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Social media use in adolescent and young adult (AYA) cancer survivors

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Cancer remains the leading cause of disease-related death in the Adolescent and Young Adult (AYA) population. AYA cancer survivors face unique challenges, particularly social–psychological impacts in identity development, coping, distress, and social relationships. Given the high prevalence of Internet use and social media engagement, AYA survivors and clinicians and organizations charged with their care are increasingly turning to social media and other technology-mediated platforms. While there has been limited empirical evidence on the utility of social media in addressing AYA survivors' needs, the last 5–6 years have experienced a growth in online, technology-mediated advocacy, and patient organizations and related publications. This review highlights key research and practical efforts, their impacts to date, and discusses future directions.

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Introduction

Cancer remains the leading cause of disease-related death in the Adolescent and Young Adult (AYA) population. Approximately 70 000 young people ages 15–39 in the US are diagnosed with cancer every year. Leukemia, lymphoma, testicular cancer, and thyroid cancer are the most common cancers among 15–24-year-olds, and among 25–39-year-olds, breast cancer and melanoma are the most common [1]. AYA cancer survivors face unique challenges, particularly social–psychological impacts in identity development, coping, distress, and social relationships [2–4]. Young adulthood is a time characterized by many developmental milestones, such as separation from parents, forming intimate relationships with a partner, starting and raising a family, completing professional education

and training, and starting a career [5]. Cancer can interrupt any of these milestones. Compared to adult cancer survivors age 55 or older, younger survivors report more concern about being physically unable to have children, difficulty pursuing the career of their choice, inability to change jobs for fear of losing health insurance, feeling angry, being less able to provide for their families' financial needs, job discrimination, and problems with family or children [6].

For all levels of support, AYA cancer survivors, as well as clinicians and organizations charged with their care, are increasingly turning to social media and other technology-mediated platforms. There are several major reasons for this trend. First, the age group (18–39) of AYA population has the highest overall social media engagement rate (89% for 18–29 year olds, 82% for 30–49 year olds [7]). Indeed, numerous publications have shown that among all demographic factors, younger age is most persistent predictor of higher likelihood of using Internet and social media for health/cancer communication [8–10]. Moreover, online communities can potentially ameliorate barriers to information and service utilization, including stigma associated with a cancer diagnosis, geographical limitations, limited access to services, cost, and time constraints [11,12].

Despite high prevalence of social media engagement, there has been limited research exploring the utility of social media in addressing the needs of AYA cancer patients and survivors. However, the last 5–6 years have experienced a growth in online, technology-mediated advocacy and patient organizations and related publications. In this review, we will highlight key research and efforts and discuss future directions.

AYA cancer survivors' use of social media today

Social Media platforms are increasingly used by cancer survivors (including caregivers) for informational as well as social and emotional support. Most of these online cancer-related communities are formed organically and rely on peer-to-peer information sharing, while a small handful were developed as part of research intervention efforts (e.g. [13,14]). Current literature on social media and AYA cancer survivors is dominated by observational studies examining the content of these online interactions. Most studies on online support among cancer survivors have focused on anonymous online forums [10,15,16,17*] instead of more interactive forms of social media, and literature about online communication among

AYAs is more limited. A few studies have analyzed content of blogs written by young adults with cancer [18*,19,20]. These papers identified common themes discussed by survivor-bloggers, including the physical burdens of treatment (most commonly functional impact, fatigue, and pain), uncertainty about future health and career, grief over treatment-induced infertility, physical and emotional isolation, guilt over cancer's impact on their children, positive changes in life perspective after cancer (such as increased gratitude), use of the Internet as a social bridge to the 'outside world', and the challenge of reaching a 'new normal' as a cancer survivor after completing treatment.

Despite its popularity, Facebook (used by nearly 3/4 online adults) and other social media [21], has received only limited scholarly attention as a naturalistic source of cancer support or a platform for intervention. For example, one study examined the impact of a 12-week Facebook-based intervention to increase physical activity in young adult cancer survivors [22,23]. One study analyzed the content posted in a Facebook group of a nonprofit breast cancer organization to determine how the Facebook platform is used [24], and another study cataloged over 600 breast cancer groups identified on Facebook and determined the key purposes to include fundraising, awareness, and support [25]. The dearth of research evaluating the level of peer-to-peer support provided on Facebook is notable, since a qualitative study of younger AYAs (age 12–25) found that participants preferred either one-on-one/in-person intervention or message boards/Facebook as a modality for program delivery [26*]. Another set of social media-based intervention studies tested a customized social networking and video blog program to promote social support in a pilot sample of 14 young adult cancer survivors [27,28*].

To truly understand the landscape of cancer support for AYAs on social media, it is important to identify current prominent online communities for AYA Cancer survivors that are not captured by published studies on the topic. Going beyond published literature and gleaning from findings from qualitative interviews with AYA survivors [29], we highlight a number of social media communities below. First, Facebook Groups serves an important online platform where AYA survivors gather and share information and experience. Survivors reported using Facebook groups organized by advocacy or non-profit organizations (most of which also provide in-person programs and services) as opposed to healthcare providers. In this way, the Facebook groups are largely an extension of the organization serving to foster a continuous online community [29]. A quick search on July 21, 2015 revealed a number of popular Facebook Groups for supporting and connecting AYA survivors. For example, *Stupid Cancer* (298 000 likes) represents a well-known and trusted organization for AYA cancer survivors, and its Facebook

Page posts cancer-related scientific discoveries, personal narratives, media coverage generating ample discussions. Further, young adult cancer survivors describe accessing private Facebook groups associated with organizations such as The SAMFund, First Descents, and Team Fight, which serve as online communities connecting members who participated in offline programs [29]. Finally, many other cancer-specific organizations (e.g. the Leukemia & Lymphoma Society and Young Survival Coalition, an organization serving young women with breast cancer) generate high level of engagement (loosely measured by high 'Likes' counts). In interviews, young adult cancer survivors describe how these disease-specific groups provide a useful platform to exchange information about treatment options, side effects, and long-term consequences of cancer and its treatment. Notably, Facebook is a popular platform for meeting and communicating with other young adult cancer survivors, especially because its ubiquity among young adults ensures that users are on the site at all hours of the day, facilitating speedy responses to posts [29]. Twitter, though less popular than Facebook, is used by some AYA survivors for obtaining news and articles about cancer from researchers, journalists, and cancer care organizations [21,29].

Social media in support of AYA cancer survivorship: promises and cautions

As many social media platforms enable social support and information exchange among AYA survivors, the online environment is also increasingly cluttered with information of mixed quality. The literature and observations of successful efforts point to a number of useful guideposts for sustaining effective social media efforts. First, it is important to consider the close link between in-person and online communities from the same entity (e.g., Stupid Cancer), including the shared trust individuals may develop for the group. A survivor might join a Facebook group to explore and test out the community, and once comfortable, they might be inclined to attend an in-person event sponsored by the same organization. Conversely, one might first attend a program (e.g., a *First Descents* outdoor trip for cancer survivors), and later stay in touch via the group's Facebook page. 'Brand loyalty' to a social media group can develop through the link between in-person and online connections.

Moreover, social media interactions have been considered in terms of a trade-off, one that is between confidentiality and privacy protection and ease of access and information sharing [30]. For example, Facebook has low access threshold and can easily link up with people and communities, but privacy protection is a challenge and a concern for some patients. Generally 'tech savvy', AYA survivors hold diverse views on this trade-off. A qualitative study suggests that some were totally open on Facebook, while others' privacy concerns prevented their active Facebook engagement and they avoid discussing

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