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Cancer Caregivers Information Needs and Resource Preferences

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Abstract

This study sought to characterize the need for information about personal psychosocial care, providing direct care, and managing care among cancer caregivers, and explore preferred resources for caregiving information.

Methods—Data comes from cross-sectional telephone interviews of 1,247 family caregivers, which included 104 cancer caregivers.

Results—A majority of cancer caregivers expressed one or more information need for each of the three content categories. Four out of ten caregivers expressed needing information about managing physical and emotional stress. A significantly higher percentage of male caregivers reported needing more information pertinent to providing direct care than females. Heightened objective burden was significantly associated with caregivers preferring to receive information from health professionals than informal sources (e.g., Internet), while the opposite was found among caregivers with lower objective burden.

Conclusion—These findings suggest that specific types of information and resources may be most relevant to specific subgroups of cancer caregivers.

Keywords

Caregiving; information needs; information resources; Internet

Introduction

A relative or friend of a cancer patient may assume diverse responsibilities during a patient's course with disease and into survivorship. Tasks might include providing hands-on or direct care (e.g., monitoring machines) and managing a patient's use of formal medical and long-term care [4, 1]. While providing care, these family cancer caregivers must also attend to their personal psychosocial wellness as evidence suggests that cancer caregiving is highly demanding and emotionally burdensome [13]. Heightened emotional burden places caregivers at risk for poorer health outcomes, including decreased immune function and greater risk for cardiovascular disease [6, 24, 22].

Cancer patients and their caregivers seek information to assist with better understanding or managing cancer or to provide adequate care [3, 2]. Yet, patients and their caregivers also indicate being dissatisfied with available information or that gaps, such as information on supportive care, exist [5, 2]. Similarly, a recent report on the benefit of cancer caregiver interventions in randomized controlled trials (RCT) suggests moderate benefit to caregivers, and highlighted the potential need to better incorporate information on caregiver self-care [19].

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Needs assessment or being attentive to the needs and preferences of constituents is a vital component of health-related program planning [26]. Thus, this study sought to characterize the need for information about personal psychosocial care, providing direct care, and managing care among cancer caregivers. The need for such information was further explored according to caregiver characteristics and clinically-relevant variables, as information seeking is shown to vary according to disease factors (e.g., type of diagnosis) and personal factors (e.g., demographics; coping strategy) [7, 14]. Understanding content preferences among subgroups of cancer caregivers will allow for information to be tailored via interventions. Tailoring of interventions to need and context has been named as a priority in family care [28].

Understanding the information needs may be of only partial benefit to caregivers if the information is not delivered in ways that appeal to caregivers. Most cancer-related interventions in RCT have been delivered to caregivers in a face-to-face format or by telephone [19, 25]. In contrast, few studies have incorporated web-based programming despite evidence that cancer caregivers are more likely than patients themselves to use the Internet to access information [12, 3, 19]. Exploring preferences for receiving information or resources is of value given that caregiving may present inherent limitations with regard to receiving information. Namely, providing family cancer care is highly objectively burdensome with caregivers expending many personal hours toward caregiving [13]. Many caregivers also forgo employment and leisure activities in light of caregiving responsibilities [16-18]. As such, finding time to participate in in-person or face-to-face programs may be a substantial barrier for caregivers. Indeed, a report in the head and neck cancer context notes low attendance as a barrier to program participation for head and neck cancer patients and their family members [21]. Thus, a secondary purpose of this research was to assess preferred information resources among cancer caregivers.

Materials and Methods

Data Source

Data for this secondary analysis comes from a sample of 1,247 family caregivers identified through a survey of 6,139 adults in the U.S. [16]. Of the 1,247 caregivers, 104 indicated that the primary reason for providing care was cancer. Caregivers were individuals age 18 or older, living in the U.S., and providing one or more activities of daily living (ADL) or instrumental activities of daily living (IADL) for an adult (i.e., age 18 or older). Cross-sectional interviews were conducted via telephone in 2003 by Belden, Russonello, and Stewart for the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP). A detailed explanation of the survey and sampling procedures are provided in the report entitled “Caregiving in the United States” [18].

Measures

Exploratory Variables

Caregiver Demographics: Demographic-related variables including gender, race/ethnicity, age, income, care recipient's relationship to caregiver, education level, and self-reported health (excellent; very good/good; or, fair/poor) were assessed.

Caregiving Characteristics: Primary caregiver status, distance to care recipient, choice in providing care, additional caregiving responsibilities, and the use of formal in-home or community caregiving services were assessed. Caregivers were described as either primary or secondary caregivers. Status was based on the following questions: 1) Has anyone else provided unpaid help to your (relative/friend) during the last 12-months? (Yes or no); 2) Who would you consider to be the person who provided/provides most of the unpaid care for your (relative/friend) (Self; someone else; we split it 50-50). Caregivers were considered primary caregivers if no one else provided unpaid help (question #1 “no” response) or if respondent provides most of the help (question #2 “self” response). Caregivers were considered secondary caregivers if someone else provides most of the unpaid help or split care (question #2 “someone else” or “split 50-50” responses). Distance to care recipient was assessed using the following item: “Does/did your (relative/friend) live in your household?” Responses were classified into the following three categories: (1) living with care recipient; (2) living less than an hour away; and (3) living one hour or more from care recipient. Caregivers were also asked about their perception of having choice in assuming the caregiving role: “Do you feel you had a choice in taking on this responsibility?” (Yes or no). To assess other caregiving responsibilities, caregivers were asked, “Are there any children or grandchildren living in your household under 18 years of age?” (yes or no). Caregivers were asked about their use of in-home or community formal services to assist with caregiving, including: (1) an aide or nurse hired through an agency; (2) an aide or nurse hired independently; (3) a housekeeper hired to clean or cook; (4) use of any type of paid assistance; (5) adult day care; (6) a recreation program or camp; (7) a service such as Meals on Wheels; or (8) a service to provide transportation. A caregiver was described as using formal services if he/she reported using at least one type of service.

Clinically-Relevant Variables: To establish duration of care, caregivers were asked, “How long have you been providing/did you provide help to your relative/friend?” Response options included: occasionally, less than 6-months, 6-months to 1 year, 1 year through 4 years, 5-9 years, 10 or more years.

An objective Burden Index was used to classify objective burden or intensity of care from level one through level five. Level one reflects the lowest objective burden and level five comprises the heaviest objective burden. The Burden Index is based the Type of Care Index (i.e., number of IADLs and ADLs) and the Hours of Care Index (i.e., number of hours of care provided weekly). Both indexes are described in detail below. This measure of objective burden was established by NAC & AARP based on literature detailing care intensity and has been used in prior research [18, 17]. A description of the scoring for the index is included in the appendix of the 2004 report [18].

The Type of Care Index is based on the number of IADL tasks and the number of ADL tasks performed by a caregiver. To determine ADL, caregivers were read and asked the following, “I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you [provide/provided] this kind of help. [Do/Did] you help your friend or relative: (1) get in and out of beds and chairs; (2) get dressed; get to and from the toilet; (3) bathe or shower; (4) by dealing with incontinence or diapers; (5) by feeding him or her; (6) by giving medicines, pills, or injections.” (Yes or no was required for each ADL task). To determine IADL assistance, caregivers were asked: [Do/Did] you provide help for your relative or friend with: (1) managing finances, such as paying bills, or filling out insurance claims; (2) grocery shopping; (3) housework, such as doing dishes, laundry, or straightening up; (4) preparing meals; (5) transportation, either by driving him or her, or helping your friend or relative get transportation; (6) arranging or supervising services from an agency, such as nurses or aides?” (Yes or no was required for each IADL task). The Type of Care Index characterized caregivers whether they performed one IADL task and zero ADL; two IADL tasks and zero ADL; one ADL (with or without IADLs); or two or more ADLs (with or without IADLs).

To establish the Hours of Care Index, Caregivers were asked “About how many hours do/did you spend in an average week doing these things?” Responses were categorized as 0-8 hours; 9-20; 21-40; 41 or more hours.

Outcome Variables

Information Needs: To identify information needs, caregivers were asked to respond to the following question, “As a caregiver, for which of the following do you feel you need/needed more help or information?” Caregivers responded individually to each of the following topics: (1) keeping the person I care for safe at home; (2) managing challenging behaviors, such as wandering; (3) easy activities I can do with the person I care for; (4) managing incontinence or toileting problems; (5) moving or lifting the person I care for; (6) balancing my work and family responsibilities; (7) finding time for myself; (8) managing my emotional and physical stress; (9) choosing a nursing home; (10) choosing a home care agency; (11) how to talk with doctors and other healthcare professionals; (12) choosing an assisted living facility; (13) making end-of-life decisions; and (14) finding non-English language educational materials. These needs were further categorized into the following three categories for this analysis: (1) direct care (1-5 above); (2) psychosocial (6-8 above); and (3) care management (9-14 above).

Resource Preferences: Caregivers were asked the following, “If you were looking for information about some aspect of helping take care of your relative or friend where would you turn?” Response options included: (1) doctor; (2) nurse or other health professionals; (3) hospital or clinic; (4) family or friend; (5) Internet; (6) books, magazines, or library; (7) church or religious organization; (8) employer; (9) government agency; (10) support groups or people like me; (11) senior citizen's center; (12) aging association, group, or organization; or (13) other. For analyses, the options were categorized into the following: (1) health professional (1-3 above); (2) Internet; (3) family or friend; or (4) other (6-13 above).

Statistical Analyses

Descriptive analyses were performed to characterize information needs (individually and by category) and information delivery preferences among cancer caregivers. Chi-square analyses were also used to examine potential associations between caregiver demographics, caregiving characteristics, and clinically-relevant variables with information needs (individually and by category) and delivery preferences. Logistic regression analyses were conducted to further explore factors associated with greater information needs per content category (i.e., psychosocial, direct care, care management). Model variables included caregiver characteristics or clinically-relevant variables significantly associated with information needs in preliminary analyses. Variables in the logistic regression model were entered simultaneously. Data were analyzed using SPSS 19.

Results

Cancer Caregivers and Information Needs

The cancer caregivers in this study had a mean age of approximately 45 years and were mostly female (65%) and providing care to a parent or grandparent (or in-laws) (55.3%). A majority of the caregivers were also secondary caregivers (52%). According to the objective Burden Index, caregiving was highly burdensome or strenuous for a majority of these caregivers (55% for levels 4 and 5). Additional cancer caregiver demographics, caregiving characteristics, and clinically-relevant variables are described in Table 1, while the percentages of caregivers expressing specific information needs are presented in Table 2. The majority of cancer caregivers (72.1%) reported a desire for additional information on at least one topic, and approximately one-third of caregivers reported a need for information on five or more topics. The following sections attend to specific content categories, including information on providing direct care, care management, and managing personal psychosocial wellness.

Direct Care Information Needs—A majority of caregivers expressed having one or more information needs related to providing direct care for a cancer patient (54.8%, n=104). A higher proportion of male caregivers reported a greater number of direct care needs (i.e., three or more) (33.3%, n=36, $\chi^2(1)=7.050$, $p = 0.008$) than females (11.8%, n=68). Similarly, a greater proportion of primary caregivers (27%; n=48, $\chi^2(1)=3.919$, $p = 0.048$) and caregivers with heightened objective burden (i.e., Burden Index levels 4 and 5) (30.9%; n=55, $\chi^2(1)=11.263$, $p = 0.001$) reported three or more direct care needs than secondary caregivers (11.5%, n=52) and caregivers with lower objective burden (i.e., Burden Index levels 1-3) (4.4%, n=45), respectively. The adjusted analysis showed that males and caregivers with high objective burden were more likely to report a greater number of direct care needs than females and caregivers with lower objective burden, respectively (see Table 3).

When considering specific direct care-related information, a greater proportion of caregivers with higher objective burden (n=55) reported a need for information about managing challenging behavior (27.3%; $\chi^2(1)=9.141$, $p = 0.002$), easy activities I can do with the person I care for (45.5%; $\chi^2(1)=11.938$, $p = 0.001$), moving or lifting the person I care for (32.7%; $\chi^2(1)=3.892$, $p = 0.049$), compared with caregivers with lower objective burden (n=45; 4.4%; 14.3%; 15.6%, respectively). A greater proportion of males (27.8%; n=36, $\chi^2(1)=5.262$, $p = 0.022$) also expressed a need for information about managing challenging behaviors compared with female caregivers (10.3%, n=68). A greater proportion of primary caregivers reported a need for information about easy activities to do with the person receiving care (43.8%; n=48, $\chi^2(1)=7.015$, $p = 0.008$) compared with secondary caregivers (19.2%, n=52). Similarly, a greater proportion of caregivers living with a care recipient noted a need for information about managing incontinence or toileting problems (22.2%; n=27, $\chi^2(2)=8.465$, $p = 0.015$) than caregivers living one hour or more away (12%, n=25)) or less than an hour away (2%, n=51). A greater proportion of caregivers using paid home or community services noted a need for information about keeping a care recipient safe (44.4%; n=63, $\chi^2(2)=4.308$, $p = 0.038$) than caregivers not using paid or community services (24.4, n=41).

Care Management Information Needs—A majority of the cancer caregivers expressed having one or more information needs related to care management (51.9%, n=104). A higher ratio of minority caregivers (i.e., Asian, Hispanic and African American) reported more care management needs (i.e., three or more) (23.1%; n=52, $\chi^2(3)=6.310$, $p = .012$) than Caucasian caregivers (5.8%, n=52). Further, Asian American caregivers were most likely (44.4%, n=18) to report three or more needs, followed by African American caregivers (27.3%, n=11), Caucasian caregivers (5.8%, n=52), and Hispanic caregivers (4.8%, n=21) ($\chi^2(3)=19.043$, $p = 0.000$). Similarly, a greater proportion of highly educated caregivers (i.e., college degree or more) also reported more care management needs (22.4%; n=49, $\chi^2(2)=6.883$, $p = 0.032$) than persons with some college (14.3%, n=28) or a high school diploma or less (0%, n=26).

The distance from a care recipient and the presence of children or grandchildren in the home were also significantly associated with a greater report of care management needs in unadjusted analyses. A higher proportion of caregivers living one or more hours away were more likely to have more (three or more) care management needs (24%; n=25, $\chi^2(2)=6.343$, $p = 0.042$) compared with those living in-home (22.2%, n=27) or within one hour of a care recipient (5.8%, n=52), while higher proportion of caregivers without children or grandchildren living in the home (21.7%, n=60) reported more care management needs than caregivers with children or grandchildren in the home (4.5%; n=44, $\chi^2(1)=6.029$, $p = 0.014$). While controlling for significant variables, only education remained a significant predictor of care management needs. Specifically, caregivers with less education (i.e., a high school degree or less) were less likely to report greater care management needs than caregivers with a college degree or more (see Table 4).

Several demographic and caregiving characteristics were associated with specific care management-related information needs. Specifically, minority caregivers expressed a greater need for non-English language educational materials (15.4%; n=52, $\chi^2(1)=8.667$, $p = 0.003$) than Caucasian caregivers (0%, n=52). A higher percentage of caregivers without children or grandchildren living in the home (n=60) reported a need for information about choosing a home care agency (25%; $\chi^2(1)=5.863$, $p = 0.015$) and information about end-of-life care (41.7%$\chi^2(1)=4.078$, $p = 0.043$) than caregivers with children or grandchildren in the home (n=44; 6.8% and 22.7%, respectively). A higher proportion of caregivers who perceived themselves as not having had a choice in providing care (34.4%, n=32) reported a need for more information about choosing a home care agency than caregivers who perceived themselves to have had a choice (9.9%; n=71,$\chi^2(1)=9.913$, $p = 0.002$).

Psychosocial Information Needs—Over half (53.8%, n=104) of the cancer caregivers expressed having had one or more information needs related to personal psychosocial care. A greater proportion of minority caregivers reported the highest number of psychosocial needs (i.e., three) (50%; n=52, $\chi^2(1)=3.994$, $p = .046$) than Caucasian caregivers (30.8%, n=52). Caregivers with heightened objective burden (56.4%; n=55, $\chi^2(1)=11.926$, $p = 0.001$) and caregivers living in-home (55.6%; n=27, $\chi^2(2)=6.059$, $p =0.048$) were also more likely to report greater psychosocial information needs than caregivers with lower objective burden (22.2%, n=45) and caregivers living within one hour of care recipient (28.8%, n=52) or more than one hour or more away (48%, 25), respectively. Of these variables, high objective burden was the only variable significantly associated with greater psychosocial needs (see Table 5).

The need for information about balancing family and work (55.6%; $\chi^2(1)=14.812$, $p < 0.001$), finding time for oneself (54.5%; $\chi^2(1)=12.415$, $p < 0.001$), managing one's emotional and physical stress (56.4%; $\chi^2(1)=7.582$, $p =0.006$) was greater among higher objective burden caregivers (n=55) compared with caregivers with lower objective burden (n=45; 17.8%; 20%; 28.9%, respectively). Caregivers with a college degree or additional higher education (46.9%; n=49, $\chi^2(2)=7.761$, $p =0.021$), as well as caregivers living with a care recipient (61.5%; n=26, $\chi^2(2)=11.427$, $p = 0.003$), also reported a need for information about balancing work and family responsibilities than caregivers with some college (44.4%, n=27) or a high school diploma or less (15.4%, n=26) or caregivers living one hour or more away (44%, n=25) or less than an hour away (23%, n=52), respectively. Similarly, a greater proportion of caregivers living with a care recipient noted a need for information about managing emotional and physical stress (66.7%; n=27, $\chi^2(2)=9.337$, $p = 0.009$) than caregivers living one hour or more away (44%, n=25) or less than an hour away (30.8%, n=52). A greater proportion of caregivers using paid home or community services noted a need for information about finding time for oneself (46%; n=63, $\chi^2(1)=3.869$, $p = 0.049$) than caregivers not using paid or community services (26.8, n=41).

Resource Preferences

Caregivers reported varying preferences for receiving information about some aspect of helping to care for a cancer patient. Caregivers most often reported that they would turn to a health professional (i.e., doctor, nurse, other health professional or hospital or clinic) (44.3%), followed by the Internet (22.7%), family and friends (16.5%) or other resources (16.5%). No demographic variables were associated with preference for resources.

Cancer caregivers with higher objective burden (levels 4 and 5) were more likely to report that they would turn to health professionals (58.5%; $\chi^2(3, n=53) =12.721$, $p = 0.005$) for caregiving information than caregivers with low objective burden (n=41; 29.3%). Caregivers with low objective burden (n=41) were more likely to prefer the Internet (24.4%) and family and friends (29.3%) than caregivers with high objective burden (18.95% and 5.7%, respectively). Having children or grandchildren in the home was also significantly associated with information delivery preferences ($\chi^2(3) = 7.854$, $p = 0.049$). A higher percentage of caregivers with children or grandchildren in the home noted they would turn to the Internet (28.6%, n=42) than caregivers without children or grandchildren in the home (18.2%, n=55). Information needs (individuals or by content category) were not shown to be associated with information delivery preferences.

Discussion

The present research contributes toward the goal of developing, refining, and implementing cancer caregiving interventions by characterizing the information needs and preferred resources for receiving caregiving information among a sample of cancer caregivers. This sample of caregivers differs in important ways compared to previous reports of cancer caregivers. Compared to other reports in which a majority of the cancer caregivers were spouse-caregivers and were living with the patient [20, 23], a majority of the cancer caregivers in this sample were caring for a parent or grandparent and lived outside of the patient's home. A majority of caregivers in this sample are also described as secondary caregivers. However it is important to note that some of these “secondary” caregivers may evenly split care with another unpaid caregiver. The potential exists that such caregivers may provide substantial care. Thus, comparisons between primary and secondary caregivers should be viewed with caution.

Findings from this study support the recent recommendation that future cancer caregiver interventions incorporate self-care content [19]. A majority of the cancer caregivers expressed one or more information needs for each of the three content categories (i.e., personal psychosocial care, providing direct care, and care management), while slightly more than four out of ten cancer caregivers expressed needing information about managing emotional and physical stress. The need for personal psychosocial care content was particularly evident among caregivers with elevated objective burden. As such, interventions for caregivers with heightened objective burden (i.e., many IADLs/ADLs and care hours) should incorporate information on balancing family and work; managing emotional and physical stress; and finding time for oneself.

Cancer caregivers were also shown to differ with regard to the need for content pertinent to providing direct care and care management, and these insights may enlighten future efforts to tailor information to subgroups of caregivers. For example, male caregivers were more likely to report a need for information relevant to providing direct care, and specifically noted was the need for information about managing challenging behaviors. Given that slightly more than three in ten family caregivers are male, providing males with direct care content may be particularly important. Further, gender differences regarding the need for direct care information are interesting in light of findings that women are more likely to be placed in nursing homes than men [8]. Although an increased likelihood of placement among women may be due to various factors, including longevity of life among females compared to males, cultural beliefs and values may impact upon decision-making toward family care, especially among non-spouse males. Over a majority of the caregivers in this study were caring for a non-spouse/partner (i.e., a parent or grandparent or in-law).

Caregivers with heightened objective burden were also more likely to express a greater number of direct care needs for a cancer patient in the controlled analysis. This finding is likely indicative of the caregiver performing more direct care tasks as patient functioning declines. It may be particularly helpful to target high objective burden caregivers in order to provide them with information relevant to performing direct care activities. Caregivers with high objective burden were specifically shown to report a need for information about managing challenging behaviors, performing easy activities with a care recipient, and moving and lifting a care recipient.

Report of care management needs was also shown to differ with respect to education level in the controlled analysis. Findings indicated that caregivers with lower education levels were less likely to report more care management information needs than those with more schooling. Additional study regarding the role of education as it pertains to caregiver care management information needs and practices is recommended, since that socioeconomic status is shown to be associated with care management decisions (e.g., use of formal or nursing home care) [8, 15]. Similarly, with regard to specific care management-related information, bivariate analyses also noted that a greater proportion of persons from minority populations reported a need for non-English materials. Future research in the cancer caregiving context should continue to incorporate non-English content.

Of additional note is the potential impact of having children or grandchildren living in the home on care management-related information needs. Bivariate findings indicated that children or grandchildren living in the home were associated with lower caregiver report of needing information related to use of formal home-care and end-of-life care. Future research would benefit from ascertaining whether having in-home assistance, including hospice care, is less desirable among caregivers with children or grandchildren living in the home. This would further inform the need for education on how to integrate home-related care for those with children in a home. In contrast, a greater proportion of caregivers who lacked choice in providing care reported needing information about use of a home care agency. Research in the dementia care context has shown that caregivers who feel trapped within their caregiving role were more likely to admit patients to nursing home care [9]. Therefore, for these caregivers, information regarding decision-making related to alternative care or how to deal with feelings of lacking choice may be helpful.

Understanding the preferred resources for receiving caregiving-related information in the cancer context is essential in light of the growing number of cancer caregivers, evolving information delivery sources, and the changing health care system and regulations (e.g., HIPAA). Our findings indicate varying preferences for receiving caregiving-related information among the cancer caregivers. Yet, a preference for receiving caregiving-related information via health professionals is also most evident among caregivers experiencing high objective burden. Effectively incorporating caregivers into the oncology clinical context is complex. Currently, the degree of caregiver involvement in the clinical context varies across institutions and clinicians, while privacy policies, such as HIPAA, inherently impede the flow of information from clinician to relative or friend. Other challenges within the context of clinical care include caregiver socio-cultural beliefs and values, literacy and comprehension levels, and the relationship quality of the caregiver and care recipient. Yet, as indicated in this study, cancer caregivers, and particularly those with elevated objective burden, note a preference toward receiving information from health professionals. In light of these barriers, research in the immediate future must work toward developing and assessing strategies for incorporating caregivers into the oncology clinical context [11, 10, 1].

A related concern is the degree to which clinicians are prepared to address self-care concerns with caregivers, to identify distressed caregivers, and to uniformly make referrals. Given that a majority of the cancer caregivers expressed the need for information on personal psychosocial care, and slightly more than four out of ten caregivers wanted information on managing physical and emotional stress, future interventions should incorporate educating clinicians on relevant caregiver self-care content.

In contrast to caregivers with high objective burden, a preference for informal resources (i.e., Internet or family and friends) is most evident among caregivers experiencing lower objective burden. This suggests that the delivery of information through informal sources (e.g., Internet) may be targeted best to those caregivers with lower objective burden. In particular, this report indicates receptivity toward the Internet as a tool for accessing caregiving-related information for those with lower objective burden. However, to date, interventions incorporating this tool are limited in general or aimed at specific populations [19]. The presence of a child in one's home was associated with a caregiver's preference toward using the Internet as a way to access needed information. It is possible that for these caregivers, the Internet is a commonly used household tool.

Limitations

These data were not collected originally to assess information needs and delivery preferences of cancer caregivers. Further, as the questions related to information needs and resource preferences were not open-ended, additional information needs may exist among this population. Further, there was no assessment as to the degree of need for information. Clinical data on patient cancer diagnosis and stage was not collected. However, objective care burden (i.e., number of care hours and IADLs/ADLs) was included in this analysis. A higher number of care hours has been shown to be positively associated with cancer stage [27]. Cancer-specific care tasks (i.e., other than IADLs/ADLs) were not collected, and such information would have strengthened the analysis. Future research should clearly delineate between primary and secondary caregiver status and include co-caregiver option for those who evenly share care. Additional limitations include the cross-sectional (versus longitudinal) nature of the data, the modest number of cancer caregivers and the relatively low response rate of the original sample. However, for the increasing number of cancer caregivers in the coming years, these findings begin to illuminate key needs and opportunities for improvement.

Conclusion

These findings suggest that content may need to be tailored to subgroups of cancer caregivers, such as male caregivers or those with high objective burden. Further, the findings also note varied preferences for information resources, including the finding that caregivers with higher objective burden prefer health professionals, while those with lower objective burden prefer informal sources (e.g., Internet and family or friends). As such, research in the immediate future must work to develop and assess strategies for incorporating caregivers into the oncology clinical context.

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Table 1

Cancer caregiver characteristics

Measure	**n (%)**
Age in years (n=104)	$\bar{x}$ = 45.89 (SD=16.17)
Gender (n=104)	
Female	68 (65.4%)
Male	36 (34.6%)
Race/Ethnicity (n=102)	
White	52 (51%)
Black	11 (10.8%)
Hispanic	21 (20.6%)
Asian	18 (17.6%)
Income (n=96)	
<$30,000	27 (28.1%)
$30,000-$49,000	24 (25%)
$50,000-$99,000	29 (30.2%)
$100,000 or more	16 (16.7%)
Education (n=103)	
High school or less	26 (25.2%)
Some college or technical college	28 (27.2%)
College degree or higher	49 (47.6%)
Health (n=102)	
Excellent	24 (23.5%)
Very good or good	16 (58.8%)
Fair or poor	18 (17.6%)
Care recipient's relationship to caregiver (n=103):	
Spouse/companion	9 (8.7%)
Parent/grandparent (or in-law)	57 (55.3%)
Sibling (or in-law)	11 (10.7%)
Offspring	1 (1%)
Other relative	7 (6.8%)
Non-relative	18 (17.5%)
Care status (n=100)	
Primary caregiver	48 (48%)
Secondary caregiver	52 (52%)
Distance from care recipient (n=104)	
In-home	27 (26%)
Less than one hour away	52 (50%)

Measure	**n (%)**
One hour or more away	25 (24%)
Hours of Care Index (n=100)	
0-8	34 (34%)
9-20	27 (27%)
21-40	19 (19%)
41 or more	20 (20%)
Type of Care Index (n=104)	
1 IADL/0 ADL	4 (3.8%)
1+ IADL/0 ADL	26 (25%)
1 ADL (with or without IADL)	13 (12.5%)
2+ ADL (with or without IADL)	61 (58.7%
Duration of Care (n=102)	
Less than 6-months	37 (36.2%)
6-months to 1 year	24 (23.1%)
1-4 years	30 (28.8%)
5-9 years or more	7 (6.9%)
10 or more years	4 (3.9%)
Objective Burden Index (n=100)	
1 (lowest)	17 (17%)
2	16 (16%)
3	12 (12%)
4	36 (36%)
5 (highest)	19 (19%)
Use of Paid/formal In-home or Community Assistance (n=104)	
Yes	63 (60.6%)
No	41 (39.4%)
Caregiving Choice (n=103)	
Yes	71 (68.9%)
No	32 (31.1%)

Table 2

Caregiver information needs (n=104 unless noted)

Information Category	Information	# (%) affirming need for information
Direct Care	Keeping the person I care for safe at home	38 (36.5%)
	Managing challenging behaviors, such as wandering	32 (30.8%)
	Managing incontinence or toileting problems (n=103)	10 (9.7%)
	Easy activities I can do with the person I care for	32 (30.8%)
	Moving or lifting the person I care for	26 (25%)
Psychosocial	Balancing my work and family responsibilities (n=103)	39 (37.9%)
	Finding time for myself	40 (38.5%)
	Managing my emotional and physical stress	45 (43.3%)
Care Management	Choosing a nursing home	12 (11.5%)
	Choosing a home care agency	18 (17.3%)
	Choosing an assisted living facility	11 (10.6%)
	How to talk with doctors and other healthcare professionals	30 (28.8%)
	Making end-of-life decisions	35 (33.7%)
	Finding non-English language educational materials	8 (7.7%)

Table 3

Logistic regression: reporting three or more direct care needs (n=96)

Predictor	***B***	**SE**	**Exp*(B)***	***P***
Care Status				
Primary	1.225	.684	3.404	.073
Secondary	-	-	-	-
Gender				
Male**	1.844	.655	6.580	.004
Female	-	-	-	-
Burden Level				
High (level 4 and 5)**	2.914	1.093	18.438	.008
Low (levels 1-3)	-	-	-	-

* $p < .05$

$^{**}p < .01$

Table 4

Logistic regression: reporting two or more care management needs (n=103)

Predictor	***B***	**SE**	**Exp*(B)***	***P***
Race/Ethnicity				
Caucasian	-.325	.470	.722	.489
Minority (Black, Hispanic, Asian)	-	-	-	-
Children or Grandchildren in Home				
Yes	-.741	.489	.477	.129
No	-	-	-	-
Education				
<=HS*	-1.722	.699	.179	.014
Some college	-.597	.532	.551	.262
College or more	-	-	-	-
Distance				
In home	-.349	.629	.705	.579
< 1 hour away	-.787	.559	.455	.159
1 or more hours away	-	-	-	-

** p < .01

* p < .05

Table 5

Logistic regression: reported three psychosocial information needs (n=100)

Predictor	***B***	**SE**	**Exp*(B)***	***P***
Race/Ethnicity				
Caucasian	-.846	.444	.429	.057
Minority (Black, Hispanic, Asian)	-	-	-	-
Objective Burden				
High (level 4 and 5)[**]	1.502	.459	4.490	.001
Low (levels 1-3)	-	-	-	-

[*] p < .05

[**] p < .01