Original Article

Young Adult Cancer Caregivers' Exposure to Cancer Misinformation on Social Media

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BACKGROUND: The objective of this study was to describe young adult cancer caregivers' exposure to cancer misinformation on social media. **METHODS:** Eligible participants were 18 to 39 years old, used social media weekly, and cared for an adult patient with cancer diagnosed 6 months to 5 years before (N = 21). Recruitment occurred from August 2017 to June 2018 in person at oncology clinics and online. Semistructured telephone interviews were recorded and analyzed with grounded theory methods through 2 rounds of coding ($\kappa = 0.88$). **RESULTS:** Caregivers were on average 29.1 years old, female (76.2%), non-Hispanic White (90.5%), college educated (57.1%), and caring for a spouse/partner (47.6%). Caregivers were exposed to a variety of cancer misinformation topics; some felt uncertain in their caregiving ability when confronted with cancer misinformation. Caregivers crosschecked online sources and consulted trusted individuals (eg, family, friends, and health care providers) to determine the quality of cancer-related information and manage cancer misinformation. **CONCLUSIONS:** Cancer misinformation on social media may influence caregiving behaviors and decision making. Whether caregivers correctly and consistently identify cancer misinformation on social media is unknown. Supporting digital literacy to mitigate cancer misinformation on social media may improve young cancer caregivers' access to credible cancer information. ***Cancer* 2020;0:1-7**. © *2020 American Cancer Society*.

LAY SUMMARY:

- Cancer misinformation on social media affects young adult cancer caregivers' perceptions of their social support network.
- Caregivers differ in how they evaluate cancer information for quality and in how this information influences their health behaviors and caregiving decisions.

KEYWORDS: caregiver, misinformation, social media, young adult.

INTRODUCTION

Health misinformation includes false, inaccurate, or incomplete information; rumors; ineffective alternative therapies; discourse promoting skepticism about medical guidelines; and misleading or untrue health-related advice.[1,2] Social media–based health misinformation is increasingly common[3,4] and often receives more attention than accurate information.[5] The prevalence of cancer misinformation on social media depends on topic and platform. In multiple studies, misinformation comprised 30% of tweets about gynecological cancer,[6] one-third of Facebook posts had medically inaccurate or untested claims,[7] and 77% of YouTube videos about prostate cancer contained misinformation.[8]

Patients with cancer and their caregivers may be at risk for acting on cancer misinformation (eg, stopping chemotherapy) or experiencing negative psychological sequalae from cancer misinformation (eg, second-guessing treatment decisions).[5,9] Additionally, evidence suggests that patients' physical health is affected by caregivers' mental and physical health.[10] Thus, when cancer misinformation threatens health and well-being, this may affect both caregivers and patients.

Young cancer caregivers may be particularly susceptible to negative influences of misinformation because of their high level of unmet need for information and medical decision making.[11] This may drive them to social media, where they have robust networks, to seek cancer information.[9,12-14] Young caregivers' high levels of social media use, limited exposure to severe illness, lack of experience with caregiving tasks and skills,[15] and generally low health literacy[16] may compromise their ability to identify and manage cancer misinformation online. Access to high-quality cancer information is critically

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See editorial on pages 000-000, this issue.

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important for young caregivers to gain insight into caregiving tasks and responsibilities, make informed health care decisions, and learn about supportive resources.

Cancer caregivers seek and use social media for cancer information[12,14,17] and report varying levels of fear and mistrust of cancer information on social media.[12,18,19] For these reasons, we explored how young adult cancer caregivers may experience and process cancer misinformation on social media. Although research on social media–based cancer misinformation often evaluates the validity of claims, we elicited participants' perceptions and experiences in handling what they perceived to be cancer misinformation on social media. Perceived support, including information support, may have a greater impact on well-being than enacted support[20,21]; thus, we were interested in the behaviors and decision making of young adult caregivers who perceived that they had encountered cancer misinformation. Describing perceived exposure to cancer health misinformation and its influence is an initial and necessary step to understanding the impact of cancer misinformation on caregiver well-being.

MATERIALS AND METHODS

The Cancer Family Caregiving Experience Framework provided the theoretical foundation for this work, which explains that as social needs are met, caregivers' abilities to fulfill their roles are improved.[10] Guided by the framework, we explored how young adult cancer caregivers may be exposed to and process cancer misinformation on social media. We propose that cancer information seeking on social media, and thereby cancer misinformation exposure, compose a critical part of the sociocultural context in which caregivers exist.[10] This study was a secondary analysis of semistructured interviews from a larger study on young caregivers' use of social media for social support. This study was approved by the University of Utah institutional review board and conformed to ethical standards.[10]

Participants and Recruitment

Eligible participants were 18 to 39 years old, spoke English, used social media at least once per week, and engaged in caregiving for a patient with cancer diagnosed 6 months to 5 years before. Caregivers were recruited from August 2017 to June 2018 with flyers, social media advertisements, and referrals from patients with cancer who provided their contact information. There were 354 patients screened, and 61 caregivers were potentially eligible. Thirteen of these caregivers were ineligible (eg, due to patient time since diagnosis, their age, or being nonusers of social media). This left 48 eligible caregivers: 8 declined, 6 were unreachable, and 34 participated (participation rate, 70.8%). Caregivers completed informed consent and a semistructured interview over the telephone. The interview script was informed by a literature review of young adult cancer caregivers' use of social media for social support. The script was reviewed and edited by adolescent and young adult cancer patient navigators and an adolescent and young adult oncology patient and family advisory board. Semistructured interviews were conducted by the first author and were continued until data and thematic saturation was achieved.[22]

Data Collection and Management

Caregivers participated in guided, open-ended interviews with semistructured components, which allowed for latitude in topics raised. When they were asked about uncomfortable experiences, bad advice, and cancer misinformation, the topic of cancer misinformation emerged as a discussion topic for a notable subset of interviewees (21 of 34 [61.8%]). This report focuses on the 21 participants who discussed cancer misinformation. Additional questions probed about experiences with cancer misinformation and/or bad advice on social media. Interviews for these 21 participants were 41 to 79 minutes long; they were audio-recorded and transcribed and then quality-checked for transcription accuracy. Thirty-four sociodemographic, cancer, social support, and social media use questions were asked and stored in REDCap.

Sociodemographic, Cancer, and Social Media Variables

Self-reported sociodemographics included age, sex, ethnicity, employment, insurance, marital status, education, and caring for others besides the patient. Cancer patient variables included patient age, relationship to the caregiver, and time since diagnosis. Social media use was classified as daily, weekly, monthly, or no current use for Facebook, Instagram, and Twitter. Descriptive statistics were calculated in Stata 14.2.

Interview Analysis

Transcripts were coded in NVivo 11. Initially,[23] 10% of the interviews were inductively and topically coded by 2 authors; this resulted in 321 codes that described content related to participant exposure to misinformation on social media (eg, types of cancer misinformation) and how they processed this content (eg, how cancer misinformation is evaluated). These initial codes were compiled and compared, and similarities and differences were discussed to reach coder consensus. With the refined coding scheme,[23] an additional 10% of the interviews were double-coded by 2 authors, and interrater reliability was calculated; this demonstrated a "strong" level of intercoder agreement ($\kappa = 0.88$).[24] Codes with zero or negative agreement were discussed and revised, and the final coding scheme was applied to all interviews.

Process and analytic memos were documented by coders concerning coding decisions, definitions of applied codes, and emergent interpretations of the coded data.[25,26] Next, coded data related to cancer misinformation were aggregated and examined further for content and themes; this resulted in the 6 categories described in the Results section.

RESULTS

Sociodemographic, Cancer, and Social Media Characteristics

Caregivers were on average 29.1 years old and were primarily female (76.2%), non-Hispanic White (90.5%), employed (81.0%), insured (100.0%), married/partnered (66.7%), college graduates or higher (57.1%), and caring for others besides the patient with cancer (66.7%; Supporting Table 1). Participants had been engaged in caregiving for a median of 1.3 years (SD, 0.8 years). Patients with cancer were 19 to 76 years old (mean, 38.4 years) and typically a spouse/partner (47.6%) or a parent (19.0% mothers and 9.5% fathers; Supporting Table 2). Caregivers overwhelmingly reported daily use of Facebook (71.4%) and Instagram (57.1%), and only 4.8% used Twitter; 81.0% spent 1 to 2 hours on social media daily (data not shown).

Qualitative analysis resulted in 6 categories describing caregivers' experiences with cancer misinformation on social media: 1) exposure to cancer misinformation, 2) caregiver management of cancer misinformation, 3) influence of cancer health information on caregiver well-being, 4) evaluating the quality of cancer misinformation, 5) cancer misinformation topics, and 6) format of cancer misinformation.

Exposure to Cancer Misinformation

When they were asked about uncomfortable situations, bad information, or unsolicited advice that they had experienced on social media, 21 participants discussed cancer misinformation; 16 (76.2%) experienced cancer misinformation on social media, and 5 (23.8%) reported that they were familiar with cancer misinformation but had not experienced it directly on social media. Cancer misinformation on social media was described by participants as "bad" or "misleading" information because it was perceived as being opinion based or not medically sound.

Caregivers were exposed to cancer misinformation from many sources ranging from family to strangers. Caregivers who had large followings on social media or managed social media accounts with or for the patient with cancer described posts from individuals or organizations about untested theories and attempts to sell "cancer cure" products on their pages because of their high number of followers. Cancer misinformation took a variety of formats, including articles, videos, and images. Some caregivers' exposure was so frequent that they described seeing cancer misinformation on social media "all the time". One of the 5 participants who reported that they had not experienced cancer misinformation on social media explained, "I do think it's largely because I haven't publicized what's going on … that (misinformation) is definitely part of what I was trying to deter."

Caregiver Management of Cancer Misinformation

Caregivers who perceived that they had been exposed to cancer misinformation on social media often dismissed what they considered to be inaccurate, untruthful, or unsound advice. Although the majority of caregivers felt confident at identifying cancer misinformation, if they were skeptical about cancer information on social media, they had devised strategies for validating information. Before acting on cancer information that caregivers perceived to be misleading or untrue, they consulted other sources on the internet, trusted family or friends, the patient with cancer, and health care providers. A caregiver suggested that, "Unless you know exactly the kind of information to search for online, it's really tricky to find good information on the internet. Even if you find something that you think is accurate and legitimate, you still should talk to your doctor about it." Multiple caregivers mentioned that the cancer patient's health care providers cautioned them to avoid seeking cancer-related health information online. See additional quotes in Supporting Table 3.

Influence of Cancer Misinformation on Caregiver Well-Being

In some cases, inaccurate content negatively affected caregivers' well-being. Caregivers felt that their caregiving ability was being called into question when they received private messages through social media that contained information or advice that they perceived to be medically unsound. These direct confrontations left caregivers feeling that their online social networks did not trust the decisions they were making with, or for, the patient with cancer. Unsolicited advice received through private messages included urging caregivers to seek out different health care providers or facilities, to try untested cancer therapies, and to experiment with home remedies for symptom management. One caregiver described how she felt after receiving a private message with misinformed content, saying, “I just thought, you know, this is so overwhelming. And what I feel like is people are second guessing what we feel is appropriate for her and for our family … and so yeah, that did bother me.”

Deciphering the validity of cancer-related health information on social media was distressing to some caregivers. It was not always clear to caregivers whether the information that they received was accurate or not. Caregivers worried about letting down the patient with cancer if they either acted on misinformed information or, in contrast, did not act on advice that could help the patient.

Caregivers felt frustrated and affronted when individuals outside their usual social network contacted them directly with cancer misinformation on social media. A typical example of this was a caregiver whose extended family member, with whom the caregiver did not have a close relationship, private-messaged her a link to a documentary with “an easy way to cure [cancer]”. The caregiver was skeptical about the motives behind what she perceived to be misleading information about cancer treatment. She said, “People would give me stuff, I’d kind of be like yeah, that’s stupid, no. We’re at [cancer hospital]. There’s not a better cancer hospital. You really don’t think they know what they’re doing?” Additional supportive quotes are in Supporting Table 4.

Evaluating the Quality of Cancer Misinformation

One of the most influential factors that determined how caregivers judged the quality and accuracy of content that they consumed on social media was the source of the information. Specifically, caregivers regarded the reputation and trustworthiness of individuals or organizations that authored or reposted cancer information and their perceived intentions to be highly important in determining the accuracy of cancer information on social media. Caregivers felt confident in information shared on social media by certain members of their social networks who had professional experience or training in health-related areas such as medicine, nursing, pharmacy, and nutrition. However, cancer misinformation on social media that came from sources that caregivers interpreted as being for profit, promising “cancer cures,” and promoting untested supplements or nutritional advice upset them because they believed that these sources were spreading cancer misinformation that was intended to take advantage of them or would be unsafe for the patient with cancer.

The quality of personal relationships with individuals who shared information influenced how caregivers perceived the information and whether they deemed it of high or low quality. Close friends and family members were deemed more trustworthy on social media than unknown or new social connections. Caregivers were tolerant when well-meaning family or friends, with whom they often had close relationships, shared cancer misinformation on social media because, as one caregiver described, “I understand the people that are doing that are doing that out of love, and that they really are misinformed and they don’t know that it doesn’t help. And they don’t know that it might hurt.”

Cancer Misinformation Topics

Participants varied considerably in their perceptions of cancer misinformation topics to which they were exposed on social media, which included 3 broad categories: advice, cautions, and conspiracy theories. Advice included nutritional advice, miracle cancer cures, and seeking of second opinions. Cautions included cautions to avoid chemotherapy, causes of cancer, and side effects of treatment. Conspiracy theories included “crackpot theories,” “doctors are evil,” and “big pharma is hiding the cure.” Additional examples and supporting quotes are in Supporting Table 5.

Caregivers perceived that the level of inaccuracy of cancer misinformation ranged from benign to severe (eg, recommendation to end chemotherapy) and that it conflicted with advice from health care providers. Caregivers often distrusted nutritional advice, cures for cancer or side effects, chemotherapy avoidance because it is “poison,” “natural” cures, causes of cancer, and “crackpot” theories. Summarizing her frustration with her social network’s misinformed cancer advice, a caregiver said, “There were and still are a lot of people that just told us, you know, do a foot bath, try essential oils, doctors are evil, go get treated in Mexico. They just had all these kind of crazy cures or reasons why he got cancer that I was like, okay, then you clearly have no idea.”

Format of Cancer Misinformation

Caregivers described cancer misinformation appearing in personal social media posts, responses, video and images, "shared" content such as reposted news or magazine articles, and private messages on social media. The highest level of exposure to cancer misinformation occurred after the cancer patient's diagnosis was shared publicly on social media, and misinformation was less present over time. This was reportedly due to copious amounts of unsolicited advice with misinformed content, often from well-meaning family and friends, which caregivers attributed to the idea that "everyone thinks they're a doctor." Caregivers also reported that the patient with cancer received social media posts, links, and articles in greater volume and at a higher frequency than they did.

DISCUSSION

Our goal was to describe how young adult cancer caregivers experience and process what they perceive to be cancer misinformation on social media. Nearly two-thirds of caregivers in our sample experienced cancer misinformation. Social media was an integral part of their daily lives and a prominent information resource. Despite cautions from health care providers to avoid online cancer information, caregivers often received information about cancer and caregiving on social media and subsequently experienced cancer misinformation.

Young adults' widespread social media use underscores the need for clinicians and public health experts to recognize the important role of online social networks in the cancer experiences of young caregivers.[12,27,28] Our findings suggest that an opportunity exists for clinicians and caregivers to approach cancer misinformation directly. Oncologists who engage with patients with cancer on social media provide a legitimate resource that is easily accessible and reliable,[29] and thus provide opportunities for the promotion of high-quality online information about cancer and caregiving in the online communities that caregivers use for cancer information. Proactive approaches may help to counteract the influence of social media–based cancer misinformation on young caregivers' well-being and decision making.[30,31] Thus, rather than discouraging cancer information seeking online, preemptively preparing caregivers and patients for the onslaught of information that they may receive from their online networks and encouraging vigilance in verifying the accuracy of cancer information may be helpful.[12]

Although misinformation is often studied for its impact on health behaviors and decision making, our results suggest the potential deleterious effect of cancer misinformation on interpersonal relationships. Young adult cancer caregivers report higher levels of stress, depression, and unmet information needs in comparison with older caregivers.[32] Social media removes the social buffer that face-to-face discussions afford, and this leads to what our participants described as bluntly delivered criticisms, often in the form of what they perceived to be cancer misinformation. Receiving cancer misinformation through specific actions (eg, private messaging) was described as stressful and anxiety producing by participants because they felt that this was a direct way for members of their social network to express dissatisfaction with their caregiving abilities or decision making that would not have occurred during face-to-face discussions. An established body of research has documented the potential impact of caregiver psychological health on both caregiver and patient health outcomes.[10] If cancer misinformation negatively influences young caregivers' perceptions of their social support availability, this has potential to negatively influence their well-being and the well-being of patients with cancer. The high prevalence of depression, anxiety, and unmet needs among young cancer caregivers in comparison with older caregivers calls for study of the unique social stressors that may influence young caregivers' psychological well-being, and these findings suggest that social media cancer misinformation contributes to their psychological well-being.

Caregivers generally felt confident in identifying and disregarding cancer misinformation; however, there was some variation in their capability with social media, which might introduce differential vulnerabilities to misinformation. For example, some participants were proficient users of social media—enough so to create and manage large followings—whereas others were less savvy, with their caregiving experience being the first time that they actively used social media. Thus, although it is promising that caregivers perceive themselves to be capable of avoiding cancer misinformation on social media, those who claimed that they had not experienced cancer misinformation on social media may simply have failed to recognize misleading content. Caregivers who act on misinformed content risk making decisions that are deleterious to their own health and that of the patient with cancer (eg, stopping, delaying, or refusing conventional treatments). Racial and ethnic minorities, immigrants, and those with lower educational attainment have less confidence in seeking online health information, demonstrate lower health literacy,[17] and have different patterns of social media use. When taken together, disparities in sociodemogrpahics, education, and health literacy may increase the likelihood of these individuals acting on cancer misinformation. Furthermore, subpopulations of young cancer caregivers who have limited engagement with health care providers, such as racial/ethnic minorities, LGBTQ+ individuals, and those of lower socioeconomic status,[33] may also be susceptible to cancer misinformation claims, although this has not previously been studied. Understanding why young caregivers act on cancer misinformation (eg, to gain control,[34] to address unmet needs,[11] or because of low health literacy[16]) and which subpopulations are most at risk is critical to determining the impact of cancer misinformation on young adult cancer caregiving experiences, treatment decisions, psychological health, and well-being.

Digital health literacy is an individual's ability to search for, select, appraise, and apply online health information.[35] The theory of misinformation spread on social networks explains that an individual's ability to evaluate information for quality (eg, digital health literacy) influences his or her exposure to and spread of misinformation.[36] Digital health literacy plays a critical role in misinformation consumption and whether or not an individual acts on misinformation.[16] Evaluating caregiver digital health literacy at the cancer patient's initial diagnosis may help to identify caregivers who are at risk for viewing and acting on online cancer misinformation.

There are promising strategies for mitigating the negative influence of misinformation on social media beyond user-centric efforts. In response to public outcry, some social media platforms have initiated new crowdsourced tools to report suspicious information[37]; however, the enforcement of policies for cancer misinformation has yet to be actualized. Emerging studies have attempted to establish predictive tools to mitigate misinformation on social media, but these are focused on Twitter,[2] which only 4.8% of our participants used. The extent to which social media platforms will implement such tools is unknown. Theoretically, informed testing[36] of the feasibility and efficacy of predictively identifying and removing cancer misinformation may be of benefit, but it merits ethical consideration of balancing individual rights with protecting the public from cancer misinformation. From this study, we cannot determine factors that influence exposure to cancer misinformation (eg, believability and tone[38]) or the source of cancer misinformation (eg, followers vs bots[31]), but identifying these predictors could provide targets for larger scale mitigation of cancer misinformation on social media.

Other factors related to social media use (eg, active vs passive user behavior), social media platform preferences (eg, Facebook vs YouTube), and factors related to volume (eg, number of followers and network composition) may also influence how cancer misinformation influences young caregivers. Finally, as digital natives, young caregivers may be more equipped and skilled at identifying and handling cancer misinformation than older caregivers, although this has not been previously studied.

This study has limitations that may influence generalizability. Specifically, purposive sampling for qualitative studies often results in small sample sizes but elicits rich descriptions of young caregivers' use of social media and cancer misinformation experiences. Many caregivers were caring for similarly aged patients with cancer, and age may influence exposure to and influence of cancer misinformation. Our study was cross-sectional, and time since diagnosis likely influences online information seeking; this means that a participant's description of misinformation may be influenced by recall bias, particularly for those further from diagnosis. Finally, what our participants described as cancer misinformation is not a comprehensive list of all cancer misinformation topics.

In conclusion, the benefits and pitfalls of social media use for cancer information merit attention and careful consideration in the digital age. A first step toward this goal is characterizing cancer misinformation on social media. Social media is a valued source of emotional and information support for young adult cancer caregivers that easily accommodates their busy lifestyles and diverse caregiving situations. However, cancer misinformation along with other negative outcomes associated with social media use (eg, loneliness, depression, and social comparison)[39,40] suggests that young cancer caregivers could benefit from guidance on using social media to their greatest benefit and on avoiding negative outcomes.

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CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

AUTHOR CONTRIBUTIONS

Echo L. Warner: Study conceptualization and design and leadership of data collection, analysis, interpretation, and writing. **Austin R. Waters:** Support of study conceptualization, data collection, analysis, and interpretation and leadership of the literature review. **Kristin G. Cloyes:** Support of study conceptualization, recruitment, data collection, analysis, and interpretation. **Lee Ellington:** Support of study conceptualization, recruitment, data collection, analysis, and interpretation. **Anne C. Kirchhoff:** Support of study conceptualization, recruitment, data collection, analysis, and interpretation. All authors wrote, edited, and approved the article and take accountability for it.

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