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Social Media:

Support for survivors and young adults with cancer

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Abstract

Social media use is ubiquitous among young adults. Young adults with cancer must make important decisions about where, what, and how to share information on social media. Oncology nurses are in a unique position to start conversations about the risks and benefits of social media use. This column aims to review a variety of social media platforms that may be used by young adults with cancer and provide guidance to nurses on initiating open dialogue with young adults about social media usage.

Keywords

social media; web-based support; young adults with cancer; survivors

A cancer diagnosis and treatment can change everything, particularly when they occur during young adulthood (i.e., ages 18–29 years) (Arnett, 2012). Young adults with cancer face challenges inherent to living with the disease (Scott, 2016) while accomplishing usual developmental tasks. These tasks include gaining the education and experience needed to join the workforce and establish a career, developing a personal identity and values system, becoming financially and functionally independent from parents, and cultivating social networks and meaningful relationships beyond the family (Arnett, 2012).

Among the decisions young adults make after a cancer diagnosis is whether to maintain their presence on social media (i.e., digital and Internet-based platforms that allow users to create and exchange content [Kaplan & Haenlein, 2010]) or in web communities (i.e., a user-generated platform that allows communication of information, interaction, and collaboration among large audiences, such as within health care [Boulos & Wheeler, 2007; Grajales, Sheps, Ho, Novak-Lauser, & Eysenbach, 2014]). If young adults decide to maintain their presence, subsequent decisions follow, such as when and what to disclose about their experience with cancer.

Ninety percent of young adults use social media (Perrin, 2015), and the usage of social media by young adults with cancer is likely no different from that of the general population. Social media platforms, such as Facebook, Twitter, Instagram, YouTube, Snapchat, and blogs, allow people to connect with others and share information about their life, including health concerns. Each of these platforms are part of many young adults' everyday lives (Love & Donovan, 2014; Perales, Drake, Pemmaraju, & Wood, 2016). For young adults with cancer, social media also offers a means to connect with new communities, particularly peers of the same age who know firsthand about living with cancer. Through social media and the Internet, young adults can develop friendships and deepen connections with their peers in the cancer community. Within this virtual community, they can share fears and seek advice about making decisions about treatment, preserving fertility, managing symptoms, disclosing their diagnosis to potential romantic partners, attending school, and working during treatment and survivorship. Therefore, young adults with cancer may feel less socially isolated and more empowered to engage in the management of their illness. Finally, social media allows individuals with cancer to construct an account of their lives that will survive, even if they do not (Scott, 2016).

Along with their many benefits, social media and online support pose risks to users, including young adults with cancer. For example, impulsive dispatches of sensitive health information and personal identifiers can occur in response to intense emotions, without careful reflection on the potential consequences (National Council of State Boards of Nursing, 2011). Close family members and employers may learn of a young adult's health information online instead of in person. In addition, when young adults, particularly women, become aware of upsetting events, such as disease recurrence or death among peers living with cancer, through social media, they can experience psychological distress (Hampton, Rainie, Lu, Shin, & Purcell, 2015).

Nurses are provided guidance about protecting patient privacy and confidentiality when using social media, and they are cautioned against sharing work-related behaviors and intense emotions (National Council of State Boards of Nursing, 2011). However, young adults diagnosed with cancer may lack guidance from oncology nurses about what to consider when using social media to share their cancer experience. The purposes of this column are to cite existing social media platforms for young adults diagnosed with cancer (some not widely known outside the young adult cancer community) and to encourage nurses to educate young adult patients about the safe use of social media.

Social Media and Web-Based Resources

For young adults with cancer, the dynamic nature of social media platforms can facilitate crucial connections with peers and a method of coping with their illness (D'Agostino, Penney, & Zebrack, 2011). Some resources for young adults with cancer were created with confidentiality and safe sharing in mind. All resources discussed in this section can be found in Figure 1.

Blogging, the oldest and most established form of social media (Grajales et al., 2014), is a method of social connection that young adults can actively participate in throughout treatment and into survivorship. These web-based diaries or journals (Boulos & Wheeler, 2007; Perales et al., 2016) provide a means to share one's feelings through expressive writing (Keim-Malpess et al., 2013). A variety of platforms exist in the blogging world. Patients or family members affected by cancer can share information or express thoughts and feelings about their situation by creating a blog on easy-to-use and often free sites, such as WordPress. Sites like CaringBridge, PostHope, and CarePages offer opportunities to create free personal journals to relay updates to friends and family who have subscribed to the page. All of these options provide young adults living with cancer a means to communicate with their community and also process their experience. The nonprofit organization Stupid Cancer maintains a blogroll (i.e., a directory of blogs) written by young adult patients and survivors (Perales et al., 2016).

Social networking sites allow individuals and special interest groups to create profiles in either public or semipublic forums. One example is Facebook, which allows individuals to develop a community and control who is able to see posted information (Grajales et al., 2014). The special interest groups may be established by age or geography and provide information about local in-person meetups and/or cyber support groups for patients and survivors. For example, Stupid Cancer has geographic-specific groups on Facebook. The social networking platforms Snapchat, Instagram, Flickr, Tumblr, and Twitter can be used to relay messages and/or images to either private or public communities. In these platforms, hashtags may be used to streamline content to a specific group (Perales et al., 2016). Some Twitter handles related to young adults with cancer include [@ayacancer](#), [@yacancer](#), [@TeenageCancer](#), and [@TeenCancerUSA](#).

Some cancer-related organizations and foundations sponsor specific disease- or young adult-related social networking sites. Oftentimes, young adults with cancer do not meet patients their age at their treatment center or where they reside, so they depend on social networking sites for age-appropriate, cancer-related support. Some of these organizations and foundations also offer message boards, support groups, and/or links to other important resources known to interest patients. In addition, healthcare agencies, such as the National Cancer Institute, have begun to develop their own social media presence on the Internet. These agency sites may be more accessible to young adults who prefer dynamic information and online social connections (Perales et al., 2016). They may also allow patients treated in the same location to connect with one another.

Talking With Young Adult Patients and Survivors About Social Media Usage

Oncology nurses are encouraged to share these resources with young adult patients and survivors, and converse with them about their social media presence and its potential benefits and risks. They should ask young adults about their sources of social support and if they are using any social media platforms, encourage them to think critically about where they share information and whether their current platforms are the most appropriate and secure ways to share personal health information, and suggest that they consider forums created specifically for young adults with cancer and that they give thoughtful consideration to privacy and confidentiality. If they ask advice about where to post, nurses should help them decide by asking the following questions:

- Do you want to post to a specific audience or to the general public?
- Do you want to post or do you want others to write with/for you in the event that you are not feeling well enough to write?
- Do you want to see comments on your posts?
- Have you thought about setting expectations for how people close to you should expect to receive information from you?
- How do you want your family members and friends to share information about your condition and/or pictures of you on social media?

"Oftentimes, young adults depend on social networking sites for age-appropriate, cancer-related support."

In addition to asking all these important questions, nurses should remind young adults to assess their feelings about social media use throughout their illness trajectory. At diagnosis, they may feel overwhelmed, withdrawn, and in shock. As a result, they may not be interested in seeking online support, or they may continue to use social media as they have before and share information publically without considering the immediate and long-term consequences. Oncology nurses should talk with young adults about social media and web-based resources on a regular basis, so that they can hear about options as their needs for emotional support, information, and advice change.

Conclusion

Social media use is ubiquitous among young adults, including young adults with cancer. Some social media platforms have been created specifically for young adults with cancer. Nurses have an opportunity not only to make young adults with cancer aware of these sites but to encourage critical thinking about what and how they want to share personal health information with others.

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AT A GLANCE

- Social media provides information, interaction, and support to young adults with cancer.
- Young adults with cancer must make important decisions about how to maintain their presence on social media.
- Young adults with cancer may benefit from guidance from oncology nurses about how and what to share on social media.

BLOGS

A web page created by either an individual or group that displays personal and/or informal diary-style writing

- www.blogger.com
- www.wordpress.com
- www.typepad.com

CANCER CARE

Offers a 15-week online support group for young adults aged 20–39 years who have completed cancer treatment

- www.cancercare.org/support_groups

CANCER SUPPORT COMMUNITY

Group Loop: A place where teenagers living with cancer can connect with peers and find support and education. The site includes discussion boards, an instant messenger, a video journal, and personal blogs.

- www.online.grouploop.org/boards/community.php

The Living Room: A safe place to connect with others affected by cancer. The site includes online cancer message boards, including one for patients in their 20s and 30s.

- www.online.cancersupportcommunity.org/community

My Life Line: Provides an opportunity to create a personal website that features treatment updates, guest messages, learning links, a helping calendar, and more

- www.mylifeline.org

CAREPAGES

A website that allows users to create blogs to help cope with illness and connect with friends and family members; usually closed groups

- www.carepages.com

CARINGBRIDGE

A website that allows users to create personal health journals and connect with family and friends; usually closed groups

- www.caringbridge.org

CRITICAL MASS

Formerly the Livestrong Young Adult Alliance. This advocacy organization unifies all in the community who aim to eliminate barriers to quality cancer care for young adults and help them to thrive after

being diagnosed with cancer. "Mission control" allows users to search for programs, services, and resources by zip code.

- www.criticalmass.org

FACEBOOK

A social media and social networking site that allows users to create an individual profile and exchange messages, pictures, and links; post updates; connect with organizations and specific groups; and find out about parties and events in their area

- www.facebook.com

FLICKR

A website that allows users to share personal photos and videos publically or privately

- www.flickr.com

GIVEFORWARD AND YOUCARING

A free fund-raising platform that users can share with other friends through social media sites and raise funds for medical procedures and treatment

- www.giveforward.com

INSTAGRAM

A social networking platform that allows the public or private sharing of photos and videos; users can follow accounts of other individuals or groups.

- www.instagram.com

INSTAPEER

A free mobile application created by Stupid Cancer that allows users to instantly and anonymously join a community of patients, survivors, or caregivers. Participate in discussions, exchange ideas, and receive support from others who "get it." The application can be downloaded to a smartphone or tablet.

LACUNA LOFT

Encourages, empowers, and connects survivors and young adults living with cancer. It offers wellness support, peer support, and workshops on creative writing, drawing, guided mediation, and journaling.

- www.lacunaloft.org

LIVESTRONG

Offers a comprehensive guide for young adults living with cancer, including information about fertility preservation, finances, and healthy lifestyle, and provides support and an opportunity to connect with other patients

- www.livestrong.org/we-can-help/young-adults

PODCASTS

Digital audio files on specific topics that are available for automatic download to a computer, smartphone, or other portable media player; users can subscribe to specific podcasts through websites.

- *The Stupid Cancer Show*: www.iheart.com/show/The-Stupid-Cancer-Show/?episode_id=27192491

- *AYA Cancer Chat: Life Interrupted*: www.chop.edu/health-resources/aya-cancer-chat-life-interrupted

POSTHOPE

Offers easy-to-use websites for people during times of need; includes privacy options and fund-raising links

- www.posthope.org

SNAPCHAT

An image- and media-sharing mobile application that allows public and private messages and content sharing

- www.snapchat.com

STUPID CANCER

A nonprofit organization that comprehensively addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health, and social media; the website includes a host of resources and support options, including blogs written by patients with cancer and survivors.

- www.stupidcancer.org

TUMBLR

A website where users can post multimedia and short-form blogs, as well as follow other users

- www.tumblr.com

TWITTER

A social networking platform where registered users write and read messages, or tweets

- www.twitter.com

YOUTUBE

A video-sharing website; registered users are able to upload, view, rate, share, and comment on videos that have been posted by other users.

- www.youtube.com

FIGURE 1.
RESOURCES FOR YOUNG ADULTS WITH CANCER AND CAREGIVERS