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Recreational Travel of Patients with Brain Tumor and Their Caregivers: Context, Preparation, and Impact

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Abstract

Background: Caregivers are engaging in recreational travel with the neuro-oncology patients they care for, yet there is little scientific research on this phenomenon.
Aim: The purpose of this study is to examine the experiences of recreational travel among caregiver–patient with brain cancer dyads from the perspective of the caregivers. Specifically, we examined (1) context (i.e., why and when) of recreational travel, (2) the caregiver's travel preparations, and (3) the impact of the travel on caregivers.
Design: Descriptive thematic analysis was conducted on transcripts of unprompted caregiver discussion of recreational travel, defined as any trip or vacation taken by caregiver and patient with the purpose of recreation lasting at least overnight.
Setting/Participants: Caregivers of patients with brain cancer enrolled in an eight-week support intervention at an NCI-designated Cancer Center (NCT04268979). Incidental discussion of recreational travel during weekly phone intervention sessions was identified from structured interventionist notes.
Results: Fifteen caregivers discussed recreational travel. The context of travel was often to focus on quality of life upon treatment cycle completion. Preparation often included accommodating patients' needs. Care teams' practical support and validation for the trip were identified as useful resources. Caregivers most often described the emotional impact of travel, which was often complex and bittersweet.
Conclusions: Travel with a patient with brain cancer may be an important goal for caregivers and could help create meaning and memories, but can also present challenges. Early and clear communication from the care team can play a role in supporting meaningful trips.

Keywords: caregiver; leisure; neuro-oncology; psychosocial; travel

Key Message

Caregivers are engaging in recreational travel with neuro-oncology patients they care for. Trips are often planned at the end of treatment cycles. Travel can create important memories and support coping, but highlights patient decline and burden for caregivers. Clear and early care team communication is critical in supporting these trips.

Introduction

Many patients with cancer at end of life choose to focus on quality versus quantity of life. Often an important contributor to quality of life is recreational travel and spending time with family.[1] Specifically, recreational travel is an opportunity to make memories in symbolic places with loved

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ones.[2,3] Although there is inherent risk,[4] patients with cancer and caregivers have reported patient psychosocial benefits to recreational travel while on treatment, including a form of escapism, enhanced personal identity, and health.[5]

However, little work has focused on recreational travel in neuro-oncology caregiver–patient dyads.[3,6] These patients may have a similar desire for recreational travel as other patients with advanced cancer, but additional barriers may exist to planning and executing travel due to rapid disease progression, poor prognosis, patient's cognitive or behavioral changes, or side effects from cancer and treatment.[7,8] Furthermore, patients with brain tumor may rely more on caregivers to overcome these issues and participate in travel. Few studies capture the experience of caregivers in planning recreational travel with the person with a brain tumor for whom they provide care.

The purpose of this qualitative study is to examine the experiences of primary caregivers in planning and engaging in recreational travel with a person living with brain cancer.

Methods

This study used a targeted, deductive approach to conduct descriptive thematic analysis[9] of qualitative data gathered as part of a larger randomized controlled trial at an NCI-designated Comprehensive Cancer Center in Florida between February 2020 and January 2024 (NCT04268979). Eligibility criteria included English-speaking/writing and ability to complete questionnaires including by proxy. Caregivers were required to identify as providing primary, unpaid, support for patients with a new or recurrent brain tumor in the last nine months. All study procedures were approved by the Advarra Institutional Review Board (Protocol 19731). Informed consent was obtained from patient and caregiver study participants.

As part of the caregiver-focused intervention, described elsewhere,[10] participants completed demographic questionnaires at enrollment and caregivers who were randomized to the intervention engaged in weekly 30-minute phone calls with a trained nonclinical caregiver navigator over eight weeks. In manualized sessions,[11] trained caregiver navigators[12] conducted assessments and used problem-solving and motivational interviewing approaches to help caregivers identify support and develop coping strategies. While travel discussion was never prompted as part of the intervention, caregivers often discussed recreational travel in the context of applying strategies. No differences were identified in demographics between intervention and control caregivers.

Navigation sessions were audio-recorded and transcribed verbatim. Navigators completed structured session notes[13] regarding the participant's concerns, the navigator's assessment, and next steps and referrals. Notes were reviewed by the first author to identify any sessions in which recreational travel was discussed. Recreational travel was defined as any trip or vacation taken by caregiver and patient with the purpose of recreation lasting at least overnight.

Transcripts of these sessions were then each read and analyzed by study PI, who has expertise in qualitative analysis and psycho-oncology caregiving, and two caregiver navigators, who had contextual knowledge of caregivers as interventionists, to independently identify themes around (1) the context of the trip, including why and when caregivers and patients planned travel, (2) preparations taken by caregivers prior to the trip, and (3) how caregivers describe the impact of the trip. Coders discussed each transcript and identified quotes within each theme until consensus was achieved. Themes and representative quotes were then reviewed by other authors with expertise in psycho-oncology and experience in caregiving for verification. The quality of this study was assessed with the Consolidated Criteria for Reporting Qualitative Studies checklist (see Supplementary Table S1). Demographic data were summarized using descriptive statistics.

Results

Demographics

Caregiver navigation notes from 15 caregivers (of 92 total) included discussion of a recreational trip. Caregiver–patient dyad demographics are shown in Table 1. Exemplar quotes within our coding tree are shown in Table 2.

Travel themes

Context. Trips ranged from international sightseeing trips to more modest local road trips to visit friends or family. Often caregivers described planning a trip during a "break" in treatment—either when a treatment cycle was over or when it was clear that treatment had not been effective. For some, travel represented going back to normal, but for others, it meant doing something new. Many named the patient being able to spend time with loved ones as a key reason for travel.

Preparations. One major aspect caregivers mentioned impacting their travel preparations was specifically how long patients were expected to maintain function. Many caregivers described the extra planning and preparation that went into traveling with a person with brain tumor. For example, there was a need to ensure accommodations and activities had accessibility and safety features, such as wheelchair accessibility or handrails. Most caregivers discussed travel with their care teams after deciding to travel and found them to be supportive. Providers offered practical help, such as additional prescriptions or information about insurance coverage and what to do in an emergency, and validation around taking the trip.

Impact. Caregivers primarily described the emotional impact of travel. Many caregivers were energized by making plans and reported that travel held joy and relaxation, both for the patient and for themselves. However, sometimes trips did not live up to expectations. The additional planning and responsibilities, in addition to managing changes in the patient's personality and abilities in a new environment, sometimes caused more stress for caregivers. Furthermore, caregivers noted that travel and spending time with family could be exhausting for patients. This was true both physically and emotionally, as the trip could highlight the patient's decline and potential mortality. In fact, some caregivers noted that how others reacted on the visit crystalized changes in the patient and their own role in care.

Table 1. Caregiver and Patient Demographics

	*Caregivers (*n = *15)*		*Patients (*n = *15)*	
	Mean	*SD*	*Mean*	*SD*
Age (years)	60.5	9.21	64.4	9.74
	n	*%*	*n*	*%*
Gender				
Male	3	20.0%	10	66.67%
Female	12	80.0%	5	33.33%
Race				
White	14	93.33%	15	100%
Other	1	6.67%	0	0.00%
Ethnicity				
Hispanic or Latinx	2	13.33%	0	0.00%
Highest level of education				
High school diploma	2	13.33%	1	6.67%
Some college	3	20.0%	6	40.0%
Four-year degree	5	33.33%	5	33.33%
Postgraduate degree	5	33.33%	2	13.33%
Hours spent working for pay per week				
35 hours or more	3	20.0%	4	26.67%
Less than 35 hours	2	13.33%	0	0.00%
Not working	10	66.67%	10	66.67%
Retired	7	46.67%	7	46.67%
On medical leave	1	6.67%	3	20%
Other	2	13.33%	0	0.00%
Financial situation				
More than adequate	2	13.33%	2	13.33%
Comfortable	9	60.0%	9	60.0%
Not very good	3	20.0%	4	26.67%
Missing	1	6.67%	0	0.0%
Relationship with patient				
Spouse or partner	13	86.67%		
Parent (parent-in-law)	1	6.67%		
Child	1	6.67%		
Live in same house with patient				
Yes	14	93.33%		
No	1	6.67%		
Length of time providing care				
Years	5.5	1.5		
Months	9.83	12.2		
Hours spent providing care weekly	30.2	39.9		
Karnofsky Performance Scale Score			80.29	11.93

SD, standard deviation.

Discussion

While some research exists on the safety of travel, particularly medical travel,[4] little has focused on recreational travel, and even less on neuro-oncology patients and their caregivers. Caregivers in our study largely reported discussing their trips with providers and receiving important support. However, this was primarily done after the decision to travel, sometimes in recognition of a possible "last chance" after a failed treatment cycle. Not all caregivers mentioned discussing travel with their providers, and although there were no medical mishaps mentioned, this could be a missed opportunity to ensure patient safety. Research suggests that many patients with brain tumor are unaware of their life expectancy,[14] which may prevent more proactive travel plans. While patients and caregivers value communication and are open to care options that may prioritize quality-of-life goals,[15] such as recreational travel, communication about these topics with providers is often not clear.[16] Better proactive communication around prognosis and goals of care may have allowed more caregivers and patients to plan travel.

There are risks for patients associated with travel, including infection, complications, and overexertion.[4] Caregivers must ensure that the patient can be cared for safely in a new context. Additionally, treatment for brain cancer frequently creates financial toxicity for patients and their families.[17] This may impact funds available for travel or to make a trip safer or more comfortable. While ambitious travel to achieve "bucket list" items may be a goal,[18] it is important for patients and caregivers to be realistic about the patient's capacity and

Table 2. Themes and Subthemes with Exemplar Quotes

Context	
Timing of Travel	"Actually it was on our ride home from [meeting the] oncology neurosurgeon. . . [He] said, 'okay, we're not going to talk about slice and dice. . . he'll never be the same if that happens.' . . .So we're riding home. . .and [the patient] says to me, 'Let's take a trip'. . . Within a week I had called Royal Caribbean. . . [His tumor] is growing. . . And they're watching, but we're opting for quality, not quantity." (ID 169)
Changing Goals of Care	"I was gonna say my priority now is quality of life. Now we're done with the radiation and we can... You know, [the patient]'s worked her whole adult life and go-go-go. What are things that you'd like to enjoy now?" (148)
Purpose for Travel	"We'll go stay with [the patient's family]. . . That way we at least get a chance to visit with other relatives and loved ones and get them in-person updates because everybody wants to know what's going on because they care so much about her – really about both of us." (125)
Preparation	
Considering Patient Function	"I know nobody can give you a golden bullet of time frames or anything like that, but it might just be helpful to find out averages and things like that so we can make some future decisions on vacation and spending time and doing the things we want to do instead appointments and how we can do that." (172)
	"They have a boat there that you take out every day. . . So, that's the huge benefit. They just put it in the water, and they clean it, and gas it, and all that stuff. So, you can just jump in and go. And I was afraid I was going to have to take a wheelchair. And that he didn't have enough strength to wheel down. But [the patient did an evaluation and] I think now it will be okay." (122)
Support from Providers	"We don't want to leave the United States. . . in case we have an emergency. . . The doctor gave us a prescription for in case there are some neurological issues there that we need to address. . . It's better to go on vacation, it's better that you do something outside of just coming here and doing therapy." (191)
Impact	
Joy and Relaxation	"And then I'm trying to get everything done before we go out of town next week. Just get all my work stuff out and all that. You know it's just a lot of little loose ends, thinking about packing, getting all the trip stuff together. . . I'm very excited. [We've been watching] little travel videos so that she could see what she's going to see." (198)
	"We were out on the lake for a couple hours. Right before my wife went to sleep, she goes, 'I think this was the best day I've had since I got sick in July.'. . . I did eventually relax [too] but it took a while to find that. But I told my wife we really have to find ways to do more of that. Not that you can go take a two-and-a-half-hour sunset cruise every day, that's just not realistic, but we have to a way to unwind every day a little bit." (125)
Unmet Expectations and Stress	"So, the trip was horrible. [The patient] thought it was good. It was horrible to me. . . part of the issue is that his personality changes. . . He kept saying he wanted to drive and go to the bait shop and get this and that. So, I had to hide the keys. . . He's still fighting that he can do these things. . . We finally got to the beach. . . and I had to cart everything, push him in a wheelchair. And then, he can't tie a hook and I don't know how to do that. So, he's trying to teach me. It was a very stressful day." (122)
	"I needed. . . to recuperate from the [time] with my kids. I love them. And my grandkids—love them too. But what I realized on this trip is we need more privacy now. It was hard for him to rest and if he don't get good rest, I don't get good rest. It sets off this whole chain reaction." (131)
Coming to Terms with Mortality	"Being around them and having them experience what I experience every day was a little challenging because it did bring up a lot of emotion. They don't see her every day. I'm with her every day. So I see the good and the bad and it's not as big of a shock to me. . . .For them to see her kind of . . .not as strong. That it kind of hit them a little bit harder. (198)
	"I noticed changes in his speech and walking and stuff when we got home. And I'm sure it was just from exhaustion. But I think it was bittersweet, to be honest. Because you know why you're doing it. And it's not like the last time. . . [but the] next time, if there is the next time, he won't be able to travel." (192)

needs to ensure that both patient and caregiver can manage the demands of travel.

Many caregivers reported that travel was associated with bittersweet emotions. Caregivers noted that the trip marked a "last time" and highlighted the patient's decline and their increasing responsibilities. Recognizing and accepting these emotions may be a difficult but necessary part of preparing for the patient's potential death. Preparedness for death is associated with more awareness and acceptance of the terminal nature of the disease[19] and may be associated

with better post-loss adjustment.[19] Meaning-making strategies, including living in the "here and now" and enhancing relationships, can improve psychological adjustment.[20] As such, traveling and connecting with friends and family may be a healthy way to manage emotions that arise upon the end of a brain cancer treatment cycle, especially one that was not successful.

Limitations

This analysis represents a relatively small, homogenous sample of neuro-oncology caregivers who initiated discussion of recreational travel as part of a research intervention. Our sample may have had relatively more resources and access to travel than average neuro-oncology dyads. As discussions were not prompted, we may have failed to capture some caregivers who engaged in recreational travel, including those that may have traveled independently for respite. We also did not capture the experience of caregivers and patients who considered recreational travel but ultimately decided against it. Future research could more systematically focus on recreational travel decision making and experiences in a more diverse population of caregivers and patients.

Conclusion and Practice Implications

Our analyses, drawn from the caregiver perspective, can help set expectations for future caregivers and provide guidance for providers to understand why and how some patients and caregivers engage in recreational travel and how these trips may enhance meaning. Future research could develop resources or communication interventions to help providers assess and assist neuro-oncology patients and their caregivers considering travel.

Authors' Contributions

M.R. contributed to study conception and design. Data preparation and analyses were performed by M.R., K.W., and O.R. The first draft of the article was written by M.R., and all authors commented on previous versions of the article. All authors read and approved the final article.

Data Availability

The datasets analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Advarra Institutional Review Board (Protocol 19731).

Consent to Participate

Informed consent was obtained from all individual participants included in the study. All identifying information has been removed.

Author Disclosure Statement

The authors have no relevant financial or nonfinancial interests to disclose.

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Supplementary Material

Supplementary Table S1

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