaires. Further, because eSNAP did not save data (when a session was closed, that user's data was erased), some participants may not have spent as much time as they wanted or needed to engage with the data. This, combined with the lack of prompts to review data, may have led to the low numbers of participants who had revisited their eSNAP data at the follow-ups and reduced the psychological impact of eSNAP.

The inability to revisit the eSNAP website was also mentioned in the open-ended feedback about the intervention; several caregivers mentioned that eSNAP would have been helpful at various points in their care trajectory. In fact, some research indicates that caregivers of patients with primary malignant brain tumor have consistently high needs, but these needs vary by domain over time [33]. In response to this and to encourage more engagement, we are developing the back-end of the database to facilitate user data storage that would allow users to save their data and review it later.

Our pilot intervention was also designed to be very low-touch, in regards to the technology and the approach of the intervention, to determine how users interacted with eSNAP on their own; in the future we plan to incorporate prompts to remind participants to review and update their eSNAP visualizations over time. Additionally, we plan to integrate an alert to be sent to clinic staff, such as a social worker, when caregivers report a lack of support in eSNAP. This provides an important opportunity to identify those who may benefit from social work referral. In this way, caregivers can receive proactive psychosocial services and potentially prevent caregiver distress.

Limitations

The primary limitation of this pilot study is the relatively homogenous participant sample of mostly Caucasian family caregivers drawn from an NCI-Designated Comprehensive Cancer Center. Although education and income levels had some variability, all participants had access to technology and were relatively tech-savvy. Caregivers drawn from smaller

community cancer centers or those with less familiarity with technology may be more difficult to recruit or retain and may have different opinions about a web-based app.

Conclusion

There is a need to encourage family caregivers of patients with primary malignant brain tumor to engage their existing social network resources to help alleviate caregiver burden. eSNAP is a web-based tool to help this population catalogue and visualize their resources with the goal of priming their availability. The current pilot study shows that implementing a study of eSNAP in neuro-oncology clinics is feasible and users like the app and find it useful. Our findings also suggest minor changes to the intervention to increase participant usage over time.

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Abbreviations

eSNAP electronic Social Network Assessment Program

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Fig. 1.
eSNAP intervention example

Figure 2.
Enrollment flow chart

Table 1

Caregiver and patient demographics

Characteristic		Number of people (%)		
		Case	Control	Total
Caregiver age		56.7 (29–80)	59.1 (44–75)	57.8 (33–80)
Patient age		49.4 (22–76)	55.2 (32–72)	51.3 (22–76)
Caregiver gender	Female	22 (75.9)	8 (80)	30 (76.9)
	Male	7 (24.1)	2 (20)	9 (23.1)
Patient gender	Female	13 (46.4)	3 (30)	16 (42.1)
	Male	15 (53.6)	7 (70)	22 (57.9)
Caregiver race	White/Caucasian	26 (92.9)	10 (100)	36 (94.7)
	African-American	1 (3.6)	0	1 (2.6)
	Other	1 (3.6)	0	1 (2.6)
Caregiver ethnicity	Non-Hispanic	26 (92.9)	9 (90)	35 (92.1)
	Hispanic	2 (7.1)	1 (10)	3 (7.9)
Caregiver relationship to patient	Spouse	16 (55.2)	9 (90)	25 (64.1)
	Parent	5 (17.2)	0	5 (12.8)
	Sibling	1 (3.4)	0	1 (2.6)
	Child	6 (20.7)	1 (10)	7 (17.9)
	Other	1 (3.4)	0	1 (2.6)
Length of relationship		33.9	31.5	33.7
		(3–57)	(8–57)	(3–57)
Caregiver level of education	Less than high school	0	0	0
	High school graduate or equivalent	6 (21.4)	3 (30)	9 (23.7)
	Some college or vocational school	6 (21.4)	3 (30)	9 (23.7)
	College graduate (4 years)	6 (21.4)	1 (10)	7 (18.4)
	Some graduate or professional school	0	1 (10)	1 (2.6)
	Graduate or professional degree	10 (35.7)	2 (20)	12 (31.6)
Caregiver employment	Not currently employed	3 (10.7)	0	3 (7.9)
	Retired	11 (39.3)	3 (30)	14 (36.8)
	Part-time	4 (14.3)	1 (10)	5 (13.2)
	Full-time	10 (35.7)	6 (60)	16 (42.1)
Caregiver household income	Less than \$10,000	2 (7.4)	0	2 (5.4)
	\$10,000 – \$24,999	3 (11.1)	0	3 (8.1)
	\$25,000 – \$39,999	4 (14.8)	3 (30)	7 (18.9)

Characteristic		Number of people (%)		
		Case	Control	Total
	\$40,000 – \$49,999	3 (11.1)	0	3 (8.1)
	\$50,000 – \$74,999	3 (11.1)	2 (20)	5 (13.5)
	\$75,000 – or more	8 (29.6)	5 (50)	13 (35.1)
	Prefer not to answer	4 (14.8)	0	4 (10.8)
Patient tumor type	Glioblastoma multiforme	17 (56.7)	6 (20)	23 (76.7)
	Astrocytoma grades I-III	4 (13.3)	3 (10)	7 (23.3)
	Oligodendroglioma	4 (13.3)	1 (3.3)	5 (16.7)
	Other	5 (16.7)	0	5 (16.7)

Table 2

eSNAP user experience and likeability, rating from 7 (strongly agree) to 1 (strongly disagree)

	Mean	Range	SD
I could understand the information presented in the app	6.4	2–7	1.1
The app was easy to understand	6.3	2–7	1.2
90% of the people I know could use the app the first time they tried it	6.2	3–7	1.1
The organization of the information in the app makes sense	6.2	2–7	1.2
The way to move through the app made sense to me	6.2	2–7	1.3
The app presents information in a meaningful way	5.9	2–7	1.3
I could use the information from the app to inform my thinking about my caregiving situation	6.1	3–7	1.1
Using the app could help me understand what my support network looks like	6.0	2–7	1.5
Seeing my support resources organized in this way would be helpful	5.9	2–7	1.6
Using this app would make me feel more confident that I have support if I need it	5.8	2–7	1.4
The app is flexible enough to help me in my own caregiving situation	5.8	2–7	1.4
The app effectively provides information that would support me as a caregiver	5.6	1–7	1.7
The app showed information that could be useful to me	5.6	1–7	1.6
The app could show me a complete picture of someone's situation	5.1	1–7	1.4
The words used in the app are not like those I would use	2.7	1–7	1.5
Even with training most of the people I know would not be able to use the app effectively	1.9	1–7	1.8
I would like to use this app	5.6	2–7	1.5
I would recommend other caregivers use this app	5.7	2–7	1.5
I was frustrated when using this app	2.1	1–7	2.0
I would resist using this app	1.8	1–6	1.4