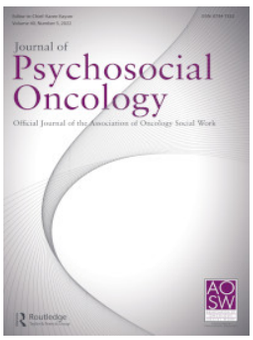

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ARTICLE

Cancer content and social media platform influence young adult cancer caregivers' social support on social media

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ABSTRACT

Purpose: To determine how social media platform and cancer content is associated with the presence of social support in responses to young adult cancer caregivers' (YACC) posts.

Design: We retrospectively collected YACC's Facebook and/or Instagram posts and all responses from the first six months of caregiving.

Sample: Eligible YACC were 18-39, caring for a cancer patient diagnosed 6 months-5 years prior, spoke English, and used social media weekly.

Methods: Social media posts and responses were manually coded for five social support types, then transformed to depict the proportion of responses per post representing each type of support. Using mixed-effects models, we compared the distributions of responses with social support types by platform (Facebook vs. Instagram) and cancer content (no vs. yes).

Findings: More responses contained emotional support on Instagram than Facebook (B = 0.25, Standard Error (SE)=0.09, p = 0.007). More responses with cancer content contained validation support (B = 0.20, SE = 0.07, p = 0.002), but fewer contained emotional (B=-0.17, SE = 0.07, p = 0.02) and instrumental support (B=-0.06, SE = 0.02, p = 0.001) than posts without cancer content.

Conclusions: Studying the responsiveness of social media followers by platform and cancer content provides a foundation for intervention development.

Implications for psychosocial providers: Emphasizing the suitability of different social media platforms for particular support seeking behaviors is essential.

KEYWORDS
cancer information; caregiver; social media; social support

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Background

Social media are increasingly used by young cancer patients and caregivers for connecting with others, finding information about cancer, and discovering resources.[1,2] Social media use can produce feelings of trust and help users create and maintain new relationships.[3] National organizations emphasize the need for technology-based interventions in cancer care and recognize social media as a tool to support YACC.[4] Eighty-four percent of cancer caregivers express interest in using social media, with 54% endorsing social media for emotional and 77% for informational support.[5] While national organizations and caregivers recommend social media to enhance cancer caregiving experiences, information is needed about factors that influence YACC's social support on social media.

We evaluated the distribution of social support in responses to YACC's social media posts by platform (Facebook vs. Instagram) and cancer-related content (no vs. yes). We were interested in the support provided to YACC by their followers, so we analyzed only responses to YACC's original posts. Our analysis was exploratory but was driven by YACC describing different types of social support on their social media.[6–8] We hypothesized that responses to YACC's posts with cancer-related content would contain more social support than posts without cancer-related content, and that support would differ by platform.

Methods

Participants

YACC were recruited through flyers, social media, referrals from cancer patients diagnosed 6 months-5 years prior, and currently ages 18 and older. Caregivers were 18-39 years old, used social media (i.e., Facebook, Instagram), and provided care for a cancer patient for at least 6 months. Of 354 cancer patients screened, 61 potential caregivers were identified, 13 were ineligible. This left 48 eligible caregivers; n = 8 declined, n = 6 we were unable to contact, and N = 34 participated (participation rate = 70.8%). Enrolled caregivers completed informed consent, a brief survey/telephone interview, and provided access to their social media for manual extraction of posts from the patient's diagnosis to six-months.

Social media data collection and mixed methods integration

Participants' social media posts from Facebook and Instagram were transformed through manual coding.[9] Using definitions from the Stress and

Coping Social Support Theory we coded for the presence (yes, no) of five types of functional social support: emotional, informational, instrumental, companionship, and validation.[10] Double coding occurred on 10% of the sample (k = 0.95). Then, we randomly sampled 10% of each participant's posts, with equal representation from each month after diagnosis, and applied the coding scheme, resulting in n = 2,298 posts from n = 33 participants (n = 1 participant had zero posts). There were n = 188 posts lacking a codable expression of social support, and n = 20 shared posts predating the cancer diagnosis. For consistency, these posts were excluded, resulting in a final sample of n = 2090 posts. For this analysis, we limited our data to N = 1,527 responses that were made to YACC's posts; that is, we excluded the original posts (n = 563), but included the response posts as this is where the social support exchange occurs.

Sociodemographic, patient cancer factors, and social media variables

Sociodemographic and social media variables were collected. Social media variables indicated the presence of cancer-related content in original posts (yes, no) and the type of platform (Instagram, Facebook). The total number of likes, comments, and shares, for each original post (e.g., the post which the response was made to), presence of visual content and word count for each response was recorded. *Data analysis*

Descriptive statistics were calculated for YACC survey and social media variables. We calculated the proportion of responses per post that contained each type of social support. Each row in the final dataset represents a single social media post and includes continuous social support outcome variables with separate values for each type of social support. We used linear mixed-effects models to assess the proportion of support type per post while controlling for repeated measures and allowing for individual variation in the number of posts. We estimated the fixed effect of either platform or cancer content while controlling for random effects of individual variation between participants. Estimated unstandardized beta coefficients (B) and standard errors (SE) were used to evaluate differences in social support by 1) platform and 2) cancer content. Analyses were performed in Stata 14.2 and R 3.6.1, with significance at $p < 0.05$.

Results

YACC sociodemographic and social media descriptives are shown in Supplemental Tables 1 and 2. In Table 1, emotional support was most common in responses to YACC's posts (72.1%) followed by informational (20.4%), validation (17.3%), companionship (3.1%), and instrumental

Table 1. Definitions, prevalence, and examples of different types of social support on social media (N = 1,527).

	Definition	N[1]	%[1]	Examples
Emotional	Sympathy, caring, acceptance	1,101	72.1	"You are amazing!" "Keep smiling, stay positive!"
Information	Knowledge, information, advice, alternative action	312	20.4	Links to articles/videos about caregiving or cancer questions.
Validation	Feedback, social comparison	265	17.3	"My mother was diagnosed with breast cancer, too."
Companionship	Availability of persons to spend time with	47	3.1	Online support groups, chats, or events.
Instrumental	Transportation, household chores, childcare, finance	17	1.1	Crowdsourced fundraising on social media, offers to perform actions related to childcare, transportation.

[1]Totals exceed N = 1,527 or 100% because responses contained multiple types of support.

(1.1%). Definitions and examples of social support are in Table 1. Significantly more responses contained a higher proportion of emotional support on Instagram compared to Facebook (B = 0.25, SE = 0.09, p = 0.007, data not shown). Compared to social media posts without cancer-related content, there were significantly fewer responses to posts with cancer-related content that contained emotional (B=-0.17, SE = 0.07, p = 0.02) and instrumental support (B=-0.06, SE = 0.02, p = 0.001). There were significantly more responses to posts with cancer-related content that contained validation support (B = 0.20, SE = 0.07, p = 0.002), than posts without cancer-related content.

Discussion

Young adult in general tend to perceive Instagram as less desirable for emotional support,[16] however among YACC we found significantly more responses with emotional support on Instagram compared to Facebook. Our findings suggest Instagram may be a key source of emotional support during challenging circumstances, like cancer caregiving, and highlight the dynamic and ever-changing use of social media platforms. Furthermore, posts about cancer may be rare on Instagram, creating the perception that it is inappropriate content to share, but followers may react in a supportive way. YACC may cultivate more emotionally supportive relationships through Instagram, compared to relationships on Facebook; especially important because relationships influence how likes and comments are interpreted, the potential benefits of social media use, and the type of social support exchanged between users.[11] Uncovering platform differences suggests researchers should modify interventions based on platform use to strengthen social support.

We found more validation support for posts with cancer-related content but fewer responses with cancer-related content had emotional and

instrumental support. YACC's online networks likely include other young adults who often lack experience with severe illnesses, and thus may not feel confident responding to a YACC's post about cancer. Alternatively, people on social networks likely reach out to YACC privately via direct message or offline to provide emotional and instrumental support, interactions which we did not capture. While all types of social support have value, individuals seeking emotional or instrumental support on Instagram may receive support that is incongruent with what they had been seeking, which can be detrimental to coping. Thus, for less common types of support YACC should consider diversifying support requests online and using offline outlets, such as in-person networks and local community supports.

Informational support was the second most common response to YACC's social media posts. The rise of misinformation exchanged on social media is a growing public health concern.[12,13] When seeking informational support online, users may be influenced by internal (e.g., health literacy) and external factors (e.g., inconsistency between sources).[14] YACC's informational support is permeated with misinformation.[15] When YACC seek information online their support networks may not be equipped with the knowledge or resources to meet these requests with reliable information. Further, when YACC gain information on social media, they may not be prepared to interpret that information, evaluate its quality, or transform it into actionable knowledge. Research evaluating the influence of misinformation on YACC decisions and relationships, and longitudinal research evaluating the effect of information quality is needed before interventions to improve social support can fully utilize social media.

Clinical teams who interact with YACC should encourage them to leverage social media for social support, and advise about ways to use social media to maximize benefit (e.g., Instagram for emotional support) while explaining the potential pitfalls of social media (e.g., incongruent support, unsupportive responses, misinformation).[7,15] For example, YACC may benefit from discussing how relationships with networks differ by platform, to be wary of cancer-related misinformation, and how online communication differs from face-to-face interactions. Further, YACC coping may differ online due to the absence of non-verbal cues and the opportunity for YACC to reflect on their experience more deeply during online interactions.[16] Posting about caregiving experiences online may make YACC more attuned to caregiving demands and stress, and so clinicians emphasizing the availability of in-person supports is essential.

Our sample contained more posts on Facebook than Instagram, reflecting disproportionately higher use of Facebook than Instagram.[17] The range of time since diagnosis may have influenced the way individuals interact

on social media given the passage of time and rapid changes in social media structure and use. Our sample primarily consisted of urban non-Hispanic white heterosexual women; social media used for social support by other YACC may be underrepresented and fundamentally different.

Conclusions

Supportive resources are needed in the spaces, online or physical, where YACC engage their social networks.[4] We found differences in social support by platform type and cancer content on YACC's social media. Future research is needed to explore relationships between users and YACC, social media platform variability, congruency between social support sought and support received, and the impact of cancer misinformation.

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Author contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Echo Warner, Austin Waters, Taylor Nelson. Additional mentorship on data management and analysis was provided by Andrew Wilson and Ye Sun. The first draft of the manuscript was written by Echo Warner and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Availability of data and material

The data used in this study are available from the corresponding author within reasonable request.

Consent to participate

Informed consent was obtained from all participants included in the study.

Disclosure statement

The authors have no conflicts of interest to disclose.

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the University of Utah Institutional Review Board (IRB_00097575).

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