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# Social support enactments on social media during the first 6 months of young adult cancer caregiving

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## Abstract

**Purpose** To explore how family/friend young adult cancer caregivers (YACC) used social media for social support in a cross-sectional retrospective mixed-methods study.

**Methods** Eligible YACC were recruited online and in-person from September 2017 to June 2018, were 18–39 years, used social media weekly, and cared for an adult cancer patient diagnosed 6 months–5 years prior (N = 34). Social media posts were randomly sampled, and content analyzed for five types of social support (emotional, informational, validation, companionship, instrumental). Generalized linear models were fit to estimate changes in the prevalence of social support in posts over the 6-month period following diagnosis.

**Results** The investigators analyzed N = 2090 social media posts, 26.9% made by YACC, and 73.1% by followers; 36.8% were cancer-related. The most common type of social support for YACC on social media was emotional (63.3%), followed by informational (27.7%), validation (15.3%), companionship (5.7%), and instrumental (1.3%). When controlling for platform (e.g., Instagram), the odds of posts containing emotional support decreased significantly over the first 6 months of caregiving (adjusted odds ratio [aOR]: 0.90, 95%CI 0.85–0.94), while informational (aOR: 1.15, 95%CI 1.09–1.21) and companionship (aOR: 1.12, 95%CI 1.02–1.24) support increased.

**Conclusions** YACC and their followers share emotional and informational support on social media. Next steps should determine how social media may improve (e.g., social support) or hinder (e.g., misinformation) cancer caregiving throughout survivorship.

**Implications for Cancer Survivors** Caregivers and patients should be aware of possible fluctuations in social media support after diagnosis and the utility of using social media for different types of social support.

**Keywords** Adolescent and young adult · Cancer caregiver · Family caregiver · Social media · Facebook · Instagram

## Background

Young adults, ages 18–39, are increasingly adopting cancer caregiver roles [1]. As of 2015, there are an estimated 1.46 million young adult cancer caregivers (YACC) in the United States [2]. YACC enter a caregiving role during a transitional stage of life [3, 4]. As new caregivers, they must integrate caregiving duties with existing responsibilities of young adulthood, such as completing their education, starting new careers, and potentially caring for young children [5], all areas in which older caregivers may be more established. Caregiving may be new for YACC who are often unfamiliar with severe illness [6, 7].

While caring for a loved one with cancer can have positive aspects like strengthening relationships and creating positive memories [5, 8], YACC are at particular risk for negative effects of caregiving [5]. They often have multiple and cross-generational caregiving responsibilities (e.g., children

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and parents), and YACC may experience role reversal when engaged in caregiving for a parent or grandparent [5]. These challenges have potential negative consequences [7], including YACC putting aside personal aspirations and delaying key developmental milestones (e.g., financial independence), when they take on a cancer caregiving role. Caregiving as a young adult also limits social engagement, which can lead to feelings of isolation and depression [5, 9, 10]. This is potentially problematic as young adult caregivers in general are most likely to be single, and caregiving may limit opportunities for developing new relationships. Compared to older cancer caregivers, YACC report greater stress and depression during the first 6 months of caregiving [11]. Mitigating the overall burden and the psychological impacts of caregiving among YACC is a national priority because they are increasingly engaged in caregiving efforts that are critical to maintain patient support that our taxed healthcare system cannot sustain alone [1, 12, 13].

Having access to robust social support may alleviate some negative impacts of caregiving on YACC. Previous research suggests that social support mediates burden among caregivers of patients with functional impairment [14], and is negatively related to depression, loneliness, and burden among cancer caregivers [14–17]. Likewise, social support has protective effects on health [18–20], and may shield YACC from becoming overburdened [21]. Given the uniqueness of their caregiving role and their likelihood of negative psychosocial effects compared to older cancer caregivers [7], YACC require innovative solutions for engaging their social networks for support.

YACC are part of the millennial and Z generations [22], often referred to as digital natives [23, 24]. While in-person support differs from online support, in the USA, an estimated 88–97% of young adults use social media [11, 25] to gain social support, garner feelings of trust, and establish and maintain close relationships [18, 26]. When it comes to their health, young adults use social media to provide updates about personal health information, request guidance or feedback about disease, and receive information and emotional support [25, 27, 28]. In a digital age where online social networks are a natural extension of YACC's existing communities, social media is likely a natural resource for social support. However, the limited literature available on YACC's social media use has not assessed the types and prevalence of social support enactments (e.g., comments, replies) on social media between YACC and their followers.

A growing body of literature supports studying the types of social support on social media among YACC. In 2015, 84% of cancer caregivers expressed interest in using social media as a resource for coping with cancer [29]. Of these, 54% endorsed a need for emotional support and 77% endorsed information support [29]. Cancer caregivers also endorse the use of social media to help coordinate care, avoid scheduling conflicts, and to update others [29]. Social media content on Twitter about young adult cancer encompasses a range of emotional expressions including hope, sadness, fear, humor, and anger [26], demonstrating that social media is used as an outlet during cancer experiences. Further, users who seek emotional support tend to remain involved in online social communities longer than those who seek information support [30]. While this research clearly demonstrates a need for social support and a preference among cancer caregivers for using social media to meet these needs, it does not identify the prevalence or types of support enactments on social media. The broad age range of caregivers in prior studies makes it difficult to determine the types of support young caregivers receive from and share with followers on social media. This study addresses this literature gap by evaluating five types of social support enactments on social media with a specific focus on YACC.

The purpose of this study was to determine the extent to which five types of functional social support enactments were present between YACC and their followers. The types and prevalence of posts containing each type of social support were quantified on YACC's personal social media pages during the first 6 months of caregiving. In prior interviews, YACC acknowledged that they disclose their caregiving roles on social media at varying levels [31], with some YACC never disclosing their family member's cancer diagnosis online even though social media is a key source of connection in their lives. Therefore, to quantify the enactment of social support, it was determined that posts on the YACC's social media pages were eligible for this study regardless of whether they were cancer-related or not. This study was guided by the Stress and Coping Social Support Theory which posits five different actions that individuals perform to show support and help relieve stress, which are classified into five categories: emotional, informational, companionship, validation, and instrumental [32, 33]. It was hypothesized that (1) emotional and informational support would be the most prevalent types of social support enacted on YACC's social media pages over the 6 months following the cancer diagnosis and (2) that the prevalence of posts containing any type of social support would decrease over time. Both hypotheses are consistent with findings in prior studies of non-YACC samples.

## Methods

The investigators collected and analyzed content from YACC's personal social media pages for the 6 months following their loved one's cancer diagnosis. Any post by a YACC and any comment in response to a post were defined as an enactment of social support. All enactments were content analyzed for types of social support. Posts that did not contain social support were excluded. This work is part of a larger research study on young adult cancer caregiving and was approved by an institutional review board [34].

## Social support definitions

In this study, functional social support refers to the specific actions that are provided by YACC's followers on social media [20]. Each type of functional social support is intended to address different social needs [32]. Theoretically, as social needs are met a YACC's ability to cope with their caregiving role improves, which in turn likely mediates the relationship between the stress of their caregiving role and their health [32]. Definitions of functional social support and examples of their applications to social media are shown in Supplementary Table 1.

## Participants and recruitment

Recruitment occurred through flyers, social media, and in-person. Flyers were posted in clinic waiting areas, restaurants, and at a cancer resource library and wellness center at a cancer institute. Social media advertisements were shared by regional, national, and international young adult cancer and caregiving organizations. In-person referrals occurred through in-patient and out-patient settings. Nursing staff informed patients about the study and a research assistant invited patients to refer their primary caregiver to the study by providing their name and contact information. Cancer patients, who were diagnosed between 6 months and 5 years prior and were ages 18 and older, were asked to refer their primary caregiver. Eligible caregivers were currently aged 18–39 years, spoke and understood English, had been engaged in caregiving for a loved one with cancer for at least 6 months, and currently used social media at least once per week (i.e., Facebook, Instagram). Current use of social media was defined similar to prior studies [35]. The first 6 months of caregiving is considered an acute period of adjustment for both cancer patient and caregiver [36], during which social support may or may not be achieved or sustained.

Of 354 cancer patients screened, 61 potential caregivers were identified, 13 were deemed ineligible (e.g., patient's time since diagnosis, age, non-social media user). 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 semi-structured telephone interview.

## Qualitative data collection and management

Participants were interviewed by the first author (ELW) over the telephone (range 41–79 minutes) about their caregiving experiences, social media use, and preferences for future uses of social media in healthcare settings. The interviewer had graduate level training in public health and nursing research and experience interviewing adolescent and young adult cancer patients and young adult caregivers. Interviews were recorded, transcribed, and quality checked prior to analysis. Data and thematic saturation was reached at N = 34 interviews. Quality checks included consistency in questions asked, topics covered during the interviews, evaluation of the tone and rapport, and debriefing meetings to discuss interviewing techniques and questions asked. Thirty-four additional close-ended questions were asked about sociodemographics, the cancer patient, and social media use. Survey data was imported into REDCap for storage and cleaning.

## Sociodemographic and cancer variables

Sociodemographic variables included age at interview, gender, ethnicity, race, employment status, insurance status, marital status, educational status, and caregiving for others besides the patient. Cancer patient variables included patient age at interview, relationship with caregiver, diagnosis, and time since diagnosis.

## Mixed-methods data integration

Mixed-methods integration occurred at multiple stages throughout the study and at different levels of the approach. A convergent mixed-method design was employed for this study [37]. Qualitative and quantitative data were collected iteratively to allow for reflexivity in how the social media data were collected and prepared for analysis. During data analysis, qualitative and quantitative data were analyzed together, and interview data was used to describe the boundaries of social media for exchanging social support during a cancer experience and how social support enactments changed over time. Finally, integrating the results of the qualitative and quantitative data enhanced interpretation of the findings because qualitative data contextualized the quantitative findings. Representative quotes related to change in social support on social media over the first 6 months of caregiving are presented with the statistical results.

## Qualitative analysis

Using NVivo 11, open coding was applied to 10% of the interviews by ELW and ARW resulting in 321 codes [38]. A coding scheme was created in which similar codes were grouped together based on content. The coding scheme was reviewed by all members of the research team and revised after feedback. In the second cycle focused coding [38], the revised coding scheme was applied to an additional 10% of the interviews, which were double coded by ELW and ARW. Interrater reliability was "strong" ($\kappa = 0.88$) [39]. To finalize the coding scheme, codes with zero or negative agreement were refined to minimize discrepancies. The final coding scheme was applied to all 34 interviews.

Responses to the question "Has the way you use social media changed at all since you started taking care of someone with cancer?" were analyzed and are presented with the statistical results below to describe reasons for changes in social support that occurred over time after the cancer diagnosis and how this influenced YACC's perceived well-being. Qualitative feedback about changes in social support during the first 6 months of caregiving that arose in other sections of the interview were also identified via analytic memos, which were created throughout data collection and analysis [40, 41]. Qualitative data were synthesized for integration with the quantitative social media data to provide a narrative about the change in social support enactments from the perspective of YACC, as is often done as part of data integration in mixed-methods studies [42–44].

### Social media data collection and management

The social media data collection and management procedures were developed for this study based on pilot work collecting Instagram posts [45], and feedback from an adolescent and young adult patient and caregiver advisory board. Study materials were reviewed by the advisory board who agreed that, similar to the general population, Facebook and Instagram were the most commonly used social media platforms by young cancer caregivers, thus these platforms were the focus of the social media data collection. Social media data were extracted from each participant's individual Facebook and Instagram pages manually following the interviews for a 6-month period beginning at the date of patient diagnosis. For this analysis, 10% of the social media posts from each participant were randomly sampled, with equal representation from each month after diagnosis, resulting in n = 2298 social media posts in the sample from n = 33 participants. One participant had not created any social media posts during the 6-month period of data collection even though they regularly logged onto and viewed social media sites. A coding scheme was applied to these posts to indicate: year of post, post source (whether the post was made by the YACC vs. follower), type of post (original post, response post), cancer-related post (yes, no), visual content, indicating a photo or video post (yes, no), shared post, indicating the post was shared to the YACC's social media page by a follower (yes, no), and platform (Facebook, Instagram). The total number of likes, comments, shares, and word count for each post were also recorded.

Data transformation, a mixed-methods technique, was performed to create social support outcome variables from the text of social media posts [42–44]. For this data transformation, definitions from the Stress and Coping Social Support Theory were used to code for the presence (yes, no) of five types of functional social support: emotional, informational, instrumental, companionship, and validation [32, 33]. Any post on the caregiver's "wall" or "feed" during the 6-month timeframe was coded. Thus, the post could have been directed toward and/or created by the YACC, patient, a follower, and/or family unit. Double coding occurred on 10% of the sample resulting in high inter-rater reliability (k = 0.95). The coding scheme was then applied to the remaining posts by the lead author and two research assistants. During coding there were n = 188 posts that did not contain a codable expression of social support (e.g., posts with hidden content) and n = 20 shared posts which predated the cancer diagnosis. For consistency, these n = 208 posts were excluded from further analysis resulting in a final sample of N = 2090 posts.

### Social media data analysis

Descriptive statistics were calculated for the sample of social media posts using Stata 14.2. The number and proportion of posts containing each type of social support were summarized across all participants and by month since diagnosis to assess the prevalence of posts containing each type of social support. Generalized linear models were fit for each type of social support over the 6-month period with a binomial family and logit link using the *eform* command to produce adjusted odds ratios (aOR) and 95% Confidence Intervals (CI), with significance set at $p < 0.05$ [46]. These models were adjusted for platform type because social support enactments differ by platform [47]. The investigators analyzed social support enactments on an aggregate level (i.e., across all participants) to quantify a broad summary of changes in social support over the first 6 months of caregiving with the goal to enrich and contextualize the qualitative feedback.

## Results

### YACC sociodemographic and patient cancer characteristics

Caregivers were 29.0 years old on average (standard deviation (SD): 4.72, range 21–38, data not shown), 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%, Supplementary Table 2). Cancer patients were on average 37.0 years (SD: 13.77, range 19–76) and usually a spouse/partner (52.9%) or parent (17.6% mothers, 5.9% fathers) and diagnosed with leukemia/lymphoma (35.3%), breast (17.6%), or another cancer (47.1%, Supplementary Table 2).

## YACC social media characteristics

Of the N = 2090 posts analyzed, there averaged 63.3 posts per participant ranging from 1 to 359 (median = 29; SD 88.1, Table 1). Only 14.5% of posts were original posts, meaning that the YACC posted the content to their own page, compared to the majority of posts which were responses to these initial posts (85.5%). Over one-third of posts were cancer-related (36.8%) while the remaining posts were general enactments of social support. Three-quarters of posts were made on Facebook (75.4%); 24.6% were from Instagram. Additional social media characteristics are shown in Table 1.

## Summary of five types of functional social support on social media during the first 6 months of caregiving

Overall, the total number of posts per month declined in the 6 months following the patient's diagnosis, with a marked decrease after the first month (Supplementary Figure 1). In Table 2, overall the most common type of social support enactment (e.g., any post or response made between YACC and their followers) was emotional support, which was enacted in 63.3% of all posts (average 220.5 posts per month, SD 105.8), followed by informational (27.7%, average 96.7 posts per month, SD 26.0), validation (15.3%, average 53.2 posts per month, SD 31.1), companionship (5.7%, average 20.0 posts per month, SD 5.7), and instrumental support (1.3%, average 4.7 posts per month, SD 4.5).

## Change in social support enacted on social media during the first 6 months of caregiving

Across all YACC, the number of social media posts decreased for all types of social support over the first 6 months of caregiving (Fig. 1). However, the proportions of social media posts with social support varied (Fig. 2). When controlling for platform, over the 6-month period following the patient's

**Table 1** Characteristics of social media posts (*N* = 2090 posts from *N* = 33 YACC)

| | Range | Mean | Median | Standard deviation |
|---|---|---|---|---|
| **Total number of social media posts** | 1–359 | 63.3 | 29 | 88.1 |
| **Total number of likes per post** | 0–659 | 166.4 | 119 | 193.9 |
| **Total number of comments per post** | 0–105 | 30.0 | 14 | 33.3 |
| **Total number of shares per post** | 0–1,500,000 | 3498.6 | 0 | 53,814.4 |
| **Word count per post** | 0–848 | 13.5 | 6 | 34.2 |
| | ***N*** | | **%**[1] | |
| **Year of post** | | | | |
| 2014 | 6 | | 0.3 | |
| 2015 | 121 | | 5.8 | |
| 2016 | 248 | | 11.9 | |
| 2017 | 1607 | | 76.9 | |
| 2018 | 108 | | 5.2 | |
| **Post origin** | | | | |
| YACC participant | 563 | | 26.9 | |
| Follower | 1527 | | 73.1 | |
| **Type of post** | | | | |
| Original post | 303 | | 14.5 | |
| Response post | 1787 | | 85.5 | |
| **Cancer-related post** | | | | |
| Yes | 769 | | 36.8 | |
| No | 1321 | | 63.2 | |
| **Visual content (video or photo)** | | | | |
| Yes | 896 | | 42.9 | |
| No | 1194 | | 57.1 | |
| **Shared post** | | | | |
| Yes | 195 | | 9.3 | |
| No | 1895 | | 90.7 | |
| **Platform** | | | | |
| Facebook | 1575 | | 75.4 | |
| Instagram | 515 | | 24.6 | |

[1] Percentages may not equal 100% due to rounding

**Table 2** Odds of posts containing each type of social support over the first 6 months following the cancer patient's diagnosis (*N* = 2090 posts, *N* = 33 YACC)

| Type of support | Total number of posts[1] | %[1] | Mean number of posts per month | Standard deviation | aOR[2] | 95%CI | *p* value[3] |
|---|---|---|---|---|---|---|---|
| Emotional | 1323 | 63.3 | 220.5 | 105.8 | **0.90** | **0.85–0.94** | **<0.001** |
| Informational | 580 | 27.7 | 96.7 | 26.0 | **1.15** | **1.09–1.21** | **<0.001** |
| Instrumental | 319 | 15.3 | 53.2 | 31.1 | 0.92 | 0.75–1.14 | 0.44 |
| Companionship | 120 | 5.7 | 20.0 | 5.7 | **1.12** | **1.02–1.24** | **0.02** |
| Validation | 28 | 1.3 | 4.7 | 4.5 | 1.04 | 0.97–1.11 | 0.22 |

[1] Totals to not equal $N = 2090$ or 100% because $n = 280$ posts contained more than one type of social support

[2] Separate models fit for each type of social support

[3] Adjusted for platform type, bold indicates statistical significance at $p < 0.05$

diagnosis, the odds of posts containing emotional support decreased significantly (aOR: 0.90, 95%CI 0.85–0.94, $p < 0.001$), while the odds of information (aOR: 1.15, 95%CI 1.09–1.21, p < 0.001) and companionship support increased (aOR: 1.12, 95%CI 1.02–1.24, p = 0.02; Table 2). In a secondary analysis, there were significantly more posts on Instagram that contained expressions of emotional support (75.5% vs 59.3%, p < 0.01), while Facebook had a higher proportion of instrumental (1.6% vs 0.4% p = 0.03), companionship (6.3% vs 3.9%, p = 0.04), and validation support (18.9% vs 4.1%, p < 0.04), and there were no differences for informational support.

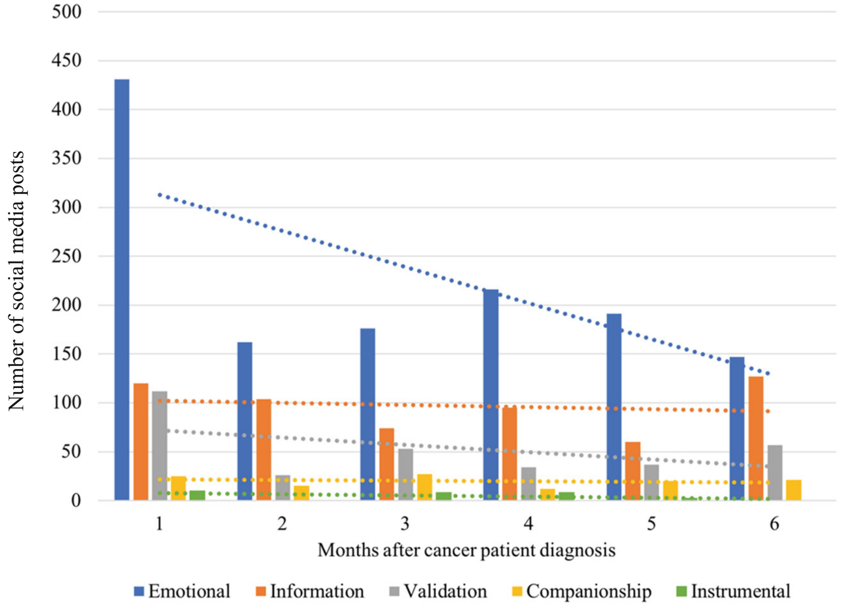
## YACC perspective on changes in social support on social media over the first 6 months of caregiving

Qualitative analysis of interview data provided context about the change in social support on social media over the first 6 months of caregiving. These findings provide a narrative of YACC's perspective of changes in social support on social media during this time period.

### Spike in the extent of social support enacted online during the first month of caregiving

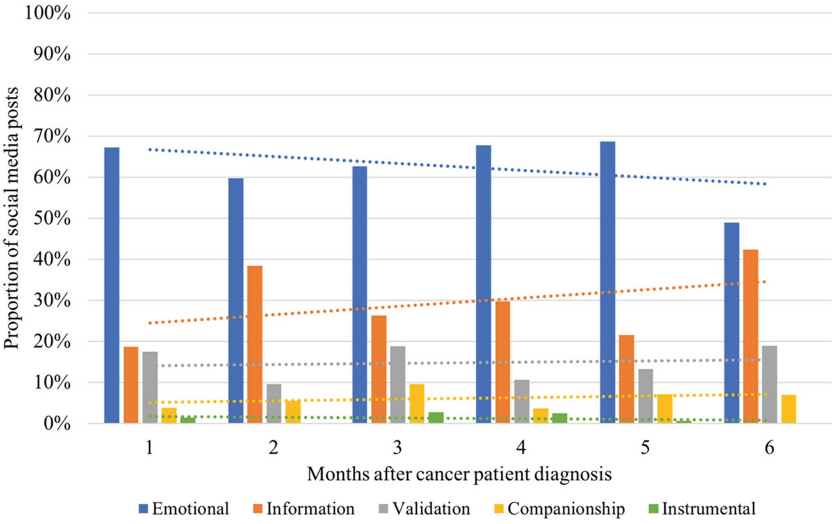
YACC described the first month after the cancer diagnosis as an intense time of communication with their social networks, and their social media pages reflected this, showing more posts exchanging social support during the first month (Fig. 1). Caregivers had insights as to why their social networks engaged with their initial updates about the cancer patient. For example, followers provided social support on social media because they identified with what the YACC was going through, a form of validation support. A participant described this as, "When you see a post [with] something sad, like "Hey, I have cancer" or "Hey, my brother has cancer" … everyone

**Fig. 1** Change in the total number of posts containing each type of social support over time since patient diagnosis (*N* = 2090 posts, *N* = 33 YACC)



There were n=280 posts which contained more than one type of social support.

**Fig. 2** Change in the total proportion of posts containing each type of social support over time since patient diagnosis ($N$ = 2090 posts, $N$ = 33 YACC)



There were n=280 posts which contained more than one type of social support.

knows that's something that could happen to anyone. They engage in those posts because they have feelings for it. It relates to them in some way, shape, or form." A decline in support was commonly noted in the subsequent months, described as, "There's always like a real fervor right at the beginning and then after three months or so it kind of dies down a little bit…we didn't need as much support."

### Active versus passive use influences the extent of social support enactments online

YACC believed that the frequency of their updates influenced the amount of social support they received on social media. By increasing the frequency of their posts, YACC were connecting more with members of their social network by sharing information about the cancer patient, the patient's prognosis and treatment, and how they as a family unit were coping with cancer. In contrast, YACC felt that when their posts were less frequent or less "shocking" they received less social support. One caregiver described, "When he was first diagnosed, and probably within those six months, I gave a lot of updates on social media. I connected people and it allowed them to know what was going on, and so, then people wanted to help. But, when I don't post because either we're just in this lull or [there's] not really anything to update, it sounds evil, but people kind of forget about you, even though you're still kind of going through stuff." Over time caregivers posted updates about the cancer patient less frequently either because they are more accustomed to managing caregiving responsibilities, or because they did not experience supportive responses from prior posts. Furthermore, caregivers tended to make updates on their social media platforms based on the patient's status, not their own well-being, so the support on their social media was often directed toward the patient's well-being or the family unit.

YACC who passively used social media for their caregiving role—that is they did not post about cancer on social media—believed that their followers were unable to provide cancer-related social support. Some YACC who generally felt uncomfortable posting about private happenings in their life did not feel hindered by their lack of social support enactments on social media. Yet, this was not the case for all participants; some YACC chose to go outside their "comfort zone" and commented that their willingness to open up to their followers in a new way by posting about cancer influenced the social support they experienced on social media. A caregiver described this, saying, "[Social media has] kind of changed me a little bit I guess, helped me be a little bit more open…it breaks the ice a little bit... it was never something I used on a real personal level like this before. So maybe that's why it was a little uncomfortable too, because I'd never really gotten under that superficial level…and this was definitely a personal deep part of our lives that we shared on Facebook." YACC who were passive users noted that they gained cancer-related information support on social media in more private ways by following cancer and/or caregiving advocacy groups without disclosing the cancer patient's diagnosis publicly.

### Social network composition influences the extent of social support enactments online

Interestingly, caregivers noticed declines in social support shortly after the initial diagnosis, primarily from followers whom they considered acquaintances. One YACC described this saying, "The casual people that are your casual friends on social media that spike interest when something crazy happens and then they just fall away…" In contrast, close family members and friends continued to provide social support both on social media and offline, because they knew the details of the YACC and patient situation. These close ties provided support regardless of the time since diagnosis. YACC, who cultivated a larger number of followers during this time period believed that by increasing their number of followers they had more opportunities for social support. One caregiver described this increase saying, “Having a [Facebook] page allows [information] to spread, it’s not just going to people here in the state, it’s going throughout the nation. It’s gone throughout the world. I mean, we had people from France, Australia, England…Without the Facebook page it wouldn’t be as outreaching, we wouldn’t have got the amount of support that we’re getting now… it gives [us] that light, it gives [us] that hope. You can see all the success stories and you no longer become a statistic.”

### Suboptimal social support leads to less frequent enactments

Multiple participants reevaluated relationships with their followers who failed to respond in a supportive way or provided incongruent support on social media (e.g., individuals provided information support when emotional support was sought after). One caregiver described this saying, “The crazy thing is cancer definitely shows your true friendship and it shows your true colors.” Caregivers who posted about cancer on social media and received negative feedback felt frustrated with their social network, and this led them to post less frequently about cancer. A caregiver described her frustration with what she perceived were insincere responses to her social media posts, “…after [I posted about] her diagnosis there were people that I hadn’t talked to in a really long time [who] would react with a crying face or something like that and I would never hear anything else. There were no texts. No phone calls. I didn’t get a message. Like there was no follow-up.” YACC with negative experiences acknowledged that by not posting on social media about their cancer experience, there was less potential for them to receive both positive and negative social support with their followers.

## Discussion

This study evaluated the prevalence of functional social support enactments on social media between YACC and their followers during the first 6 months of cancer caregiving. These findings suggest that YACC rely heavily on social media for emotional support and information. Similar to studies among other samples [48], emotional and informational support were sustained at higher prevalence on social media over time compared to other types of support. While the investigators hypothesized that all types of social support would decline over the first 6 months of caregiving, the proportions of information and companionship support, two of the five types of social support that were studied, increased during this time period. Possible interpretations of the findings are discussed and followed by limitations of the current study that underscore future research priorities.

Cancer caregivers are not formally recognized in clinical cancer care settings, meaning that their personal care needs often go unmet [49]. For example, despite their critical need for help to manage emotional stress, only 29% of cancer caregivers report being asked by healthcare providers about their own care needs [49]. At the same time increasing the availability of supportive care personnel (i.e., social workers, patient navigators) in young adult oncology programs is a critical need across the USA [50]. These results highlight an opportunity for supportive care personnel to address unmet social support care needs among YACC. For example, given the sustained prevalence of emotional and informational support enactments on social media, supportive care personnel may consider evaluating the usefulness of social media as a tool for YACC who express frustration or discomfort communicating their social support needs. An evaluation of this type would require that supportive care personnel recognize and establish that some YACC are not comfortable disclosing cancer information online either due to their own discomfort or reticence from the cancer patient about having their diagnosis disclosed online. This evaluation could occur in the initial stages of the cancer diagnosis when the caregiver and patient are beginning to communicate with their social networks about their support needs. Evaluating the usefulness of YACC using social media to communicate their support needs may help them capitalize on their existing social network to their most benefit during cancer. Future implementation research is necessary for determining optimal approaches for supportive care personnel to partner with YACC in evaluating the role of social media as a social support resource.

It is unsurprising that YACC actively use social media to enact informational support, given that 64% of American adults highly trust information found on the internet or social media [51]. Despite questionable quality of cancer information on social media, YACC often turn to social media in attempts to fulfill the unmet informational needs they experience [52]. Many hospitals, non-profits, and cancer advocacy groups have already recognized the opportunity to use social media as a platform for reaching young adults experiencing cancer. An earlier study documented that 32% of Instagram posts about young adult cancer originate from these organizations [45]. While organizations have an exciting opportunity to effectively disseminate cancer-related health information and resources through social media, information seeking on social media brings about potential challenges given the widespread dissemination of misinformation on these platforms [53]. Access to information on social media and other internet sources has drastically altered the accessibility of health information in recent decades, yet future studies assessing how YACC evaluate and judge the quality and credibility of cancer and caregiver related information found on social media is urgently needed.

The finding of lower prevalence of instrumental, companionship, and validation support is likely because certain types of social support do not lend themselves to online engagement. Caregivers who experience unfulfilled support needs in these areas may do so because they do not openly seek these supports, and because it is difficult for their social networks to provide this kind of support on social media, but this needs further study. While some YACC may already have adequate offline support in these areas, others may need to seek these social resources in other ways. Supportive care personnel may be able to help YACC more effectively utilize their social networks by coaching them on ways to seek support while recognizing and discussing that unfulfilled support needs in these areas may require caregivers to seek these types of support offline [13]. Offline resources available for YACC may include instrumental (e.g., institutional grants, government assistance, fundraisers), companionship (e.g., local events for young cancer patients and caregivers), and validation (e.g., connecting to caregiving or young adult cancer organizations either through social media, other online formats, or in-person) supports. Still, if YACC are unaware of these resources, they may continue to be underutilized.

There is a notable drop in the prevalence of posts containing social support enactments on social media after the first month of caregiving, and this phenomenon has been previously described in the caregiving literature and was noted by caregivers in this study [36]. The interviews with YACC explained that an initial surge in support occurs when their followers first learn about the YACC's caregiving role, but then support declines as the caregiver becomes more accustomed to their role and seeks less support, has their support needs fulfilled, or foregoes needed support on social media because their followers have not been responsive or unhelpful. YACC may benefit from learning about this potential decline in support and receiving guidance about how to engage in their social network, or alternatively about resources that are available to fill the void of support that networks are not equipped to sustain over longer periods of time. While not assessed in this study, it is likely that followers enact support for YACC in response to an update about the cancer patient. While YACC may feel supported by these enactments, their followers may not be aware of the YACC's own well-being, thereby limiting followers' responsiveness to the support needs of YACC. Furthermore, it is possible that posting too frequently, or not frequently enough, leads to fewer opportunities for support enactments, and the point at which posting frequency leads to loss of social support among cancer caregivers should be a focus of future research.

This study provides an overview of social support enactments on social media between YACC and their followers. The investigators were unable to assess how factors like engagement, composition, and size of social networks influence enactments of social support. However, these factors may be important determinants of a social network's responsiveness to support requests as the nature of relationships on social media (e.g., friends, family, acquaintance) may preclude the type of support that followers are equipped to provide to the caregiver [54]. The sample of posts reflects substantially lower word count, yet a higher number of likes and comments per post than prior analyses of Instagram posts related to young adult cancer [45], and reasons for this should be explored in future research. Future work should also assess the dynamic enactments of support between YACC and their followers through the use of social network analysis to determine the extent to which social networks are responsive to YACC requests for specific types of support [55].

Given the risk of negative psychosocial health outcomes in the first 6 months of caregiving for YACC [52], evaluating the types, prevalence, and change in functional social support on social media over the first 6 months of cancer caregiving among YACC is a first step toward developing social media-based support for this growing cohort of cancer caregivers. Knowing the types of social support enacted on social media may inform support seeking opportunities that YACC do not access otherwise [56]. Future research should consider the benefit of including social media contacts and engagement in assessments of the YACC support system, distinguish the interface used to enact digital support and the mix of relationship type [5] and communication modalities, and determining how to effectively coach YACC to manage social media to maximize support and minimize negative interactions (e.g., anticipate withdrawal of loose social media ties over time).

This study is limited in that the sample of social media posts was extracted from a small group of participants recruited primarily in the Intermountain West. In mixed methods, purposive sampling may limit generalizability [57]. However, the information gained by integrating YACC's perceptions with social media post analyses outweighs potential threats to external validity that may be present with a small sample size. Due to the retrospective nature of the interviews, there may be recall bias and the investigators' interpretations of social support may not accurately reflect how YACC felt when they were newly caring for a cancer patient. However, the narrative synthesis of the interview and the social media data is intended to situate the results in the appropriate context of how YACC interpreted their enactments of social support with their social media followers. While some participants did not disclose the cancer patient's diagnosis online, YACC who opt out of disclosing the cancer patient's diagnosis still gain cancer-related social support on social media [34]. Furthermore, YACC likely spend time on social media during which they are not actively posting, but rather may be reading posts or articles from other followers.

These activities may contribute in meaningful ways to a YACC's well-being (either positively or negatively), but this was not examined in the current study. Further, both positive and negative psychological outcomes have been associated with social media use and future studies that evaluate patterns of social media use among YACC that are associated with supportive posts may be helpful. Non-textual social media data (e.g., Facebook stickers, photos) were not analyzed.

A further limitation of this work is the grouping of Facebook and Instagram data together for analysis because some platforms may be better equipped for certain types of support. While the analysis of individual variation in the enactment of social support over time using effects models would provide detail on individual changes in social support, the dynamic nature of social media posts limited this approach for the current analysis. Future studies that are designed to identify individual-level variation in social support enactments on social media among YACC are needed. It is also notable that our sample is drawn from Utah, which generally has lower age at marriage compared to other parts of the USA, and this may explain why there was a higher prevalence of spousal caregivers in our sample than expected. A final consideration is that, for a variety of reasons, some YACC do not disclose their family member's cancer diagnosis or their role as a cancer caregiver on social media. For these individuals, the extent to which the social support enactments with their followers during their initial caregiving relates to or benefits them in their role as a cancer caregiver is unknown.

In summary, social support enactments on social media may provide YACC with different types of social support to address their diverse needs [56]. These findings explore the changes in types of functional social support enactments between YACC and their followers on social media over the first 6 months after the cancer patient's diagnosis. Understanding the extent of social support on social media during this time frame is a crucial step to inform targeted supportive care interventions for YACC that use innovative social technology. Interventions that provide coaching to YACC on how to use social media to optimize social support are needed to address the higher levels of unmet need expressed by YACC compared to older caregivers. Social media-based interventions for YACC would most likely benefit from having offline components such as the inclusion of supportive care personnel, like a patient navigator or social worker. Furthermore, the effect of social support through social media on YACC's health outcomes has yet to be studied, and this is a critical area of future research.

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**Data availability** The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Declarations

**Ethics approval** This study was approved by the University of Utah Institutional Review Board and was performed in accordance with ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

**Conflict of interest** The authors declare no competing interests.

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