OUTCOMES OF AN ELECTRONIC SOCIAL NETWORK INTERVENTION WITH NEURO-ONCOLOGY PATIENT FAMILY CAREGIVERS

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Abstract

Introduction—Informal family caregivers (FCG) are an integral and crucial human component in the cancer care continuum. However, research and interventions to help alleviate documented anxiety and burden on this group is lacking. To address the absence of effective interventions, we developed the electronic Support Network Assessment Program (eSNAP) which aims to automate the capture and visualization of social support, an important target for overall FCG support. This study seeks to describe the preliminary efficacy and outcomes of the eSNAP intervention.

Methods—Forty FCGs were enrolled into a longitudinal, two-group randomized design to compare the eSNAP intervention in caregivers of patients with primary/secondary brain tumors against controls who did not receive the intervention. Participants were followed for six weeks with questionnaires to assess demographics, caregiver burden, anxiety, depression, and social support. Questionnaires given at baseline (T1) and then 3-weeks (T2), and 6-weeks (T3) post baseline questionnaire.

Results—FCGs reported high caregiver burden and distress at baseline, with burden remaining stable over the course of the study. The intervention group was significantly less depressed, but anxiety remained stable across groups.

Conclusions—With the lessons learned and feedback obtained from FCGs, this study is the first step to developing an effective social support intervention to support FCGs and healthcare providers in improving cancer care.

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Keywords

Social network; family caregivers; social support; intervention

INTRODUCTION

Informal family caregivers (FCGs) provide physical care and emotional support to patients and are an integral part of the health care team [1]. However, while there is ample research that has focused on neuro-oncology patients, less research has concentrated on the FCG solely [2]. Many cancer FCGs report feeling unprepared and overwhelmed by their role [3], with anxiety, fear, and insecurity invading their everyday lives [4]. These feelings of burden have been shown to adversely impact caregiver quality of life, psychological and physical health [5, 6].

Those caring for patients with primary malignant brain tumor (PMBT) may be especially at risk for high burden due to the rapid progression of disease, significant physical debilitation, cognitive decline, and personality and behavior changes associated PMBT [3, 7, 8]. Despite the recognition of these complications, there has been little prospective systematic longitudinal research with caregivers of patients with PMBT [2, 9]. The majority of work has been qualitative or descriptive with few interventions designed for or tested within the population of neuro-oncology caregivers [2, 10]. These intervention studies have focused on areas such as psychoeducation, problem-solving/skills building, complementary and alternative medicine, and various therapies focused on the interpersonal, family/couples, and existential, with the greatest benefits observed in those that were structured and goal-oriented [10].

Recognizing the challenges FCG face, where can assistance be introduced or strengthened during the daily challenges of caregiving? Social support is a key area that, when utilized effectively, can help alleviate FCG burden and the negative impacts that caregiving may have on a person's psychological and physical health [11–14]. However, social support is unfortunately not always effectively used for a variety of reasons, and has been identified as a particular area of concern for FCGs [4]. Research shows that many caregivers underutilize the support available to them and instead try to handle everything themselves [15–17]. Often FCGs feel a responsibility to provide care and a desire to protect the rest of their network from fear or anxiety [10, 18]; immersing themselves in caregiving tasks which often distances them from those who could provide support [10]. FCGs are often too overwhelmed to identify or organize available support resources [15–17] or underestimate the capability or willingness of their support networks to help [19]. The problem of support is further compounded by shortcomings in referral of caregivers to psychosocial support services, which are often limited and reactive [20]. This results in many caregivers who do not utilize services, or reach out too late to get the most benefit [21]. However, social support has been documented as lowering levels of burden [11–13] and leading to better health and improved quality of life [14, 22]. Social support is an area that has been shown to alleviate burden, yet FCGs may not know how best to take advantage of the support already existent in their life, and healthcare providers may not have the right tools to help patients and FCG.

Neuro-oncology patients and their FCGs are an important, understudied group that lack effective interventions to help alleviate burden. To address this gap, we developed the electronic Social Network Assessment Program (eSNAP) with input from caregivers and providers to automate the efficient capture and visualization of neuro-oncology FCG social network data for both FCGs and healthcare providers. The aim of eSNAP is to ultimately reduce caregiving burden by helping caregivers visualize their existing social network resources (For a full description of the development of eSNAP, see Reblin et al. [23]). eSNAP is based on ecomapping; ecomaps are visualizations, based on a clinical interview process used in supportive care, to depict the size, strength, quality, and function of a person's social network. Ecomaps can highlight barriers in social support, such as under-utilized existing support, reduce cognitive load, offer a new way to organize information, and can provide new insights about caregivers' social networks [24]. Visualizations may activate social support by making existing resources more salient under stressful conditions. Research in other populations has shown that creating visualizations facilitates understanding of social network resources, including highlighting unrealized resources, and facilitates discussions with health care providers and others about social network resources [15, 16, 23, 24].

We conducted a pilot study to determine the feasibility of implementing the eSNAP intervention in a neuro-oncology clinic and gathering longitudinal data [25]. As part of this pilot, we gathered data on the preliminary effectiveness of eSNAP. Our hypothesis was that those who used eSNAP would have lower distress and burden at the 3-week and 6-week follow ups.

METHODS

Design

A longitudinal, two-group randomized design was used to compare the eSNAP intervention in caregivers of patients with primary brain tumor against controls who did not receive the eSNAP intervention.

Sample

Participants were recruited from a neuro-oncology clinic at an NCI-designated comprehensive cancer center from May to August 2017. 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. The patients of these caregiver participants had, on average, a Karnofsky score of 75 and were diagnosed 32 months before caregiver enrollment (Table 1). Informed consent was obtained from all individual participants included in the study.

Experimental intervention: eSNAP

eSNAP is a web-based application; participants are able to engage in the tool via a webpage, which is available on a variety of operating systems and can be used on a variety of machines (tablet, PC/Mac computer). Within eSNAP, users list people/groups who do or could help within six categories of support: (1) hands on, (2) informational, (3)

communication, (4) financial, (5) emotional, and (6) self-care. A visualization of the support network is created based on data entry. If users identify fewer than 3 resources in a category, they see a recommendation to add resources for that category from a list available within the tool. However, all users were able to navigate to view resources in any category if they wished. Resources include reputable information sources (e.g. ACS/NCI websites) and national or local community services (e.g. Hope Lodge housing). A PDF was created of the user's network visualization and selected resources; a paper/electronic copy was provided to users.

Procedures

Potential participants were identified through clinic schedules, which were screened for patient diagnosis. Patients with primary brain tumors, regardless of their time since diagnosis or treatment status, were approached as long as they were established patients undergoing active treatment at Moffitt Cancer Center. Patients who had a person with them were approached by the researcher after they had checked in, either once they had been put in their exam room or in a quiet, private space in the waiting room. The researcher explained the study to the caregiver and patient, verified that the person accompanying the patient was considered the primary caregiver, invited caregiver participation, and obtained written informed consent from caregivers wishing to participate. Participants completed eSNAP on a laptop computer while waiting for the patient's provider, which usually took about 10–15 minutes to complete. After consent, participants were randomly assigned to either receive eSNAP or usual care (questionnaires only) in a 3:1 ratio. After randomization, participants who received eSNAP were asked to complete their visualization on the eSNAP app, and evaluate it immediately afterwards. All participants were asked to complete follow up questionnaires electronically at 3 weeks (T2) and 6 weeks (T3) after completion of the baseline questionnaire (T1). Email reminders were provided two and five days after T2 and T3 due dates, with a phone call after one week if the questionnaire was still incomplete. While caregivers were reminded of their participation in the study, they were not prompted to review their eSNAP visualization at these time points.

Measures

Demographics were assessed at T1 in order to gather traits on both caregiver and patient, including age, gender, race/ethnicity, relationship, education level, employment type, and income.

Caregiver burden was measured using the 12-item Zarit Caregiving Burden Scale [26] at T1, T2, and T3. The short form has been shown to be valid and reliable [26, 27] and has successfully been used in advanced cancer caregiving populations [28]. The scale shows good sensitivity and has also been used to identify changes over time [29]. Caregiver burden is a good predictor of anxiety and depression [30] and caregiving has been demonstrated to be an independent risk factor for mortality [31].

Distress was assessed using the 14-item Hospital Anxiety and Depression Scale (HADS) [32]. Each item on the questionnaire is scored from 0–3 (no to high anxiety); a summed score is calculated for each 7-item subscale between 0 and 21. This scale has been validated

among cancer FCGs in both screening and research to predict psychological function [33] and there is some evidence to suggest the scales are sensitive to change over time [34].

We assessed whether intervention participants had reviewed their eSNAP visualization at T2 and T3 by simply asking if they had referred to the eSNAP printout in the last 3 weeks (*yes or no*). Participants were also asked to rate how satisfied they were with their support networks on a Likert-type scale of 1 (*not at all satisfied*) to 5 (*very satisfied*).

Analysis

Preliminary analyses (independent-groups t-tests, chi-square) were conducted to determine baseline differences between groups. Mixed models were used for the primary analysis to determine differences in distress, burden, and social support between eSNAP and control groups at 3 weeks and 6 weeks, while controlling for scores at baseline. There were no prompts built into the intervention for caregivers to review eSNAP materials. As such, this analysis largely represents the long-term effect of the one-time exposure to eSNAP. Because of the exploratory nature of the pilot and small sample size, p values were set at .10.

RESULTS

Demographics and Baseline Characteristics

Forty caregivers enrolled in the study (80% recruitment rate). Ten caregivers refused participation. Though no demographic or systematic refusal data was collected on these caregivers, common reasons for refusal included feeling too busy or not wanting to spend more time in the clinic. As shown in Table 1, most participants were white (94.9%) non-Hispanic (92.1%), female (75%), and were on average 57.3 years old (range 29–80 years). Participants had known the patient for an average of 33.2 years (range 3–57 years) and were mostly spouses (64.1%) of the patient. Patients were on average 52.2 years old (range 22–76 years) and most were male (52.5%). There were no demographic differences between participants who were randomly assigned to receive the intervention and those who were randomly assigned to the control condition.

At enrollment, participants reported they were either moderately or very satisfied with their support at baseline (n=38, 84.2%). Participants reported relatively high burden (M=12.35, SD=8.25; 29.7% of caregivers had a score indicating severe burden [27]) and distress (M anxiety=8.32, SD=3.84, 21.6% had a score indicating high anxiety; M depression=9.62, SD=3.40; 40.5% had a score indicating high depression [33]). Table 2 shows anxiety, depression, burden, and social support scores over time for the control and intervention group.

There were no significant differences in baseline support, distress, or burden between participants who received the intervention and those that did not (ps>.167). However, analysis of demographic characteristics showed that caregiver sex and relationship to patient were significantly related to all outcome variables (p<.10) and were thus controlled for in future analyses.

Outcomes

At three weeks, 92.5% of participants completed questionnaires and 6 of the intervention participants reviewed their eSNAP visualization. At six weeks 80% completed questionnaires and 6 intervention participants reviewed their eSNAP visualization. Four of these participants were consistent across time; two participants who said they reviewed eSNAP at T2 did not review again at T3, but two different participants had newly referred to eSNAP at T3.

Mixed model analysis showed that across groups over time, there was no significant change in helpfulness of social support (F=1.266, p=.294), anxiety (F=1.806, p=.179) or burden (F=1.820, p=.177). Depression significantly increased across time for all participants (F=3.225, p=.05). Focusing on comparisons between intervention and control participants, we found no significant effect of the intervention on helpfulness of social support (F=.005, p=.945), anxiety (F=.776, p=.38) or burden (F=.254, p=.617). Those who received the intervention were significantly less depressed (estimated M= 9.795 vs 11.822; F=3.432, p=.072). There were no significant interactions between condition and time.

DISCUSSION

While there is a body of research indicating the high level of burden and distress associated with caring for patients with PMBT [2, 3, 7, 8, 35], the majority of work has been done on small samples, often qualitatively, and at a single time point [2]. Our longitudinal results are an important addition to the current literature. Further, our study represents one of the few interventions to support these family caregivers as a self-directed, one-time exercise for only caregivers. Many interventions include the caregiver *and* patient [36, 37] or only the patient [38–40] and are led by trained personnel or medical professionals at multiple meetings [41]. However, major barriers to the sustainability of many interventions include the need for resources and staff capacity required to enact them [42]; interventions that provide cues to alter behavior may be a promising strategy for long-term success [43]. Though more work is needed to strengthen the intervention, this pilot represents an important first step in development of a less-resource intensive caregiver-focused intervention and our conservative implementation demonstrates promising effects to reduce caregiver distress.

There has been little prospective systematic research to understand the support process in FCGs of patients with PMBT longitudinally [9]. Some research indicates burden lessens over time as caregivers learn to navigate their new role or manage their expectations [4, 44, 45]. However, our findings are more consistent with other work [46, 47] that shows caregivers of patients with PMBT have consistently high burden and distress at baseline which does not attenuate over time. These varied results may be due to the different disease trajectories patients take and the resulting differences in the objective burden experienced by caregivers, or the different abilities of caregivers to cope with new stressors, which were not controlled for in our pilot study. While burden may certainly attenuate in this time frame in other populations [29], more research is needed to understand variation in the neuro-oncology caregiver experience over time.

Over the course of the 6-week study period, we found perceived social support and caregiver burden and anxiety stayed consistently high. Depression also maintained a consistently high score in the intervention group but increased over time in the control group, suggesting that eSNAP may have had a protective effect. Sherwood et al. [2] notes in their review of neuro-oncology family caregiving interventions that researchers may not be able to *reduce* distress but can focus on preventing an *increase* of distress over time. Our study results are consistent with this suggestion, and provide promising avenues to prevent the increase of psychological burden. Further, it is not uncommon to see ceiling effects in measures of perceived support. Perceived helpfulness of support is distinct from potential negative aspects of support, such as unwanted advice, and may not reflect actual utilization of support [48].

Though the use of eSNAP may have activated processes that reduced depression in caregivers, an alternative explanatory mechanism may have been a placebo effect in offering any intervention. A recent meta-analysis on distress in caregivers of patients with PMBT highlighted a feeling of isolation and lack of support from health care systems [49]. Offering an intervention may have shown caregivers that they were being heard. This adds impetus to develop more tools to support this population.

Limitations

Our findings were likely impacted by the limited use of the app available to participants, resulting in a highly conservative test of the intervention. All intervention participants used the app during down time in the clinic, between being seen by various providers (medical assistant, physician assistant, etc.). This may have created a time pressure to finish the intervention rather than allowing them to take their time to explore all the app had to offer. Additionally, due to financial constraints of app development, participants were unable to revisit the app after their initial visit at baseline. Although they received electronic PDFs of their visualization, no prompts were given to review these over time, and very few reported doing so. Finally, participants were caring for patients at various stages in their disease. Patient symptoms and disease progression likely plays an important role in the support needs of family caregivers. More work is needed to determine the most appropriate timing of the intervention.

For future implementation, we have since developed the back-end of the eSNAP website to allow for participant data to be saved securely and reviewed later through a login procedure. Further, prompts to refer back to eSNAP are planned at regular intervals. We anticipate these changes will improve eSNAP engagement and have a greater impact on outcomes. We also plan to implement the intervention early in the care trajectory to set caregivers on a path for success for the remainder of the patient's treatment; early caregiver support has been linked to improved psychosocial outcomes [35, 50].

Conclusion

Our study represents a first step in the development of an intervention to support FCGs of patients with PMBT. There is some evidence to suggest that helping caregivers visualize their existing social network resources improves psychosocial outcomes, particularly after changes identified in our pilot work are implemented. eSNAP offers the opportunity to

implement a low-barrier means of providing first-line psychosocial care to family caregivers, which is highly needed.

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Table 1

Demographics

Variable	Total Sample N=40		eSNAP N=30		Control N=10	
	Freq	%	Freq	%	Freq	%
Caregiver female	30	75.0	22	73.3	8	80.0
Patient female	19	47.5	16	53.3	3	30.0
Caregiver White	37	94.9	27	93.1	10	100.0
Patient White	36	90.0	26	86.7	10	100.0
Caregiver Education Level						
High school graduate or equivalent	9	23.7	6	21.4	3	30.0
Some college or vocational school	9	23.7	6	21.4	3	30.0
College graduate (4 years)	7	18.4	6	21.4	1	10.0
Graduate or professional school	1	2.6	0	0.0	1	10.0
Some graduate or professional school	12	31.6	10	3.4	2	20.0
Caregiver household income						
Less than $10,000	2	5.4	2	7.4	0	0.0
$10,000 – $24,999	3	8.1	3	11.1	0	0.0
$25,000 – $39,999	7	18.9	4	14.8	3	30.0
$40,000 – $49,999	3	8.1	3	11.1	0	0.0
$50,000 – $74,999	5	13.5	3	11.1	2	20.0
$75,000 – or more	13	35.1	8	29.6	5	50.0
Prefer not to answer	4	10.8	4	14.8	0	0.0
Patient tumor type						
Glioblastoma multiforme	23	57.5	17	56.7	6	60.0
Astrocytoma grades I–III	7	17.5	4	13.3	3	30.0
Oligodendroglioma	5	12.5	4	13.3	1	10.0
Other Primary Brain Tumor	5	12.5	5	16.7	0	0.0
Caregiver employment						
Not currently employed	3	7.9	3	10.7	0	0.0

Variable	Total Sample N=40		eSNAP N=30		Control N=10	
	Freq	%	Freq	%	Freq	%
Retired	14	36.8	11	39.3	3	30.0
Part-time	5	13.2	4	14.3	1	10.0
Full-time	16	42.1	10	35.7	6	60.0
Caregiver relationship to patient						
Spouse	25	64.1	16	55.2	9	90.0
Parent	5	12.8	5	17.2	0	0.0
Sibling	1	2.6	1	3.4	0	0.0
Child	7	17.9	6	20.7	1	10.0
Other	1	2.6	1	3.4	0	0.0
	Mean	SD	Mean	SD	Mean	SD
Patient age	52.2	16.5	50.5	17.1	57.2	14.2
Caregiver age	57.3	11.4	56.7	11.9	59.1	10.0
Relationship length	33.2	15.4	33.9	16.4	31.5	13.2
Patient Karnofsky score at T1	75.0	15.4	74.3	17	77.0	9.5
Time (months) from patient diagnosis to T1	32.0	46.0	30.4	43.2	37.0	57.0

Table 2

Caregiver outcome means and standard deviations over time

Variable	Total Sample			eSNAP			Control		
	Mean	SD	% over cutoff[*]	Mean	SD	% over cutoff[*]	Mean	SD	% over cutoff[*]
Burden T1	12.4	8.3	29.7	11.7	1.6	22.2	14.1	2.6	50.0
Burden T2	12.9	8.4	38.9	12.7	1.6	34.6	13.3	2.6	50.0
Burden T3	15.4	11.1	51.5	14.3	2.1	45.8	15.6	3.5	66.7
Anxiety T1	8.3	3.8	21.6	8.6	0.7	25.9	7.6	1.2	10.0
Anxiety T2	8.0	3.3	25.0	8.2	0.6	34.6	6.7	1.0	0.0
Anxiety T3	8.2	4.1	18.2	8.5	0.8	25	7.7	1.3	0.0
Depression T1	9.6	3.4	40.5	9.1	0.6	37.0	10.9	1.0	50.0
Depression T2	10.8	3.5	55.6	10.4	0.7	50.0	11.9	1.1	70.0
Depression T3	10.9	3.6	60.6	9.9	0.6	54.2	12.7	1.0	77.8
Social support T1	4.5	0.8	84.2	4.4	0.9	78.6	4.7	0.5	100.0
Social support T2	4.4	0.9	75.7	4.4	0.9	77.8	4.3	0.9	70.0
Social support T3	4.1	1.1	71.9	4.2	1.0	78.3	4.0	1.2	55.5

[*] Cutoff criteria:

Burden: Score of 16–48 (clinically significant burden)

Anxiety: Score of 11 or more (clinical case)

Depression: Score of 11 or more (clinical case)

Social support: Percent reporting moderately to very satisfied