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Acquisition of Social Support and Linguistic Characteristics of Social Media Posts About Young Adult Cancer

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Purpose: Social media (SM) is a burgeoning source of social support for young adults (YAs). We explored the language used to communicate about YA cancer on Instagram and for indicators of social support (i.e., number of likes and comments).

Methods: Instagram posts using #youngadultcancer were randomly selected ($N=50$). Text and hashtags were collected, and posts were coded for gender (female and male), treatment status (active treatment and survivorship), type of user (individual and organization), and caregiver status (yes and no). Indicators of social support, valence (e.g., positive vs. negative terms), and lexical content (e.g., emotional terms and pronouns) were measured using Yoshikoder and Linguistic Inquiry Word Count and compared by gender, treatment status, type of user, and caregiver status.

Results: Survivors' posts had more likes compared to those in active treatment (mean: 54.5 vs. 32.3, $p=0.03$). Individuals' posts had more comments than those of organizations (mean: 5.3 vs. 1.2, $p=0.01$). More positive (30%) than negative (13%) terms were used by survivors ($p<0.01$) and those in active treatment (20% vs. 9%, $p=0.04$). Individuals' used more positive than negative language ($p<0.01$), whereas organizations used equally positive and negative terms. Survivors used more emotional terms (79.6% vs. 34.9%, $p<0.01$) and fewer pronouns (mean: 39.5 vs. 71.7, $p=0.01$) than those in active treatment. Organizations (71.0%) used more emotional terms than individuals (55.9%, $p=0.03$).

Conclusions: We describe how Instagram users communicate about YA cancer and whether the language they use garners social support. Studying online language use may help YA patients, caregivers, and organizations use SM to gain social support.

Keywords: social media, content analysis, social support, supportive needs, Instagram

Introduction

Social media (SM) are online tools used to communicate, share information, host user generated data, construct social communities, and create open dialog.[1] In 2016, 97.5% of young adults (YAs) used SM,[2] more than any other age group.[1] Increasing SM use among YAs suggests that online peer networks are likely an important but underutilized source of social support during a cancer experience. A scoping review of the literature from 2004 to 2015 concludes that while the use of SM for social support is an emergent phenomenon, SM tools are increasingly being utilized for social support, with the most common types of support being emotional and informational.[3–6] YA may strategically seek support online with "weak ties" when "stronger ties," such as close friends/family members, fail to provide support, provide unwanted support, or provide support that is not helpful.[7] Weak ties may provide novel information, connections to other social groups, and objectivity.[8,9] YAs also use SM for its accessibility,[10] connecting with similar others,[4,11] health information,[4,6] and establishing/maintaining relationships.[1] We use the number of likes and comments as an analog for measuring expressions of social support, referred to as indicators of social support. Describing indicators of social support and characteristics of the text used in SM posts about YA cancer may help identify users who seek social support from SM. This research builds a case for studying the language used by organizations and individuals, including patients and caregivers, to seek and acquire social support in online YA cancer communities.

YAs have evolving and diverse social needs.[12,13] A cancer diagnosis during these formative years can be isolating and

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disruptive to social well-being for patients and caregivers.[14,15] YA cancer caregivers and survivors experience poor social functioning after diagnosis,[15,16] and survivors report poorer social support than controls.[17] Robust social support positively affects cancer patients' health[18] and improves quality of life.[19] Social support mediates caregiver burden among those caring for patients with functional impairment[20] and is inversely related to depression, loneliness, and burden among cancer caregivers.[20–23] After a cancer diagnosis, YA patients and caregivers may reach out to peer SM networks to seek social support by asking questions about health, sharing information, and fostering relationships.[1,6,24] Improving social support among Instagram users may enhance coping and reduce negative outcomes among YA patients and caregivers, but more research is needed to understand the language used to seek and acquire social support on Instagram.

Studying social support and linguistic characteristics on Instagram directly aligns with the National Cancer Institute's emphasis on bringing cancer research to individuals in their existing communities.[25] YAs historically have been more difficult to involve in cancer research than older adults; therefore, use of SM as a data source is a promising way of addressing this research disparity. Although Instagram is among the top five SM platforms used by YAs, almost no studies have described indicators of social support or the linguistic characteristics of posts about YA cancer on Instagram. In 2016, over 80% of YAs report using Instagram regularly.[2,26] Instagram is composed of multiple types of users (individuals, healthcare organizations, businesses, and nonprofits), and is used for storytelling through online postings of photos and text. To our knowledge, this is the first study of Instagram posts about YA cancer.

YA cancer organizations are increasingly using SM for outreach and patient support. In the past decade, national organizations have called for technology-based interventions that use SM to support YA patients and caregivers after a cancer diagnosis.[27,28] However, whether the language used by organizations is similar or different from individual Instagram users is unknown. Before developing interventions, exploratory research is needed to describe how YAs and YA cancer organizations communicate about YA cancer.

This descriptive cross-sectional study pilots the use of content analysis to examine textual data of Instagram posts about YA cancer to describe (1) indicators of social support, (2) valence (i.e., positive/negative terms), and (3) linguistic content (e.g., emotional terms/pronouns). We hypothesized that some Instagram users would acquire more social support than others (e.g., females vs. males), there would be differences in the valence of posts by disease progress (e.g., survivors would have more positive terms [e.g., fun] than negative [e.g., sad]), organizations would use more positive than negative terms, and more second-person singular pronouns (e.g., your) in attempts to use Instagram for marketing.

Methods

This research was deemed exempt by the University of Utah's Institutional Review Board.

Data and sampling

The sampling unit was the text and hashtags of original Instagram posts. Eligible posts were tagged with the hashtag #youngadultcancer and collected between March and May 2016. Due to privacy settings, only public posts were collected. There were $N = 1136$ posts from which 50 posts were selected, using a random number generator to select the position of each eligible post. To promote a diversity of user experiences, the sample was limited to only one post per account. If a randomly selected post belonged to a previously sampled account, the next consecutive post from a different account was collected. Text was manually extracted from Instagram posts and compiled into a single document. Hashtag symbols (#), emoticons, URL links, and usernames were removed.

Independent variables and codes

Categorical coding units were classified for each post using a coding schema. First, we coded type of user (organization and individual). Then among individuals, we coded treatment status (active treatment, survivorship, and unknown), gender (female, male, and unknown), diagnosis (leukemia, lymphoma, colorectal cancer, breast, and other), and caregiver status (self-identified caregiver, not caregiver/unknown). For both individuals and organizations, the type of post (photo, video) and length of each post were measured (i.e., word count). Coding was determined by reading the post in context, including images, to ensure the most accurate code was assigned. Once the random sample was collected, it became apparent that some of the initial codes were not relevant to the selected posts. For example, none of the posts contained videos; therefore, the video variable was excluded. Selected units for analysis included the following: gender, type of user, treatment status, and caregiver status. Posts with missing data were excluded: gender ($n = 12$) and treatment status ($n = 19$).

Outcome variables

There is no existing standardized method for measuring social support on Instagram. Thus, our main outcome variables were analog indicators of social support, defined as the number of likes and comments on each post. This definition was selected based on its prior use and the presence of these features across SM platforms.[29,30] Number of likes and comments per post were extracted manually. Other outcome variables included valence and lexical content, defined using two coding dictionaries: (1) a project-specific dictionary constructed and applied using Yoshikoder and (2) a proprietary dictionary and content analysis platform, Linguistic Inquiry Word Count (LIWC),[31,32] widely used in content analysis research. A customized Yoshikoder dictionary was created based on previous SM research and the descriptive analyses.[33] Yoshikoder was used to measure the proportion of positive and negative terms in each post. The following terms, including lemmatizations (i.e., groups of words with inflections removed to create a single term for analysis, such as friend, friends, friendly), were used to define positivity (* indicates lemmatized terms), such as love, good, friend*, happy, LOL, well*, great, haha*, best, better, fun, please*, hope, and thank. Negativity was defined using the following terms and lemmatizations: hate, miss, bad, bore*, shit*, hurt*, craz*, lost, damn*, fuck, stupid*, kill*, hell, fuckin*, and wrong*. One additional negative term ''suck*'' was included given its frequency. Using these definitions, Yoshikoder was applied to automatically code the valence of posts.

The second coding dictionary, LIWC, is a software program that classifies nearly 6400 words and word stems marking sociocognitive content (emotional, cognitive, and structural categories).[32] LIWC is a powerful textual analysis tool for SM data because it is capable of reading and classifying netspeak and text-messaging terms (e.g., b4, :), and lol).[32] LIWC was used to increase the validity of inferences about the lexical content of Instagram posts. LIWC categories were selected based on the original research question, hypotheses, and preliminary findings, including emotional tone (higher number indicates positive upbeat style and lower number indicates anxiety, hostility, and sadness[34]), personal pronouns (e.g., I, them, and her), first person singular (e.g., I and mine), first person plural (e.g., we and us), second person singular (e.g., you and your), third person singular (e.g., she and him), third person plural (e.g., they and their), impersonal (e.g., it and those), positivity (e.g., love and nice), negativity (e.g., hurt and ugly), all pronouns combined, social processes (e.g., daughter and friend), biological processes (e.g., health and sexual), time orientation (e.g., end and until), and personal concerns (e.g., home and money).[32]

Content analysis

A stop list was applied before analysis to limit the influence of noncontent words (e.g., the, and). Length of posts and frequency of occurrence of specific words were generated using Voyant 2.0[35] and NVivo 11. The number of likes and comments were compared by gender, treatment status, type of user, and caregiver status using t-tests in Stata 13. Textual data were then grouped according to categorical coding units with adequate variation for making statistical comparisons, including treatment status (active treatment vs. survivorship) and type of user (organization vs. individual). Z-tests, t-tests, and chi-square tests compared the proportion of text or mean number of words within each Yoshikoder and LIWC category by treatment status and type of user.

Results

The complete sample of text included $N = 3244$ words. The most frequently occurring words were as follows: cancer, young, adult, chemo, worry, I'm, day, lymphoma, survivor, and today. The most frequent types of words were as follows: nouns (36.3%), verbs (11.7%), prepositions (9.9%), and adjectives (9.0%). Most posts were from females (70.0%), individuals (68.0%), and those in active treatment (42.0%). Ten percent of posts were from caregivers. Posts were on average 64.9 words (Table 1).

Indicators of social support

Posts made by survivors had more likes on average (54.5 vs. 32.3, $p = 0.03$) compared to those in active treatment, but did not differ in number of comments (Table 2). Individuals had more comments than organizations (5.3 vs. 1.2, $p = 0.01$), but similar number of likes. Although not significantly different, females had more likes (43.2 vs. 5.3, $p = 0.15$) and comments (5.2 vs. 1.0, $p = 0.24$) than males did, and caregivers had fewer likes (28.2 vs. 37.0, $p = 0.64$) and comments (2.2 vs. 4.2, $p = 0.44$) than noncaregivers.

Table 1. Characteristics of Instagram Posts

	N	%
Gender		
Male	3	6.0
Female	35	70.0
Unknown/NA	12	24.0
Diagnosis		
Leukemia	2	4.0
Lymphoma	9	18.0
Colorectal	2	4.0
Breast	2	4.0
Other	4	8.0
Unknown/NA	31	62.0
Type of user		
Organization	16	32.0
Individual	34	68.0
Treatment status		
Active treatment	21	42.0
Survivorship	10	20.0
Unknown/NA	19	38.0
Type of post		
Photo	50	100.0
Video	0	0.0
Caregiver status		
Caregiver	5	10.0
Not caregiver	45	90.0
	Mean	*SD*
Word count	64.9	65.1
No. of likes	36.1	39.6
No. of comments	4.0	5.5

SD, standard deviation.

Valence

Those in active treatment used more positive (20%) than negative terms (9%, $p = 0.04$; Fig. 1). Survivors used more positive (30%) than negative (13%) terms ($p < 0.01$). There were more positive (52%) than negative (26%) terms in individuals' posts ($p < 0.01$), but equal proportions of positive (6%) and negative (6%) terms used by organizations ($p = 1.00$).

Linguistic content

Survivors used more emotional terms (79.6%) than those in active treatment (34.9%, $p < 0.01$; Table 3). Those in active treatment used more pronouns overall compared to survivors (mean: 71.7 vs. 39.5 words, $p = 0.01$).

Organizations used more emotional terms (71.0%) than individuals (55.9%, $p = 0.03$). Individuals used more pronouns overall than organizations (mean: 110.0 vs. 17.7 words, $p = 0.04$). Specifically, individuals used more first person singular ($p < 0.01$), second person singular ($p < 0.01$), and impersonal pronouns ($p = 0.04$), whereas organizations used more first-person plural pronouns ($p = 0.02$). Figure 2 contains examples of eligible Instagram posts.

Discussion

SM is used to represent cancer experiences and to elicit social support by creating posts that request information and

Table 2. Comparison of Social Support by Gender, Treatment Status, Type of User, and Caregiver Status ($N=50$)

	Likes, mean (SD)	p[a]	*Comments, mean (SD)*	p[a]
Gender[b]				
Male	5.3 (0.58)	0.15	1.0 (1.0)	0.24
Female	43.2 (44.5)		5.2 (6.0)	
Treatment status[b]				
Active treatment	32.3 (16.2)	**0.03**	4.7 (5.2)	0.17
Survivorship	54.5 (37.8)		8 (7.5)	
Type of user				
Individual	36.9 (26.1)	0.84	5.3 (6.0)	**0.01**
Organization	34.4 (60.3)		1.2 (2.3)	
Caregiver status				
Caregiver	28.2 (12.8)	0.64	2.2 (2.9)	0.44
Not caregiver	37.0 (41.6)		4.2 (5.7)	

[a] Indicates a *t*-test comparing mean values.
[b] Posts with unknown or not applicable data were excluded.
Bold indicates significance at $p < 0.05$.

emotional support.[6,24,36] Our study contributes new evidence that differences exist in the language used by YAs and YA cancer organizations, by individuals in active treatment and survivorship, and in the acquisition of likes and comments, a rudimentary representation of social support, between different types of Instagram users. These findings may inform SM messages for YA cancer patients and caregivers, to support and strengthen them throughout their cancer experiences.

We identified differences in how individuals and organizations communicate on Instagram. While individuals used more positive than negative text, organizations included equally positive and negative terms. This discordance may be problematic for YA cancer organizations intending to communicate with YA cancer patients and caregivers, potentially contributing to organizations receiving fewer comments than individuals. Language style matching improves perceived feelings of social support in online cancer communities,[5] likely because online communication relies more heavily on written social cues than in-person communication does. For example, without social cues like facial expressions or body language, using highly emotional language in a SM post may influence how a user responds to that post. Therefore, organizations and researchers developing SM posts for YA cancer patients and caregivers may consider using language that YAs use on Instagram. Specifically, messages with positive language may be preferred when discussing YA cancer. Given that individuals received more comments than organizations, organizations may also consider highlighting a personal story in their posts to directly connect with their followers.

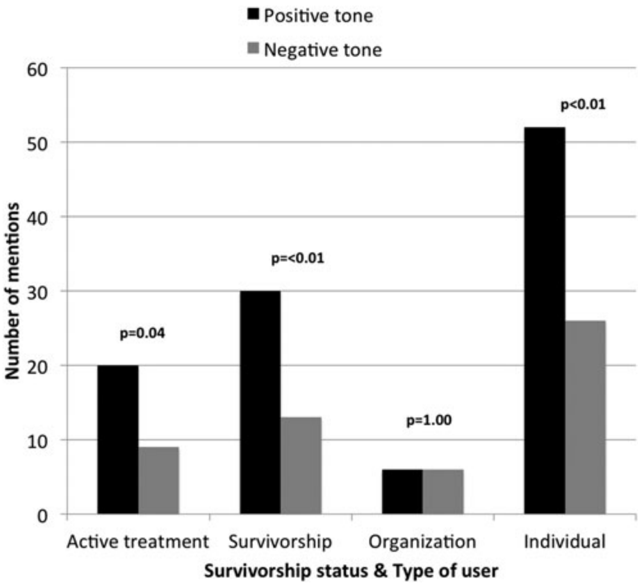

FIG. 1. Chi-square tests of positive and negative language of posts using Yoshikoder.

Those in active treatment and survivorship used more positive than negative language. Maintaining a positive outlook after a cancer diagnosis is beneficial for psychological and social well-being.[37–39] YAs may find it difficult to discuss negative thoughts or experiences about cancer on SM if using negative language results in less support from their online peer networks. Despite wanting to be supportive, peer networks may be unresponsive to posts with negative language about cancer because dealing with severe illness is not a normative task for YA, they may be unfamiliar with cancer patient and caregiver needs,[16,40,41] and they may be unsure how to formulate a supportive and sensitive response. Instagram posts with negative language should be further studied to understand how social networks respond or fail to respond, to identify alternative outlets for negative thoughts during YA cancer experiences, and to ensure adequate support is available to YA to address their concerns.

During active treatment users posted more emotional terms than during survivorship. Using SM to acquire emotional support is common in online cancer communities.[36,42,43] Emotionally supportive SM posts may contain support groups, peer connections, social work/counseling, and bereavement services. Studying the effect of emotionally supportive messages on coping and quality of life among cancer patients and caregivers is needed, particularly during active treatment when YA may need specialized emotional support.

Individuals used more first person singular, second person singular, and impersonal pronouns than organizations. These

Table 3. Linguistic Inquiry Word Count Categories by Survivorship Treatment Status and Type of User in Linguistic Inquiry Word Count

	Active treatment	*Survivorship*		*Individual*	*Organization*	
LIWC category	N *(%)*	N *(%)*	p[a]	N *(%)*	N *(%)*	p[a]
Emotional Tone	532 (34.9)	861 (79.6)	**<0.01**	1469 (55.9)	442 (71.0)	**0.03**
Personal pronouns (first, second, third)	150 (9.8)	76 (7.0)	0.99	328 (0.1)	38 (0.1)	**0.04**
First person singular	98 (6.4)	60 (5.5)	0.83	160 (0.1)	9 (0.01)	**<0.01**
First person plural	14 (0.9)	3 (0.3)	0.98	12 (0.0)	15 (0.02)	**<0.01**
Second person singular	9 (0.6)	6 (0.5)	0.55	15 (0.0)	9 (0.01)	**0.02**
Third person singular	25 (1.6)	3 (0.3)	0.99	29 (0.01)	2 (0.0)	0.07
Third person plural	4 (0.3)	4 (0.4)	0.32	8 (0.0)	3 (0.0)	0.49
Impersonal pronouns	62 (4.1)	44 (4.1)	0.50	104 (0.04)	14 (0.02)	**0.04**
Posemo	74 (4.86)	57 (5.26)	0.32	135 (5.1)	25 (4.0)	0.88
Negemo	66 (4.33)	25 (2.31)	0.99	93 (3.5)	10 (1.6)	0.99
	Mean (SD)	*Mean (SD)*	p	*Mean (SD)*	*Mean (SD)*	p[b]
All pronouns	71.7 (76.2)	39.5 (43.6)	**0.01**	110.0 (118.8)	17.7 (17.8)	**0.04**
Social processes	37.8 (54.3)	17.4 (27.8)	0.17	56.7 (82.6)	17.8 (35.9)	0.14
Biological processes	73.8 (76.6)	60.6 (66.4)	0.09	140.2 (150.0)	30.8 (38.3)	0.10
Time orientation	80.3 (89.8)	46.6 (40.4)	0.39	123.4 (125.6)	25.7 (28.0)	0.22
Personal concerns	9.5 (8.3)	7.6 (6.4)	0.33	16.7 (13.5)	8.2 (8.6)	0.09
Overall	104.4 (207.6)	79.4 (176.7)	**<0.01**	186.3 (387.2)	47.0 (110.5)	**<0.01**

[a] Indicates a z-score calculation with *N* and %.
[b] Indicates a *t*-test with mean and SD.
Bold indicates significance at $p < 0.05$.
LIWC, Linguistic Inquiry Word Count.

findings support prior research indicating that posts which acquired social support used more first-person singular pronouns than posts with no replies.[44] Individuals may use pronouns to describe their own experiences with cancer or to seek information from their social network. Similarly, there was more pronoun use among those in active treatment compared to those in survivorship. Users who are undergoing cancer treatment may use more first person pronouns to actively share their experience on Instagram, whereas those who are finished with treatment may use second person singular of impersonal pronouns to discuss cancer more generally. Continued study of how pronoun use influences the acquisition of social support on SM may elucidate ways for YA cancer patients and caregivers to communicate about cancer with their social network.

Survivors acquired more likes than those in active treatment. One reason for this may be that new online social networks are cultivated after a cancer diagnosis, reaching a more robust socially supportive environment during survivorship than at initial diagnosis. However, to our knowledge, no research has studied the change in social support acquired on SM over the cancer treatment trajectory among YA cancer patients or caregivers or changes in the composition of their social networks. Identifying periods during the cancer treatment trajectory in which YAs are especially vulnerable to poor social support is a top priority for future work.

While nonsignificant, it is notable that females received more social support than males. Considering that females use SM for emotional exchanges, whereas males use SM for seeking information, this finding may reflect differences in the type of support sought by gender.[45] Despite equal distribution of Instagram users by gender in the general population,[2] our random sampling of Instagram posts with a YA cancer hashtag produced fewer posts from males than females. Oversampling of males may be warranted in future research of YA cancer communities on Instagram. Caregivers reported fewer likes and comments than noncaregivers, although this difference was not statistically different. Differences in the type of social support sought by gender and caregiver status on SM should be tested in larger samples.

While this study is novel in its utilization of Instagram as a data source, there are some limitations. The majority of codes in this study label manifest content (e.g., type of user, diagnosis, and word count). The validity of manifest codes may be limited because Instagram posts do not always explicitly state whether someone is a survivor or undergoing active treatment. Thus, some cases were coded at the discretion of the authors or were left blank in the case of uncertainty, resulting in some missing data. Likewise, we were unable to accurately determine age and thus did not incorporate age in our analyses. Based on a lack of validated definitions and measurements for assessing social support on Instagram, we adopted likes and comments as an analog of social support. Analyzing the number of likes and comments on Instagram posts does not explain how likes and comments are interpreted by Instagram users or how this type of response influences well-being. We did not consider the proportion of likes or comments per total number of followers.

This early work contributes new knowledge on an emergent phenomenon of Instagram as a social support mechanism for YA cancer patients and caregivers and points toward future research questions. Future work should prioritize the development of a SM specific definition of social support that can be modified for different SM platforms. Given the variability of SM use by age, future studies should weigh the benefits and costs of directly engaging users to improve the validity of personal data

FIG. 2. #youngadultcancer Instagram posts.

such as age. We did not assess intentions of SM users, but studying whether YAs are intentionally using SM to seek social support, and how this process occurs, is an immediate next step. Although not a part of this study, examining changes in social support, actions of users, and social network composition over time may reveal gaps in support and opportunities for interventions among YA cancer patients and caregivers.

Conclusions

YAs use supportive services to assist them with navigating complicated healthcare systems and insurance, balancing family and career responsibilities, and maintaining financial, social, and psychological well-being. Despite the recent focus on improving supportive services and making cancer care more patient centric,[46] YA cancer patients and caregivers generally report many unmet needs.[47,48] SM is a novel tool for sharing information about supportive services that may fulfill YA cancer patients' and caregivers' unmet needs. This study described the social support, valence, and linguistic content of Instagram posts about YA cancer. These findings define the context for communicating with YAs about cancer on Instagram and other SM platforms, and are a first step for implementing supportive interventions for YA cancer patients and caregivers on SM.

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