Published in final edited form as:

Psychooncology. 2017 July ; 26(7): 935–942. doi:10.1002/pon.4117.

Promoting Improved Family Caregiver Health Literacy: Evaluation of Caregiver Communication Resources

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Abstract

Objectives—Family caregivers of cancer patients have a vital role in facilitating and sharing information about cancer, revealing a need to develop caregiver health literacy skills to support caregiver communication. The goal of this study was to investigate caregiver print materials and develop and assess a new caregiver communication resource titled *A Communication Guide for Caregivers*TM.

Methods—Using a model of six domains of caregiver health literacy skills, print cancer education materials were collected and evaluated for caregiver communication support. A new caregiver communication resource was also developed and assessed by caregivers and healthcare providers. Caregivers reviewed content and assessed utility, relatability, and reading quality. Healthcare providers also assessed whether the material would be understandable and usable for cancer caregivers.

Results—Only three of the 28 print materials evaluated were written at the recommended sixth grade reading level and only five addressed all six caregiver health literacy skills. Readability scores for *A Communication Guide for Caregivers*TM were at the sixth grade level and caregivers reported its contents were relatable, useful, and easy to read. Healthcare providers also rated the material as easy for patient/family members of diverse backgrounds and varying levels of literacy to understand and use.

Conclusions—Existing print-based caregiver education materials do not address caregivers' health literacy skill needs and are aimed at a highly literate caregiving population. *A Communication Guide for Caregivers*TM meets health literacy standards and family caregiver and

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provider communication needs. The findings are relevant for healthcare professionals who provide cancer education.

Keywords

cancer caregiver; oncology caregiver; family communication; cancer education

Background

Family caregivers in oncology often serve as a liaison between the patient and clinicians, relaying information between the two to enact shared decision-making and enable patient engagement [1]. Caregivers also are involved in day-to-day decisions, relaying content about health issues and concerns with members of their social network [2]. With their pivotal role in cancer care, caregivers' demand for information has increased and they have been left to actively advocate for their own support and informational needs [3, 4]. Meanwhile, decades of caregiving research illustrates that family caregivers continue to have high unmet information needs [5, 6] and experience distress and anxiety as a result of poor communication with family, friends, and providers [4, 7, 8].

Seeking, accessing, and understanding health information on behalf of patients are important caregiver health literacy skills that impact the quality of cancer care and the overall cancer experience [8]. Yuen et al. posit that there are six domains of family caregiver health literacy skills: understanding information, accessing information, the caregiver's relationship and communication with the care recipient, relationships and communication with healthcare providers, communication within support systems, and managing the challenges of caregiving [9]. Health literacy involves not only caregiver level characteristics, such as cognitive and functional skills, but also healthcare system processes, structures, and providers [10].

While healthcare providers are tasked with sharing information with the patient and family and providing education about cancer treatment and care, caregivers perceive that staff are too busy to care and describe being ignored, disrespected, and receiving poor explanations and conflicting information [4, 11]. Poor communication with healthcare providers results from caregiver difficulty in understanding medical language and feeling overwhelmed by the amount and type of information provided [11]. The hospital environment also contributes to communication difficulties, as there is often too much noise and providers are too busy [11]. Family reported communication problems with healthcare providers also include a lack of privacy during conversations and a lack of attention to caregivers' well-being [12]. Caregivers who have provided care at home prior to hospitalization also feel undervalued by hospital staff, ignored, and their coping needs neglected [13]. Especially at the patient's end of life, mutual understanding between caregiver and provider can improve this end of life experience. However, many caregivers report additional distress due to poor communication, leaving them feeling uncertain about their role [14].

Caregivers also experience communication difficulties with patients and other family members. Patient-caregiver communication may be concordant or discordant depending on their communication history and/or family communication pattern [15]. The patient's

willingness to discuss advance care planning topics, for example, is influenced by the caregiver's attitudes, concerns, and health-related burdens [16]. Conflict with other family members and friends can also trigger anxiety between the cancer patient and primary family caregiver [7].

Caregivers report a desire and need for understanding and support from relatives [17], yet communication difficulties also occur between family members due to differing communication styles, the desire to protect each other or avoid topics, or as a result of previous conflicts [18]. Patient and caregiver disagreement about family involvement in health information and decision-making is associated with dysfunctional family communication [19]. Healthcare providers report that one of the primary barriers to discussing a patient's goals of care is disagreement among family members about medical decision-making [20].

Family caregiver health literacy is impacted by a variety of cultural and social factors. These factors include level of acculturation and language [21], limited English proficiency [22, 23], use of translators [23], lack of available educational materials in languages other than monolingual English or bilingual English/Spanish [23], and health beliefs. Cultural factors result in a limited desire/ability to participate in treatment decision-making, misunderstanding of cancer stage/stage awareness, less desire/need for cancer information, inaccurate assessment of risk, and fewer questions asked to healthcare providers [21-23].

The caregiver's ability to communicate about cancer is influenced by the healthcare system and community factors, as caregivers increase their own health literacy when they are able to learn from others [9]. According to the U. S. National Library of Medicine, the appropriate level of educational health information should range between 6th and 7th grade reading level [24]. Plain language guidelines are recommended to address health literacy needs, calling for print materials to include use of the active voice, use of second person, limited medical jargon with key medical words defined, and short sentences of 15 words or less. Commonly, print materials are evaluated for readability to ascertain the reading grade level and determine reading ease. Although there has been limited research on the readability of caregiver print materials, one study found that few hospice print materials meet the criteria of sixth grade reading level and medical terms used were not always directly explained [25].

This project came out of work on a currently funded R25 cancer education program grant funded by the National Cancer Institute to develop a national communication training program for oncology nurses. Based on interactions with participants who attended a two day communication training course and in the process of developing curriculum material, the need for a family caregiver communication resource became apparent. Few theory-based tools have been developed to address caregiver communication and to assess the communication needs and preferences of caregivers' who are caring and making decisions for cancer patients [26]. Our goal was to investigate materials for family caregivers that provide communication support in the six domains of caregiver health literacy skills as well as appeal to varying levels of health literacy. We also set out to develop and assess our own communication resource titled *A Communication Guide for Caregivers*TM.

Methods

Evaluation of Current Print Materials

Background research was conducted to explore available caregiver print materials related to health literacy skills as defined by Yuen et al. All National Cancer Institute designated cancer centers ($n=69$) and national cancer associations in the United States were used to search for materials in the following ways:

- (1) Internet search using the name of the cancer center and “caregiver”
- (2) Search of the organization's website under “resources” or “patient and family”
- (3) Using the organization's internal search function on its website for “caregiver” and/or “family” and/or “resources.”

In addition, a broad Internet search was conducted using the following combinations of words: cancer and caregiver guide, caregiver guide, cancer caregiver guide, cancer and family and guide, cancer caregiver resources. Finally, print only resources were collected at the supporting institution's family resource center.

In some cases, the organization reviewed did not advertise its own resources, but listed additional resources provided by outside organizations. These additional organizations and resources were then reviewed for available caregiver materials. Video only and full-length books were not included in the final set of resources.

Readability tests were conducted for each print resource to calculate reading grade level using the Simple Measurement of Gobbledygook (SMOG) and Flesch-Kincaid Reading Ease [27]; both tests are endorsed by the National Institute of Health. The SMOG produces an overall grade level score and Flesch-Kincaid calculates the difficulty of a reading passage. The higher the Flesch-Kincaid score, the easier the text is to read, with a score of 90-100 easily understandable by an average 11-year-old student, 60-70 easily understood by 13-15 year-old students, and 0-30 easily understood by college graduates. In addition, we assessed whether the material addressed each of the six domains of cancer caregiver health literacy skills.

Development of A Communication Guide for Caregivers™

The guide emerged from the COMFORT™SM Communication Curriculum, a national health communication curriculum to improve patient-centered communication. The COMFORT training program is based on four main ideas: (1) it is important to understand the patient's life and story; (2) family caregivers need support; (3) it is necessary to care for the patient and the caregiver's heart and mind as well as body; and (4) the communication process is created among patient, family, and providers. After a thorough review of literature, the Caregiver Communication Typology [15] and City of Hope Family Quality of Life Model [28] were used to develop content for each cancer caregiver health literacy skill in line with the principles of COMFORT. Content was developed and reviewed by experts in nursing and communication. The guide is based on caregiving research and includes caregiver quotes and stories, which incorporate cultural and social factors impacting

caregiver health literacy. Table 1 shows the table of contents of the guide and the represented six domains of cancer caregiver health literacy.

In the first phase of development, a convenience sample of family caregivers was provided with the guide content, in hard copy or as a link with digital access. It is important to note that only content was provided and pictures and graphics were not included. Caregivers were surveyed between one to three days after reading the content. Each caregiver provided background information and completed a series of questions aimed at examining the readability, utility, and perceived usefulness of the content. The Institutional Review Board of the supporting university approved this study.

In the next phase of development, content for the guide was revised based on caregiver feedback and formal layout and design of a print copy was produced. Interprofessional healthcare providers who had participated in continuing education courses hosted by City of Hope National Medical Center in the last two years were sent an email invitation to review the guide using the Patient Education Materials Assessment Tool (PEMAT). The PEMAT was developed by the Agency for Healthcare Research and Quality and is used by healthcare providers to assess education materials to determine if the material is easy to understand and act on for patient/family members of diverse backgrounds and varying levels of health literacy [29]. Composed of 26 items, the PEMAT identifies design elements such as content, word choice and style, organization, layout and design, use of visual aids, and action steps for the user. Providers rate each design element as agree, disagree, or not applicable. Agree scores indicate that a characteristic occurs throughout the material 80%-100% of the time. A percentage score is calculated, with a higher percentage indicating higher understandability and actionability. Providers were also asked to provide qualitative comments about the guide.

Data Analysis

Demographics and survey items were summarized using the Statistical Package for the Social Sciences (SPSS) to produce descriptive statistics (frequency and mean scores). Qualitative comments from family caregivers and healthcare providers were grouped by positive themes and suggested recommendations for content changes.

Results

Table 2 provides an overview of print materials currently available for family caregivers that include content caregiver health literacy skills ($n=28$). Publication dates ranged from 2001 to 2015 and materials were published by 25 unique agencies, including NCI designated cancer centers (32%), nonprofit cancer organizations (16%), caregiver organizations (16%), medical centers (12%), cancer support groups (8%), and other (12%). Overall, the SMOG reading level score averaged an 8.84 grade level (eighth grade and nine months) and a Flesch-Kincaid reading ease score of 59.3 (easily understood by 13-15 year-old students).

Three guides scored at the sixth grade level, two from the National Cancer Institute (SMOG scores at 6.3 and 6.1) and the other from St. John Providence Health System (SMOG score 6.2). These three guides were also easiest to read, with Flesch-Kincaid scores at 77, 77.7,

and 76.3, respectively. Table 2 displays a summary of the guide content in terms of caregiver health literacy skills. Overall, only five (17.9%) materials addressed all six caregiver health literacy skills, with 68% addressing at least three caregiver literacy skills.

Readability scores for *A Communication Guide for Caregivers*TM were also at the sixth grade level (SMOG, 6.4) and Flesch-Kincaid reading ease score was 77. Demographics for caregivers reviewing the new resource are summarized in Table 3 (caregivers). Caregivers ($n=160$) were primarily female (71%) and had provided care for more than one year. The average age of caregivers was 43 years old and more than half were no longer providing care (53%). Healthcare providers ($n=118$) represented all areas of the nation and were overwhelmingly nurses (65%), followed by social workers (22%) and other professionals (13%). The majority of healthcare providers represented more than 16 years of clinical care experience (70%).

On average, it took 23.74 minutes for caregivers to read the guide's content. On a scale of 1 (not at all) to 10 (very much), caregivers reported high relatability with the content (mean=8.52) and high usefulness (mean=8.24). Caregivers also reported that the content was easy for them to read (mean=9.31, with 10 being 'very easy to read'). Communication with the patient was rated as the most useful content (40%), followed by communication with family (27%), and communication with healthcare providers (18%). Caregivers (63%) reported that the least useful content of the guide was communication with family members who are far away.

Across all healthcare providers, the guide was scored as having high understandability (mean=98 out of 100) and high actionability (mean=97 out of 100) for caregivers. Qualitative feedback from both caregivers and providers is provided in Table 4, demonstrating that both stakeholders have a strong need for the material. Caregivers expressed a desire to have had this information earlier in the course of illness and providers believed the material would benefit family caregivers. Recommendations for specific changes included identification of additional topics and resources as well as acknowledgement of the readability level of the material.

Discussion

The results from this study reveal a high need for family caregiver health literacy support and suggest acceptability for a health literacy approach in oncology interventions. Currently available print materials examined in this study illustrate the continued problem of producing information materials that have higher than national recommended health literacy levels. Health literacy levels across the United States show that nearly one-third of the American population have basic or below-basic health literacy skills [30]. Results of this study demonstrate the need for *A Communication Guide for Caregivers*TM as a health literacy resource or intervention tool for family caregivers. The readability of the guide is consistent with similar material produced by the National Cancer Institute and is in line with national literacy standards. It is important to note that the Internet is increasingly the primary resource for family caregivers who seek health information and resources about caregiving. Future research should further explore digital and interactive tools, including mobile

applications and social media sites specifically designed for family caregivers. This study was limited to resources available in the United States.

Analysis of caregiver and provider feedback on *A Communication Guide for Caregivers*TM revealed that caregivers and providers perceive a family caregiver health literacy intervention as useful. Caregivers reported that the material had high relatability and usefulness, and communication with the patient was the most useful subject material. These findings support research on communication and cancer that highlight the complexity of family communication and patient-caregiver communication. Caregivers commonly feel responsible for the psychological well-being of the patient [31] and attempt to protect the patient and maintain hope by avoiding diagnosis and illness trajectory discussions [32]. Caregivers in this study noted that they wished they had had the resource during their caregiving experience as a way of improving communication and their overall cancer caregiving experience.

Caregivers reported that the guide was too easy to read and recommended modifying the language. However, this feedback supports the researcher's targeted goal of developing a plain language for guide for caregivers about communication.

Our intended focus was to create awareness of communication topics, struggles, and strategies for communicating about cancer. Thus, we do not envision modifying the plain language approach of the guide, but will work to incorporate additional sources as well as the continuum of care in future editions.

Communication is commonly a psychosocial barrier to caregiving, with behavioral changes necessary to navigate the health system in order to identify and achieve healthcare goals. Providing cancer education offers an opportunity to address caregiver concerns, including identifying topics that require further information and advice and encouraging caregivers to ask for more information, which serves to validate the caregiver's role and legitimize topics central to the patient's care [33]. Especially among caregivers who have lower levels of self-confidence, information and education needs to be provided in a way that fosters self-confidence and self-recognition of their role and contribution to care [33]. Research on caregiver education about pain and symptom management has shown that such interactions should include establishing trust, promoting self-confidence, and assessing understanding [34].

Caregiver health literacy has not been studied in regard to patient decision-making, health information, or health services utilization, yet research has shown that caregivers play an influential role in the patient's decision-making process [9]. Caregiver interventions targeting health literacy skills are necessary to assist family members with communication about cancer and cancer decision-making [35]. Interventions for family caregivers in cancer care have been shown to significantly reduce caregiver burden, improve caregiver coping, increase caregiver self-efficacy, and improve quality of life [6]. The next steps for this work will be to develop the resource as a formal nursing-led intervention that involves decision-coaching, shared decision-making, and transitions in care. Future work with this guide will

need to take into account caregiver cultural background and diversity as well as varying family types and patterns.

Conclusion

The National Cancer Institute has identified the important role of family caregivers in treatment and plan of care decisions, as well as in expectations of patient outcomes [36]. Fostering family caregiver health literacy skills is one way to facilitate caregiver involvement and *A Communication Guide for Caregivers*TM incorporates communication strategies that address cultural, social, and system level barriers. The guide includes conversation starters, questions to ask, definitions for medical jargon, and words of advice for managing the stress of caregiving. A digital copy of the guide is available at our website [37]. Future work will include the development of a formal family caregiver health literacy intervention, using the guide in an in-person session to incorporate communication skills development and decision support for caregivers.

Acknowledgments

**Research reported in this publication was partially supported by the National Cancer Institute of the National Institutes of Health under award number R25CA174627. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Table 1

Framework for Contents of the Communication Guide for Caregivers™

	A Communication Guide for Caregivers™	
Family Caregiver Health Literacy Component *	Section	Content Description
<ul style="list-style-type: none"> • Relationship with the care recipient <ul style="list-style-type: none"> ➢ Communication with the care recipient ➢ Understanding the care recipient • Access to information <ul style="list-style-type: none"> ➢ Proactivity and determination to seek information ➢ Information presented in quality formats 	1) Communication with the Patient	Process how to take care of someone with cancer, address disagreements, and share information
<ul style="list-style-type: none"> • Managing the challenges of caregiving <ul style="list-style-type: none"> ➢ Self-care ➢ Role recognition and understanding caregiver rights ➢ Attitudes, approaches, and emotional challenges • Support Systems <ul style="list-style-type: none"> ➢ Financial and legal support ➢ Practical support ➢ Psychosocial support Social support 	2) Communication with Other Family Members 3) Communication with Family Members who are Far Away	Consider family structure, caregiver roles, and ways to ask for help Chart the cancer journey and discuss ways to involve distant family members in care
<ul style="list-style-type: none"> • Relationship with healthcare providers <ul style="list-style-type: none"> ➢ Active engagement with healthcare providers ➢ Supported by healthcare providers to understand information • Understanding information <ul style="list-style-type: none"> ➢ Understanding the healthcare system ➢ Understanding the disease, treatment, and potential outcomes ➢ Understanding information for day-to-day care ➢ Processing health information 	4) Communication with Health Care Providers	Deconstruct medical jargon, offer questions to ask healthcare providers, and provide online resources

* Reference: Yuen, E. Y., Dodson, S., Batterham, R. W., Knight, T., Chirgwin, J., & Livingston, P. M. (2015). Development of a conceptual model of cancer caregiver health literacy. *Eur J Cancer Care (Engl)*. doi: 10.1111/ecc.12284

Table 2

Readability Scores of Select Caregiver Guides that Include Communication Content

*** Family Caregiver Health Literacy Skills										
Agency	Title	SMOG Reading Level *	Flesch-Kincaid Reading Ease Score **	Access	Understanding	Relationship with health care providers	Relationship with care recipient	Managing caregiving challenges	Support systems	Total
AARP	AARP Guide to Caregiving	9.2	59.2				✓	✓	✓	50%
American Cancer Society	What You Need To Know as a Cancer Caregiver	7.3	71	✓	✓	✓	✓	✓	✓	100%
Cancer Support Community	When a Woman You Care About Has Breast Cancer	8.5	62.6	✓	✓	✓	✓	✓	✓	100%
Caregiver Action Network	A Guide to Improving Doctor/Caregiver Communication	9	57.1			✓				16.7%
Caregiver Magazine	Ovarian Cancer: Helping Caregivers Communicate and Cope	10.9	46.7			✓	✓	✓		50%
Caring Ambassadors	Caregiver Choices	9.5	56.7		✓	✓		✓	✓	66.7%
City of Hope	A Caregiver's Guide	9.4	54	✓	✓	✓	✓	✓	✓	100%
Dana Farber Cancer Institute	Taking Care of Yourself	8	66.6	✓		✓	✓	✓		66.7%
Family Caregiver Alliance	Taking Care of YOU: Self-Care for Family Caregivers	8.2	64.5			✓		✓		33.3%
Fox Chase Cancer Center	Caregiver Resource Guide	7.7	66.1		✓			✓	✓	50%
Janssen Biotech	A Caregiver's Guide to Caring for the Patient with Prostate Cancer	9.3	60.6	✓		✓	✓	✓	✓	83.3%
Johns Hopkins Medicine	Take Care: A Guide for Family Caregivers	8.1	61.8	✓		✓	✓	✓	✓	83.3%

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*** Family Caregiver Health Literacy Skills										
Agency	Title	SMOG Reading Level*	Flesch-Kincaid Reading Ease Score**	Access	Understanding	Relationship with health care providers	Relationship with care recipient	Managing caregiving challenges	Support systems	Total
Livestrong Foundation	Communicating with your Partner	9.5	49.1				✓			16.7%
Memorial Sloan Kettering Cancer Center	A Guide for Caregivers	7.6	67.7	✓	✓	✓	✓	✓	✓	100%
Mesothelioma Cancer Alliance	Caregiver Resource Guide	11.4	44.9	✓				✓		33.3%
National Alliance for Caregiving	Care for the Family Caregiver: A Place to Start	10.1	50.8	✓	✓			✓	✓	66.7%
National Bone Marrow Transplant Link	Caregivers' Guide for Bone Marrow/Stem Cell Transplant	9	59.5				✓	✓	✓	50%
National Cancer Institute	Family Caregivers in Cancer	9.1	55.7	✓			✓	✓	✓	66.7%
National Cancer Institute	Family Caregiver in Cancer: Roles and Challenges	12.8	25.3	✓		✓	✓	✓	✓	83.3%
National Cancer Institute	When Someone You Love Has Advanced Cancer	6.3	76.3	✓	✓	✓	✓	✓	✓	100%
National Cancer Institute	When Someone You Love Is Being Treated For Cancer	6.1	77	✓		✓	✓	✓	✓	83.3%
Ohio State Univ. Cancer Center	Support for Caregivers	7.7	65.6	✓				✓		33.3%
PIMA Council on Aging	How To Be a Resilient Caregiver	9.1	58.7		✓	✓	✓	✓	✓	83.3%
St. John Providence Health System	Personal Communication Guide for Families/ Caregivers of Individuals with Serious Illness	6.2	77.7				✓			16.7%

*** Family Caregiver Health Literacy Skills										
Agency	Title	SMOG Reading Level *	Flesch-Kincaid Reading Ease Score **	Access	Understanding	Relationship with health care providers	Relationship with care recipient	Managing caregiving challenges	Support systems	Total
UCSF Osher Center for Integrative Medicine	A Handbook for Family Caregivers of Patients with Serious Illness	10.1	53.5	✓	✓	✓	✓			66.7%
	U. of Michigan Comprehensive Cancer Center	8.8	57.1					✓		16.7%
U. of Minnesota Pediatric Blood & Marrow Transplantation Center	Being a Caregiver	10.1	48.9							0%
Wake Forest Baptist Health	Taking Care of You: Support for Caregivers	8.5	66.6					✓		16.7%

* SMOG = “Simple Measurement of Gobbledygook,” produces the overall grade level attainment needed to understand the passage. McLaughlin, G., SMOG grading: A new readability formula. *Journal of Reading*, 1969. 12(8): p. 639-646.

** The Flesch-Kincaid Reading Ease formula uses average sentence length and average number of syllables per word to calculate the difficulty of a reading passage. The higher the score, the easier the text is to read. A score of 90-100 is easily understood by the average 11-year-old. A score of 60-70 is easily understood by the average 13-to 15-year-old. A score of 0-30 is easily understood by the average university graduate.

*** Reference: Yuen, E. Y., Dodson, S., Batterham, R. W., Knight, T., Chirgwin, J., & Livingston, P. M. (2015). Development of a conceptual model of cancer caregiver health literacy. *Eur J Cancer Care (Engl)*. doi: 10.1111/ecc.12284

Table 3

Demographics of Caregivers

Age	<i>n</i> =160 (%)
18-29 years	46 (28.75%)
30-49 years	51 (31.88%)
50 +	62 (38.75%)
Not Reported	1 (.63%)
Gender	
Male	44 (27.5%)
Female	114 (71.25%)
Not Reported	2 (1.25%)
Geographical Regions	
Northeast (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Vermont)	0 (0%)
Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Missouri, Nebraska, Ohio, South Dakota, Wisconsin)	8 (5%)
South (Florida, Georgia, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, Washington DC)	140 (87.5%)
West (Alaska, Arizona, California, Colorado, Montana, Nevada, Oregon, Utah)	10 (6.25%)
Not Reported	2 (1.25%)
Length of Time as Caregiver	
< 6 months	38 (23.75%)
< 1 year	44 (27.5%)
2-5 years	62 (38.75%)
> 5 years	15 (9.38%)
Not reported	1 (.63%)
Relationship to Patient	
Spouse	24 (15%)
Adult child	50 (31.25%)
Sibling	15 (9.38%)
Other relative	71 (44.38%)
Type/Location of Cancer	
Head/Neck (mouth, sinus, eye, throat, face)	6 (3.75%)
Digestive system (stomach, liver, pancreas, colon, gastric, esophagus)	33 (20.63%)
Respiratory tract/thorax (lung, thorax)	26 (16.25%)
Musculoskeletal (bone, Rhabdomyosarcoma)	5 (3.13%)
Breast	41 (25.63%)
Blood (lymphoma, leukemia, myeloma)	12 (7.5%)
Male reproductive system (bladder/urinary, prostate)	12 (7.5%)
Female reproductive system (ovary, uterus, cervix, vagina, bladder)	19 (11.88%)
Brain and central nervous system	3 (1.88%)
Other sites ("entire body," Melanoma)	3 (1.88%)

Status of Patient	
Currently receiving treatment	34 (21.25%)
Completed treatment/remission	40 (25%)
Patient deceased	86 (53.75%)

Table 4

Provider and Caregiver Qualitative Feedback

	Positive Feedback	Suggestions/Recommendations
Providers	<p>"This is a beautiful and very useful publication -- something I have needed in my practice for quite some time."</p> <p>"I feel the caregiver guide will be a really nice tool to use when talking with caregivers about their roles and also how to take care of themselves."</p> <p>"I would definitely recommend that my colleagues ... use this tool for newly diagnosed or active treatment patients."</p> <p>"The format and material was quick and easy to read. I can picture several patients' family members for whom English is a second language benefiting from this material."</p>	<p>"Consider including a section on spiritual questions and struggles that cancer patients might experience and that caregivers might also struggle with."</p> <p>"The terminology ... is so oversimplified as to be misleading at times."</p> <p>"Add specific suggested sites, such as NCI, ACS, Leukemia and Lymphoma Society -- those that have more accurate and specific knowledge per tumor site."</p>
Caregivers	<p>"I really wish I had something like this a few years ago... I think this could have really helped me to understand things better."</p> <p>"It was a very good, detailed guide. It hit on point. I wish I had something like this to read when I was going through all of this with my mama. It would have really helped."</p> <p>"It would have been very beneficial if I had the information ahead of time and during the cancer treatment. What not to say, what not to take personally, and how it affects the patient mentally as well as physically. I could have definitely used during his diagnosis and treatment. As a caregiver, it's already a shock to you; however, to know how to communicate would have helped."</p>	<p>"The format seems to be targeting someone in grade school rather than an adult. I would have preferred it to be in paragraph form with just an overview of the common issues that are faced by caregivers rather than the detailed descriptions of the scenarios that were presented."</p> <p>"The guide did not talk enough about the reality of your loved ones facing death."</p> <p>"Common sense guide."</p>