Health Communication in the Digital Age: Young Adult Experiences in Sexual Health, Body Image, and Cancer

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**"Health Communication in the Digital Age:
Young Adult Experiences in Sexual Health, Body Image, and Cancer"**

presented by

Allison Baker

candidate for the degree of Doctor of Philosophy and hereby certify that it is worthy of acceptance.

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Date: 16 December 2020

Health Communication in the Digital Age:
Young Adult Experiences in Sexual Health, Body Image, and Cancer

A dissertation presented

by

Allison Baker

to

the Department of Social and Behavioral Sciences

in partial fulfillment of the requirements

for the degree of

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Health Communication in the Digital Age:
Young Adult Experiences in Sexual Health, Body Image, and Cancer

Abstract

Young adulthood is a developmental stage traditionally characterized by developing autonomy from parents, transitioning from school to work, forming one's own family, and other similar milestones that shape the trajectory of later life. Shifting norms and deep economic constraints have delayed young adults' achievements of these milestones in recent decades, leading to unique health challenges in this population. One area in which public health can address the unique needs of young adults is health communication, especially given young adults' near universal connection to the Internet and social media and the implications of these communication technologies for health. This dissertation focused on health communication issues in young adulthood with particular (but not exclusive) attention to opportunities and challenges posed by the Internet and social media. It used qualitative methods to explore three different health communication topics among three different young adult populations.

In Chapter 1, I examined sexual health information issues among young adult sexual minority cisgender women and non-binary individuals assigned female at birth. Through thematic analysis of in-depth interview data, I identified three broad themes: 1) sources of sexual health information; 2) sexual health information needs; and 3) preferences for sexual health information delivery. Participants discussed and critiqued the Internet, other mass media, health care providers, school-based sex education, family, and peers/partners as sources of sexual health information. They expressed a need for customized, non-heteronormative information pertaining to sexually transmitted infection risk and prevention. They preferred receiving information from health care providers, the Internet, and other mass media, and some also suggested school-based sex education and peer education as methods for delivering information.

In Chapter 2, I investigated how lesbian, gay, bisexual, transgender, and other sexual- and gender-minority (LGBTQ) young adults exhibit media literacy in conversations about body image and appearance ideals. Through thematic analysis of focus group data, I found that participants demonstrated media literacy under five themes: 1) Media convey dominant cultural and LGBTQ appearance ideals; 2) Dominant cultural and LGBTQ appearance ideals conveyed in media shape viewers' attitudes; 3) Appearance ideals conveyed in media are unrealistic and manipulated; 4) Promotion of appearance ideals is financially motivated; and 5) Learning social media literacy is important. Aside from documenting participants' media literacy, these findings offered critical insights about the range of appearance ideals experienced by this population and the unique roles of traditional and social media in promoting those ideals.

In Chapter 3, I examined content related to young adult cancer on Instagram to better understand the platform's role in young adult cancer experiences. I conducted qualitative content analysis of a set of publicly available Instagram posts with the hashtag #youngadultcancer. I found that most posts were posted by individual users, who were typically women cancer survivors. Of the survivors, about half were survivors of breast cancer, with blood cancers, colorectal cancer, and thyroid cancer being the next most common. Groups such as non-profit organizations, community groups, and companies also posted, along with meme accounts. I found that posts had five primary functions: documenting life, publicizing/fundraising, raising awareness, sharing a meme or viral graphic, and selling/promoting. Survivors’ “documenting life” posts, analyzed in greater depth, covered six cancer-related themes: cancer care experienced in the present time, support, philosophy/mindset, cancer care experienced in the past, appearance/body image, and discussion prompts. Overall, I concluded that Instagram is an active site of communication about young adult cancer that offers a glimpse into some survivors’ experiences. I proposed several needs that young adult cancer survivors might meet by using Instagram in relation to cancer.

Together, these findings convey a wide-ranging sampling of the health communication issues faced by today’s young adults and the public health researchers and practitioners who serve them.

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Introduction

Young adulthood, roughly 18–26 years of age, is a developmental stage traditionally characterized by developing autonomy from parents, transitioning from school to work, forming one's own family, and other similar milestones that shape the trajectory of later life.[1] Shifting norms and deep economic constraints have delayed young adults' achievements of these milestones in recent decades. As argued in a landmark Institute of Medicine report,[1] these conditions have created unique health challenges, including heightened stress, riskier health behaviors, and difficulty accessing healthcare, for many young adults, underlining the importance of treating this group as a distinct population in public health work.

One area in which public health can address the unique needs of young adults is health communication. Today's young adults are digital natives, having grown up amidst dramatic advancements in information and communication technologies.[2,3] The growth of social media has made mass communication more interactive and participatory, with individual users actively creating and engaging with content online.[4,5] Young adults demonstrate these shifts more than any other age group: a recent survey of U.S. young adults ages 18–29 found that 100% use the Internet,[6] 96% own a smartphone,[7] and 90% use at least one social media site.[8] The implications of these changes for the health of young adults is an active area of research, covering such topics as young adults' use of the Internet for health information seeking,[9] the psychosocial impacts of young adults' media use,[e.g.,10,11] and health-related content on social media.[e.g.,12,13] New communication technologies hold great promise for public health initiatives with young adults, but much more research is needed to understand their influence (including for different social groups) and their utility alongside other, more traditional forms of health communication (e.g., counseling by healthcare providers).[1]

This dissertation contributes to the growing body of research on health communication issues in young adulthood, with particular (but not exclusive) attention to opportunities and challenges posed by the Internet and social media. It uses qualitative methods to explore three different health communication topics among three different young adult populations.

Chapter 1 focuses on the health communication topic of *sexual health information* and the population *sexual minorities assigned female at birth (AFAB sexual minorities)*; this includes sexual minority cisgender women (SMW) and non-binary individuals. Young adult SMW have unique sexual health needs and higher rates of some poor sexual health outcomes compared to their heterosexual peers.[14-17] Unequal access to relevant sexual health information may contribute to sexual orientation disparities in sexual health among women,[18-20] but research on sexual health communication among SMW is sparse. In particular, while studies have begun to document SMW's sexual health knowledge gaps,[e.g.,21,22] they have not thoroughly examined their experiences and perspectives on acquiring sexual health information from various sources or assessed their sexual health communication preferences. Further, few studies have focused on young adult, racially/ethnically diverse populations. To address these gaps, in Chapter 1, we conducted a qualitative study based on interviews with a racially/ethnically diverse sample of AFAB sexual minorities. Using thematic analysis, we investigated this population's sexual health information sources, needs, and preferences.

Chapter 2 focuses on the health communication topic of *media literacy in the prevention of body and eating concerns* and the population *lesbian, gay, bisexual, transgender, and other sexual- and gender-minority (LGBTQ) young adults*. LGBTQ young adults are at increased risk for body dissatisfaction and disordered eating.[23,24] Appearance ideals, or societal attitudes about what physical characteristics are attractive and desirable, contribute to these body and eating concerns and are learned, in part, through media messages.[25,26] Media literacy, or the knowledge and skills to critically evaluate media,[27] may protect against these harms.[28] This construct has long been part of eating disorder prevention work[29] and has recently expanded to include media literacy as it relates to social media.[30] However, studies have not investigated media literacy among LGBTQ young adults, who are active social media users.[31] To begin to address this gap, in Chapter 2, we conducted an exploratory study with focus groups of LGBTQ young adults. Using thematic analysis, we investigated the research question: How do LGBTQ young adults demonstrate media literacy—particularly social media literacy—in conversations about body image and appearance ideals? More generally, we sought to generate useful insights on the intersections of traditional media, social media, and appearance ideals in the experiences of LGBTQ young adults.

Chapter 3 focuses on the health communication topic of *cancer-related social media content* and the population *young adult cancer survivors*. Young adult cancer survivors face numerous physical and psychosocial challenges throughout the trajectory from diagnosis to long-term survivorship.[32] Research suggests that survivors use social media to discuss these concerns and meet some of their cancer-related support needs.[33-35] The social media platform Instagram seems to be particularly useful for self-expression and conveying narratives about cancer.[36,37] However, few studies have examined cancer-related Instagram content, and none have done so qualitatively with a specific focus on young adults. As such, little is known about the role of Instagram in young adult cancer experiences. In Chapter 3, therefore, we conducted a qualitative content analysis of publicly available Instagram posts about young adult cancer. Our primary research question was: What content related to young adult cancer is posted to Instagram, and who posts it? Focusing on a subset of posts, we also asked a more specific question: What do young adult survivors share about their cancer experiences on Instagram?

Chapter 1

Sexual Health Information Sources, Needs, and Preferences of Young Adult Sexual Minority Cisgender Women and Non-Binary Individuals Assigned Female at Birth

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Abstract

Background: Young adult sexual minority women (SMW) have unique sexual health needs and higher rates of some poor sexual health outcomes compared to their heterosexual peers. Unequal access to relevant sexual health information may contribute to sexual orientation disparities in sexual health among women, but research on sexual health communication among SMW is sparse.

Methods: In-depth interviews conducted in 2016–2017 investigated sexual health communication in a sample of 29 racially/ethnically diverse cisgender women and non-binary individuals assigned female at birth who were between 19 and 36 years of age and identified as a sexual minority. Data were analyzed using a thematic analysis approach that involved inductive and deductive coding to identify themes.

Results: Three broad themes were identified: 1) sources of sexual health information; 2) sexual health information needs; and 3) preferences for sexual health information delivery. Participants discussed and critiqued the Internet, other mass media, health care providers, school-based sex education, family, and peers/partners as sources of sexual health information. Participants expressed a need for customized, non-heteronormative information pertaining to sexually transmitted infection risk and prevention. They preferred receiving information from health care providers, the Internet, and other mass media, and some also suggested school-based sex education and peer education as methods for delivering information.

Conclusions: Participants expressed clear desires for relevant, high-quality sexual health information delivered through a variety of channels, especially the Internet, other mass media, and health care providers.

Policy Implications: Findings call for policies that improve provision of sexual health information through health care providers, online resources, and school-based sex education.

Introduction

Sexual health, including prevention of sexually transmitted infections (STIs) and cervical cancer, is an important yet understudied aspect of the health and well-being of young adult sexual minority women (SMW; e.g., lesbian and bisexual women; women with same-sex sexual partners).[38] Relative to their non-sexual minority counterparts (e.g., heterosexual women; women with only male sexual partners), some groups of SMW are less likely to receive sexual health services (e.g., human papillomavirus [HPV] vaccines, Pap tests, STI tests)[14,39-41] or engage in safer sex behaviors (e.g., using a condom or other barrier method)[42,43] and may be at higher risk of poor sexual health outcomes (e.g., some STIs, teen pregnancy).[14-17] Prior research suggests that sexual health and health care disparities between SMW and non-SMW are due to a range of structural factors, including stigma and discrimination in the health care system in particular and society in general[44,45] as well as financial barriers to health care.[46,47] Another structural factor that may underlie sexual orientation disparities in sexual health among women is limited access to high-quality sexual health information customized to the specific and unique needs and concerns of SMW.[18-20]

The Structural Influence Model of Health Communication[48] provides a theoretical understanding of how differences in access to sexual health information may contribute to sexual health disparities between SMW and non-SMW. This model posits that one mechanism by which social determinants of health result in health disparities is through *communication inequalities*, defined as "the differences among social groups in their ability to generate, disseminate, and use information at the macro level and to access, process, and act on information at the individual level."[49, p.222] Put another way, social factors structure unequal communication experiences between particular groups. Communication may include, for example, actively looking for health information (i.e., information seeking) and being exposed to health information through routine media use (i.e., information scanning).[50] Those communication experiences in turn determine between-group differences in health-related outcomes, such as knowledge about a health issue, engagement in health behaviors, and disease incidence.[48] In the case of SMW, the underlying structural disadvantages associated with bias, discrimination, and stigma related to their multiple social identities, including sexual orientation, gender, race/ethnicity, and socioeconomic position, may limit access to communication of sexual health information and thereby impact sexual health-related outcomes.[48]

There is emerging evidence supporting the presence of communication inequalities in the context of young SMW and sexual health. For example, adolescent and young adult SMW have difficulty obtaining information—from health care providers,[51-54] schools,[51,55-58] and parents[57,59]—that is accurate, relevant to their sexual behaviors, and respectful of their sexual orientations and gender identities. Online sexual health information resources may be more accessible and pertinent to SMW[18,60-64] but of dubious quality.[65,66] Indeed, studies have found that SMW lack accurate information about and knowledge of female-to-female STI transmission, including sexual risk behaviors and safer sex practices.[21,22,56,67-70]

Prior research examining access to sexual health information among SMW has made meaningful contributions but also has notable limitations. First, while studies have begun to document SMW's sexual health knowledge gaps, they have not thoroughly examined their experiences and perspectives on acquiring sexual health information from various sources or assessed their sexual health communication preferences. In particular, knowing how SMW prefer to obtain sexual health information may be important for designing customized health promotion interventions for this group.[71] Second, studies about sources of sexual health information among

SMW have rarely focused on young adults specifically. Because young adulthood is an important developmental stage for establishing health-promoting habits, transitioning from pediatric to adult medical care, and forming a sexual orientation identity,[1,72] and because young adults are at relatively high risk for STIs,[1] understanding sexual health communication issues in this particular age group is critical. Third, existing research has generally relied on predominantly White samples,[22,51,67] all racial/ethnic minority samples,[68,70] or samples drawn from outside the United States,[69] and has therefore not drawn comparisons between racial/ethnic groups in a U.S. context. To address these gaps in the scientific literature, we conducted a qualitative study to investigate sexual health information sources, needs, and preferences in a racially/ethnically diverse sample of young adult SMW in a major U.S. city. Findings from this study will help inform future research and health promotion interventions that facilitate access to relevant and accurate sexual health information customized to the specific needs of young adult SMW, with the goal of reducing communication inequalities and improving sexual health in this understudied and underserved population.

Methods

Participant Recruitment and Sampling

We used a purposive sampling strategy to recruit study participants (N=29) according to the eligibility criteria: assigned female sex at birth (AFAB); identifies as a woman; identifies as lesbian, bisexual, or queer; resides in Boston, Massachusetts; and ages 18 to 36 years. This age range captured participants who had ever been eligible for the HPV vaccine, which was the focus of the parent study from which this study was drawn. (See Agénor et al.[21] and Jahn et al.[73] for study information and findings.) To recruit participants, we posted Craigslist ads and contacted email listservs, Facebook groups, and community-based, health care, and student organizations that serve local SMW. We also conducted snowball sampling through peer social network referral.[74-76] We used maximum-variation sampling[75,76] to enroll participants who were diverse in terms of age and sexual orientation identity. We used quota sampling[75,76] to achieve approximately equal numbers of participants identifying as White (n=14) and as people of color (n=15; including but not limited to Black, Latinx, Asian, and multiracial individuals), which allowed for comparisons between these racial/ethnic groups.

Data Collection

Trained interviewers conducted in-depth, semi-structured, English-language interviews with each participant from November 2016 to November 2017 in Boston, Massachusetts. Interviews took 40–80 minutes (mean: 60 minutes), were conducted face-to-face in a private room, were audio recorded with participants' written informed consent, and were completed using a semi-structured interview guide. The interview guide, which was grounded in the research literature and reviewed by experts in the sexual health of SMW,[77] comprised open-ended questions and probes related to: sexual health care experiences and concerns; STI beliefs and risk perceptions; sexual health information acquisition; and recommendations for communicating sexual health information to SMW. Example questions included *"Tell me about the last time you saw a healthcare provider about your own sexual or reproductive health. What type of health information and resources did you receive during this visit?"* and *"What type of health information do you think would be most helpful in terms of preventing HPV infection [probe: and in terms of safer sex practices] among lesbian, bisexual, and queer women? How would you like to receive this information?"* At the end of the interview, participants completed a short demographic survey (see Table 1.1 for characteristics measured). Each participant received a $25 gift card for their time. The Office of Human Research Administration at Harvard Longwood Medical Area approved all research activities.

Data Analysis

Interviews were transcribed verbatim and entered into Dedoose[78] for thematic analysis.[79] The first author began the analysis with data immersion—closely reading each transcript and recording general impressions in written memos. She then developed and refined the codebook. The initial codebook included deductive codes (based on the research question and literature) and inductive codes (based on the first three transcripts and general observations from the data).[80] The first author organized and refined the codes through discussion with the research team and application to additional transcripts and then applied the final codebook to all transcripts. In the next step of analysis, the first author extracted coded text pertaining to sexual health information and entered it into a database arranged as a conceptually clustered matrix,[81] which she used to identify themes and examine patterns based on participants' sexual orientation identity, race/ethnicity, and age. The major themes into which codes were classified were: 1) *sources of sexual health information*, 2) *sexual health information needs*, and 3) *preferences for sexual health information delivery*. The research team discussed and provided feedback on study findings throughout the data analysis and interpretation process.

Reflexivity and Positionality

Critical reflection on the research process and researchers' roles in it, including researcher positionality in relation to the population being studied, is an important task of rigorous qualitative research.[82-84] In this study, the first author is a White, heterosexual, cisgender woman in her early thirties. Her academic training is in public health and health communication. She has completed coursework and has prior research experience in lesbian, gay, bisexual, transgender, and queer (LGBTQ) health. The research team comprised members who are sexual minorities, people of color, and experts in health communication, sexual health, social epidemiology, and research with LGBTQ young adults and LGBTQ people of color. Thus, the research team overall includes both insiders and outsiders of the multiple social identities under study (i.e., racially/ethnically diverse young adult SMW).

Results

Study Population

Participant characteristics are provided in Table 1.1. Participants ranged in age from 19 to 36 years, with most (n=20) being age 26 years or younger. All participants were AFAB and identified as cisgender sexual minority women upon study entry. However, 4 identified as gender non-binary at the interview, reflecting the fluid nature of gender identity depending on time and context.[85,86] We opted to include these participants and hereafter refer to our study population using the more inclusive phrasing “AFAB sexual minorities” instead of “SMW.”

Most participants (n=23) identified their sexual orientation as queer; the other most commonly reported sexual orientation identities were bisexual (n=9), gay (n=7), and lesbian (n=6). About half (n=14) identified as White and about half (n=15) as people of color, including seven Asian/Pacific Islander, five Black, one Latina/Hispanic, and two biracial participants. (Both biracial participants identified as Asian/Pacific Islander and White). All participants who shared their education level (n=24) had at least some college education. The majority (n=18) reported a private doctor’s office as their usual source of sexual health care.

Sources of Sexual Health Information

Participants described a wide range of sexual health information sources, including mass media, health care providers, school-based sex education, family, peers, and partners, with

Table 1.1
Sample characteristics (N=29).

Characteristic	n (%)
Age (years)	
18-26	20 (69)
27-36	8 (28)
Missing	1 (3)
Race/ethnicity	
White	14 (48)
Asian/Asian American or Pacific Islander	7 (24)
Black or African American	5 (17)
Latina or Hispanic	1 (3)
Bi/Multiracial	2 (7)
Gender identity	
Cisgender woman	25 (86)
Non-binary	4 (14)
Sexual orientation identity[a]	
Queer	23 (79)
Bisexual	9 (31)
Gay	7 (24)
Lesbian	6 (21)
Heterosexual	1 (3)
Another sexual orientation identity	3 (10)
Educational attainment	
≤ High school diploma or GED	0 (0)
Some college or Associate’s degree	5 (17)
Bachelor’s degree	6 (21)
Some graduate school	5 (17)
Graduate degree	8 (28)
Missing	5 (17)
Employment status[a]	
Working for pay	21 (72)
Student	11 (38)
Not working for pay	0 (0)
Missing	5 (17)
Health insurance status	
Private	23 (79)
Public	1 (3)
None	0 (0)
Missing	5 (17)
Usual source of sexual health care[a]	
Private doctor’s office	18 (62)
Community health center	5 (17)
Hospital clinic	3 (10)
Planned Parenthood clinic	3 (10)
Somewhere else	4 (14)
None	3 (10)

[a] Selection of multiple response options permitted.
Note: Percentages may not add to 100% due to rounding and possible selection of multiple response options.

variable quality and relevance to their lives as AFAB sexual minorities. They discussed instances of actively seeking out and passively being exposed to information from these sources but also noted important ways in which these sources had not met their needs.

Mass media. Many participants pointed to the Internet as their main source for sexual health information, stating that they conducted web searches, sought out trusted institutions (e.g., Centers for Disease Control and Prevention [CDC]), or, less commonly, followed websites and social media accounts that sometimes shared such sexual health information (e.g., Planned Parenthood). Internet resources were generally viewed positively. However, a few participants noted that the quality of online information varied. For example, this 26-year-old White bisexual/queer cisgender woman (ID 9) stated:

> It's good that there's lots of information out there. I think it's often hard to know how verifiable it is…I've definitely gotten in loops of message forums about people sharing experiences or information that may or may not be true.

Participants also mentioned television shows and ads as sources of information about HPV specifically. For example, one 32-year-old Black bisexual/queer cisgender woman (ID 31) said, "There's been this new campaign flooding my Hulu. It was effective, let me tell you! It was a terrible commercial, but now I'm informed that men and women should get the HPV vaccine."

Health care providers. Participants reported varied experiences in receiving sexual health information from their health care providers. Many described provider visits in which sexual health was not discussed in detail, even when the reason for the visit was a Pap test or routine STI screening. For example, a 21-year-old White bisexual cisgender woman (ID 22) said, "I went for my annual and my gynecologist didn't even ask me about my sex life, period. She never asked about my sexual orientation, or how many partners I had, if I was seeing anyone. Nothing. Zero questions."

Many described sexual health conversations with providers that were not sensitive to their needs as AFAB sexual minorities. These conversations typically assumed sexual partners of a different sex/gender, emphasized pregnancy or contraception over other sexual health concerns, or implied that AFAB sexual minorities were not at risk for STIs. For example, one 24-year-old White queer cisgender woman (ID 6) recounted a provider visit in which the sexual health conversation ended when she said that she was engaging in sex with women: “She was like ‘OK, as long as you're not having penetrative sex, then keep on doing what you're doing.’” This participant recalled feeling “very angry” about not receiving any sexual health information from her provider after disclosing her sexual orientation.

Some participants described how negative interactions with providers hindered communication about sexual health topics. These interactions were usually portrayed as having been judgmental, rude, ignorant, or biased in response to participants’ sexual behaviors or aspects of their identity, like sexual orientation, gender, age, and/or race/ethnicity. For example, one 21-year-old White queer/pansexual cisgender woman (ID 2) said that after she disclosed her sexual orientation identity, her provider told her, “You don’t look gay.” This participant went on to explain, “While I would have liked to talk about my health and risks of being sexually active at that time, I didn’t want to have that conversation with that person after that comment.” Another participant, an Asian queer cisgender woman (age not given; ID 24) who had worked as a sexual health educator, said this about contraception discussions with her providers: “I always notice their surprise when I have questions or when I correct them or question their judgments. And it’s like kind of a nasty shock, like oh they’re not expecting that and it’s not welcome for me to question their authority.” She suspected that this was related to stereotypes about her race/ethnicity, gender, or a combination of the two.

In contrast, some participants noted that their providers spoke respectfully with them about their sexual relationships and sexual practices and offered customized, practical sexual health information. For example, one 24-year-old White queer/lesbian cisgender woman (ID 25) stated:

> I told her about this change that had happened, and what I was doing sexually. And she just took it in stride completely; her face didn't show anything. Like 'OK now [you're dating] women. OK so just so you know, there are these risks associated with oral sex between women.' She just right away was able to switch gears completely. It was very cool.

School-based sex education. Many participants, especially younger participants, brought up their middle school or high school sex education and described it as having inadequately covered the sexual health information they needed. This was typically because of an emphasis on abstinence, neglect of sexual minority sexual health concerns, or general poor quality. As one 23-year-old White gay cisgender woman (ID 21) described, "in terms of factually getting information, I felt like there was nothing here for me...there was no mention of what to do if you're not cisgender and heterosexual."

Several participants said that they had encountered sex education in college, through classes, campus health promotion, or extra-curricular activities. Most described this positively, noting its relevance to a range of sexual orientations and gender identities. For example, one 26-year-old White bisexual/queer cisgender woman (ID 9) remembered the health promotion materials available on her college campus:

> RAs [resident assistants] would have them on their doors and it would be condoms and dental dams and lube and all kinds of different things, so I liked the inclusiveness of that, and the information that was available at student health services was inclusive of different sexualities and genders.

Family. When asked about the sexual health information that they received from their parents or other family members, participants provided a wide range of responses. Many participants, especially those identifying as Asian and/or White, described resistance on the part of their parents and/or themselves to discuss sexual health. For example, a 21-year-old Asian pansexual/bisexual non-binary participant (ID 12) said of their family: “We don’t really talk about sexual or reproductive health. I don’t recall having ‘the talk’ with my parents." As another example, a 21-year-old White bisexual cisgender woman (ID 22) described that when she tried to initiate a discussion about a sexual health topic, her mother was not receptive:

> So when I told her I wanted to get the IUD [intrauterine device], she said ‘you’re not having sex are you?’ and I was like ‘no I’m just getting this for fun!’ I think…because I was not in a relationship at the time, she was repressing the fact that ‘oh my daughter is sleeping around’ or something. It makes it more difficult to talk to her about things like that.

On the other hand, several participants, most of whom identified as White, Black, or Latina, described instances of getting sexual health information from their family members. These family members included mothers, fathers, and sisters. Some said that their parents encouraged them to seek out Pap tests and other sexual health services, as in this example from a 24-year-old White queer/lesbian cisgender woman (ID 25) about seeing a gynecologist: “I think my mom routinely sees someone similar, and she felt like ‘OK you’re getting to this age where even if you’re not having sex, you should just be thinking about that part of your health.’” Among participants who reported receiving sexual health information from their families, only a few mentioned obtaining information specific to AFAB sexual minorities. For example, only two participants said that they had spoken with a family member about specific barrier methods to prevent female-to-female STI transmission, including dental dams, plastic wrap, and gloves.

Peers and partners. Many participants reported speaking comfortably about sexual health with friends, describing peer discussions about contraception and about STI prevention, testing, and experiences. In contrast, a few participants observed that conversations among sexual minority friends tend to downplay STI risk and normalize not using dental dams. One 23-year-old biracial (Asian/White) queer cisgender woman (ID 30) said that she “definitely” has talked about STIs with friends, but “that is mostly a conversation with my friends who identify as straight…I don’t think I’ve ever had this kind of conversation with queer friends.”

Most participants reported discussing STIs with their sexual partners, typically before engaging in sex. Participants usually described these conversations as brief and focused on STI testing and infection status, but a few pointed to the conversations as opportunities for exchanging STI prevention information. One 22-year-old Asian lesbian cisgender woman (ID 17) described how she conversed with a new partner:

> There was like a lot of education happening in that conversation about protection and things, and I asked her ‘what do you think to worry about and what do you think our options are?’ And she had no idea so I kind of walked through it. And then I was like, ‘So we’re not trying to prevent pregnancy, clearly, but like if we’re worried about STIs and things like that then we should think about protection.’

Sexual Health Information Needs

Participants identified gaps in their own sexual health knowledge and in the sexual health information to which they were exposed. They expressed needs for information about risks and prevention of STIs and, more broadly, information without heteronormative assumptions about sexual orientation, gender, and sexual behaviors.

STI risk and prevention information. Many participants recognized that they had limited knowledge about STI risk and prevention. As one 23-year-old White gay cisgender woman (ID 21) stated, “I don’t really know what lesbian preventing STIs looks like.” There was a common belief that AFAB sexual minorities, in particular those identifying as gay or lesbian, were at lower risk for STIs, as described by this 33-year-old Black lesbian non-binary participant (ID 14): “I’m going to be honest, in terms of STIs, I just feel like…I’m a lesbian, I’m probably not going to…be as exposed, as heterosexual, or bisexual folks.” Participants explained that there was generally a lack of STI information customized to their needs as AFAB sexual minorities. They called for information about safer sex practices and specific ways in which STIs can be transmitted among AFAB sexual minorities. For example, one 22-year-old White gay non-binary participant (ID 26) requested “information about how you can contract STIs and HPV in different ways,” elaborating, “So like can you get it from using sex toys? Can you get it if someone is digitally penetrating you? If you’re digitally penetrating someone else? Can you get it from oral sex?”

Non-heteronormative sexual health information. Participants identified the heteronormative bias of available sexual health information. For example, one 34-year-old Asian queer cisgender woman (ID 20) said:

> As a woman in this society…everyone is worried that you are going to get pregnant or [get] some type of STI from a man. And we're just going to beat this into you, that you need to have a condom happening somewhere. And then I started dating women…and nobody was talking about anything like that.

Several described a need for sexual health information that addresses a diverse range of sexual activities and sexual partnerships with both AFAB and assigned-male-at-birth sexual partners, and that does not assume gender or sex of sexual partners and types of sexual behaviors. For example, one 22-year-old White gay non-binary participant (ID 26) requested “other kinds of information that doesn’t just assume you’re having a single kind of sex with a single kind of person and actually go into what different kinds of things could look like.” They elaborated that such information “doesn’t only assume you’re only having sex with one person, and just uses language that is more neutral in that regard and in terms of gender and sexuality.” Another participant, a 26-year-old White queer/lesbian cisgender woman (ID 3), described a need for information that is “less geared to identity or the gender of partners, and more geared to the [sexual] acts.”

Preferences for Sexual Health Information Delivery

Participants shared their opinions on methods of delivery for sexual health information and strategies for reaching AFAB sexual minorities with this information. They emphasized the Internet, other mass media resources, and health care providers but also mentioned school-based sex education and peers, noting particular strategies for improving these potential sources.

Mass media. Many participants believed that Internet-based resources would be useful for sharing sexual health information with AFAB sexual minorities. One 31-year-old White lesbian cisgender woman (ID 4) conveyed what she saw as a main benefit of this approach, saying, “It protects your privacy when you’re still figuring out your sexual orientation and allows you to explore that information on your own in a good setting."

Participants expressed support for the dissemination of sexual health information through media campaigns, including shareable content posted on relevant social media sites; pamphlets, posters, and ads in places such as health clinics and public transportation; and television commercials. They called for these to use imagery and language either customized specifically to AFAB sexual minorities or inclusive of a diverse range of sexual orientation and gender identities. One 32-year-old Black bisexual/queer cisgender woman (ID 31) mused:

> That would be really amazing if there were advertisements that were directed…explicitly towards queer folks in general. What would that even look like?…It’s not just about people who identify as queer, it’s about anyone who’s having sex. And that could be sex with any kinds of partners from any kinds of backgrounds, gender and otherwise. So you would be addressing a larger population.

Health care providers. Most participants believed that health care providers should be a key source of sexual health information. As one 22-year-old Asian lesbian cisgender woman (ID

17) described, STI prevention should be "incorporated into any generic check-up because it's a whole part of your body that's very important and needs to be worried about even if you don't want to talk about it." Participants stressed that providers should display sensitivity toward their patients' sexual behaviors, sexual orientations, and gender identities. Some participants, including a 27-year-old Black queer cisgender woman (ID 23), specified that they would want to receive sexual health information from providers who were specifically trained to work with AFAB sexual minority patients:

> I hope that they're trained in speaking to lesbian, bisexual, queer, trans women and just know…what sorts of things could come up in a conversation about sex, so that they're not surprised and not confused, and the patient doesn't feel like they're in a position where they have to then explain to the provider what their concern is.

Along these lines, participants expressed demographic preferences for their providers. Several preferred a woman, a few participants of color preferred a woman of color, and some preferred providers who identified as a sexual or gender minority or served these groups through their work or advocacy. Participants noted that such providers might be more relatable or better understand their sexual health needs.

School-based sex education. Some participants, especially those who identified as bisexual or queer, thought that schools could be a good place to provide sexual health information relevant to AFAB sexual minorities. One Asian queer cisgender woman (age not given; ID 24) shared:

> I feel like that knowledge is not out there, they're not teaching how to have safe sex with a strap-on 101 in sex ed. So making sex ed less heteronormative and…talking about things like gloves and dental dams in middle and high schools would probably be huge to making those things not so obsolete and not just things like weird party favors available at the health center that you're never going to use because you don't know anybody else who uses them.

Participants proposed ideas for supplementing existing sexual health curricula in schools, including by having non-profit organizations visit schools to teach additional material and by having sex education taught in community centers or other after-school destinations.

Peers. A few participants stated that they would like to receive sexual health information from similarly identified peers trained in sexual health. A 21-year-old Asian pansexual/bisexual non-binary participant (ID 12) explained that sexual or gender minority young adults may place particular importance upon the social identities of sexual health educators:

> [Getting information from a queer woman] just feels more natural because a lot of the time, and maybe it's just my experience with my queer friends, but they are really angsty about people telling them what to do because they are finally out and they can finally do whatever the hell they want…And I feel like having some White, old White woman or old White man talk to them would bring out the angst in them rather than actually get some message across.

Discussion

In this study, AFAB sexual minority participants described and critiqued numerous sources of sexual health information. They reported acquiring sexual health information primarily from the Internet; receiving some information from other mass media; and having mixed experiences with health care providers, schools, family, peers, and partners as sources of sexual health information. Participants also discussed their needs and preferences for obtaining sexual health information. In terms of informational content, they expressed two main needs: STI risk and prevention information specific to sex between AFAB sexual minorities and non-heteronormative sexual health information. In terms of informational delivery, participants' preferences largely mirrored the information sources they reported already using but with areas for improvement. They wanted to continue receiving sexual health information from the Internet but also wanted health care providers to be a key source of information. They also saw opportunities to reach SMW through school-based sex education, mass media campaigns, and peer educators.

That the Internet emerged as a typical and preferred information source is consistent with previous research among young adults and SMW. Other research has documented SMW's use of the Internet to access sexual and reproductive health information, describing online resources, in part, as a supplement to the inadequate, heteronormative information offered elsewhere.[18,62,63] On the other hand, the finding that participants wished to receive information from health care providers adds a new facet to research on patient-provider communication in this population. Existing research has focused on challenges in clinical interactions, such as issues disclosing one's sexual orientation or difficulty obtaining non-heteronormative, customized information.[51-54,87,88] Indeed, Healthy People 2020 points to the scarcity of health care providers skilled in sexual and gender minority issues as a key social determinant of health among lesbian, gay, bisexual, and transgender individuals.[89] Participants identified these concerns but also indicated a clear desire to obtain sexual health information from health care providers, if those providers are sensitive to and knowledgeable about their specific sexual health needs.

Descriptions of middle and high school-based sex education in this study align with related research among sexual minority individuals[58,90-94] in which respondents have generally reported a heteronormative bias in their school-based sex education or a lack of sex education entirely. For example, a large national survey of middle and high school students found that only 6.7% had received LGBTQ-inclusive sex education at school, and 22.4% had received no school-based sex education.[93] This is consistent with recent reporting from the Sexuality Information and Education Council of the United States,[95] which found that just 28 states require schools to provide sex education, 11 states require sex education to be inclusive of minority sexual orientation identities, and 9 states require sex education to avoid mentioning LGBTQ identities or present them negatively. Our finding that college-level sex education was described more positively is encouraging but perhaps surprising given reports of continued marginalization of sexual minority students on college campuses[96-98] and the failure to even measure provision of LGBTQ-focused sex education in the only recent, national survey we could identify related to sexual health promotion at U.S. colleges and universities.[99] It is also important to note that while our sample was highly educated, many AFAB sexual minorities may not have access to college and the sexual health information resources it affords.

Past research on SMW's sexual health communication with families is extremely limited but generally aligns with and gives context to our findings. Through interviews with a small sample of sexual minority young men and women in the Southeast United States, Estes[57] found that participants had experienced little discussion about sex at home, with the conversations that did occur focusing on heterosexual concerns. Participants in Estes' study described their parents as uncomfortable talking about sex and lacking knowledge about lesbian, gay, and bisexual sexual health. Similarly, Newcomb et al.'s focus group study[59] with the parents of lesbian, gay, bisexual, and transgender adolescents found that many parents cited discomfort and poor understanding of non-heterosexual sex as barriers to discussing sexual health with their children; the latter was especially common among parents of lesbian and bisexual cisgender girls. These findings suggest that parents' lack of comfort and knowledge may have contributed to participants in our study having received scant sexual minority-specific information from their parents.

Participants' stated need for non-heteronormative sexual health information, especially about STI risk and prevention in the context of AFAB-to-AFAB sex, supports others' findings that SMW do not know enough about their risk for STIs and how to practice safer sex with women.[22,56,67-70] For example, in Muzny et al.'s focus group study[68] with adult African American SMW in the Southern United States, many participants believed there was very little risk of transmitting STIs between women, did not know how to get and/or use preventative barrier methods, and expressed a need for reliable sexual health information. Similarly, through qualitative interviews with adult lesbian and bisexual women living in Australia, Power et al.[69] found a common perception that sex between women is safe from STI risk, especially if neither woman has ever had a male partner. Participants in that study attributed these ideas in part to the absence of sexual minority women, and the emphasis on condoms and penetrative sex, in typical sexual health information.

The present study had some limitations. First, only one person, the first author, developed the initial codes and themes, which may have introduced bias. We took multiple steps to mitigate potential bias, including organizing the data in a matrix display, which systematized the search for patterns and negative evidence;[81] acknowledging points of disagreement throughout the description of themes; iteratively discussing and refining the codebook and thematic interpretations with other members of the research team, including those who had conducted the interviews, throughout the analysis; and incorporating academically and sociodemographically diverse perspectives on the research team, including experts in the study topic and members of the study population. A second limitation is that all participants were located in a single U.S. city, all who reported education had at least some college, and most had private health insurance coverage. Thus, findings may not apply to young adult AFAB sexual minorities in other locations, such as rural areas, with different communication environments for sexual health information and different levels of support for sexual minority populations. Individuals with less education or with public or no health insurance may have different perspectives and encounter additional or specific barriers with regard to sexual health information. A third limitation is that because of sampling limitations (namely, small numbers of participants from particular social identity groups), we could make only tentative comparisons among participants in relation to race/ethnicity, sexual orientation identity, and age, and no comparisons by gender identity. More thorough examination of these dimensions may be important for understanding the sexual health information experiences, needs, and preferences of socially and economically diverse AFAB sexual minorities, including those who are multiply marginalized.

This study's findings have implications for public health research, practice, and policy. Future qualitative research should explore sexual health information issues among groups of AFAB sexual minorities not widely represented in this study, such as those with lower education levels, those without private health insurance, and those living in other geographic areas. This work should use sampling designs that allow for robust and detailed subgroup comparisons. Future qualitative research should also explore underlying reasons for the sexual health information access challenges identified in this study; for example, studies could investigate why health care providers do not always provide customized sexual health information to AFAB sexual minority patients. Findings could also be triangulated with other qualitative (e.g., sexual health information document review) and quantitative (e.g., survey) research that documents the specific types and quality of sexual health information acquired from various sources and associations with sexual health behaviors and outcomes among diverse groups of AFAB sexual minorities. Evidence from such research would help identify the best channels for sharing customized sexual health information and areas for improving sexual health communication among young adult AFAB sexual minorities.

In terms of practice and policy, our findings call for improved availability of non-heteronormative sexual health information customized to the specific needs of young adult AFAB sexual minorities, especially related to STI risk and prevention in the context of AFAB-to-AFAB sex. An important priority should be to improve health care providers' ability to share such information by bolstering their content knowledge, culturally competent communication skills, and institutional support. Existing resources at the level of undergraduate medical education,[e.g.,100] clinical practice,[e.g.,101-104] and institutional policy[e.g.,105-108] provide guidelines for medical educators, clinicians, and administrators undertaking this work. Resources related to shared decision-making and patient-centered care may be particularly helpful for improving clinicians' skills in communicating with AFAB sexual minorities and understanding their individual needs and preferences;[109,110] however, guidance specific to racially/ethnically diverse sexual minority patients is sparse and needs further development.[111-113] Policies that encourage adoption and continued development of these guidelines should be prioritized.

Other practices supported by this study's findings include offering internet-based resources, public communication campaigns, school-based sex education, and peer education, provided that these efforts are inclusive of a range of social identities and sexual behaviors. Delivering information through trustworthy online resources and social media accounts would align with how individuals already obtain information and may have large potential reach. A recent review by Wadham et al.[114] showed the wide range of web-based and other new digital media interventions that already have been developed to promote sexual health among young people, with mixed effectiveness. Approaches included online training modules, instant messaging and text messaging, social media campaigns, interactive websites, and entertainment-education videos streamed online. The authors identified strategies that seemed to be beneficial for program success, including drawing from existing programs or theory, customizing content for specific audiences, and working with communities to develop programs. Although several online programs have been developed to promote sexual health among sexual minority young men,[e.g.,115,116] we are aware of just one with content for sexual minority young women: Mustanski et al.'s Queer Sex Ed intervention.[117] This comprehensive sexual health education program was customized for sexual and gender minority youth and was found to be feasible to deliver online, positively received by participants, and efficacious for a variety of outcomes such as safer sex knowledge. These examples provide a strong starting point for developing internet-based resources that cater to young adult AFAB sexual minorities. In terms of policy, one possible strategy is to expand the online communication efforts, including informational websites and social media campaigns, of well-known government health agencies (e.g., CDC, as cited by study participants) in the area of young adult AFAB sexual minorities' sexual health. Another policy priority should be to mandate comprehensive, LGBTQ-inclusive sex education across the nation's schools. Together, these interventions may help facilitate equitable access to high-quality sexual health information that meets the unique and specific needs of AFAB sexual minorities, and in turn, help promote sexual health in this understudied and underserved population.

Chapter 2

Media Literacy and Appearance Ideals Among LGBTQ Young Adults

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Abstract

In the context of body image promotion and disordered eating prevention, media literacy may be protective against harmful appearance ideals communicated by traditional and social media. However, studies have not investigated media literacy among one at-risk group that is particularly active on social media: lesbian, gay, bisexual, transgender, and other sexual- and gender-minority (LGBTQ) young adults. This study investigated how LGBTQ young adults exhibit media literacy in conversations about body image and appearance ideals. We conducted focus groups with 30 LGBTQ undergraduate students and analyzed the data using thematic analysis. Participants demonstrated media literacy under 5 themes: 1) Media convey dominant cultural and LGBTQ appearance ideals; 2) Dominant cultural and LGBTQ appearance ideals conveyed in media shape viewers' attitudes; 3) Appearance ideals conveyed in media are unrealistic and manipulated; 4) Promotion of appearance ideals is financially motivated; and 5) Learning social media literacy is important. Findings offer critical insights about the range of appearance ideals experienced by this population and the unique roles of traditional and social media in promoting those ideals. We suggest further research on social media and media literacy for the prevention of body and eating concerns among LGBTQ young adults.

Introduction

Body dissatisfaction is a key risk factor for disordered eating[118,119] and is also associated with increased risk of depression, anxiety, impaired quality of life, and risky health behaviors.[120-125] This dissatisfaction can stem from perceived differences between one's appearance and an ideal appearance, such as is portrayed in popular media.[126] Body dissatisfaction and disordered eating are prevalent and persistent in adolescence and young adulthood,[127-131] suggesting that this is an important age range for intervention to improve body image and prevent body and eating concerns. To this end, this paper investigates media literacy, a construct that may protect against body dissatisfaction and disordered eating,[28] and appearance ideals among sexual and/or gender minority young adults, who are at increased risk for such concerns.[23,24]

Sociocultural Influences and the Role of Media Literacy

Sociocultural models of body image and disordered eating suggest that appearance ideals, or societal attitudes about what physical characteristics are attractive and desirable, shape beliefs about appearance that in turn lead to body dissatisfaction.[132,133] In the Western context in which much of this work has taken place, examples of appearance ideals include thin bodies for women and girls[133] and muscular bodies for men and boys.[134,135] According to the Tripartite Influence Model, a widely studied sociocultural model of body image and disordered eating, appearance ideals are learned through family, peers, and mass media, and they lead to body dissatisfaction via two mediating pathways: internalization (accepting and aspiring to appearance ideals) and appearance comparison (comparing one's appearance to that of peers).[25,26,136,137] While examining and intervening upon all sources of appearance ideals is worthwhile for promotion of positive body image, focusing on the role of media may be particularly critical for today's young adults, who have grown up amid profound transformation of the media environment due to technological progress.[3,138] Research has not solidified a causal link between media exposure and the development of body dissatisfaction and disordered eating; however, it is evident that media messages communicate particular appearance ideals and negatively impact some individuals (e.g., those with preexisting body concerns or those prone to comparing themselves with others perceived as more attractive).[126,139,140]

Being able to actively reject—rather than internalize and compare oneself to—the appearance ideals conveyed in media may help to protect against their potential harm.[141] Doing so requires *media literacy*, which can be defined as the set of knowledge and skills necessary to use, understand, and critically evaluate media.[27] The media literacy framework proposed by Primack et al.[142,143] explicates three domains of media literacy core concepts, summarized in Table 2.1. Interventions designed to foster media literacy for the prevention of body and eating concerns include exercises such as identifying media representations of appearance ideals, considering the strategies used to create them (e.g., image editing), and petitioning companies to promote more realistic messages.[29] Media literacy has been a part of such intervention work since at least the mid-1990s;[144] however, research on the effect of media literacy on body image and disordered eating is inconclusive.[e.g.,145-151] In their systematic review of this literature, McLean et al.[28] found some evidence that media literacy may be protective against body concerns (e.g., body dissatisfaction) but not against disordered eating. Wilksch and Wade[29] reviewed intervention studies specifically and found mixed evidence. They called for more thorough research—including more consistent, replicable programs and better understanding of which audiences can benefit (i.e., which age, gender, and eating disorder risk groups)—to justify the continued use of media literacy-based interventions. Notably, none of the studies included in

Table 2.1
Domains and core concepts from the Primack media literacy framework and corresponding themes from study findings.

Domain	Core Concepts	Study Themes
Messages and meanings	*Media messages…*	
	• Communicate values and points of view	• 1: Media convey appearance ideals
	• Can be interpreted differently from person to person	N/A
	• Can influence attitudes and behaviors	• 2: Appearance ideals conveyed in media shape viewers' attitudes
	• Are carefully constructed with various production techniques	• 3: Appearance ideals conveyed in media are unrealistic and manipulated
Representation and reality	*Media messages…*	
	• Reframe and/or filter reality	• 3: Appearance ideals conveyed in media are unrealistic and manipulated
	• Omit information	• 3: Appearance ideals conveyed in media are unrealistic and manipulated
Authors and audiences	*Authors of media messages…*	
	• Focus on particular audiences	N/A
	• May be motivated by profit and/or influence	• 4: Promotion of appearance ideals is financially motivated

N/A=Not applicable; thematic findings did not pertain to this Core Concept.
Domains and core concepts from Primack, Gold, Switzer, Hobbs, Land, & Fine, 2006; Primack, Sidani, Carroll, & Fine, 2009.

these reviews, and none that we could find across the literature on media literacy-based eating disorder prevention, focused on underserved populations such as sexual and gender minorities.

Social Media Literacy

One limitation of most existing media literacy research in the context of body and eating concerns is that it does not specifically address the influence of social media. Social media refers to a variety of web-based platforms, such as social networking sites, through which users create and share content and interact with one another.[5] It differs from traditional media, such as television and magazines, where media professionals create content for audiences to passively consume.[152] This limitation is especially concerning for young adults, a demographic that is both highly engaged in social media use[153] and vulnerable to the influence of peers (i.e., other social media users) in regard to body and eating concerns.[154] There is growing evidence of associations between social media use and body and eating concerns, with longitudinal and experimental research indicating that this relationship may be causal to some extent (see Holland and Tiggemann[155] for a review). Appearance-focused social media use, such as using highly visual platforms,[156-158] viewing pictures of attractive celebrities and peers,[159] viewing retouched Instagram photos,[160] and engaging with photos on Facebook,[161] seems to be particularly detrimental.

A few studies have begun to address the lack of attention to social media in media literacy work related to body and eating concerns.[30,141,162-165] For example, McLean et al.[30] piloted an intervention meant to foster *social* media literacy, described as critical thinking about media focused on “understanding motivations for friend and celebrity [social media] postings and the selection and modification of images to present one’s ‘best’ self.” [p. 848] In the intervention, adolescent girls who received social media literacy lessons saw significant improvements in body image, disordered eating, and media literacy relative to the control group. In an experiment with female undergraduate students, Vendemia and DeAndrea[164] found that believing women's Instagram selfies (i.e., photos taken of themselves) were digitally altered was negatively associated with thin ideal internalization. On the other hand, in an experiment with young adult women, Anixiadis et al.[163] found that thinking about media literacy concepts did not protect against the impact of thin-ideal Instagram images on negative mood and body dissatisfaction. Taken together, these studies suggest that integrating social media literacy into positive body image promotion and disordered eating prevention work is promising but warrants further study.

Addressing Health Inequities: LGBTQ Young Adults

Another limitation of existing media literacy research in relation to body and eating concerns is inattention to sexual orientation and gender identity. This is important because lesbian, gay, bisexual, transgender, and other sexual- and gender-minority (LGBTQ) populations, including adolescents and young adults specifically, are at heightened risk for body and eating concerns in comparison to heterosexual and/or cisgender populations.[23,24,166-170] (Evidence for this is somewhat inconsistent among sexual minority women; see Calzo et al.[23] for a review.) Research suggests that stress stemming from the experience of stigma and discrimination—termed minority stress due to LGBTQ individuals' marginalized minority social positions—may play a role in these disparities.[171-175] The influence of social media may be particular salient among LGBTQ young people, who spend more time on the Internet than their cisgender and/or heterosexual peers[31,176] and rely on online spaces to explore and express their identities, develop social connections, and seek information on LGBTQ issues.[31,177-180]

Incorporating a focus on sexual orientation and gender identity is therefore important for future work in media literacy to prevent body and eating concerns.

The Present Study

To better understand the role of media literacy in the body and eating concerns of LGBTQ individuals and to help establish a foundation for this avenue of prevention work, we conducted an exploratory study with focus groups of LGBTQ young adults. We investigated the research question: How do LGBTQ young adults demonstrate media literacy—particularly *social* media literacy—in conversations about body image and appearance ideals? More generally, we sought to generate useful insights on the intersections of traditional media, social media, and appearance ideals in the experiences of LGBTQ young adults. This research will inform the nascent effort to incorporate social media literacy into programs to prevent body and eating concerns, and it will offer critical information on an at-risk and understudied population. While our focus is on LGBTQ young adults, some findings from this research will also apply across sexual orientation and gender identities to young adults broadly.

Methods

Data originated from a larger, mixed-methods study that employed focus groups and an online survey. In the present analysis, we concentrated on the focus group data, and we used the survey data to describe and contextualize the focus group sample.

Participants and Procedure

We recruited participants through flyers, email listservs, social media announcements, and events at two universities in a large city in the Northeast United States. We selected these schools to provide a diversity of student experiences, with one being a private and primarily residential campus and the other being a public and primarily commuter campus; the latter also has particularly high rates of racial/ethnic diversity and first-generation college students. Study recruitment materials described the study topic as “body image for LGBTQ young people,” and some materials specifically mentioned eating disorder prevention. To determine eligibility, interested individuals completed a brief web-based screening questionnaire. Individuals were eligible to participate if they were undergraduate students at either university, were 18–30 years old, and identified as LGBTQ or reported same-gender attractions.

Data were collected from November 2017 to April 2018. Individuals who completed the screening questionnaire and met the eligibility criteria received a link to the online survey, which took approximately 15 minutes to complete. The survey measured sociodemographic characteristics, body weight satisfaction, and disordered eating and weight control behaviors. (See Table 2.2 for survey measures and response options.[181-183]) The screening questionnaire and survey were administered using REDCap (Research Electronic Data Capture).[184] After completing the online survey, participants enrolled in one of seven focus groups (four at the private university, three at the public university), each with two to six participants. Each focus group lasted approximately two hours and was audio recorded and professionally transcribed. Discussion topics included social identities, appearance ideals in general and in LGBTQ communities, sources of those appearance ideals, and preferences for body image workshops tailored to LGBTQ young adults. For example, in an activity adapted from The Body Project,[185] participants described the appearance of a “perfect person” in dominant U.S. culture, how these ideas are learned, and what the consequences of this ideal appearance are, according to media representations. After completing both the online survey and the in-person focus group discussion, participants received a $20 gift certificate to Amazon.com and a list of local resources for eating disorder treatment, health services, and support for LGBTQ youth. All study activities were approved by the Institutional Review Board of Northeastern University.

Analyses

We conducted thematic analysis[186] of the focus group data using Dedoose.[78] The first step was data familiarization, including close reading and note taking. We then created a preliminary codebook with inductive codes based on observations from the data and deductive codes based on the Primack media literacy framework[142,143] (see Table 2.1), with one code representing each core concept. To ensure accurate definitions of the core concepts for coding purposes, we drew additional details from the media literacy theories[187,188] upon which the Primack framework was based. The first author applied the preliminary codebook to the first two transcripts, refined it with input from the research team, and then applied the final codebook to all seven transcripts. She then downloaded the coded text excerpts from Dedoose and sorted them by emergent patterns to construct themes,[186] again incorporating critical feedback from the research team. We calculated descriptive statistics from the survey data using Stata 14.[189]

Researcher Positionality

To consider possible sources of bias and help ensure study rigor, we reflect on our social identities relative to the study population and prior knowledge of the topic area.[82-84] The first author identifies as a White, heterosexual, cisgender woman in her early thirties. She studies public health, focusing on health communication and qualitative methods, and has completed coursework and research in LGBTQ health. The senior author identifies as a White, queer, cisgender woman and parent; she has expertise in LGBTQ adolescent/young adult health and qualitative methods for public health research. In this study, the senior author conducted the focus groups with assistance from the first author, and the first author led the data analysis.

Others on the research team consulted on analysis and interpretation, lending further expertise in health communication, developmental psychology, and LGBTQ health.

Results

Sample Characteristics

Characteristics of the study sample (n=30) are presented in Table 2.2. Participants' mean age was 19.70 years (*SD*=2.23). The majority identified as non-Hispanic White (63%, *n*=19) and as cisgender women (60%, *n*=18). Participants reported a variety of sexual orientation identities, the most common being bisexual (30%, *n*=9) followed by pansexual (17%, *n*=5), lesbian/gay (17%, *n*=5), and queer (13%, *n=4*). Participants on average reported a moderate level of body weight satisfaction (response options 1–5 with higher scores indicating greater satisfaction, *M*=2.71, *SD*=0.99). One third of participants (33%, *n*=10) reported engaging in a disordered eating or weight control behavior at least monthly in the past year. The most commonly reported behaviors were binge eating (27%, *n*=8) and fasting to control weight (13%, *n*=4).

Thematic Findings

The thematic analysis examined how participants demonstrated media literacy in focus group conversations about body image and appearance ideals. Broadly, we found that participants identified media as sources of appearance ideals (Theme 1) and understood that those ideals shape viewers' attitudes (Theme 2). Participants described ideals as unrealistic and described how they were promoted, in part, through manipulated appearances depicted in media (Theme 3). Participants recognized that media producers who communicate appearance ideals may be financially motivated (Theme 4). Finally, participants agreed that social media topics should be included in body image workshops (Theme 5). Participants discussed LGBTQ issues explicitly in themes 1, 2, and 5. In the sections that follow, we describe each theme in detail

Table 2.2

Sample characteristics (N=30)

Characteristic	n (%)	Mean (SD)	Median (IQR)
Age (years)	-	19.70 (2.23)	19 (19–20)
Sex assigned at birth			
Female	27 (90)	-	-
Male	3 (10)	-	-
Gender identity			
Cis woman	18 (60)	-	-
Nonbinary, genderqueer	6 (20)	-	-
Trans man, transmasculine	3 (10)	-	-
Cis man	2 (7)	-	-
Agender	1 (3)	-	-
Sexual orientation			
Bisexual	9 (30)	-	-
Pansexual	5 (17)	-	-
Lesbian/gay	5 (17)	-	-
Queer	4 (13)	-	-
Mostly straight/heterosexual	3 (10)	-	-
Questioning	2 (7)	-	-
Another (e.g., asexual)	2 (7)	-	-
Race/ethnicity			
Non-Hispanic White	19 (63)	-	-
Latinx or Hispanic White	4 (13)	-	-
Asian or Asian American	4 (13)	-	-
Black or African American	2 (7)	-	-
Multiracial	1 (3)	-	-
School			
Private university	19 (63)	-	-
Public university	11 (37)	-	-
Subjective socioeconomic status[a]	-	6.17 (1.74)	6.5 (5–7)
Body mass index (kg/m^2)[b]	-	25.01 (7.17)	22.94 (19.57–28.25)
Body weight satisfaction[c]	-	2.71 (0.99)	2.71 (1.71–3.29)
Disordered eating and weight control behaviors[d]			
Binge eating	8 (27)	-	-
Fasting to control weight	4 (13)	-	-
Taking laxatives	2 (7)	-	-
Making self throw up	0 (0)	-	-
Taking diet pills without a doctor's advice	0 (0)	-	-
Any disordered eating or weight control behavior	10 (33)	-	-

SD=standard deviation; IQR=interquartile range

[a] Measured using the socioeconomic status version of the MacArthur Scale of Subjective Social Status (Adler & Stewart, 2007; Adler, Epel, Castellazzo, & Ickovics, 2000). Participants selected their position on a 10-point scale representing the worst-off (1) to best-off (10) people in the United States in terms of money, education, and employment.

[b] Calcuated using self-reported height and weight. An outlier value of 48.24 kg/m^2 accounts for the large standard deviation.

[c] Measured using 7 items from the *Body Esteem for Adolescents and Adults, Weight Subscale* (Mendelson, Mendelson, & White, 2001). Response options ranged from 1 to 5 with higher scores indicating greater body weight satisfaction.

[d] Defined as having engaged in the behavior at least monthly in the past year, by self-report.

and note its relation to media literacy constructs from the Primack framework[142,143] when applicable (summarized in Table 2.1). We attribute all direct quotes to participants using bracketed group and participant numbers (e.g., [G2.P6]) to illustrate the range of perspectives informing the findings.

Theme 1: Media convey appearance ideals. One of the core concepts from the Primack framework is that media messages communicate specific values and points of view.[142,143] Participants showed an understanding of this concept when they identified the set of appearance characteristics that traditional media and social media portray as desirable and the viewpoints from which these media depict LGBTQ appearance ideals.

Subtheme 1.1: Media convey dominant cultural appearance ideals. When asked to describe the appearance ideals of a “perfect person” in dominant U.S. culture, participants listed characteristics such as a lean physique, straight teeth, shiny hair, and unblemished skin. All groups gave examples of Eurocentric appearance ideals, most explicitly light-colored skin. In two groups, participants also noted that dominant U.S. culture increasingly values the curvy physique that they described as typical of African American feminine appearance ideals, or a combination of features that they described as racially “ambiguous.” Participants tended to differentiate characteristics by binary gender norms (i.e., women vs. men), which some called out explicitly. As one participant said, the culturally perfect person is “either masculine or extremely feminine. On extremes, like there’s no room for androgyny.” [G5.P4] When asked how these appearance ideals are promoted, participants consistently pointed to various forms of traditional media, such as advertising, as well as peer- and celebrity-generated social media. One participant summarized it this way: “I feel like the obvious ones like the radio, TV, magazines [promote appearance ideals], but now I feel like it’s way more social media” [G4.P2]

Participants said that media messages convey the idea that embodying an ideal appearance leads to positive outcomes like happiness, wealth, and popularity. For example, one participant described seeing the following media message: “We’ll get everything we want. We’ll get the guy we want, we’ll get the girl we want, we’ll get the car, get the job…acceptance in general in society within families, within friends, within everything.” [G6.P3]

Subtheme 1.2: Media convey LGBTQ appearance ideals. We also asked each focus group to describe appearance ideals within LGBTQ communities. Their responses conveyed a mix of LGBTQ stereotypes and community norms. Many discussed the idea of specific, contrasting “types” or sets of appearance ideals within particular sexual orientation identities. For example, one participant said: “Just very stereotypically, I feel like both gay and lesbian can have two categories…for gay it can be either very masculine or very flamboyant gay, and then for lesbian there’s very butch lesbian…” [G6.P2] Another participant completed this thought, saying, “And then there’s femme.” [G6.P1] A participant in a different group described attractive types among gay men as “the ‘twink’ where you’re small or the ‘jock’ where you’re tall and big and muscular.” [G3.P2] Participants suggested that under these typologies, the masculine gay type and the femme lesbian type align generally with dominant appearance ideals for men and women. Some suggested that under community norms, ideals for lesbian women are less rigid than those of gay men and less rigid than is suggested by the butch/femme framing. For example, one participant said, “you can have anyone in the middle [of butch and femme] or none of that at all, too, and they’d still be considered beautiful.” [G3.P1] A few participants noted stereotyped ideals for bisexual women to be highly feminine and sexually provocative. One participant said, “It’s not true but I feel that the perfect appearance for bisexual women is to be sexual. A sexual object.” [G5.P1] Participants did not specify appearance ideals for bisexual men.

Gender nonbinary appearance ideals were not widely discussed; when they were, they were described as being slim, androgynous, and White race/ethnicity. Appearance ideals for transgender men and women were generally described as aligning with dominant masculine and feminine ideals, respectively, and in particular 'passing' or being perceived as cisgender. One participant said, "I think a lot of people…judge trans people's attractiveness by their ability to assimilate as cis, and…if you're clocked [recognized] as trans, there's something less attractive about you." [G2.P6]

When asked about the sources of appearance ideals in LGBTQ communities, participants discussed both traditional media and social media but described them in different ways. Participants said that traditional media, specifically television and film, largely shows stereotypes and mainstream expectations for how LGBTQ people should look and act, presenting LBGTQ characters in superficial ways that entertain heteronormative and cisnormative audiences (e.g., through comedy or sexualization of women). As one participant said, "[On the television show] Queer Eye, you see five gay men and how fabulous they are…Or if you're watching a movie with college kids or something, they're encouraging girls to hit on other girls when they're hyper feminine." [G7.P2] In notable contrast, one participant praised the show Brooklyn 99 for its bisexual Latina character played by a bisexual Latina actress (Stephanie Beatriz), saying, "I almost cried watching it because it was so accurate to my own coming-out story." [G3.P1] Traditional media celebrities were occasionally mentioned as sources of LGBTQ appearance ideals. Examples included musicians Beyoncé and Cher, who one participant described as iconic among transgender women, and the genderfluid model and actor Ruby Rose, who participants said exemplifies androgynous appearance ideals.

In discussing social media as a source of LGBTQ appearance ideals, participants focused more on community norms (given that social media content is created by users) and acknowledged pros and cons. A few noted that social media depicts personal stories of LGBTQ people. Participants in one focus group described this as a way for LGBTQ users to learn about their identities. At the same time, several participants said that social media, especially dating apps, promote a limited set of appearance ideals. As one participant said, "I like that the Internet exposes you to a lot more because I wouldn't have been exposed [to LGBTQ content] at all if it weren't for the Internet. But…they do have very idealized versions of these things." [G6.P2] Another participant in this focus group described social media as a particularly potent source of LGBTQ appearance ideals because of its implied authenticity:

> I think it's a lot easier to put [ideals] in your head when you're seeing online posts because there's still a lot more of an implication that what you're seeing online, on social media, is realer than what you're seeing on television. [G6.P4]

Participants described social media posts about transgender individuals' transition experiences as an important source of appearance ideals for that community. For example:

> I see a lot of trans people who document their transitions, like once they start taking hormones and stuff. So I think a lot of ideals…are promoted by trans people who transition and they're like, 'Oh hey look at me I'm taking hormones, look at my progress the first month to a year to three years later!' So it's kind of a cool thing but it also encourages the ideal that trans people have to transition to be valid. [G7.P3]

One particular social media category, dating apps used by sexual minority men (e.g., Grindr), was mentioned numerous times as a source of harsh and discriminatory appearance ideals for gay men. One participant said of Grindr, "It's a very superficial app in general, and you'll see people's profiles, like, 'no fats, no femmes, no insert race here.'" [G3.P2]

Theme 2: Appearance ideals conveyed in media shape viewers' attitudes. In addition to identifying the role of media in promoting appearance ideals, participants demonstrated an understanding that these ideals can be internalized and negatively influence the thinking of those who view them. They provided examples of how the dominant cultural and LGBTQ appearance ideals depicted in media affect what people find attractive and expect others and themselves to look like. This exemplifies the Primack framework core concept that media messages influence attitudes and behaviors.[142]

Subtheme 2.1: Dominant cultural appearance ideals conveyed in media shape viewers' attitudes. While some participants reported rejecting dominant cultural appearance ideals, many acknowledged internalizing and being influenced by them. As one participant said, "It's been pushed for so long in my life that I think that those things are attractive, and I wonder how much my opinion would be different if the media portrayed different standards of beauty." [G3.P3] Some participants talked about feelings of body dissatisfaction that result from exposure to appearance ideals. One stated, "society is forcing all of these body ideals on us to a point where we don't know what we want our bodies to look like, we just know we shouldn't be happy with our bodies as they are right now." [G6.P1] Participants also discussed how dominant cultural appearance ideals conveyed through social media, specifically, lead to unhealthy social comparison. For example, one participant said:

> I've dealt with people in my past relationships looking up to these Instagram models or something and they'll come to me and be like, 'Well I don't look like that, they look way better.' And then I have to deal with their insecurities because of the social media aspect, just social media alone. And I think it's just alarming. [G7.P2]

Subtheme 2.2: LGBTQ appearance ideals conveyed in media shape viewers' attitudes. Participants also discussed the negative influence of LGBTQ ideals conveyed in media. They described effects on the attitudes of society generally and of LGBTQ people themselves. In terms of society generally, some discussed how traditional media's limited representation of LGBTQ people makes it difficult for the general public to understand or accept LGBTQ individuals. One participant suggested this in relation to celebrity Caitlyn Jenner, who came out publicly as transgender in 2015:

> When Caitlyn Jenner transitioned, everyone was talking about it like it was this huge deal…People just couldn't wrap their minds around the idea of being transgender. They often confuse it with drag queens like RuPaul's Drag Race, and that's the acceptable form of cross-dressing when it's for entertainment and when it's for laughs…but I guess society never quite caught up to accepting trans people. [G6.P3]

Several participants noted that LGBTQ individuals who do not conform to the expectations depicted in media risk having their sexual orientation and/or gender identities misinterpreted or challenged by others. For example, one participant said, "there's this kind of standard stereotype of what [LGBTQ people] might look like, and if you don't look like that you are kind of questioned, like, 'are you really?' or 'is this just something you're saying to get attention?'" [G3.P3] This participant specified that such pressure to conform comes from both insiders and outsiders of the LGBTQ community, but especially the latter.

A few participants gave examples of LGBTQ ideals on social media influencing LGBTQ individuals. For instance, one participant described the effect of social media imagery on gay youth beginning to explore their sexual orientation identities:

> [Social media is] where a lot of the ideals are coming from because they probably don't have any gay friends. They're questioning if they're gay or not and now they're seeing all these pictures. And it's like, 'oh okay I can either be very muscular or very thin, because that's the right way to do it!' [G6.P4]

Some noted that LGBTQ appearance ideals communicated on dating apps could make users feel insecure about their appearance or pressured to look a certain way. For example, one participant imagined this happening on Grindr: "it's like 'well I only want this ethnicity, this weight, this length…' I think you'd be like 'that really hurts and now I feel sad.' That might be a huge reason for an increase in LGBTQ eating disorders." [G4.P1]

Theme 3: Appearance ideals conveyed in media are unrealistic and manipulated. Core concepts from the Primack framework are that media messages are carefully constructed and may distort reality through reframing, filtering, and omission.[142,143] Participants widely agreed that the appearance ideals promoted in media messages reflect a manipulated version of reality, demonstrating their understanding of these core concepts.

Participants described the appearance ideals depicted in media as unrealistic and impossible to achieve. For example, after one focus group listed dominant appearance ideals, a participant described them as "Utopia. Not attainable…you can't be all of those things." [G3.P3] Another participant responded, "At the same time it's almost expected…I feel like I am disappointing people when I don't look like this, but it's not even possible to." [G3.P5] A few focus groups spoke specifically about unrealistic body shapes idealized for women, which one participant described as "basically having some weight. But only in the right places, which isn't naturally realistic because you're gonna gain weight everywhere." [G2.P4]

Participants identified three types of manipulation that promote unrealistic appearance ideals: selective sharing of content, digital manipulation of images, and physical manipulation of bodies. The first type, selective sharing of content, was mentioned only a few times and pertained specifically to social media. Participants described how celebrities and peers intentionally select what to post and omit on their social media accounts. For example, a participant in one focus group said, "Very few people actually say on social media what's actually going on in their life or they're actually really experiencing…You're very selective about what photos you post and what they show about you and what parts of you they show and how they portray yourself." [G2.P2] In another focus group, a participant described this idea in the context of dating apps, saying, "You feel like you want to perfectly capture yourself online—

picking the right pictures that make you look attractive and writing the correct bio to make yourself sound appealing." [G3.P2]

The second type of appearance manipulation identified by participants was digital manipulation of images. When asked how appearance ideals are promoted, one participant said, "Well in magazines you often see people Photoshopped. Say they have more melanin—they'll make them look lighter." [G3.P4] Another participant added that image manipulation also happens on celebrities' social media: "Celebrities' Instagram accounts make it look like they just happen to take this beautiful picture but they really spent hours editing it and choosing the right one and all that." [G3.P3] Other focus groups noted that new technologies have made image manipulation available to everyday users. As one participant said, "Now there's even apps that anyone can use to alter their face and alter their body…if you want to change how you portray yourself online, you can do that." [G4.P6] In another group, participants discussed "selfie cameras" on smartphones and social media platforms, such as a Snapchat filter that one participant described as making "your eyes bigger and your nose a little narrower." [G2.P5]

Finally, the third type of appearance manipulation identified by participants was physical manipulation of bodies themselves. Participants brought up topics like makeup, dermatologic treatments, and cosmetic surgery in relation to celebrities and popular social media users. For example, one participant said of young women on Instagram, "They're like gorgeously tan, they're toned, so they have abs, the hourglass curvy figure and absolutely flawless face…how much of that is actually real?…People can [have] lip fillers, cheek fillers, jaw reconstruction, hair extensions, false eyelashes, there's a whole list." [G5.P2] Participants noted the ideal of maintaining a "natural" appearance even while manipulating one's body. For example, during a discussion of makeup trends on YouTube, one participant observed that products are promoted to "enhance your natural body so that everyone thinks you're natural but you're not." [G6.P2]

Theme 4: Promotion of appearance ideals is financially motivated. Participants identified financial motivations behind media that depict appearance ideals, reflecting the Primack framework core concept that the creators of media messages may have motivations tied to profit and/or influence.[142,143] One participant explained:

> Instagram models make a killing like with money…It's advertising, so it's all in the clothes or the products that they use. So for example, one of my best friends she's actually Instagram famous, so people send her clothes. And she'll be like, 'ladies, do you like this body corset? I got it through here.' And then you just tag the page and that's how you make money…if you're pretty, you're rich. [G5.P4]

This participant and others in the focus group suggested that most Instagram users are unaware or uncritical of the idea that Instagram models make money for their posts. A fellow participant commented on the trend of celebrities marking promotional posts with the disclosure hashtag *#ad*: "I'm pretty sure people don't actually read that much into it. They're just like, 'oh they're using it, this person, they're trustworthy' and just form a conception about the product." [G5.P2]

In another focus group, participants discussed traditional advertisements in relation to appearance ideals and financial motivations. As one participant mused, "Some lady will be advertising a bottle of soda or something and she'll be toned and muscular and wearing a bikini or something. It's like, you're selling me soda—why is this person like this?" [G6.P1] Another participant responded, "Pretty much anyone who wants to sell you something will have ideal people on their advertisements." [G6.P4]

Theme 5: Learning social media literacy is important. Toward the end of our focus group sessions, we asked participants whether the topic of social media should be included in body image workshops and discussions. Participants answered affirmatively and pointed to the unique role of social media in their daily lives. Some focused on the apparent ubiquity of social media. As one participant said, “I think it would be extremely important to include only because it seems like everybody's obsessed with social media and obsessed with how you are perceived on social media.” [G2.P3] Another participant stated, “I think most adolescents and young adults know that social media can be toxic but it’s also not a part of their life that they’re willing to just give up. So if there’s something that they can do to change the culture of it I think that’s really important.” [G4.P6]

A few participants noted that social media serves important purposes for certain groups of users. One pointed out that it can be necessary for certain lines of work, adding, “Social media is becoming more and more of a living requirement for a lot of people, so it’s good to be critical of what we see on there.” [G2.P4] Another participant described social media as a resource for identity exploration among LGBTQ young people, saying, “I feel like social media at this point in time, is very much the go-to for people who are questioning…that’s where a lot of the information is coming from.” [G6.P4] These comments express participants’ belief in the importance of social media literacy skills as social media use is increasingly pervasive.

Discussion

This study used thematic analysis of focus group data to examine how LGBTQ young adults demonstrate media literacy, especially social media literacy, in discussions about body image and appearance ideals, and how these constructs were sometimes related to their experiences as LGBTQ community members. We found that participants demonstrated an understanding of many media literacy concepts. They pointed to media as sources of appearance ideals and gave examples of how those messages affect viewers’ attitudes. They described how media depict unrealistic ideals based on manipulated appearances, and they recognized the financial motivations that motivate media creators to perpetuate appearance ideals. In addition to these media literacy themes related to the Primack framework,[142,143] we also found that participants support discussion of social media in body image workshops. Indeed, the significance of social media was apparent across themes.

It is worth noting that two media literacy concepts from the Primack framework[142,143] did not emerge in the thematic findings (Table 2.1): that media messages can be interpreted differently from person to person, and that authors of media messages focus on particular audiences. It is possible that our participants were unaware of these media literacy concepts. However, considering participants' overall strong demonstration of media literacy, it seems more likely that these concepts were simply less pertinent to the topic and discussion prompts at hand. Clarifying LGBTQ young people's understanding of the latter concept may be particularly important given that sexual minority groups have long been key audiences for marketing messages.[190] Future research could explore this group's experiences and literacy around targeted marketing in traditional and social media as it relates to appearance ideals.

Other qualitative studies[165,191,192] and thought-listing experiments[146,163,193] have also found that, with basic prompting, adolescents and adults display at least some appearance-related media literacy. For example, in a focus group study about social media and body image with early adolescent girls, Burnette et al.[165] found high levels of media literacy in their sample. Participants acknowledged that viewing peer- and celebrity-generated social media leads to appearance comparisons, and they described both social and traditional media as artificial and heavily edited. Young men and women in Easton et al.'s qualitative study[191] described fitness content on social media as unrealistic and untrustworthy, noting that it relies on production techniques like good lighting, shows only highlights of users' lives, and may have ulterior (e.g., financial) motives. In Anixiadis et al.'s experiment,[163] young adult women were shown thin-ideal Instagram images and asked to share what came to mind. Many listed thoughts that exhibited media literacy; for instance, 49.5% of participants said that the photo was intentionally posed, and 30.8% said that the photo seemed altered in some way. The present study extends these previous findings to show how a young adult LGBTQ sample demonstrates media literacy in relation to appearance. In doing so, it documents critical insights about the intersections of media and appearance ideals in the daily lives of LGBTQ young adults.

Participants in this study spoke fluently about both dominant cultural appearance ideals and LGBTQ appearance ideals and the ways in which these ideals affected them. Their comments indicate that LGBTQ young adults regularly navigate dominant cultural appearance ideals in tandem with an array of LGBTQ appearance ideals, with the latter coming from both within and outside of the LGBTQ community. Further, LGBTQ appearance ideals are sometimes structured by dominant cultural appearance ideals (e.g., norms of masculinity and femininity) and other times stand in stark resistance to them (e.g., nonconforming gender expression). Several other qualitative studies have also found that LGBTQ participants are aware of and feel pressure to conform to appearance ideals originating from dominant culture, LGBTQ culture, or both.[194-202] For example, in interviews with sexual minority women in the United Kingdom, Smith et al.[194] found that most participants were dissatisfied with their bodies and aspired to a thin and toned "heteronormative" body ideal. They also noted norms related to appearance in LGBTQ spaces, and some found that conforming to these norms was important for acceptance within the community. The multiple layers of appearance ideals described in our study and others suggest that young people with marginalized identities may have to cultivate a particularly complex media literacy that is robust to several overlapping sets and sources of ideals. While media literacy research in the area of body and eating concerns has to this point not focused on diverse populations, future work could explore this idea with LGBTQ groups and others with marginalized identities.

Reflecting basic tenets of the Tripartite Influence Model,[25,137] participants described media sources of appearance ideals and shared ways in which they and their peers had internalized and compared themselves to these ideals. However, study findings also highlight two limitations of the Tripartite Influence Model in describing the current media environment in relation to appearance ideals. First, because social media is founded on peer-generated content and interpersonal communication, it serves as both a media influence *and* a peer influence. (It may also function as a family influence, though participants in this study did not discuss communicating with family members on social media.) Thus, the three parts that give this model its name are not clearly delineated in the context of social media. Second, the directionality of media influences is complicated: social media users are not just exposed to media messages; they also produce them. Future work should seek to clarify the role of social media—and the position of its users as both recipients and creators of media messages—in the Tripartite Influence Model.

When it came to sources of LGBTQ appearance ideals specifically, participants described traditional media as portraying LGBTQ people in superficial, often stereotyped ways that entertain cisnormative and heteronormative audiences and shape their expectations of how LGBTQ people look. Participants described social media in mixed terms: they noted that it offers personal stories and information about LGBTQ identities, but that it also promotes a limited set of appearance ideals, which can be harmful. Dating apps, especially those catering to sexual minority men, were mentioned frequently in this regard. These assessments of LGBTQ representation and appearance ideals in media in some ways align with other research findings.

While LGBTQ identities are increasingly visible on television and portrayed in positive ways, not all subgroups are adequately represented, and stereotypes remain.[203,204] In a recent qualitative study, McInroy and Craig[205] found that LGBTQ young adults appreciated traditional media's role in validating LGBTQ identities and bringing them into public dialogue, but they described portrayals as stereotyped and limited in their depiction of specific LGBTQ subgroups and other social identities. In contrast, they described new media, such as the Internet and social media, as a creative space where young queer users can shape the content and discussion. This fits with a growing body of research that suggests that LGBTQ young people, who are avid users of the Internet and digital technologies,[31,206] rely on online spaces to explore and express their identities, access supportive communities and resources, and connect with peers.[31,180,207-211]

At the same time, there is substantial evidence to suggest that using social media has a damaging effect on body and eating concerns for both general and LGBTQ populations, especially when that social media use is focused on appearance.[155-161] Using dating apps is associated with negative outcomes related to body image and unhealthy weight control behaviors in general populations[212-214] and with lower self-esteem and other negative psychosocial outcomes in some sexual minority men.[215,216] There is also a well-documented phenomenon of dating apps used by sexual minority men, such as Grindr, promoting stringent appearance ideals, body objectification, and discrimination.[199,217-219] Taking this research evidence together with our findings, we posit that LGBTQ young adults who use social media may face a tension between its identity-affirming, information-sharing, and social connection benefits and its risks related to body and eating concerns. Further, just as others have suggested that the visibility and validation offered by targeted tobacco marketing may make LGBTQ audiences particularly vulnerable to it,[220] we suggest that the importance of social media to some LGBTQ young adults may make them especially susceptible to its risks in relation to body and eating concerns.

This study had some limitations that are important to acknowledge. The first author coded the transcripts and developed the themes as a single analyst, which may have introduced bias. We tried to mitigate this by 1) coding based on an existing, clearly defined media literacy framework and 2) checking themes with the analysis team including the senior author, who facilitated the focus groups and is deeply familiar with the data. Another limitation is that the sample had limited racial/ethnic and gender diversity, with the majority of participants identifying as non-Hispanic White and as cisgender women. The sample was also drawn from two universities in a single U.S city. Findings may have limited applicability to LGBTQ young adults with other sociodemographic characteristics. For example, this study might not have captured issues related to the particular media consumed by social identity groups who were not well represented in the sample. University students may have stronger media literacy, or stronger critical thinking skills in general, than peers with less education. Finally, it is possible that by advertising the study's focus on body image and eating disorders, we attracted participants who were already interested in or knowledgeable about media issues pertaining to body image.

An important goal of this exploratory study was to generate suggestions for future research related to media literacy for the prevention of body and eating concerns. First, the prominence of social media in participants' discussions, oftentimes without specific prompting, was noteworthy. This supports increased focus on social media in body and eating concern research and intervention development with young adults generally, building on work that has already been done in this space.[e.g.,30,155] Participants' comments also support further study of dating app use in the context of young adult body and eating concerns. For instance, to our knowledge no studies have yet examined the effect of social media literacy on the association of dating app use with body and eating concerns.

Second, study findings support the development of body and eating concern prevention interventions that foster media literacy, including social media literacy specifically, with LGBTQ young adults. Even though participants in our study demonstrated media literacy, we could not establish that all participants thoroughly understood all the concepts, and it was not clear that participants regularly critique media messages as they see them (versus just when prompted in a focus group setting). Interventions could work to develop these skills, but they must be thoughtfully adapted to meet the specific needs of LGBTQ young adults, including subgroups within this population. Content should reflect the many types and sources of appearance ideals listed above and their intersections with harmful stereotypes and stigma. Content should also consider the unique and sometimes beneficial role that social media may serve in the lives of LGBTQ young adults. Finally, given that the evidence base for such interventions is still being established and is extremely limited for social media literacy and for LGBTQ populations, high-quality evaluation plans as described by Wilksch and Wade[29] are essential.

Third, future qualitative research should investigate issues related to media literacy, social media literacy, and appearance ideals in LGBTQ populations that were not well represented in this sample in terms of sexual orientation identity, gender identity, race/ethnicity, and education level. For example, one participant in our study suggested that appearance ideals on social media may be particularly influential for individuals who are questioning their sexual orientation identity, but only 7% of our sample described themselves that way. It might be helpful to explore this idea—and the role of social media literacy in this context—with individuals who are actively questioning their sexual orientation identity.

The findings of this exploratory study shed light on important issues of media literacy and appearance ideals in the everyday experiences of LGBTQ young adults, a group that disproportionately suffers from body and eating concerns. Participants demonstrated media literacy in discussing the media sources of appearance ideals that affect them. The insights they shared, especially around social media, can shape future media literacy interventions and research in efforts to prevent body and eating concerns in this population moving forward.

Chapter 3

Young Adult Cancer on Instagram: A Qualitative Content Analysis

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Abstract

Background: Young adult cancer survivors face numerous physical and psychosocial challenges throughout the trajectory from diagnosis to long-term survivorship. Research suggests that survivors use social media to discuss these concerns and meet some of their cancer-related support needs. However, little is known about the role of Instagram, a social media platform that is popular among young adults, in this context.

Objective: The goal of this study was to describe Instagram content related to young adult cancer, with a particular focus on content that young adult cancer survivors share about their individual cancer experiences.

Methods: We manually collected a sample of 331 publicly available Instagram posts with the hashtag #youngadultcancer that were posted from September to November 2019. We conducted qualitative content analysis by developing and applying two inductive coding schemes. The first coding scheme focused on key characteristics of the posts and their primary functions and was applied to all posts. The second coding scheme focused on cancer-related thematic content and was applied only to a subset of posts (those posted by individual cancer survivors with the primary function of "documenting life", n=145).

Results: Posts were posted by three types of users: individuals (n=207, 62.5%), groups (n=102, 30.8%), and meme accounts (n=21, 6.3%). Of the individual users, most were women (n=197, 95.2%) and cancer survivors (n=194, 93.7%); very few were health professionals (n=8, 3.9%). Of the cancer survivors, the most common cancer types were breast (n=96, 49.5%), blood (n=27, 13.9%), colorectal (n=23, 11.9%), and thyroid (n=13, 6.7%). Posts had five primary functions: documenting life (n=161, 48.6%), publicizing/fundraising (n=95, 28.7%), raising awareness (n=30, 9.1%), sharing a meme or viral graphic (n=25, 7.6%), and selling/promoting (n=17, 5.1%). Six cancer-related themes emerged in the subset of posts in which cancer survivors documented their lives: cancer care in the present time (n=86, 59.3%), support (n=57, 39.3%), philosophy/mindset (n=47, 32.4%), cancer care in the past (n=43, 29.7%), appearance/body image (n=43, 29.7%), and discussion prompts (n=31, 21.4%).

Conclusions: Instagram is an active site of communication about young adult cancer that offers a glimpse into some survivors' experiences. We propose several needs that young adult cancer survivors might meet by using Instagram in relation to cancer. We also identify implications for future research and for clinical and public health practice.

Introduction

An estimated 83,700 individuals ages 20–39 years will be newly diagnosed with cancer in the United States in 2020.[221] Critical efforts by the National Cancer Institute beginning in 2006[222] have led to a proliferation of research that recognizes young adults as distinct from pediatric and older adult cancer survivors in terms of the biological and psychosocial experience of cancer and its repercussions.[223] One area where research gaps remain is supportive care for young adult cancer survivors' health-related quality of life, encompassing the physical and psychosocial health impacts of cancer and challenges returning to school and work.[223] Recent studies have observed that young adult cancer survivors use social media to discuss these concerns and meet some of their supportive care needs.[33,34,224-226] However, little of this research has been conducted using Instagram, a social media platform that is particularly popular among young adults.[8] In this study, we examined content related to young adult cancer on Instagram to explore the use of Instagram as a cancer communication platform and its role in helping young adult cancer survivors meet their cancer-related support needs. (A terminology note: Throughout this paper we define "cancer survivors" as anyone living after being diagnosed with cancer,[227] but we acknowledge that this is not universally accepted within the cancer community. We define "young adults" roughly as ages 18–39 years, but we acknowledge variation in the research literature [e.g., 223,228] and cite references that use other age ranges, as necessary and appropriate.)

Cancer in Young Adulthood

Types of cancer most commonly diagnosed in young adults include thyroid cancer, breast cancer, lymphomas, leukemia, testicular cancer, brain cancer, melanoma, sarcomas, colorectal cancer, and gynecologic cancers.[221] While cancer is a top cause of disease-related death in this age group,[229] the overall five-year relative survival rate for 15 to 39-year-olds with cancer is high at 86%.[230] In the trajectory from diagnosis to long-term survivorship, young adults must navigate many of the same challenges as older adults with cancer, such as learning about their disease, enduring treatment, monitoring long-term health risks, and coping with psychological concerns.[32,231] In addition, they must undergo developmental tasks of adolescence and early adulthood. As Zebrack[232] describes, these include developing one's identity, independence, educational and/or career paths, body image, social and romantic relationships, and family plans—all of which can be seriously disrupted by the physical and psychosocial stressors of cancer diagnosis and treatment.

Studies have found that many young adult cancer survivors struggle with these challenges and have unmet needs related to managing them.[233,234] In a large survey of recently diagnosed survivors ages 15–39 years, a majority of respondents reported unmet informational needs relating to cancer recurrence, treatment options, and long-term side effects of treatment. In the same study, among those indicating a need for seeing a mental health care provider and participating in a support group (27.5% and 19.2% of respondents, respectively), more than half said these needs were not met.[235] In another example, a longitudinal study with survivors ages 15–29 years examined changes over time in four social domains: living with parents/guardians, financial independence from parents/guardians, working status, and educational status. Results indicated that many participants were worse off in these domains after being diagnosed with cancer (compared to 6 months prior to diagnosis), with 65% of participants still worse off in at least one domain a year after diagnosis. The authors suggested that clinicians should help patients anticipate these impacts and connect them with supportive services.[236]

Social Media and Young Adult Cancer

One way in which young adults with cancer might address some cancer-related information and support needs is by turning to social media. Aichner and Jacob[5] define social media as “web-based applications and interactive platforms that facilitate the creation, discussion, modification and exchange of user-generated content,” [p. 258] including social networking sites, video and photo sharing sites, social gaming, blogs, and forums, among others. According to the Pew Research Center, nearly all U.S. young adults ages 18–29 use the Internet,[6] and 90% use social media.[8] For young adults with cancer, there are many available options for creating and engaging with cancer content and connecting with peers online. Types of social media that survivors use in relation to cancer include online forums and support communities, personal blogs, and social networking sites.[237,238] Several groups that serve young adults with cancer, such as non-profit organizations and specialized medical centers, are also active on social media.[238]

Uses and gratifications theory from the field of communication proposes that individuals intentionally select media to use in order to meet their particular needs.[239,240] Research by Whiting and Williams[241] suggests multiple needs that individuals satisfy by using social media: social interaction, information seeking, passing time, entertainment, relaxation, expressing opinions, identifying topics to discuss with others, convenience, sharing information about themselves, and observing others. Further, as one might expect given differences between social media platforms, the specific motivations for using social media vary from one platform to another.[36,242]

In the context of young adults with cancer, a uses and gratifications perspective illuminates how social media use may serve specific purposes. Cancer survivors in a few studies have reported using social media to meet informational and psychosocial needs related to cancer.[33-35,243,244] For instance, in a qualitative study with survivors ages 13–24 years in England, participants described using Facebook to connect with other survivors and find information about cancer-related social events; using an online forum to find coping strategies and peer support; using WhatsApp to chat with family, friends, and other cancer patients; and using YouTube to watch videos about cancer procedures, patient stories, and well-being topics.[33] Analyses of cancer-related content on blogs,[224,225,245] online forums and support communities,[226,246,247] and social networking sites[37,248-251] have observed that these platforms are used to exchange information and emotional support, document cancer experiences and challenges, explore and express identities, process thoughts and emotions, and raise awareness about cancer issues. Finally, aside from research on cancer specifically, evidence suggests that adolescents and young adults use social media to engage in developmental tasks such as developing social relationships and forming identity,[252,253] as well as to learn about health topics and find others with similar health concerns.[9]

Despite these ways in which social media may benefit young adult cancer survivors, it may also pose health risks. Evidence from general populations finds that social media use is associated with psychosocial concerns such as mood and body image issues among some users.[e.g.,10,11,161,254,255] Social media can be a source of health misinformation[248,256-258] and other content that may be harmful to health.[e.g.,12,13,259] In addition, cancer survivors report encountering distressing information and unwanted communication, alongside the positive benefits mentioned above, when using social media in relation to cancer.[33-35,244] To be able to anticipate potential drawbacks of using social media to meet cancer-related needs, it is important to investigate the types of cancer-related content that various platforms include.

The Present Study

Instagram is a social media platform that is highly popular among young adults.[8] Posts consist of captioned images and/or videos, and they can be organized and searched with a hashtag system. Content may be public or private, and users can interact with one another in several ways.[260] Primary reasons for using Instagram, among college students in one study, were surveilling others, being "cool," documenting one's life, and displaying one's creativity. The authors attributed the latter two motivations, in particular, to the platform's emphasis on images and captions relative to other platforms.[261] In the same vein, another study compared college students' motivations for using Instagram, Facebook, Twitter, and Snapchat, finding that Instagram was especially valued for self-expression.[36] These findings suggest that Instagram serves a particular function for its users and offers a unique view of their perspectives—including, perhaps, those who use it to document their cancer experiences. Indeed, one comparison of cancer content on Twitter and Instagram found that the former was used more for conveying factual information, while the latter was used more for sharing illness narratives.[37]

Despite Instagram's seemingly unique role at the intersection of social media and cancer, few studies have examined Instagram content related to cancer, and none have done so qualitatively with a specific focus on young adult cancer. As such, very little is known about the role of Instagram in young adult cancer experiences, including how young adult cancer survivors use Instagram and the messages they encounter on it. In this exploratory study, we conducted a qualitative content analysis of publicly available Instagram posts about young adult cancer. Our primary research question was: *What content related to young adult cancer is posted to Instagram, and who posts it?* We also asked a more specific question: *What do young adult survivors share about their cancer experiences on Instagram?* Findings from this study will describe a popular health communication platform and offer insight on young adult cancer experiences, suggesting ways in which Instagram use helps meet important informational and support needs among young adult cancer survivors.

Methods

Data Collection

The study sample was drawn from publicly available Instagram posts with the hashtag #youngadultcancer posted from September to November 2019. While there are numerous cancer-related hashtags in use on Instagram, we selected #youngadultcancer because of our interest in the young adult age group and cancer experiences generally (i.e., no single type of cancer). At the start of data collection on September 20, 2019, searching this hashtag generated 16,377 posts.

We collected data in a two-step process repeated for each of seven batches of data, as summarized in Figure 3.1. In the first step, we searched for the hashtag using Instagram's search bar on a desktop web browser. We selected the 50 most recent posts and saved their URLs in a spreadsheet. We skipped over ineligible posts, which were those that contained a video, were captioned in a language other than English, or were unavailable. We collected URLs in this way seven times from September 20, 2019 to November 7, 2019, varying the time of day and waiting eight days between batches so that data were collected once each day of the week. This was designed to capture variability over time while remaining feasible for manual data collection, given that automated data scraping would have violated the platform's terms of use.[262] The initial sample consisted of 350 posts.

The second step took place 30 days after the first step for each batch of data. This allowed time for users to edit posts, delete posts, or make posts or accounts private before we saved content for inclusion in the sample.[263] We used the Instagram mobile application for iOS to save screenshots of each post that was still publicly available, including all photos, the

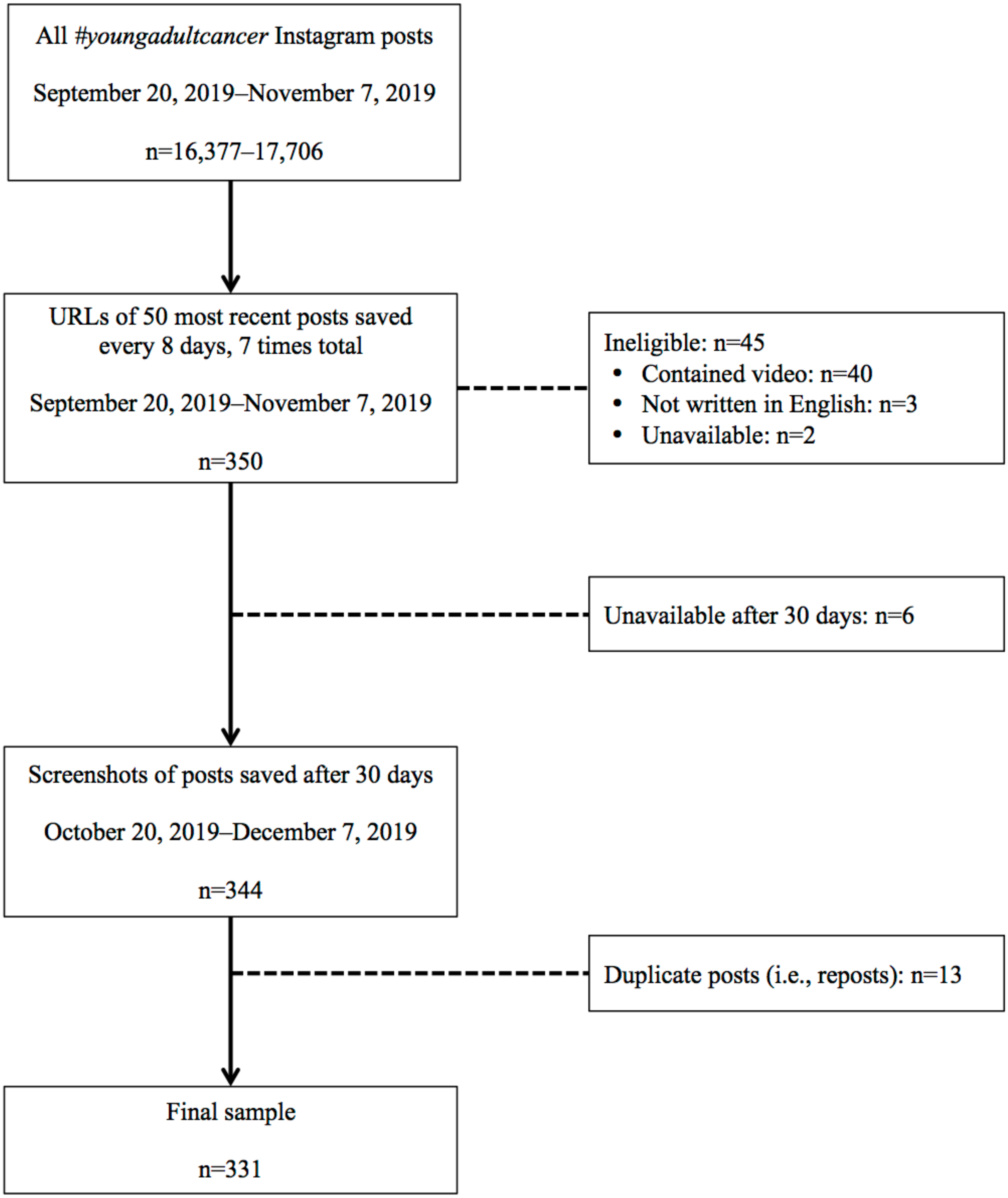

Figure 3.1
Sampling strategy.

caption, and any comments by the user that functioned as extended captions. We also saved a screenshot of the user profile. Six posts that had been deleted or made private were excluded. Finally, we removed from the sample 13 posts that were duplicative of previously sampled posts (i.e., reposts). The final sample consisted of 331 posts.

Analysis

We conducted qualitative content analysis using methods adapted from Schreier.[264] The unit of analysis was an entire post, including the image(s) and caption. The lead author and an additional coder used a randomly selected pilot sample of posts (n=83, 25% of the full sample) to create two inductive coding schemes, described below. All coding was conducted using Microsoft Excel.

The first coding scheme focused on key characteristics of the posts (Table 3.1) and their primary functions (Table 3.2). To develop the coding scheme, the coders independently examined each post in the pilot sample and wrote detailed notes paraphrasing the content. They met to discuss their observations and identify patterns. The lead author then drafted the basic coding scheme by reducing the paraphrased content into categories and subcategories related to the posts' key characteristics (e.g., type of user, type of cancer; see Table 3.1) and primary functions (e.g., documenting life, sharing a meme or viral graphic; see Table 3.2). The coders double-coded the pilot sample (i.e., both coders independently coded every post) and met to discuss coding disagreements and refine the basic coding scheme. The coders then double-coded all remaining posts. Rates of agreement were generally high, with 4 out of 5 categories having 91.1% agreement or higher, and one category (primary function) having 77.4% agreement. The coders discussed all coding disagreements and came to a consensus on final coding decisions.

Table 3.1
Post characteristics.

Characteristic[a]	n	%
User type (n=331)		
Individual	207	62.5
Group	102	30.8
Meme account	21	6.3
Other	1	0.3
Individual gender[a] (n=207)		
Woman	197	95.2
Man	10	4.8
Other	0	0.0
Individual type[b] (n=207)		
Cancer survivor	194	93.7
Health professional	8	3.9
Other	5	2.4
Cancer type[c] (n=194)		
Breast	96	49.5
Blood	27	13.9
Colorectal	23	11.9
Thyroid	13	6.7
Brain	8	4.1
Head/neck	8	4.1
Sarcomas	5	2.6
Cervical/ovarian	4	2.1
Skin	3	1.5
Other/unknown	7	3.6

[a] Coding within post characteristic categories was mutually exclusive: each post was assigned one and only one user type, individual gender, individual type, and cancer type, as applicable.

[b] Applied only to posts coded as “individual” user type

[c] Applied only to posts coded as “cancer survivor” individual type

Table 3.2

Primary functions of posts (N=331).

Function[a]	**n (%)**	**Definition**	**Example Image(s) and Quote**
Documenting life	161 (48.6)	Documenting life experiences, thoughts, or feelings from an individual's perspective	*Images: Snapshots from a day of recreational activities.* Quote: "Officially been free of my tumor for a month! Yay! Hubs and I had a date while the kids were at my parents…Today I get my haircut. First transition haircut. Going from super long to a bob. Eek! Feeling good and nervous about next week, I meet my oncologist and get my BRCA results."
Publicizing/ fundraising	95 (28.7)	Publicizing (sharing information about) or fundraising for a non-profit organization, cause, event, community group, or informational resource	*Image: A selfie of two smiling women, both wearing T-shirts from the same organization.* Quote: "Don't forget to sign up for our first [group name] meetup, this Saturday @ noon. You can register at the link in our bio and DM us if you have any questions. We can't wait to meet you all!"
Raising awareness	30 (9.1)	Raising awareness of health issues or communicating health-promoting information	*Image: A photo of two hands holding one another, overlaid with text about colorectal cancer.* Quote: "New cases of colon and rectal cancer are occurring at increasing rates in young and middle-aged adults. Talk to a doctor about your risk for colorectal cancer and determine when it's the right time to start screening."
Sharing a meme or viral graphic	25 (7.6)	Sharing an image in the style of an Internet meme or viral graphic	*Image: A scene from the film Mean Girls with characters sitting at a cafeteria table.* Quote: "Oh, my God, Karen, you can't just ask people why they have cancer"
Selling/ promoting	17 (5.1)	Selling or promoting for-profit products or services	*Image: Two side-by-side photos of a smiling woman with long hair. She appears thinner in the second photo.* Quote: "I was able to lose 20 pounds by putting in the work. And I'll help you do the same thing!…Snag your spot now by filling out the link in my bio, and I'll be in touch with next steps!"
Other	3 (0.9)	Any post function that doesn't fit the above categories	Not applicable

[a] Coding for primary function was mutually exclusive: each post was assigned one and only one primary function.

Table 3.3
Presence of thematic content in a subset of posts (N=145).

Theme[a]	N (%)	Definition	Example Image(s) and Quote
Cancer care (present time)	86 (59.3)	Discussion of cancer care and symptoms spanning diagnosis to long-term follow-up, as experienced in the present time	*Image: A photo of a woman sitting on a couch, smiling, and hugging a dog. Her arm is wrapped and she is wearing a hospital bracelet.* Quote: "Home after 5 days on antibiotic drip getting on top of an infection. #immunotherapy might get pushed back a few days while my #neutrophils climb a little higher. Docs are all happy with my progress so far though and think I am in strongest place to start compared to others on the prior trial which is good news."
Support	57 (39.3)	Discussion or provision of social support or spiritual support	*Images: Photos of a smiling woman (without hair) in a hospital bed. A woman and man pose with her.* Quote: "Thank you all so much for the well wishes and thoughts. I'm lucky to have my amazing Mum and [username] by my side. And I will always be forever grateful to my selfless [stem cell] donor."
Philosophy/ mindset	47 (32.4)	Discussion of life philosophy or the mindset chosen for approaching life's challenges	*Image: A selfie of a smiling woman (without hair) and man outdoors.* Quote: "If there's ANYTHING I've learned these last 8 months, it's to take time EVERY single day to show gratitude and never take something for granted - no matter how seemingly small it is."
Cancer care (past)	43 (29.7)	Discussion of cancer care and symptoms spanning diagnosis to long-term follow-up, as experienced in the past	*Image: A selfie of a smiling woman (without hair).* Quote: "I am in disbelief that 2 years ago I completed my last dose of chemo. I was ecstatic. I was getting closer to that finish line! The marathon is far from over. But I'm so damn proud of that girl."
Appearance/ body image	43 (29.7)	Discussion of physical appearance and/or body image	*Images: Two selfies of a woman with a neutral facial expression. One shows no hair and a subtle facial rash; the other shows very short hair and a clear complexion.* Quote: "It's been exactly 2 months since my last chemo. My hair is growing back and it's SO SOFT!…Also the lovely rash I had on my face from Taxol is gone."
Discussion prompts	31 (21.4)	Questions or comments that encourage discussion (i.e., comments on the post)	*Images: Two selfies of a woman with a neutral facial expression. In both, her hair is short.* Quote: "My first haircut in over a year. Amazingly, I didn't cry…Anyone else have a hard time recognizing themselves after treatment?"

[a] Coding between thematic content categories was not mutually exclusive. Each category was coded as present or absent for each post. Thematic content was coded only for posts that were coded as having been posted by an individual cancer survivor with the primary function of "documenting life."

The second coding scheme focused on the cancer-related thematic content (Table 3.3) of a subset of posts: those that were coded as having been posted by an individual cancer survivor with the primary function of "documenting life." We chose this subset because we were particularly interested in what cancer survivors post about their cancer experience. Using the same process as before, the coders used eligible posts from the pilot sample (n=38) to create the coding scheme focusing on posts' major cancer-related themes (e.g., cancer care, support; see Table 3.3). Themes could be coded as either present or absent. After double-coding all remaining eligible posts (n=107), rates of agreement ranged from 80.4% to 93.5%. Again, the coders discussed disagreements and came to a consensus for final coding.

When necessary, coders referenced supplemental content to inform coding decisions. This content could include the post's hashtags, the descriptive header on the user profile, the user's other posts, and websites associated with the user. For example, to code an individual user's gender, coders looked for self-descriptions such as "mom," "wife," or "she/her" that suggested the user identified as a woman. In the absence of such clues, coders based their decision on the individual's outward gender expression.

Ethics

The Institutional Review Board of the Harvard T.H. Chan School of Public Health approved this study, determining that it was not human subjects research. We acknowledge that in the context of public social media research, the "human subjects" regulatory framework may inadequately address ethical issues, such as the privacy concerns of users whose content is sampled.[265] We adopted two practices, as suggested by Laestadius,[263] to address this. First, as described above, we waited 30 days before saving any content from posts, giving users time to change them or remove them from public view. Second, we excluded from this article any images, usernames, and other identifying information.

Results

Post Characteristics

Post characteristics are presented in Table 3.1. A large majority of posts were posted by an individual user (n=207, 62.5%). Of these, almost all were posted by women (n=197, 95.2%) and by cancer survivors (n=194, 93.7%). Very few posts were shared by health professionals (n=8, 3.9%). Of the cancer survivors, nearly half (n=96, 49.5%) were survivors of breast cancer. The other most common cancer types were blood cancers such as leukemia and lymphoma (n=27, 13.9%), colorectal cancer (n=23, 11.9%), and thyroid cancer (n=13, 6.7%).

Other user types were groups (n=102, 30.8%) and meme accounts (n=21, 6.3%). Groups included users such as non-profit organizations, online and in-person community groups, and for-profit companies. Meme accounts were those that primarily posted memes or viral graphics, defined for the purposes of this study as shareable, oftentimes altered images that convey a cultural idea or meaningful message.[266,267]

Post Functions

Primary functions of the posts are presented in Table 3.2. The proportion posted by each user type is shown in Figure 3.2. Each function is described with illustrative examples in the sections that follow. Throughout this article, for brevity and to aid in anonymization, we generally provide selected quotes from post captions rather than full text. Quotes are lightly edited for clarity. No Instagram account is referenced more than once, with one exception. (One account was referenced twice to illustrate the *sharing a meme or viral graphic* function.)

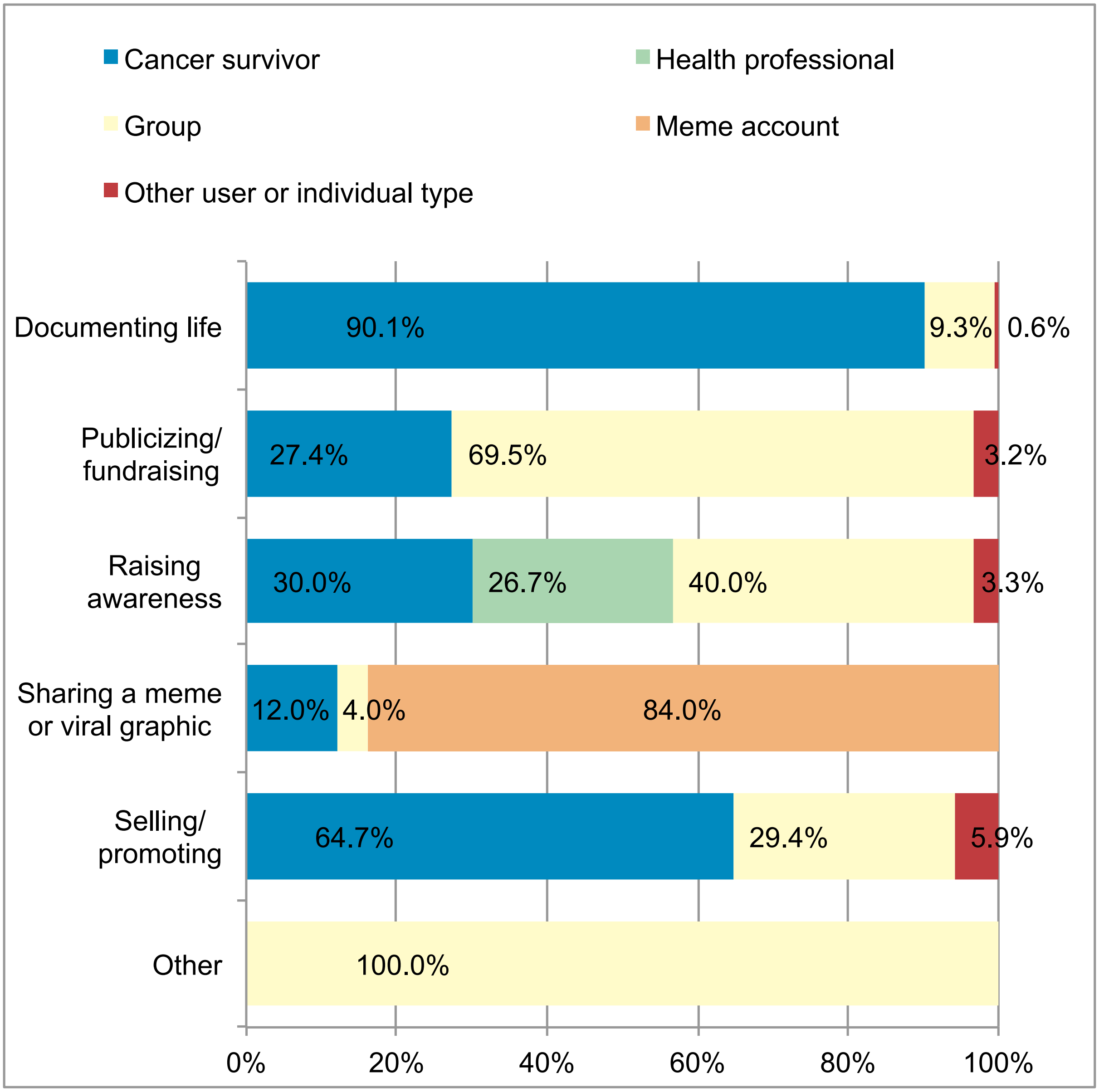

Figure 3.2
Primary post functions as posted by each user type.

Documenting life. Nearly half of the posts (n=161, 48.6%) were coded with the primary function of *documenting life*, which we defined as documenting life experiences, thoughts, or feelings from an individual's perspective. Most of these posts were shared by survivors (n=145, 90.1%). Posts were typically written with an informal tone and were sometimes laden with emotion. Topics varied widely but almost always related to cancer in some way, often intertwined with other aspects of the individual's daily life. For example, a sarcoma survivor shared a selfie (a photo he took of himself) with a neutral facial expression and wrote:

> Part of my life after cancer is getting scans every three months for the next two years. I have been anxious for most of the last three months and recently hit some emotional hard times when I had to put my dog to sleep…I got much needed good news yesterday when I got my scan results.

In another example, a breast cancer survivor posted a photo of her two children and wrote:

> There's been a lot of change in their lives recently. Starting at a new school, my husband starting at a new school too and having me start new meds and not feeling like myself. Parenting on a good day is tough. Parenting when you have cancer is so much more challenging.

The cancer-related thematic content of *documenting life* posts is further detailed in a later section of the results.

Publicizing/fundraising. About a quarter of posts (n=95, 28.7%) were coded with the primary function of *publicizing/fundraising*. We defined this as sharing information about or fundraising for a non-profit organization, cause, event, community group, or informational resource. Most of these posts were shared by groups (n=66, 69.5%), but survivors also contributed (n=26, 27.4%). These posts commonly publicized events like support groups, social gatherings, workshops, and conferences, which were usually hosted by non-profit organizations. For example, a non-profit organization shared information about a virtual meet-up. They posted a photo of a social gathering and wrote, "Whether you're talking about cancer or anything else under the sun, join together with other people who understand what it's like to go through young adult cancer. Link in bio!” Fundraising events, such as galas and running races, were also posted about frequently, along with requests for charitable donations to non-profit organizations. In one post, a non-profit organization described a retreat it was hosting for young adult cancer survivors and wrote: “Every donation helps [organization name] fund places for someone else to come along to the next weekend to get life-changing support to help make things easier. Please give.” This was accompanied by a photo of a group walking outdoors. Other posts publicized informational resources, such as online articles, blog posts, and documentary films. For instance, a non-profit organization highlighted its blog post interviewing a cancer survivor, sharing a photo of her and writing, “[Username] is a doctor, wife, mother and survivor! We hope you’ll take the time to read her full story and tell us about your experience with #chemobrain!”

Raising awareness. About a tenth of posts (n=30, 9.1%) were coded with the primary function of *raising awareness*, defined as raising awareness of health issues or communicating health-promoting information. They were shared mainly by groups (n=12, 40.0%), survivors (n=9, 30.0%), and health professionals (n=8, 26.7%). Some of these posts were shared in response to a particular cancer awareness day or month and featured disease statistics or information about symptoms or screening. For example, as part of Ovarian Cancer Awareness Month (September), a nurse practitioner shared a series of posts with informational graphics about the disease. The graphics and captions described ovarian cancer’s symptoms, risk factors, and incidence and identified resources for more information. Other posts shared health information for cancer survivors, such as tips related to treatment and side effects or strategies to support emotional well-being. In one example, a non-profit organization posted an image of a person meditating and wrote: “Fear of recurrence is significant for many cancer survivors.

Practicing meditation and other relaxation techniques can help reduce this fear." They then provided further details about meditation and listed some mobile applications that facilitate the practice.

Sharing a meme or viral graphic. Some posts (n=25, 7.6%) were coded with the primary function of *sharing a meme or viral graphic* (as defined above) and were shared primarily by meme accounts (n=21, 84.0%). These were usually variations on popular, humorous Internet memes that were edited or captioned to relate to cancer. Many of these posts originated from a single meme account and were sometimes reposted by other users. In one example, an adaptation of the "Nileseyy Niles Disappears" meme format,[268] three images showed a young man making the peace sign hand gesture and progressively fading from the picture. The post described this as depicting a cancer survivor's support system after the survivor achieves remission. In other words, the meme illustrated the experience of loss of support at the transition to long-term survivorship. In addition to these types of posts, a few posts coded as *sharing a meme or viral graphic* consisted of graphics with encouraging or inspiring text. For example, in one post, an image of well-known cancer survivor Lance Armstrong was overlaid with a motivational quote attributed to him.

Selling/promoting. Finally, a small number of posts (n=17, 5.15%) were coded with the primary function of *selling/promoting*, which we defined as selling or promoting for-profit products or services. These posts were shared mainly by survivors (n=11, 64.7%) and groups (n=5, 29.4%). Products being sold or promoted included clothing, an energy drink, air-purifying bags, and a bundle of items curated for women going through chemotherapy (e.g., a head wrap). Some cancer survivors posted about products they had been gifted or seemingly paid to promote. For example, a breast cancer survivor shared a picture of herself, smiling and posing in a bra, and said: “Thanks to [bra company] I’ve found a post-mastectomy bra that’s comfortable, practical and *gasp* sexy (HELLO LACE!!!) It even has pockets for prosthetics.” This post included the hashtag #ad. Typical promoted services were fitness, nutrition, or life coaching offered by cancer survivors for other survivors or general audiences. In one post, a blood cancer survivor who works as a personal trainer shared a photo and information about a yoga pose and wrote: “For more great poses that strengthen and stretch, let’s work together one on one. Link in bio.”

Thematic Content

Posts that were coded as having been posted by an individual cancer survivor with the primary function of “documenting life” (n=145) were coded for the presence or absence of various cancer-related themes. These are presented in Table 3.3 and described in more detail below.

Cancer care (present time). A majority of posts (n=86, 59.3%) included discussion of cancer care and symptoms being experienced in the present time (i.e., around the time the post was shared), spanning diagnosis to long-term follow-up. Survivors shared updates about their treatment including surgeries, medications, radiation, imaging, and lab tests. For example, a colorectal cancer survivor shared a photo of herself, without hair and embracing her cat, and wrote:

> I received my scan results last night and as we suspected, my current chemo is no longer working. I have some new tumors on my liver and it is enlarged. My lung tumors are remaining stable though. I have an appointment with my doctor next week to develop a new strategy to control my disease for as long as we can.

Several posts observed treatment milestones, such as counting down rounds of chemotherapy or celebrating the end of active treatment. On the day of her implanted port removal, one breast cancer survivor described feeling both anxious and excited. She added: “This is another sign that things are wrapping up. Having my port removed prepares me for my next surgery. And coming to terms that I don’t need it anymore because we are looking forward!” She included a photo of herself smiling in a hospital bed and photos of her port site. Many posts described side effects resulting from treatment. For example, a breast cancer survivor shared a photo of her open mouth and wrote: “During IV chemo, I had a couple instances of mouth sores, aka #oralmucositis but nothing like what has developed since #Xeloda round 7. Plus, an unrelenting case of #oralthrush.” She compared the feeling to “having shards of glass in your mouth at all times” and noted difficulty eating and drinking.

Support. About two-fifths of posts (n=57, 39.3%) included discussion or provision of social or spiritual support. In several posts, survivors acknowledged the individuals who had supported them, such as friends, family, and other survivors. For instance, one breast cancer survivor shared a selfie, wearing a hospital gown and smiling, and wrote:

> I have the greatest support system anyone could ever ask for. I can’t even begin to say all the amazing things I could about my boyfriend, my family, my friends, the [breast cancer account] community, and my work family. Just know I’d be lost without y’all and I love you more than you know.

In some posts, survivors asked their followers for support. A few requested specific information, such as the head and neck cancer survivor who posted a photo of herself smiling and flexing her arm, asking, “Anyone have any tips or tricks for staying active during treatment without overdoing it?” Others asked for prayers or positive thoughts. For example, a colorectal cancer survivor shared a selfie with her husband, described upcoming treatments plans, and added: “So if you don’t mind, to keep those prayers, good vibes, thoughts, and any other good juju coming my way for my follow-up with surgeon.” In addition, some posts offered support to others, such as the colorectal cancer survivor who detailed a challenging hiking experience and then encouraged her followers: “Keep going. You can do it. You are strong. You are loved. Your blessings await you. It is worth it.” She included landscape and family photos from the hike.

Philosophy/mindset. About a third of posts (n=47, 32.4%) included discussion of the cancer survivor's life philosophy or mindset chosen for approaching life's challenges. In general, these posts had a positive, uplifting tone and emphasized ideas like gratitude, joy, focus on the present, resilience, and choosing one's attitude. One blood cancer survivor posted a photo of herself with a broad smile and wrote, "When faced with adversity, it is so important to focus on what we can control and practice gratitude on what each adversity can offer us." She described cancer as "the worst thing that's ever happened" to her but also listed numerous "gifts" it had given her, such as resilience, self-love, and gratitude. In another example, also accompanied by a smiling photo, a sarcoma survivor discussed her mindset since diagnosis:

> Cancer hasn't gotten any more glamorous during these last 18 months and it has not taught me any #lifelessons worth the time it is trying to take away. It is not "part of the plan"…But it *is* happening and that is not a choice for us to make. We can only do our best to search for and find what beauty we can in this scary, gorgeous life. Lucky to have made it this far, now focusing on making the rest of my days the best of my days!

Cancer care (past). About a third of posts (n=43, 29.7%) included discussion of cancer care experienced in the past. These posts typically consisted of reflective anecdotes prompted by a significant date (e.g., anniversary of treatment completion) or other reminder of the past. They often mentioned challenges or personal growth that the survivor had experienced over time. For example, a colorectal cancer survivor posted about her diagnosis:

> One year ago, I woke up to a doctor saying those scary words, "There's a tumor. It's large." That day a surgeon told me it needed to come out ASAP. The next morning I had an abdominal resection. Two weeks later I'm in front of an oncologist telling me it's stage 3. I needed radiation. I would lose my fertility. I'm too young... 9 months of chemo... hormone replacement therapy. One year ago, I didn't know if I would be alive in a year. But here I am. Drinking wine with my besties on a Wednesday. And I'm just thankful to be here.

This was illustrated with a smiling group photo taken in a restaurant. In another post, a breast cancer shared a photo of herself without hair and wearing a face mask, reflecting:

> Some days I forget how far I've come, some days I tell myself I should be ‘better now,’ that ‘I'm healing too slow,’ and other days, like today, I'm reminded exactly how far I've come. This [photo] was taken this time last year, post 2nd round of chemo, freshly shaved head and in the most immense pain I've ever experienced...emotionally and physically.

Appearance/body image. About a third of posts (n=43, 29.7%) included discussion of physical appearance and/or body image. These were usually appearance or body image issues related to cancer treatment, such as hair changes, skin rashes, scars, weight loss or gain, or surgical changes to the body. For example, a breast cancer survivor shared photos of her radiation treatment and port sites, writing:

> Port incision is still healing, but I think it's almost there. Unfortunately, I'm not exactly in love with how it looks, and that on top of my double mastectomy, weight gain, and the way radiation is changing my skin has made it pretty difficult to find a dress to wear for my sister's wedding in a few weeks.

Several posts focused on hair loss, regrowth, and/or texture change resulting from chemotherapy. In one instance, a blood cancer survivor shared a selfie with very short hair and described the impact of shaving her head:

> Hair loss at the first sight of it even if you’re ‘ready’ still hurts and hits you like a truck going 200km/hr. No one tells you the longer you keep your hair, there’s a tingly little pain in your scalp and it drives you to a point of irritability. Today I braved the shave! It was so nerve-wracking before it happened! Once it was done I felt strong! I felt relief! I felt like myself again!

A handful of posts included appearance or body image topics outside of cancer, such as comments about the clothing or makeup individuals wore in their photos.

Discussion prompts. About a fifth of posts (n=31, 21.4%) included questions or comments that encouraged discussion (i.e., comments on the post). Topics varied widely, with some being lighthearted and conversational and others more serious. For instance, a survivor of gestational trophoblastic disease posted about celebrating a chemotherapy milestone and asked, “What are you celebrating today!?” She included a photo of herself with two others, all smiling.

A neuroendocrine cancer survivor shared her experience getting a CT scan with a painful contrast injection and said, “I find it frustrating that as a patient, unless there are tears, some [health care providers] don’t take our pain levels seriously; anyone else feel this way?” Her post included a nondescript snapshot of a staircase. In another example, a breast cancer survivor described her difficulty choosing a breast surgery and reconstruction. She then asked: “Was surgery a hard decision for you? What about reconstruction? What did you choose? Let me know!” She shared a selfie focused on her torso, wearing a paper exam gown and revealing part of her bandaged breast.

Discussion

This study employed qualitative content analysis to describe the content of publicly available Instagram posts with the hashtag #youngadultcancer. We found that most posts were posted by individual users, who were typically women cancer survivors. Of the survivors, about half were survivors of breast cancer, with blood cancers, colorectal cancer, and thyroid cancer being the next most common. Individual health professionals contributed a very small proportion of posts. In addition to individuals, groups such as non-profit organizations, community groups, and companies also posted, along with meme accounts. Posts were found to have five primary functions (defined in Table 3.2): documenting life, publicizing/fundraising, raising awareness, sharing a meme or viral graphic, and selling/promoting. Because we were especially interested in what survivors share about their cancer experience, we analyzed their “documenting life” posts in greater depth and uncovered six cancer-related themes (defined in Table 3.3): cancer care experienced in the present time, support, philosophy/mindset, cancer care experienced in the past, appearance/body image, and discussion prompts.

From the basic characteristics of posts, two findings are particularly striking: 95.2% of the individuals who posted were women, and 49.5% of the cancer survivors who posted had breast cancer. First, it is important to note that collecting data during Breast Cancer Awareness Month likely inflated the number of breast cancer posts and posts from women, an issue that we discuss in the limitations section below. Nonetheless, the dominance of breast cancer content and the disproportionate representation of women in our sample correspond somewhat to findings from other research. Two studies of cancer content on Twitter and Instagram found that cancers that typically affect women, particularly breast cancer, were mentioned particularly frequently.[37,269] In general, the breast cancer advocacy movement in the United States is large and highly visible;[270] cultural openness to discussing breast cancer could make young women with breast cancer, or women cancer survivors in general, more apt to post about their experiences on social media. It is also possible that masculinity norms, which are thought to influence men's health-related help and information seeking,[271-275] limit young adult men's public discussion of cancer on Instagram. However, a recent survey of U.S. adolescents and young adults found that while young women were more likely than young men to engage in some health-related help and information seeking online (e.g., obtaining health information, viewing others' health stories, and finding others with similar concerns), the two groups were equally likely to share their health stories on the Internet.[9] Finally, some of the gender imbalance in our data may be reflective of Instagram's greater popularity among women than men, at least in the United States.[8]

Considering our findings through the lens of uses and gratifications theory[239,240] and alongside other research, we can propose numerous needs that young adult cancer survivors might meet by using Instagram in relation to cancer. Important motivations for young adults to use Instagram are to observe and interact with others.[36,261] For those with cancer, seeing peer survivors on Instagram may help them feel less isolated in their own experiences. They can exchange support with others through requests, discussion prompts, and other interaction. This could be especially helpful for individuals who face barriers to accessing in-person support groups[276,277] or who feel uncomfortable actively participating in a group. Information seeking and sharing are other reasons for social media use.[36,241] Our findings suggest that survivors may use Instagram to seek and share information about health issues and supportive organizations, events, and resources. Using Instagram to view humorous cancer memes may provide survivors not just entertainment, which is a top motivator of Instagram use,[36] but also coping through humor and a sense of community with others who understand the joke.[278-280] Documenting one's life and expressing oneself are also key needs that young adults meet through Instagram use.[36,261] Young adults who post about their cancer experiences on Instagram may find psychological benefits in writing down their emotions,[281] cultivating a positive mindset,[225,282] and creating a narrative that makes sense of their illness and identity.[283-285] They may also share their stories to improve public awareness of young adult cancer experiences.[37] Finally, just as convenience motivates Instagram use for young adults generally,[36] survivors may find Instagram convenient for sharing updates about their illness with many people at once.[35]

The potential benefits of Instagram use among young adult cancer survivors, as described above, have not yet been empirically tested. However, a few interventions have (perhaps coincidentally) simulated aspects of the Instagram experience in private study settings, offering preliminary clues about the utility of this type of social media use. In one study, Laing et al.[285] helped adolescent and young adult cancer survivors create digital stories about their cancer experiences, combining voice recordings, images, video, and music. In interviews, participants said that creating these stories helped them communicate their stories to others, work toward psychological healing, and make sense of or find meaning in their experiences. In another study, McLaughlin et al.[286] created a private mobile social networking site called LIFECommunity, in which participants could make a profile, share photos and videos, and exchange messages. Throughout the 6-month intervention, researchers prompted participants to create and post narrative videos on various topics relevant to cancer survivorship. While the authors were unable to collect enough post-test data to evaluate intervention impacts, they found that participants who had less social support in their offline lives participated more in the intervention. This suggests that participants used the platform to satisfy unmet social support needs. A similar study was conducted by Pailler et al.[287,288] In this intervention, young adult cancer survivors used a designated study portal on a social media platform to post photographs and audio or text narratives in response to themes derived from a cancer psychotherapy program. Themes covered topics such as identity, coping, uncertainty, hope, and "living life to the fullest." Participants were encouraged to interact with one another on the platform. The 10-week intervention was found to improve depressive symptoms and quality of life, but not spiritual well-being. Overall, to the extent that private study settings translate to real-world social media use, findings from these interventions lend evidence that young adult cancer survivors may find several psychosocial benefits to posting about their experiences and interacting with peers on Instagram.

The positive and uplifting tone demonstrated in some survivors' posts, especially those about their life philosophies or mindsets, aligns with other research findings about a tendency toward positive expression when discussing cancer on social media. In a mixed methods study with young adult cancer survivors in Denmark, Stage et al.[35] found that among survey respondents who had shared images related to their cancer on social media, 67% reported sharing images with a positive tone versus 28% sharing images with a sad or negative tone. In interviews, some participants said that they try to present their cancer stories positively, while some said that the norm of positivity omits important negative perspectives. In another study, a content analysis focusing on the linguistic characteristics of Instagram posts about young adult cancer, Warner et al.[289] found that individuals with cancer used more language with positive valence (e.g., "love," "happy," "hope") than negative valence (e.g., "hate," "bad," "hurt"). Finally, in a qualitative study of Twitter and Instagram content related to National Cancer Survivorship Day, Cherian et al.[37] described posts as focusing on positive concepts such as social support, "celebrating milestones," and "rebirth vs. renewal." Similar to our study, several quotes expressed ideas such as gratitude, inspiration, embracing life, and personal growth. The authors noted their concern that some posts set unrealistic expectations for appearance and functioning in cancer survivorship. They also suggested, though, that posts in which survivors present traditionally negative body changes in a positive light might offer psychosocial benefits to both the creator and the viewer.

Building on similar findings from an analysis of breast cancer content on Instagram,[250] we found that young adult cancer content on Instagram includes both groups and individuals selling and promoting for-profit products and services. While this type of post constituted a very small proportion of posts overall (5.1%), the phenomenon is noteworthy from a health communication standpoint. Marketing on social media is common, and much of this marketing comes from social media influencers—third-party individuals who use social media and exert outsize influence through their large following.[290,291] Celebrities such as Kim Kardashian are the most prominent influencers, but "micro-influencers" with just a few thousand followers can also be paid to promote products, including over-the-counter health products and prescription pharmaceuticals.[290] Influencers cultivate intimacy and trust with their followers and use direct and surreptitious advertising techniques.[292-295] In our study, we observed a few instances of cancer survivors posting about products that they had been gifted or likely paid to promote, indicating that social media influencer marketing has reached the young adult cancer space on Instagram.

This study had some limitations. First, we sampled only publicly available posts that had English-language captions and did not contain a video. There may be important differences between the content in our sample and the content in non-English-language posts, posts with video, and posts from private accounts, which would limit generalizability of our findings. We also sampled only the most recent Instagram posts, not the algorithmically selected "Top Posts" that also appear when searching for a hashtag. If Top Posts are meaningfully different from most recent posts—for example, if they tend to come from social media influencers—our findings may not fully describe the content that an Instagram user sees when searching for #youngadultcancer. Another limitation is that because we coded post characteristics based on what we could observe from users' Instagram accounts, we may have misclassified some posts. For instance, given the complexity of gender identity, we may have made incorrect assumptions in coding users' gender. We could not assess users' age to confirm that they were in the young adult age group we sought to study. Lastly, because we sampled posts from a limited time frame, the content of our sample may have been influenced by seasonal factors. The most notable of these are cancer awareness events: September is Blood Cancer Awareness Month, Gynecologic Awareness Month, and Thyroid Cancer Awareness Month, while October is Breast Cancer Awareness Month.[296] Hashtags for awareness months were present in some of our sampled posts, which suggests that there was more content than usual relating to certain cancers, and more content from women (as some of these are primarily women's cancers), during the months when we collected data. However, we have no reason to believe that our general findings on post functions and the thematic content of survivors' *documenting life* posts would not be relevant for young adult cancer survivors broadly.

Future research should continue to investigate the function and impact of Instagram and other social media in the lives of young adult cancer survivors. More evidence is needed to understand individuals' motivations for using Instagram in relation to young adult cancer, including posting, viewing, and interacting with content. Hearing from survivors themselves through qualitative interviews or focus groups is essential. It would be important to include in this research individuals who post about their cancer experience on private Instagram accounts, since this study could not assess such content. Interviews could incorporate photo-elicitation techniques[297] prompted by participants' Instagram content. Another topic for future research is the role of social media influencers who post about young adult cancer on Instagram. Researchers could identify individuals with large followings and analyze the content of their Instagram posts, looking especially for potentially harmful content such as health misinformation or promotion of unhealthy products and practices. It may also be useful to study the impact of influencer content on young adult cancer survivors who view it and consider whether critical literacy intervention[295,298] might be needed. Finally, future quantitative research should seek to explain which young adult cancer survivors use particular social media platforms and for what activities, as well as the effects of doing so.

This study has implications for clinical and public health practice. We found that Instagram offers a window into the day-to-day lives of the young adult cancer survivors who post publicly on it; as such, it may be useful to oncology care providers wanting to better understand their patients' experiences. This is supported by findings from a qualitative study by Laing et al.,[299] in which health care providers watched and reflected on autobiographical digital stories created by young cancer survivors. Providers said that watching the stories helped them understand and empathize with the young adult cancer experience and that viewing digital stories might lead to better clinical care. Another implication for clinical practice is that providers should be aware of the ways in which young adult survivors might use Instagram and other social media platforms in relation to cancer, and the potential benefits and drawbacks of that use. Gentile et al.[300] and Walton et al.[301] offer guidance for oncology care providers who wish to discuss these issues with their patients. In terms of public health practice, we found that while there is a substantial amount and range of young adult cancer content on Instagram, relatively few posts (9.1% of our sample) function to raise awareness of health issues or communicate health-promoting information. Vraga et al.[269] reached a similar conclusion in comparing the cancer awareness campaign content on Instagram and Twitter. This suggests that there is considerable opportunity to carry out health communication campaigns on Instagram in support of young adult cancer survivors, perhaps in collaboration with highly influential users.[302] Such efforts would build on the robust cancer communication activity already taking place on Instagram to further benefit the young adult cancer survivors who use it.

Conclusion

In this dissertation, I used qualitative methods to explore health communication in young adulthood. While studying three different health communication topics and young adult populations gave breadth to the dissertation, the focus on rich qualitative data gave depth. I learned a tremendous amount.

In Chapter 1, we examined sexual health information issues among young adult sexual minority cisgender women and non-binary individuals assigned female at birth. Through thematic analysis of in-depth interview data, we identified three broad themes: 1) sources of sexual health information; 2) sexual health information needs; and 3) preferences for sexual health information delivery. Participants discussed and critiqued the Internet, other mass media, health care providers, school-based sex education, family, and peers/partners as sources of sexual health information. They expressed a need for customized, non-heteronormative information pertaining to sexually transmitted infection risk and prevention. They preferred receiving information from health care providers, the Internet, and other mass media, and some also suggested school-based sex education and peer education as methods for delivering information. We identified several implications for public health research, practice, and policy, such as improving health care providers' ability to share appropriate sexual health information and delivering web-based educational materials.

In Chapter 2, we investigated how LGBTQ young adults exhibit media literacy in conversations about body image and appearance ideals. Through thematic analysis of focus group data, we found that participants demonstrated media literacy under five themes: 1) Media convey dominant cultural and LGBTQ appearance ideals; 2) Dominant cultural and LGBTQ appearance ideals conveyed in media shape viewers' attitudes; 3) Appearance ideals conveyed in media are unrealistic and manipulated; 4) Promotion of appearance ideals is financially motivated; and 5) Learning social media literacy is important. Aside from documenting participants' media literacy, our findings offered critical insights about the range of appearance ideals experienced by this population and the unique roles of traditional and social media in promoting those ideals. We suggested avenues for further research on social media and media literacy for the prevention of body and eating concerns among LGBTQ young adults.

In Chapter 3, we examined content related to young adult cancer on Instagram to better understand the platform's role in young adult cancer experiences. We conducted qualitative content analysis of a set of publicly available Instagram posts with the hashtag #youngadultcancer. We found that most posts were posted by individual users, who were typically women cancer survivors. Of the survivors, about half were survivors of breast cancer, with blood cancers, colorectal cancer, and thyroid cancer being the next most common. Individual health professionals contributed few posts. In addition to individuals, groups such as non-profit organizations, community groups, and companies also posted, along with meme accounts. We found that posts had five primary functions: documenting life, publicizing/fundraising, raising awareness, sharing a meme or viral graphic, and selling/promoting. Survivors' "documenting life" posts, analyzed in greater depth, covered six cancer-related themes: cancer care experienced in the present time, support, philosophy/mindset, cancer care experienced in the past, appearance/body image, and discussion prompts. Overall, we concluded that Instagram is an active site of communication about young adult cancer that offers a glimpse into some survivors' experiences. We proposed several needs that young adult cancer survivors might meet by using Instagram in relation to cancer. We also identified implications for future research and for clinical and public health practice.

Overall, these dissertation findings convey a wide-ranging sampling of the health communication issues faced by today's young adults and the public health researchers and practitioners who serve them, particularly in the context of the Internet and social media. In addition to identifying areas of concern, findings suggest health communication savvy among those young adults who articulate the sexual health information they deserve, critically evaluate the appearance-related media messages they encounter, or use social media to meet some of their cancer care needs.

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