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Young adult cancer caregivers' use of social media for social support

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Abstract

Objective: To describe how young adult cancer caregivers (YACC) use social media for social support during a cancer experience.

Methods: Eligible YACC were 18 to 39 years, used Facebook and/or Instagram at least once per week, and cared for an adult cancer patient diagnosed 6 months to 5 years prior (N = 34). Recruitment of a cross-sectional sample occurred through oncology clinics in Utah and online advertising by caregiving and cancer organizations from September 2017 to June 2018. Semi-structured telephone interviews were recorded, transcribed, iteratively coded, and qualitatively analyzed, yielding four categories concerning how YACC use social media.

Results: Caregivers were most commonly spouses aged 29 years on average (range 21-38); cancer patients were 37 years (range 19-76). Analysis yielded four distinct yet related categories: Category 1: Posting about cancer on social media often begins as a strategy for YACC to efficiently provide updates about the cancer patient. Category 2: Caregivers who actively post on social media experience a variety of different functional social supports to which they otherwise would not have access. Category 3: Posting about cancer online presents an opportunity for negative consequences. Category 4: Potential for negative consequences influences how some caregivers use social media.

Conclusions: Supportive services, including social media-based supports, are needed for YACC in formats that are convenient for them as they balance their caretaking duties with their daily lives.

KEYWORDS
cancer, caregiver, Facebook, Instagram, social media, social support, young adult

1 | BACKGROUND

In the United States, 48% of all informal caregivers are young adults, with nearly a quarter between 18 to 34 years.[1] Young adult cancer caregivers (YACC) report higher physical and psychosocial burden than other caregivers.[2] Reasons for this include the often sudden onset, rapid advancement, and life-threatening nature of a cancer diagnosis combined with YACC's developmental stage.

Without proper support, unexpected caregiving can disrupt YACC's well-being, prompt fear of abandonment, and uncertainty,[3-6] which leaves YACC more vulnerable to stress, depression, isolation, and unmet needs than older caregivers.[4] While caring for a loved one with cancer brings challenges, it can be rewarding, enhance relationships, and bring meaning to life.[7,8] Cancer caregivers who feel socially supported exhibit healthier coping behaviors and outcomes.[9-12]

Unfortunately, traditional clinical and community supports often do not address YACC's needs. Oncology support services are typically not provided in the formats (online vs in-person) and settings (with similar aged peers) desirable to young adults.[7,13,14] In addition, YACC may need specialized support because they are unfamiliar with severe illnesses, have multiple caregiving responsibilities, and are typically less established financially than older caregivers.[15,16] YACC's increasing responsibility for cancer caregiving and higher risk of negative psychosocial outcomes from caregiving emphasizes their need for social support in the settings and formats desirable to them, like social media.

Between 88% and 97% of young adults in the United States use social media[17,18] to access social support, gain trust, and maintain relationships.[19,20] When it comes to health, social media is used to find information and seek advice from friends, family, and others in their social networks.[21,22] Positive and negative health and social outcomes have been linked to social media use.[23,24] Studies suggest that YACC use social media for information and emotional support, their two most common needs that are not met with existing clinical and community supports.[25-27]

Addressing the challenges YACC face is of increasing importance to minimize the negative psychosocial toll of caregiving as these roles increasingly shift to younger generations.[1,28] Using social media to support YACC may help reduce their unmet emotional support and information needs. However, information is needed about how YACC use social media during cancer experiences to accommodate their lifestyles and multiple care responsibilities. Thus, we performed semi-structured interviews to describe how YACC use social media for social support during the first 6 months of cancer caregiving. Understanding how YACC engage social networks following a cancer diagnosis is the first step toward developing technology-aided social support interventions, which are acutely needed to support the growing millennial caregiver generation.

2 | METHODS

2.1 | Theoretical foundation

The Cancer Family Caregiving Experience Framework posits that cancer caregivers experience an appraisal process wherein they assess their primary and secondary stressors, then decide how to cope with these stressors using the resources they have available.[29] Given young adults' widespread use of social media,[17,18] YACC may use social media as a resource for coping with stressors. This study was approved by the University of Utah institutional review board (IRB_00097575).

2.2 | Participants and recruitment

Eligible caregivers were 18 to 39 years, spoke and understood English, used social media at least once per week, and had been caring for a loved one with cancer diagnosed 6 months to 5 years prior. Caregivers were recruited through flyers and social media advertisements, and referrals were initiated by discussing the study with cancer patients, who provided contact information for their primary caregiver. Recruitment occurred through the Huntsman Cancer Institute, the Huntsman-Intermountain Adolescent and Young Adult Cancer Care Program, and national young adult cancer and caregiving organizations. Of 354 cancer patients screened, 61 potential caregivers were identified; 13 were deemed ineligible due to patient's time since diagnosis (n = 3), patient's age (n = 4), patient having a recurrent cancer diagnosis (n = 1), caregiver did not use social media (n = 2), or other (n = 3). This left 48 eligible caregivers; n = 8 declined, n = 6 were unreachable, and N = 34 participated (participation rate = 70.8%). Enrolled caregivers completed informed consent and a telephone interview. Telephone interviews were conducted by Echo L. Warner who was a female doctoral student with a background in public health and adolescent and young adult oncology research. Before the interviews, participants were informed the research was being done for a doctoral degree.

2.3 | Data collection and management

We asked participants semi-structured interview questions about caregiving experiences, social media use, and future interventions. There were also 34 close-ended questions about sociodemographics, the cancer patient, social support, and social media use, which were imported into REDCap for storage. Interviews ranged from 41 to 79 minutes, were audio recorded, and transcribed, then read and checked against audio recordings for discrepancies.

2.4 | Sociodemographic, cancer, and social media variables

YACC sociodemographics included: age, gender, ethnicity, employment, insurance, marital status, education, and caring for others besides patient. Cancer patient variables included: patient age and relationship. Social media use was classified as daily, weekly, monthly, or no use for Facebook, Instagram, and Twitter. Descriptive statistics were performed in Stata 14.2.

2.5 | Qualitative analysis

Using NVivo 11, transcripts were analyzed in iterative cycles moving from more general descriptive codes that labeled content, to more focused coding that aligned codes by concept and content using grounded theory methods. In first cycle open coding,[30] where descriptive content labels were used, 10% of the interviews were coded by Echo L. Warner and Austin R. Waters (a male master's level student with previous qualitative coding experience) resulting in 321 codes. First cycle generated content and process codes, and second cycle categorized these codes by identifying conceptual and content similarity. In the second cycle focused coding,[30] the coding scheme was

applied to an additional 10% of the interviews, which were double coded by ELW and ARW. In the second cycle coding, interrater reliability was "strong" (κ = 0.88).[31] Where categories were found to have zero or negative agreement, the coding scheme was revised through discussion and settled by rater consensus. We created process and analytic memos throughout data collection and analysis about procedural irregularities, meaning of ideas, and interpretations.[32,33]

The final coding scheme was applied to all 34 interviews. Final categories related to the process of using social media for social support were identified using a grounded theory technique that organizes key categories with the intention of informing theory development.[34]

3 | RESULTS

3.1 | Sociodemographic, cancer, and social media characteristics

Average caregiver age was 29 years (SD: 4.7, range 21-38). Caregivers were primarily female (70.6%), Non-Hispanic White (91.2%), employed (85.3%), insured (97.1%), married/partnered (73.5%), college graduates or higher (53.0%), and caring for others besides the cancer patient (67.6%, see Data S1). Cancer patients were on average 37 years old (SD: 13.8, range 19-76) and most commonly a spouse/partner (52.9%) or a parent (17.6% mothers, 5.9% fathers, see Data S1). Caregivers used Facebook (79.4%), Instagram (61.8%), and Twitter (2.9%) daily (see Data S1, Figure 1). Caregiving had endured for a median of 1.6 years at the time of the interview (SD: 1.1 years).

3.2 | Category 1: Social media is easier than other modes to provide updates about the cancer patient

Caregivers felt overwhelmed providing updates about the patient to family and friends and this led them to use social media as a tool for

FIGURE 1 Frequency of commonly used social media platforms

updates about the cancer patient as it was easier logistically and emotionally than other methods (Figure 2).

3.2.1 | Subcategory: Logistically—Time Saver

The time and effort required to provide updates about the cancer patient frustrated caregivers. They felt limited by email, phone calls, and text messaging because these approaches capped how many people they could communicate with simultaneously. The time spent providing updates through traditional methods interrupted their time with the patient and limited their ability to perform caregiving tasks and activities of daily living. A caregiver described, "*In a tense situation that interferes with your ability to actually...care for [the patient] because you're taking the time to speak with [loved ones] about [cancer].*" This led caregivers to use social media for updates because they could reach many people with minimal effort, leading to them having more time to focus on supporting the patient. Caregivers also believed they could protect the patient from obtrusive requests from family and friends for updates by posting on social media and that their posts benefitted both themselves and the cancer patients.

3.2.2 | Subcategory: Logistically—How it Happens

Caregivers sometimes discussed social media content with the patient before making posts, although this was not consistently reported. Permission was often obtained to post photos, health information, and treatment decisions, including the level of detail about the patient's status, on social media. Similarly, caregivers respected the patient by waiting for them to post about major milestones. For example, one caregiver commented, "*When it was bigger news, I would have to wait until she posted it so I wasn't stealing her thunder.*" Whether the caregiver posted updates online depended on the relationship and the patient's comfort with social media. For example, a sibling caregiver felt she would actively post about cancer on social media if her mother was a cancer patient because her mother often posted on social media compared to her sister, the cancer patient, who desired privacy.

3.2.3 | Subcategory: Emotionally

Sharing updates about the cancer patient online was less difficult than sharing these updates face-to-face because caregivers only had to post information once online as compared to repeatedly talking about what was going on with the cancer patient, which was emotionally burdensome. An unintended consequence of updating on social media was that caregivers felt a need to provide emotional support to others. A caregiver described this saying, "*It's super draining because you find yourself in the position to comfort them when they should be comforting you.*" Social media updates were perceived as low stress because they provided flexibility in response time which then allowed
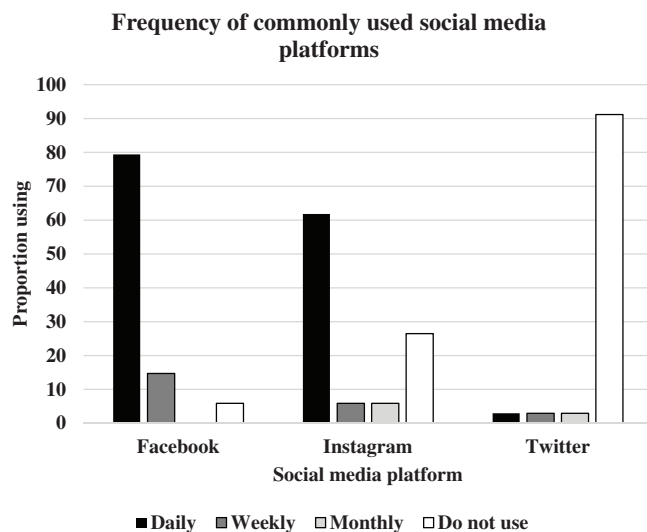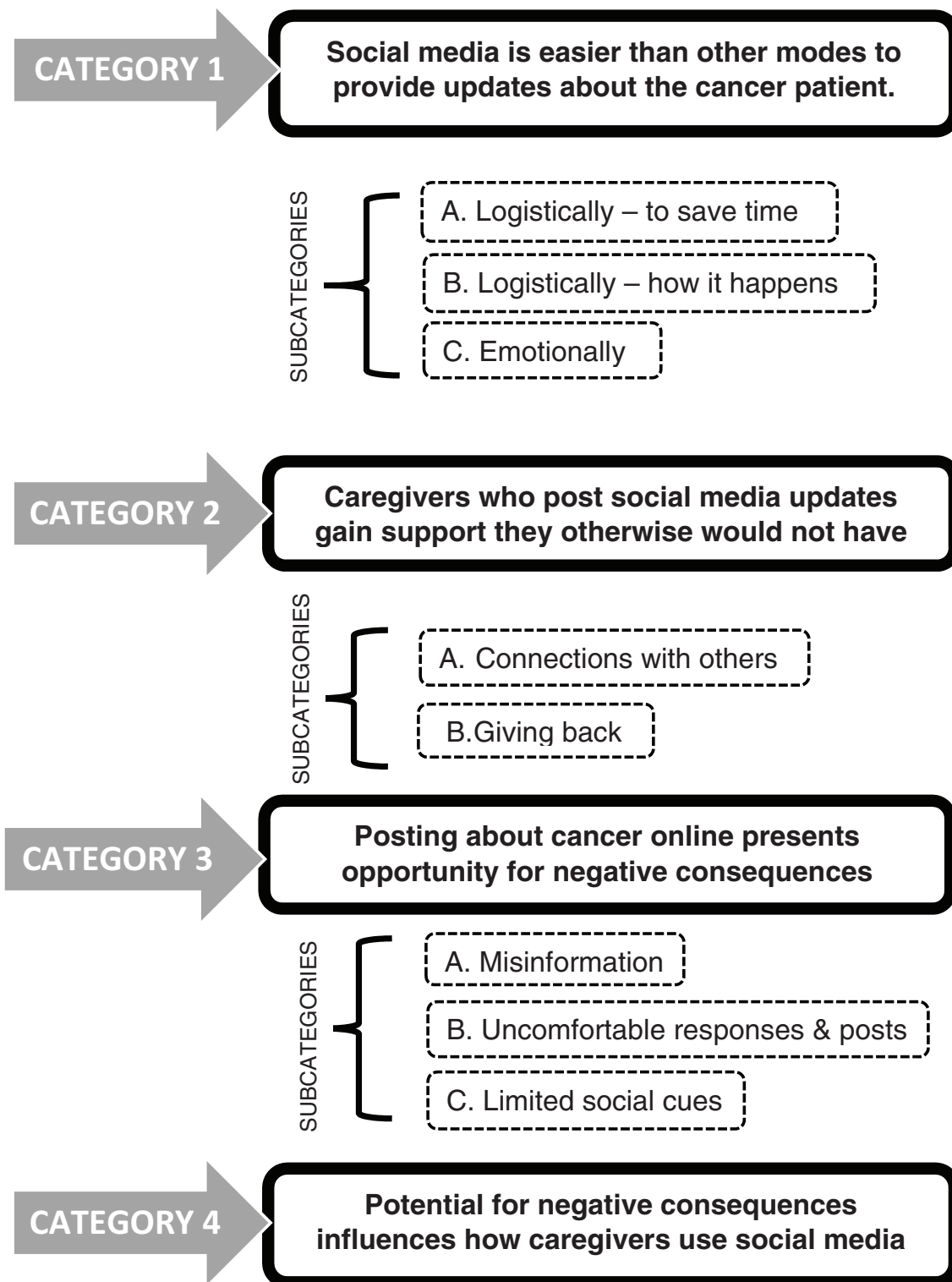
FIGURE 2 Categories and subcategories

caregivers to better accommodate the patient's needs and their other responsibilities because they were not spending as much time sharing updates with others. However, some caregivers still felt emotionally burdened with social media updates. One caregiver lamented, "*Sometimes it would be overwhelming...I just felt like it was another thing that I had to do to keep up on.*"

3.3 | Category 2: Caregivers who post social media updates gain support to which they otherwise would not have access

Posting about the cancer experience online facilitated connections with others and helped caregivers feel like they were "giving back" to

their online communities. Caregivers posted a variety of different updates, including information about themselves, the family unit, or other noncancer-related happenings, and received feedback and information, encouragement and positive responses, donation of money and meals, and felt loved and cared for through their social media use. Although caregivers initially used social media to provide updates on the cancer patient, social media became an important resource for their own support. A caregiver described, "*We set up a Facebook page for [the patient] for support...So when I [posted on this Facebook page] this time, it was just a bad day. I guess it was kinda me shouting out like, 'I'm frustrated, and I'm mad' and so, when people acknowledged it...it was kinda nice.*"

3.3.1 | Subcategory: Connections with others

Caregivers found support by connecting with others in similar situations, either through their personal networks or cancer-related groups. Some caregivers chose to expand the breadth of these connections by making public updates. Publicizing their cancer experience enabled these caregivers to surpass the reach of their offline support systems. Broadening social networks, whether publicly or privately, facilitated disease and age-specific connections that caregivers believed they otherwise would not have experienced. These connections were often preferred to in-person support groups because they permitted tailored support. A caregiver explained, "*Being a caretaker to a cancer patient could be very isolating at times, and not a lot of people understand what it means or what you're going through. And so, to speak to somebody who is going through a familiar experience was comforting.*"

3.3.2 | Subcategory: "Giving back"

Caregivers felt valued when they shared advice, knowledge or skills, and their cancer journey with newly diagnosed patients and caregivers on social media. They believed that sharing caregiving experiences brought comfort to others during difficult cancer or noncancer experiences because they were demonstrating strength and resilience. One caregiver described, "*I think [our page] has created a support group that has impacted other people's lives and given them some hope.*" Caregivers commonly posted about the patient's diagnosis and treatment to raise awareness of cancer in their social circles. They participated in cancer awareness campaigns, discussed cancer symptoms, and promoted fundraisers. Posting images of awareness events was perceived by caregivers as a way to advocate for cancer prevention.

3.4 | Category 3: Posting about cancer online presents an opportunity for negative consequences

Caregivers acknowledged negative consequences of posting about cancer on social media, including misinformation, uncomfortable responses and posts, and limited social cues.

3.4.1 | Subcategory: Misinformation

Misinformation was perceived as an expected consequence of using social media. Caregivers largely believed good intentions precluded misinformed feedback. One caregiver stated, "*I understand people [who] 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.*" Caregivers were accustomed to misinformation because they navigated it on social media outside of a cancer context. They had learned ways of coping with misinformation by ignoring it or researching information that they did not perceive as being trustworthy.

3.4.2 | Subcategory: Uncomfortable responses and posts

Uncomfortable responses and posts occurred when individuals in the social network made uneven comparisons, provided unsolicited advice, minimized the caregiver's experience, made insincere comments, or provided incongruent support. Caregivers were frustrated if they perceived others did not understand their situation. A caregiver explained, "*...it's like the comparison game...like, 'Oh, I'm so sorry. I know exactly what you're going through' but it would be like their dog passed away...It's a different level of severity.*" Caregivers perceived responses that minimized their experiences to be unsupportive and felt disappointed with insincere responses. While responses to caregiver's posts were the most common source of discomfort, some caregivers were upset when they passively viewed cancer-related posts from other caregivers or patients (eg, bereavement, end-of-life posts).

3.4.3 | Subcategory: Limited social cues

Social media diminished social cues that occur during face-to-face interactions (eg, body language), which sometimes made it difficult for caregivers to manage uncomfortable situations on social media. For example, one caregiver was caught off guard by comments on her post, "*It's hard for me to see something on social media like 'Oh I hope your sister's doing good, unfortunately, my sister or my mom didn't make it'. For me, it's really uncomfortable. You're not in front of that person, but I mean, what do you comment back? Like, I'm sorry? That doesn't really sound very sincere.*" Others felt the limited interaction on social media led to misunderstandings and made it difficult to personalize posts. Some caregivers used strategies to ameliorate the lack of social cues, like making a photo or video post.

3.5 | Category 4: Potential for negative consequences influences how some caregivers use social media

While the majority of caregivers accepted negative consequences as an expected outcome of using social media, negative consequences

led some caregivers to forego posting about cancer. Privacy, safety, fear of judgment, and criticism dissuaded caregivers from posting online about the cancer experience. Caregivers who did not post on social media still used social media for cancer-related purposes, like viewing the posts of other cancer patients or caregivers, interacting anonymously on social media groups, and providing covert updates about the cancer patient. For example, a caregiver posted pictures to update people who knew, offline, about the cancer diagnosis. She said, *"We'll post more stuff with my mom, like pictures, because it's kind of a way for family to know she's doing good."* Those who did not post about cancer on social media described gaining cancer-related information, connecting with other cancer patients or caregivers, and viewing how others are dealing with cancer.

4 | DISCUSSION

For most caregivers, the process of using social media for social support as a YACC is preceded by requests for updates about the cancer patient. As requests for updates become more time consuming and emotionally burdensome, caregivers turn to social media as a practical tool. We found that caregivers create separate pages for their patient, or sometimes use their personal pages for providing updates, and support is received as a result of these updates. While the majority of this support is perceived as positive by caregivers, negative consequences are possible, but seen as part of the trade-off of participating in social media. However, for a minority of caregivers, patient preferences, privacy concerns, misinformation, and uncomfortable responses may lead them to limit or avoid posting cancer updates on social media. These findings provide novel information about how YACC use social media for social support, a critical step in the development of future supportive interventions for YACC.

Our results inform cancer caregiver theory by explaining how the process of social media use and subsequent social support is part of the YACC experience.[29] In the current Cancer Family Caregiving Experience Model, a stress cycle occurs in which caregivers evaluate their primary (eg, patient illness) and secondary (eg, relationships, isolation) stressors.[29] Evaluation of these stressors initiates appraisal of the caregiver's stressors and how they will cope.[29] Until now, no studies have articulated how YACC use social media to cope with primary and secondary stressors or how posting about cancer on social media leads to social support. Our results suggest that as the stress of providing updates about the cancer patient becomes increasingly burdensome, caregivers use social media to manage this stress. Our findings also suggest that social media is an important source of social support for both active (ie, those who openly post about cancer) and passive (ie, those who do not post about cancer) users. Online communities, like those on social media, are a critical component of YACC's social context that has not previously been included in the caregiving model. These findings provide new information about the role of social media in the appraisal process and subsequent social support.

Our participants initiated social media use as a practical tool but continued using it to complement their offline social networks. Prior

studies show that cancer caregivers use social media for getting information and emotional support,[35] two of the five types of functional social support defined in the Stress and Coping Social Support Theory.[36,37] Given young caregiver's competing demands and high risk for isolation during a cancer experience,[7] social media may be strategically used for less common types of social support. For example, caregivers needing financial aid, a type of instrumental support,[36,37] may have a broader reach with a fundraiser shared on social media than a one-time fundraising event. The nature of cancer caregiving might present a unique situation for social support online, which may explain why validation, companionship and instrumental support is typically not described in online support studies of other diseases. Future research is needed to assess the extent to which presence of all functional support types on social media is unique to YACC.

5 | CONCLUSION

To fully support YACC, services are needed in formats that are convenient for them as they balance their caregiving duties with young adulthood. Prior research shows that young people may prefer accessing resources in online formats because this can be easier to do in terms of time and comfort level.[13] However, there is still much to be learned about the strengths and challenges of supporting YACC through online technologies. By describing how YACC use social media for social support, this study provides critical information for adapting existing cancer caregiving theory and informing the development of future supportive care resources.

5.1 | Clinical implications

Negative consequences of using social media described by our participants merit attention. As described in the Stress and Coping Social Support Theory, support that originates from inappropriate sources or in undesired forms can be detrimental to coping.[36,37] There is evidence of the negative impact of unsolicited advice and misinformation on social media,[22,38-40] and we found examples of this in our interviews. These situations were interpreted as negative consequences of using social media. Because social media use has been associated with negative outcomes like depression,[23] which is also common among cancer caregivers,[4,8] caregivers using social media for updates may benefit from clinical guidance on best practices for using social media during a cancer experience to avoid exacerbating negative mood.

There was a tendency among participants who used social media passively (ie, viewing but not interacting with social media posts) before the cancer diagnosis to hold more negative expectations for using social media as a cancer caregiver. In contrast, active social media users were adept at using social media during a cancer experience. Passive social media use has been associated with negative outcomes (eg, depression, rumination) in prior research.[24] This suggests that certain patterns of social media use may be more and less effective for eliciting social support on social media during cancer. More

work is needed to explore and define these patterns before guidelines can be developed and recommended to caregivers by supportive care professionals.

5.2 | Study limitations

Our results may overrepresent the experiences of spousal caregivers. While qualitative research provides a rich description of a phenomenon and can inform theoretical development, our sample is small and other caregivers may experience the process of using social media for social support differently. Because social media use differs by race,[18] descriptions of racial and ethnic minority caregivers' social media use is needed. Individuals may overestimate the positive outcomes of using social media. Therefore, without objectively measuring social support from caregiver's social media feeds we cannot determine the extent to which caregivers' perceived social support reflects reality. We also do not know the extent to which caregivers distinguish between different types of support or what support types are considered most valuable.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

ETHICS APPROVAL

This study was approved by the University of Utah Institutional Review Board (IRB_00097575).

DATA AVAILABILITY STATEMENT

Data sharing: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.