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Informational needs of brain metastases patients and their caregivers

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Abstract

Background. In response to a dearth of formal health information targeted towards patients with brain metastases and their caregivers, a formal informational and supportive care needs assessment was conducted.

Methods. Brain metastases patients and caregivers who attended a clinic focused on the treatment of brain metastases at a tertiary medical center completed a self-report survey to assess informational needs across 6 domains: medical, physical, practical, social, emotional, and spiritual informational needs. Univariate and multivariate analyses of associations between variables was conducted using linear regression models.

Results. A total of 109 patients and 77 caregivers participated. Patients and caregivers both prioritized medical and physical informational domains, with a large focus on symptoms and side-effect profiles, significance of brain metastases locations and their implications, available treatment options and their risks and benefits, prognoses and follow-ups if treatment is completed, and end-of-life experiences and supports. One-on-one counseling was preferred by both caregivers and patients for these domains, as well as for practical informational needs; while patients preferred pamphlets to address social, emotional and spiritual informational needs, caregivers preferred one-on-one counseling for the former two domains as well.

Conclusions. Brain metastases patients and their caregivers prioritize medical and physical informational needs, with one-on-one counseling and pamphlets being the most preferred modalities for information provision. Further exploration regarding existing non-validated resources and the development of tailored resources to address the unique needs of these patient and caregiver populations are warranted.

Keywords

Brain metastases | informational needs | patient education | supportive care needs

Recent improvements in cancer therapies have led to longer survival, resulting in an increase in the incidence of patients with brain metastases. Brain metastases develop in approximately 20% to 40% of patients with cancer, with an estimated 170 000 patients diagnosed with such metastases annually in the United States.[1–5] While prognoses vary depending on histology, performance status, age, and number of lesions, brain metastases are associated with significant morbidity and mortality, including cognitive decline, neurological impairment, and constitutional symptoms.[3–6] The side effects and toxicities associated with therapeutic modalities, which include surgery, radiotherapy, chemotherapy, corticosteroids, and antiepileptics, may further compound the symptom and quality-of-life burden associated with the diagnosis.[5]

The rising incidence of brain metastases and the changing landscape of therapeutic options has garnered growing recognition of the importance of addressing the psychosocial, physical, and emotional needs of this patient population. Adequate survivorship care requires meeting the informational and supportive care needs of this population in terms of issues relevant to their medical diagnosis, potential benefits and adverse effects of treatment options, and the cumulative impact of treatment on physical, emotional, and social functioning.[6,7] Such information can affect health outcomes, reduce anxiety, and increase feelings of control.[8,9]

Caregivers may also have unique informational and supportive care needs, given their central role and responsibility in patients' illness trajectories. Similar to patients, caregivers have been found to want proactive, forthcoming, honest and complete disclosure of information regarding medical conditions.[10,11] Previous studies have also reported a desire for information regarding future prognostic implications and associated anticipatory guidance for caregivers, compared to a larger focus on present implications and decision options for patients.[10]

Recent efforts to summarize the literature emphasized the importance of proactive information sharing for both patients and caregivers, but yielded knowledge gaps in terms of informational needs pertaining to social, emotional, and spiritual domains for both groups.[12] Informational needs regarding patients' physical effects and needs were largely unexamined among caregivers, with only a small number of studies examining informational needs pertaining to practical and medical domains.[12]

To the best of our knowledge, no study has comprehensively studied the informational needs of patients and caregivers across medical, practical, physical, social, emotional, and spiritual domains. Such an approach is important in mirroring clinical practice, where specialized brain metastases clinics and health care providers strive to support patients with multimodal programs and interventions across multiple domains.

To better understand and respond to the unique, evolving informational and supportive care needs of patients and their caregivers using a variety of modalities, the development of a comprehensive education pathway contributing to the overall quality of life and general health outcomes of these two groups has been pursued. As part of this pathway, a needs assessment was conducted using a self-report questionnaire, with a plan to better inform the development of tailored patient and caregiver resources and programs.

Methods

Participants

A cross-sectional observational study was conducted using a convenience sample. Patients and caregivers visiting the Princess Margaret Cancer Centre (PM) Brain Metastases Clinic in Toronto, Canada between January and August 2016 were invited to complete a one-time, self-administered questionnaire upon registration at the clinic. PM delivers comprehensive cancer diagnostic, therapeutic, and supportive care to cancer patients and caregivers globally. As part of its efforts to provide patient and family-centered care with a holistic model, PM has developed a specialized program for brain metastases patients, the Robert and Andrée Rhéaume Fitzhenry Brain Metastases Program within the Brain Metastases Clinic.

Patients were considered eligible if they were at least 18 years of age and had cancer diagnoses with 1 or more confirmed brain metastases. Questionnaires were completed by patients and caregivers with minimal supervision from research staff. Accompanying family members or friends were able to assist if needed. Patients and caregivers were requested to complete the questionnaire at the Clinic, or to complete it at home and deliver it to a secure drop-box located at the Clinic, which was checked on a daily basis. The questionnaire generally took 15 to 25 minutes to complete. Consent was implied by completion of the questionnaire, and participation was voluntary, optional, and anonymous.

Approval to conduct the study was obtained from the University Health Network Research Ethics Board.

Measurement Instrument

A well-used, evidence-based, non-validated questionnaire was designed in-house based on existing evidence and literature regarding patient informational and supportive care needs.[13,14,16–19] The questionnaire was tested for face validity with 5 patients and 5 health care providers prior to use, and identified problems were addressed through adjustments to questionnaire items. The questionnaire included 3 major sections:

1. Demographic and health information: Demographic information obtained in this section included: age, gender, race, fluency and level of comfort with the English language, education, types and number of supports and caregivers, whether residence is shared with supports or caregivers, employment status, annual household income, and degree of access to the Internet. An indication of patient performance status was obtained by determining the amount of help needed with daily activities. Health information obtained included: type of primary cancer associated with brain metastases, number of brain metastases, duration of diagnosis and/or treatment, number of types of treatments pursued or planned for the metastases, types of treatments pursued or planned by friends or family, and purpose of brain metastases treatments.
2. Informational needs: There were 57 items for patients and 55 items for caregivers across 6 domains: medical (9 items for both groups), practical (12 items for both groups), physical (18 items for both groups), social (5 items for patients, 4 items for caregivers), emotional (8 items for patients, 7 items for caregivers) and spiritual (5 items for both groups). For each item, the respondent was asked to rate how important the information was to

them and how in-depth they would wish to receive that information on a 3-point Likert scale, where for importance, 1 represented 'not important' and 3 represented 'very important', and for depth of information, 1 represented 'none' and 3 represented 'detailed'. Subsequent items asked respondents how they would like to receive information by ranking their three top choices from a list of modalities including: pamphlets, books, DVDs, online videos, online audios, online forums/message boards, group classes, one-on-one teaching, support groups, websites and other modalities.

3. Comments: This section contained 4 items requiring comment-style responses. Respondents were asked what their biggest informational need was, whether this need had been met, preferred format for information receipt for this need, and any additional comments or suggestions. The results of this section will be presented in a future publication.

Statistical Analysis

Continuous variables were described using means, standard deviations, medians, ranges, and interquartile ranges; categorical variables were described using frequencies and proportions.

Responses to all importance items were coded as follows: 'not important' = 1, 'somewhat important' = 2, 'very important' = 3. Frequencies and percentages are reported for each response. In addition, descriptive statistics (medians, etc.) were calculated for each importance item using the originally assigned values of 1 through 3.

A domain importance score, ranging from 0 to 100, was created for each patient by the following means: within each domain, the percentage of answered items to which they responded 'very important' (versus 'somewhat important' or 'not important') was calculated. Domain importance scores were not calculated for patients who replied "N/A" to, or left blank, all items within a domain. The domain scores reflected the importance of information relating to each domain for patients who considered one or more items applicable to themselves. Univariate analyses of associations between education level (high school or less versus some postsecondary or more) and first choice of modality for receiving information were conducted using Fisher's exact test within each domain. A linear mixed effects regression model was used to test for evidence that domain importance scores vary by domain; random intercepts were used to account for repeated importance measurements on patients. For univariate analyses of associations between domain importance scores and patient characteristics (age, gender, highest level of education completed, and position in cancer journey), distribution-free non-parametric tests (the Wilcoxon rank-sum test, the Kruskal-Wallis test, and Spearman's rank correlation test) were implemented as appropriate. Multivariate analyses were conducted using linear regression models. Backward selection with 'alpha to stay' set to 0.10 was used for model selection due to the fairly small sample size. Statistical significance was set to .05 for all analyses except for backward regression models. SAS 9.3 TS Level 1M1 was used for all analysis.

Results

Of the 252 patients and 155 caregivers approached to participate in the survey, 124 patients and 81 caregivers returned the survey, resulting in response rates of 49% and 52%, respectively. Of those patients and caregivers who returned the survey, 109 patients and 77 caregivers completed the full survey, resulting in a completion rate of 88% and 95%, respectively. A total of 150 people (99 patients and 51 caregivers) denied participating in the survey. The primary reason for declining to participate was due to lack of interest.

Patient Demographics and Health Information

Of the 109 patients that completed the survey, 65 patients (60%) were female. The mean age was 59 years. The majority of respondents were Caucasian or European (65%), endorsed very good English fluency (74%), and were comfortable receiving health information in English (96%). The highest level of schooling completed was primarily college/university level (45%). The majority of respondents endorsed having one or more immediate family members (95%) or extended family members (52%) as supports or caregivers, and endorsed living with one or more such supports (76%). The majority of respondents endorsed working on a part-time or full-time basis (40%), and annual household incomes were scattered from less than $25 000 (9%) to over $99 999 (27%). The majority of participants endorsed needing no help with daily activities of living (57%). The vast majority of participants endorsed having easy access to the Internet for health information (90%; Table 1).

Approximately half of respondents had a primary lung malignancy (51%), and over half had multiple associated brain metastases (57%). Respondents were found to be at various stages of their diagnostic and therapeutic trajectories, with some being newly diagnosed (19%), some having recently finished treatment (19%), some having long-term follow-up post-treatment (43%), some being in remission with monitoring (7%), and others having a recurrence needing treatment or having recently been treated (12%). Approximately equal numbers of respondents indicated that they had single treatments (42%) and multiple treatments (43%) being planned or pursued for their brain metastases, with stereotactic radiation being most common (73%), followed by whole brain radiation (40%). While most respondents endorsed having a single goal with pursuing therapeutic intervention (75%), they were relatively equivocal between prioritizing prolongation of survival (51%) and curative intent (43%; Table 1).

Caregiver Demographics and Health Information

There were 77 caregiver respondents in total, of which 35 caregivers (45%) were female. The mean age was 53 years. A majority of respondents were Caucasian or European (62%), endorsed very good English fluency (84%), were comfortable receiving health information in English (96%), and had easy access to the Internet for health information

Table 1 Patient Demographic and Baseline Health Characteristics

Variable		Number	Percent
Demographic characteristics (n = 106)			
Age (years)	Mean	59.0	–
	Median	59.5	–
	IQR	50–68	–
	Range	21–90	–
Sex	Male	44	40.4
	Female	65	59.6
Race	Aboriginal	3	2.8
	Arab/West Asian	2	1.8
	Black/African	2	1.8
	East Asian	15	13.8
	Latin American/Latino	1	0.9
	South Asian	4	3.7
	South East Asian	7	6.4
	White/Caucasian/European	71	65.1
	Other ('Canadian/South African [Coloured]/West Indian – Trinidadian/other')	4	3.7
English fluency (speaking and writing)	Very poor	1	0.9
	Poor	2	1.8
	Satisfactory	5	4.6
	Good	20	18.3
	Very good	81	74.3
Comfort with health information in English	Yes	105	96.3
	No	4	3.7
Highest level of schooling completed	Grade school	2	1.9
	Some high school	7	6.6
	High school completed	20	18.9
	Some college/university	18	17.0
	College/university completed	48	45.3
	Graduate school	9	8.5
	Other ('post-graduate')	2	1.9
	No response	3	–
Annual household income in recent years	<$25 000	9	8.9
	$25 000-$49 999	20	19.8
	$50 000-$74 999	19	18.8
	$75 000-$99 999	15	14.9
	$99 999+	27	26.7
	Preference to not indicate	11	10.9
	No response	8	–
Supports or caregivers (emotional, psychological, and/or physical)	1 or more immediate family members	103	94.5
	1 or more extended family members	57	52.3
	1 or more friends	26	23.9
	Other supports (CCAC, family GP, psychologist, social worker, pastor/church, sister-in-law, work)	9	8.3
	No supports indicated	4	3.7
Living status with support or caregiver(s)	Yes	83	76.1
	No	26	24.9

Table 1 *Continued*

Variable		Number	Percent
Easy access to Internet for heath information	Yes	98	89.9
	No	11	10.1
Main work-related activity	Part-time or full-time work	43	40.2
	Student	2	1.9
	Retired	39	36.4
	Home-maker	4	3.7
	Receiving disability payment	14	13.1
	Unemployed	4	3.7
	Volunteering	1	0.9
	No response	2	–
Amount of assistance needed with daily activities of living	A lot of help	3	2.8
	Some help	43	40.2
	No help	61	57.0
	No response	2	–
Health-related characteristics (n = 106)			
Primary cancer	Lung	56	51.4
	Breast	20	18.3
	Skin/melanoma	15	13.8
	Kidney	1	0.9
	Colorectal	1	0.9
	Lymphoma	1	0.9
	Back muscle	1	0.9
	Bladder	1	0.9
	Eye	1	0.9
	Liver	1	0.9
	Ovarian	3	2.8
	Stomach/esophagus	1	0.9
	Throat	1	0.9
	Thyroid	2	1.8
	Clear cell sarcoma	1	0.9
	Cervical	1	0.9
	Not known	2	1.8
Number of brain metastases	Single	29	26.9
	Multiple	62	57.4
	Not known	17	15.7
	No response	1	–
Stage of brain metastases trajectory	Newly diagnosed, treatment not started	13	12.0
	Newly diagnosed, receiving treatment	7	6.5
	Recently completed treatment (less than 3 months post-treatment)	21	19.4
	Long-term follow-up (<1 year post-treatment)	23	21.3
	Long-term follow-up (>1 year post-treatment)	24	22.2
	Remission and monitoring	7	6.5
	Recurrence with treatment re-initiated	10	9.3
	Recently completed treatment for recurrence	3	2.8
	No response	1	–

Table 1 *Continued*

Variable		Number	Percent
Number of treatment types completed or planned for brain metastases	Single	44	41.9
	Multiple	45	42.9
	Not known	13	12.4
	No treatment planned	1	1.0
	Other	2	1.8
	No response	4	–
Types of treatments completed or planned by family or friends for their brain metastases	Whole brain radiation	36	40.4
	Stereotactic radiation (gamma knife)	65	73.0
	Other form of external beam radiotherapy (eg, intensity-modulated radiotherapy)	6	6.7
	Surgery	27	30.3
	Targeted chemotherapy	12	13.5
	Pain and/or symptom control	4	4.5
	Enrollment in clinical trial (current or planned)	4	4.5
Number of primary treatment goals	Single goal	66	75.0
	Multiple goals	11	12.5
	Not known	11	12.5
	No response	1	–
Intended treatment goal(s)	Curative	38	43.2
	Survival prolongation	45	51.1
	Palliative	6	6.8
	Not known	11	12.5
	No response	1	–

(97%). The highest level of schooling completed was primarily college/university level (45%). The majority of respondents indicated that they were the primary caregiver to the attending patient (71%), and most caregivers were employed full-time or part-time (58%). The majority of respondents indicated that their care recipients required "some" assistance with daily activities of living (63%), and most caregiver respondents (45%) indicated they spent 20 or more hours per week providing care (Table 2).

Preferred Knowledge Domains of Patients

Mean importance scores were used to determine the relative importance of information from the 6 knowledge domains: physical, medical, emotional, spiritual, practical, and social). Both patients and caregivers considered the medical and physical domains to be of greatest importance (overall mixed effects regression model $P < .0001$), and both domains were equally important ($P = .87$ for patients, $P = .93$ for caregivers).

For patients, among the top 10 items rated as "very important," 80% belonged to the physical domain and 20% belonged to the medical domain. No items from the remaining 4 domains were among the top 10 items rated as "very important" (Table 4), or among the top 12 items rated as "somewhat important" or "very important." Patients considered the remaining domains (practical, emotional, spiritual, and social) to be of significantly lower importance when compared to the medical domain ($P < .0001$; Table 3).

Items in the physical domain ranked as "very important" by patients most frequently pertained to symptoms and side effects to monitor and report to the health care team (89%), and location and effect of the brain metastases (82%). Within the medical domain, information regarding follow-up visits and medical tests post-treatment (80%) and the different treatment options available with their risks and benefits (77%) were ranked as the most important. Items in the practical domain most frequently rated as "very important" pertained to the importance of having information to navigate the health care system (60%). In the social domain, information on impact of brain metastases and treatment on patients' relationship with their partners were most frequently (41%) ranked as 'very important.' The emotional domain item most frequently

Table 2 Caregiver Demographic and Baseline Health Characteristics

Variable		Number	Percent
Demographic characteristics (n = 77)			
Age (years)	Mean	52.5	–
	Median	53.0	–
	IQR	44–65	–
	Range	21–81	–
Sex	Male	42	54.6
	Female	35	45.5
Race	Black/African	3	3.9
	East Asian	14	18.2
	Latin American/Latino	4	5.2
	South East Asian	5	6.5
	White/Caucasian/European	48	62.3
	Other	3	3.9
English fluency (speaking and writing)	No English	1	1.3
	Very poor	1	1.3
	Poor	2	2.6
	Satisfactory	2	2.6
	Good	6	7.8
	Very good	65	84.4
Comfort with health information in English	Yes	105	96.3
	No	4	3.7
Highest level of schooling completed	Some high school	1	1.3
	High school completed	12	15.6
	Some college/university	9	11.6
	College/university completed	35	45.5
	Graduate school	20	26.0
Easy access to Internet for health information	Yes	75	97.4
	No	2	2.6
Main work-related activity	Part-time or full-time work	44	57.9
	Student	4	5.3
	Retired	18	23.7
	Home-maker	2	2.6
	Receiving disability payment	1	1.3
	Unemployed	3	3.9
	Self-employed	3	3.9
	On work leave	1	1.3
	No response	1	–
Caregiving responsibilities (n = 77)			
Role of primary caregiver	Yes	53	70.7
	No	22	29.3
	No response	2	–
Time per week spent on caregiving	<5 hours	12	16.4
	5–10 hours	18	24.7
	10–15 hours	4	5.5
	15–20 hours	6	8.2
	>20 hours	33	45.2
	No response	4	–
Amount of assistance required by care recipient for daily activities of living	A lot of help	9	12.2
	Some help	47	63.5
	No help	18	24.3
	No response	3	–

Table 3 Importance Scores Across Informational Domains

Informational domain	n	Mean (SD)	Median	IQR	Range
Patients					
Medical	109	67.1 (31.9)	77.8	50–88.9	0–100
Physical	103	66.5 (31.5)	75.0	41.7–94.4	0–100
Practical	106	42.6 (30.8)	41.7	16.7–66.7	0–100
Emotional	98	40.3 (37.5)	33.3	0–75	0–100
Social	101	30.8 (37.4)	0	0–60	0–100
Spiritual	86	28.1 (40.7)	0	0–60	0–100
Caregivers					
Medical	77	74.4 (25.4)	77.8	55.6–100	0–100
Physical	74	74.0 (30.1)	88.2	56.3–94.4	0–100
Practical	76	50.2 (32.7)	50	20.2–75	0–100
Emotional	69	48.2 (42.9)	42.9	0–100	0–100
Social	66	25.6 (37.3)	0	0–50	0–100
Spiritual	62	27.5 (41.5)	0	0–60	0–100

Table 4 Ten Questions Most Frequently Rated as “very important” by Patients

Informational item	Domain	Proportion endorsing as “very important”
How important is it to have information about what symptoms and side effects to watch out for and report to your health care team?	Physical	89.2
How important is it to have information about where your brain metastases are and how they affect you?	Physical	82.4
How important is it to have information on how you can deal with headaches due to brain metastases?	Physical	80.9
How important is it to have information about the follow-up visits and different medical tests you will need after treatment?	Medical	80.2
How important is it to have information about different treatment options and their advantages (like success rates) and disadvantages (like possible side effects)?	Medical	77.4
How important is it to have information about how you can manage seizures due to brain metastases?	Physical	75.3
How important is it to have information on how you can manage problems with vision due to brain metastases (like vision loss, blurred or double vision)?	Physical	75.3
How important is it to have information about how you can manage problems with dizziness, balance, and coordination due to brain metastases?	Physical	74.7
How important is it to have information on how you can manage confusion and memory loss due to brain metastases (like having a hard time finding the right words)?	Physical	72.8
How important is it to have information about hidden or long-term side effects from your treatment (like radiation necrosis – when dead tissue forms in the brain causing headaches, memory problems, and confusion)?	Physical	72.6

rated as “very important” pertained to information on coping with uncertainty about the future (51%). The spiritual domain item most frequently rated as “very important” concerned information on using spirituality to cope with the diagnosis and treatment (32%).

On univariate analysis for patients, being newly diagnosed/pre-treatment or having ongoing treatment compared with being finished treatment/follow-up/remission or recurrent, was associated with higher median importance scores for needs within the physical (94.4 vs 72.2; *P* = .02), social (60.0 vs 0; *P* = .04), and emotional domains (75.0 vs 25.0; *P* = .01). No other variables reached statistical significance in any of the domains. On multivariate analysis for patients, being female was associated with higher mean importance scores for the medical (11.3; 90% CI, 1.1–21.5; *P* = .07) domain (no other variables were retained in the medical domain backward regression model) and the physical domain (11.5; 90% CI, 1.0–22.1; *P* = .07). Being newly diagnosed/pre-treatment or having ongoing treatment was also associated with higher mean importance scores in the physical domain (13.8; 90% CI, 0.03–27.5; *P* = .10), as well as the social domain (21.8; 90% CI, 5.6–38.1; *P* = .03) and emotional domain (26.7; 90% CI, 10.3–43.2; *P* = .008). No other demographic variables were retained in the physical, social, or emotional domains. No demographic variables were retained in models for either the practical or spiritual domains. Bivariate analyses were used to determine whether patient demographics were associated with mean importance scores, but no significant differences were observed.

Preferred Knowledge Domains of Caregivers

Among the top items rated as "very important" by caregivers, 4 (40%) belonged to the medical domain and 7 (60%) belonged to the physical domain. No items from the practical, emotional, spiritual, or social domains were among the top 10 items rated as "very important" (Table 5), or among the top 12 items rated as "somewhat important" or "very important."

The physical domain items most frequently ranked as "very important" were information on location and effect of the patients' brain metastases (93%), as well as symptoms and side effects to monitor and report to the health care team (93%). The medical domain items most frequently ranked as "very important" pertained to information on the different treatment options available with their risks and benefits (91%), and on expectations during end of life and the care the patient would receive (85%). Within the practical domain, the highest ranked (69%) information need of caregivers related to information on how to navigate the health care system. The social domain item most frequently rated as "very important" was information regarding impact of brain metastases and treatment on a relationship with one's partner (34%). The emotional domain item most frequently rated as "very important" was regarding information on coping with your friend/family member's uncertainty about the future (59%). The spiritual domain item most frequently rated as "very important" was regarding information using spiritual services such as spiritual care counseling to cope with grief or loss (30%).

On univariate analysis for caregivers, female caregivers were found to have higher median scores in the practical (66.7 vs 33.3; *P* = .01), social (16.7 vs 0; *P* = .04), and emotional domains (63.3 vs 14.3; *P* = .03) compared with males. Caregivers with high school or less education had much higher median spiritual domain importance scores than those with some postsecondary or higher levels of education (52.3 vs 22.2; *P* = .03).

On multivariate analysis for caregivers, caregiving for patients in newly diagnosed, pretreatment or ongoing

Table 5 Eleven Questions Most Frequently Rated as "very important" by Caregivers

Informational item	Domain	Proportion endorsing as "very important"
How important is it to have information about where your friend/family member's brain metastases are and how they affect them?	Physical	93.2
How important is it to have information about what symptoms and side effects to watch out for and report to your friend/family member's health care team?	Physical	93.2
How important is it to have information about different treatment options and their advantages (like success rates) and disadvantages (like possible side effects)?	Medical	90.9
How important is it to have information on how you and your friend/family member can deal with headaches due to brain metastases?	Physical	88.4
How important is it to have information about what to expect during end of life and the care your friend/family member will receive?	Medical	84.7
How important is it to have information about how you and your friend/family member can manage weakness on one side of the body due to brain metastases (like weakness in an arm and leg on one side of the body)?	Physical	83.6
How important is it to have information about the follow-up visits and different medical tests your friend/family member will need after treatment?	Medical	82.7
How important is it to have information about how you and your friend/family member can manage seizures due to brain metastases?	Physical	81.7
How important is it to have information about how often your friend/family member should visit their doctor during treatment?	Medical	79.7
How important is it to have information on how you and your friend/family member can manage confusion and memory loss due to brain metastases (like having a hard time finding the right words)?*	Physical	79.1
How important is it to have information on how you and your friend/family member can manage nausea (feeling of having to throw up)?*	Physical	79.1

*11 items presented here, as last 2 items were endorsed by same proportion of caregiver participants.

treatment positions in the cancer journey was associated with higher mean importance scores in the medical (10.5; 90% CI, 0.3–20.7; *P* = .09), physical (17.3; 90% CI, 4.7–29.8; *P* = .03), practical (15.6; 90% CI, 3.0–28.3; *P* = .04), and spiritual domains (18.8; 90% CI, 1.2–36.3; *P* = .08). Female gender was also associated with higher mean importance scores in the physical (13.2; 90% CI, 1.5–25.0; *P* = .06), practical (19.7; 90% CI, 7.5–31.8; *P* = .009), social (19.4; 90% CI, 3.7–35.1; *P* = .04), and emotional domains (21.4; 90% CI, 4.5–31.3; *P* = .04). High school or lower degrees of educational status was associated with higher mean importance scores in practical (20.3; 90% CI, 2.6–38.0; *P* = .06), emotional (30.5; 90% CI, 5.9–55.1; *P* = .04), and spiritual domains (45.0; 90% CI, 21.2–68.8; *P* = .003). In addition, caregivers providing some or a lot of help with daily activities was associated with lower mean importance scores in the physical domain compared to caregivers reporting no help needed from their friend or family member with brain metastases (-18.5; 90% CI, -32.5– -4.5; *P* = .03). Variables not mentioned for a specific domain were not retained by the backward model selection process. No significant differences were found when applying bivariate analyses to determine whether caregiver demographics were associated with mean importance scores.

Preferred Method of Receiving Information

Both patients and caregivers were asked to rank their preferred method (one-on-one counseling, pamphlets, websites, online videos, DVDs, support groups, books, or other) to receive information for each of the 6 knowledge domains. While one-on-one counseling was preferred for medical, practical, and physical domain-related information sharing by patients (38%, 31%, and 37% of respondents endorsing), pamphlets were preferred for social, emotional, and spiritual domain-related information sharing (30%, 30%, and 36%, respectively; Table 6). No statistically significant associations were identified between highest level of education attained by patients and preferred method of receiving health information. Similarly, no significant associations were identified between age or degree of help needed with daily activities and patients' preferred modality by which to receive health information.

One-on-one counseling was preferred for 5 of 6 domains by caregivers (medical: 47%; practical: 43%; physical: 43%; social: 39%; emotional: 31%; Table 7). Pamphlets were the most commonly endorsed first-choice modality for information addressing spiritual needs (33.3%). Caregivers having a high school education or lower primarily preferred one-on-one counseling (60%) followed by pamphlets (30%) for information addressing the spiritual domain, whereas those with higher levels of education preferred pamphlets (34%), followed by websites (24%), one-on-one counseling (15%), and online videos (12%). Online audio (0%), group classes (0%), online forums/message boards (<5%), and other unspecified modalities (<5%) were rarely endorsed as first-choice options by caregivers.

Table 6 Preferred Methods of Receiving Information Across Domains by First-Ranked Preference for Patients

Rank	Medical	Practical	Physical	Social	Emotional	Spiritual
1	One-on-one counseling (38.3%)	One-on-one counseling (31.0%)	One-on-one counseling (37.0%)	Pamphlets (29.7%)	Pamphlets (29.8%)	Pamphlets (35.8%)
2	Pamphlets (21.5%)	Pamphlets (28.0%)	Pamphlets (28.0%)	One-on-one counseling (28.6%)	One-on-one counseling (26.6%)	One-on-one counseling, websites (16.4%)
3	Websites (9.3%)	Websites (15.0%)	Websites (8.0%)	Websites (14.3%)	Websites (13.8%)	Books, online videos (7.5%)
4	Online videos (7.5%)	Online videos (7.0%)	DVDs, other (7.0%)	DVDs (6.6%)	Books, DVDs (6.4%)	Support groups (6.0%)
5	Other (5.6%)	Books (6.0%)	Online videos, group classes (4.0%)	Books (5.5%)	Other (5.3%)	DVDs, group classes, other (3.0%)
6	Books, DVDs, group classes (4.7%)	Other (4.0%)	Books (3.0%)	Support groups, other (4.4%)	Group classes (4.3%)	Online audio (1.5%)
7	Support groups (2.8%)	DVDs, group classes, support groups (3.0%)	Support groups (2.0%)	Online videos (3.3%)	Online videos, support groups (3.2%)	
8	Online audio (0.9%)		Group classes (2.2%)		Online forums/ message boards (1.1%)	
9			Online audio (1.1%)			

Proportions may not add up to 100% due to nonrespondents and unclear or uncategorizable responses, which were excluded.
Where modalities are tied in terms of proportion of respondents selecting as first-ranked preference, they have been placed together. Therefore, number of ranks per informational domain may appear to vary.

Table 7 Preferred Methods of Receiving Information Across Domains by First-Ranked Preference for Caregivers

Rank	Medical	Practical	Physical	Social	Emotional	Spiritual
1	One-on-one counseling (46.7%)	One-on-one counseling (42.5%)	One-on-one counseling (43.2%)	One-on-one counseling (38.5%)	One-on-one counseling (31.3%)	Pamphlets (33.3%)
2	Pamphlets (21.3%)	Pamphlets (21.9%)	Pamphlets (23.0%)	Pamphlets (29.2%)	Pamphlets (26.6%)	One-on-one counseling (23.5%)
3	Websites (14.7%)	Websites (19.2%)	Websites (17.6%)	Websites (18.5%)	Websites (23.4%)	Websites (19.6%)
4	Online videos (6.7%)	Online videos (5.5%)	Online videos (5.4%)	Support groups (4.6%)	Online videos (4.7%)	Online videos (9.8%)
5	Other (4.0%)	Other (4.1%)	Other (4.1%)	Online videos (3.1%)	Support groups (4.7%)	Online forums/ message boards (3.9%)
6	DVDs (2.7%)	DVDs (2.7%)	Support groups (2.7%)	Other (3.1%)	Books (3.1%)	Other (3.9%)
7	Support groups (2.7%)	Books (1.4%)	Books (1.4%)	Books (1.5%)	DVDs (3.1%)	Books (2.0%)
8	Books (1.3%)	Online forums/ message boards (1.4%)	DVDs (1.4%)	DVDs (1.5%)	Other (3.1%)	DVDs (2.0%)
9		Support groups (1.4%)	Online forums/ message boards (1.4%)			Support groups (2.0%)

Proportions may not add up to 100% due to non-respondents and unclear or uncategorizable responses, which were excluded.
Where modalities are tied in terms of proportion of respondents selecting as first-ranked preference, they have been placed together. Therefore, number of ranks per informational domain may appear to vary.

Discussion

Patients and Caregivers Have Highest Preference for Information from the Medical and Physical Domains

The results of this cross-sectional, observational study of brain metastases patients and their caregivers suggest a large preference for information within the physical and medical domains of knowledge. The preference for information within the physical and medical domains is similar to the information needs of patients with gynecological, breast, ovarian, prostate, head and neck, and gastrointestinal cancers.[13–18] Within the medical domain, patients and caregivers preferred information on treatment options and tentative follow-up visits and tests following treatment. Caregivers also had higher preference for information relating to end-of-life care and the frequency of follow-up appointments. Within the physical domain, information relating to where the brain metastases are, and the symptoms and side effects associated with brain metastases, were of highest importance to patients and caregivers. Cancer patients' desire for information relating to prognosis, diagnosis, and treatment options has been well observed,[19] and here we show that caregivers place a similar emphasis on these areas of information need. Indeed, significant overlap between the informational needs of patients and their caregivers was observed, particularly for the medical and physical domains. Similar to previous reports, both groups prioritize information relating to treatment options and 'information about what to expect' significantly over other information.[20] As a majority (76%) of patients and caregivers were co-residing, it is likely that the similarity in their information needs also results from shared experiences, as caregivers who live with their care recipient may have a more intimate observation of the symptoms and outcomes associated with patients' illness. We postulate that the higher preference for information from the medical and physical knowledge domain by both patients and caregivers reflects their desire to be active collaborators in care.

Patients and Caregivers Prefer Receiving Most of their Information Through One-on-One Counseling

One-on-one counseling and pamphlets were the preferred modalities for information provision, the former being favored over the latter by caregivers for the majority of informational domains. The preference for one-on-one counseling and written materials we report here is similar to the preferred modalities of patients with gynecologic cancers[13,21,22] and gastrointestinal malignancies[23] and other cancer patient populations.[24] Furthermore, our results are in line with previous reports indicating a preference for face-to-face communication of new cancer diagnosis over phone or email communication.[25,26] The preference for one-on-one counseling is not surprising as Shea-Budgell et al suggest that the doctor or health care provider is the most trusted source of information for cancer patients during follow-up.[23] However, despite the overwhelming preference for receiving information from health care providers expressed by brain metastases patients and their caregivers, poor communication between patients and providers continues to be a barrier preventing optimal cancer care. A large majority of patients (72%) with primary or secondary brain tumors experience some level of cognitive impairment, which can result in poor ability to recall information discussed, and poor ability to apply self-care strategies in outpatient settings.[27] Thus this specific patient population may have particular challenges in recalling and utilizing information obtained through one-on-one counseling, and efforts to improve patient communication should be made to ensure patient information needs are delivered effectively.

Informational Gaps and Caregiving Perceptions

Among patients with brain metastases, 43% indicated 'cure' as a treatment goal. This observation suggests a gap in knowledge that needs to be addressed. In reality, the prognosis of patients with brain metastases is poor, with 2 studies reporting a median survival rate of 3 to 9 months in patients with primary lung cancer and brain metastases.[28,29] Interestingly, only a small proportion of patients (10–20%) with metastases acknowledged being terminally ill.[30] Misconceptions of disease prognosis contribute to negative consequences such as unsatisfactory management of advanced stage of illness, higher proportion of hospital deaths, and lack of or late referral to palliative care services.[31,32] On the contrary, patients who acknowledge having a terminal illness are more likely to express a preference for symptom-directed vs life-extending care and also have higher rates of hospice service use.[33,34] Thus, strategies are needed to improve communication related to disease prognosis and future treatment plans between health care practitioners and patients so that patients can have the best outcome for their prognosis.

Caregivers most commonly reported over 20 hours of support provision weekly, suggesting substantial caregiver burden. Caregivers also report a higher perception of patients' disability, with 75% of caregivers indicating that they provide assistance to the patient for daily activities. Interestingly, the majority of patients surveyed (57%) reported no help required with daily activities of living, and 40% of patients reported that they work part-time or full time. These results are different from previous reports indicating consistent agreement between family caregivers' and cancer patients' perceptions of patients' quality of life and time spent caregiving.[35] However, our results are similar to the symptom and pain incongruence reported by cancer patients and their caregivers.[36] It is unclear why such a discrepancy between perceptions of caregiving by brain metastases patients and their caregivers exist. The higher burden reported by caregivers may reflect the complexity of caregiving they are providing. Specific care tasks such as providing emotional support are reported by caregivers to be more time-consuming and difficult to perform.[37] The substantial caregiving burden reported by caregivers may also be confounded by caregivers' degree of emotional distress, which increases with phase of illness,[38] as well caregivers having a greater negative perception of patients' illness.[39]

Limitations

Our study has several limitations. First, convenience sampling limits the generalizability of these results, as our sample population was predominantly of Caucasian descent and the majority of patients and caregivers had post-secondary education. Second, it was assumed that respondents were comfortable receiving health information in English and completing an English-language questionnaire. This may not be representative of the patient population at our brain metastases clinic, and may have inadvertently resulted in those not as comfortable with English refusing participation in the survey. Third, information bias may have been introduced by using a nonvalidated measure of informational needs. Finally, patients at multiple stages of their brain metastases trajectory with different primary malignancies were combined in analysis here, as were their caregivers. While these patient populations and their associated caregiver populations may have shared informational needs, it is possible that they may also have unique needs that may not be emphasized in our findings. To our knowledge, only 1 study addressing informational needs of brain metastases patients and their caregivers has been reported.[15,20] This was an intervention study with a 12-page informational pamphlet, titled *Coping with Brain Metastases: A Guide for Patients and Caregivers*, with a combined story and fact-based writing style. This pamphlet was presented to 22 patients and 22 caregivers. The pamphlet addressed questions related to medical, physical, and practical informational needs, with very limited emotional and social domain content, and no spiritual domain content. The pamphlet was associated with increased caregiver anxiety – in particular, due to discourse regarding palliative care, end-of-life care, caregiver tips, and personal narratives. This contrasts the preference for palliative and end-of-life care information by patients in the present study. Interestingly, a combined fact and story-telling style of information delivery was preferred, and patients and caregivers both reported satisfaction with the nature of the information covered by the pamphlet.[15,20] This is in line with the informational needs prioritized and the preferred modalities for both groups identified in our study. To the best of our knowledge, no formal interventional studies have evaluated one-on-one counseling to address any of the studied informational domains, despite being largely preferred by patients and caregivers for their most valued informational domains.

Conclusion

Brain metastases patients experience significant morbidity and quality-of-life impairment associated with their diagnoses, and their care appears to be associated with notable caregiver burden. Patients with brain metastases and their caregivers prioritize information regarding symptom profiles and implications of their diagnoses, treatment benefit and side-effect profiles, necessary follow-up and testing if treatment is completed, and end-of-life planning and external care provision, if necessary. While more valued by females, those with lower educational statuses, and those in early stages of their trajectory, social, emotional, practical, and spiritual informational domains were generally of lower overall importance to both patients and caregivers.

For both groups one-on-one counseling remained the primary modality of choice for receipt of the information. There remains some misconceptions regarding patient prognosis and perception of care between patients and caregivers. These interesting results provide further guidance for the development of interventions to address informational needs. To date, no studies have formally examined any such interventions specifically addressing the studied informational domains within the brain metastases patient or caregiver populations. Pamphlets were also a modality of choice for information provision across a number of domains for both patients and caregivers. Further exploration of the effectiveness of existing resources, including non-validated programs and tools, in addressing the 6 informational domains is warranted.

In 2006, the Institute of Medicine provided recommendations that every cancer patient receive an individualized survivorship care plan (SCP).[40] Informational needs assessments such as those performed in the current study can be used to inform the contents of SCPs to ensure that patient information needs are met. Indeed, many of the top information needs desired by brain metastases patients and their caregivers, including information on diagnosis, treatment plans, and treatment side effects, are commonly included in SCPs.[40] Thus, information assessments provide an important starting point towards recognizing the specific needs of various cancer populations.

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