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Social Media and the Adolescent and Young Adult (AYA) patient with Cancer

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Abstract

Over 70,000 adolescent and young adults aged 15 to 39 years (AYA) are diagnosed with cancer each year in the US. The National Cancer Institute (NCI) has identified AYA cancer patients as a unique population. The most common cancers in this age group include tumors typically seen in pediatric patients such as acute lymphoblastic leukemia (ALL) and brain tumors, as well as cancers more typically seen in adult patients such as breast cancer and melanoma. In addition, some cancers have their highest incidence in AYA patients, such as Hodgkin Lymphoma, testicular cancer and bone tumors. AYA patients face additional unique issues due to their age, not just questions about treatment choices due to lack of data, but also questions about fertility, relationships, loss of autonomy, and interruptions in school/work with potentially significant financial complications. This age group also has very high rates of social media usage with up to 90% of adults aged 18 to 29 using social networking sites. In this review, we will describe the use of social media in AYAs with cancer and highlight some of the online resources for AYAs.

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Conflict of Interest

Miguel-Angel Perales and William A. Wood each declare no potential conflicts of interest.

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Keywords

Social media; Twitter; education; Facebook; adolescent and young adult; cancer

Introduction

According to the Pew Research Center, nearly two-thirds of American adults use social networking sites. This rate increases to 90% in adults aged 18 to 29. Furthermore, 35% of US adults have searched for medical information online. Recent data from the United Kingdom reports that 73% of people use the internet and, of these, 71% use the internet for health information. It is likely that at least a fraction of these searches are about cancer. Over 70,000 adolescent and young adults (AYA) are diagnosed with cancer each year in the US. The term AYA typically refers to patients aged 15 to 39 years. (1–3) In 2006, the National Cancer Institute (NCI) issued the Report of the Adolescent and Young Adult Oncology Progress Review Group, identifying cancer patients aged 15 to 39 as a unique population. The most common cancers in this age group include tumors typically seen in pediatric patients such as acute lymphoblastic leukemia (ALL) and brain tumors, as well as cancers more typically seen in adult patients such as breast cancer and melanoma. In addition, some cancers have their highest incidence in AYA patients. This is the case for Hodgkin Lymphoma, testicular cancer and bone tumors. Finally, there is a subset of cancers in which although the median age is reported as late 60's–70's, a smaller but significant portion of patients are being diagnosed and recognized in the AYA age group; for example this is the case in acute myelogenous leukemia and chronic myeloid leukemia (CML), thereby creating a challenging set of diagnostic and management questions for this vulnerable group of patients within cancers thought to be occurring in mostly older patients. (4–7) In this review, we will describe the use of social media in AYAs with cancer and highlight some of the online resources for AYAs.

AYA patients with cancer face unique issues

Most patients diagnosed with cancer face a number of issues that include the emotional and physical impact of the diagnosis, as well as complications from treatments. AYA patients also face additional unique issues due to their age. In particular, questions about treatment choices are significant as there are not always age-specific data on treatment-related outcomes in the AYA population and this has led to national and international efforts to better study these patients. In addition to decisions about treatments, AYA patients also confront questions about fertility, relationships, loss of autonomy, and interruptions in school/work with potentially significant financial complications, which are unique to their age group. Fertility is an issue that affects both men and women and, with an improvement in survival rates, has been identified as an important issue in AYA patients. (8–11) While clinical guidelines have focused primarily on fertility, it is increasingly being recognized that AYA concerns go beyond the scope of fertility only and include additional areas of reproductive health such as relationships, body image, sexual identity, sexuality, and contraception. (12) Another important consequence of a cancer diagnosis in AYA patients is the impact on education, with many patients interrupting their school or college education.

(13) This can result in lost earning opportunities in AYA survivors. Furthermore, AYA patients and survivors face additional financial burdens, and recent results from the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study reported that 25% of survivors were without health insurance at some time in the first 35 months after their diagnosis. (14)

Internet as a source of health information among adolescents and young adults

The internet is an important source of information, including health matters for adolescents and young adults. (15–20) For example, a survey of 10th graders reported in 2001 showed that almost half the students had used the internet to obtain health information. (15) In a slightly more recent analysis of 210 adolescents who were surveyed through focus groups, health questions were among the most common reasons for searching the internet. (16) Sixty-seven percent had used the internet to answer questions about specific medical conditions and other common topics included body image and nutrition (63% of subjects), and sexual health (56% of subjects). More recently, Fergie et al conducted two studies in adolescents and young adults. (19, 20) In the first study, the authors interviewed 34 adolescents in 9 focus groups to identify teenagers' perceptions and experiences of using social media for health questions and their assessment of the reliability of online health information. While teenagers reported being engaged both by official sites and user-generated content, they also described concerns about the reliability of the content. In a second study, the authors interviewed 40 young adults with diabetes or common mental health disorders and described how the subjects combined information from traditional search engines as well as a variety of social media platforms. (20)

Overview of social media platforms

Given the almost universal use of social media in this age group, it is not surprising that many AYA patients with cancer have turned to social media to gather and share information as well as express themselves. A brief description of the types of media that AYAs have successfully used is provided here.

Personal Webpages or Blogs

Blogs represent a form of web-based journaling that allow AYAs with cancer to express their feelings and describe their experiences with cancer. Blogs also represent an effective form of communication with many others, from friends and families of those affected, to visitors who may have been affected by cancer in other ways. These blogs are often intensely personal, provocative, and deeply moving. The organization “Stupid Cancer” has maintained a directory of several blogs of AYAs with cancer, at the following URL: <https://blog.stupidcancer.org/the-complete-adolescent-young-adult-cancer-blogroll-1a23753bae74#.ieyzwrpz6>. Online traditional media outlets can also host blogs, such as Suleika Jaouad's “Life, Interrupted” blog on the New York Times website (<http://well.blogs.nytimes.com/category/columns/life/>). Ms. Jaouad (@suleikajaouad) is a young adult who was diagnosed with leukemia and underwent a bone marrow transplant; she has

chronicled her experience during her treatment and now throughout several years of survivorship.

Message Boards

This form of media allows AYAs looking to obtain answers to cancer questions and to share their experiences to interact and learn from others like them. A list of message boards can be found at this URL: <http://stupidcancer.org/directories/forums.shtml>. Other examples of popular online fora include Patients Like Me (www.patientslikeme.com) and Smart Patients (www.smartpatients.com).

Hashtags and Tweet Chats

This form of media, hosted on the popular social media vehicle Twitter, allows AYAs to interact with one another and other community members by exchanging short bits of information or web links using the Twitter 140-character format. A commonly used hashtag, #ayacsm (short for “AYA cancer societal movement”), can be used by anyone looking to share information of relevance to the AYA cancer community. Tweet Chats are discrete periods of time during which a community hosts a conversation over Twitter using a common hashtag. Tweet Chats can be organized around specific topics or questions for the community to discuss. Disease-specific hashtags have been one method to streamline these conversations and a reliable way to form virtual communities to organize content, information, and tweet chats. (21) Many of these hashtags are used in disease-specific chats such as #bcsm (breast cancer) or #mmsm (multiple myeloma), but these are not specific to AYAs.

Web-based Secure Messaging

Instapeer (instapeer.org), an app hosted by Stupid Cancer, describes itself as “a place to connect with someone like you” (#nosurvivalalone). AYAs with cancer who may feel isolated can establish a profile on the Instapeer app, log in, and have someone they can talk with from the Instapeer community of cancer patients, survivors and caregivers at any time of the day or night. Unlike the other forms of media described so far, this form of social media is intended to be private, personal, and a source of 1:1 connections.

Patient Generated Health Data Cohorts

Increasingly, mobile phones and “wearable” health devices are linked to communities of individuals who can contribute data and share experiences. Apple’s “Research Kit” (www.apple.com/researchkit) hosts large cohort studies, such as the “Share the Journey” study for breast cancer survivors. Wearable activity monitors such as FitBit (www.fitbit.com) are also associated with groups of individuals who can inspire one another to become more active and to lead healthier lifestyles. It is likely that AYA-focused communities will emerge through research cohorts and wearable device groups in the coming years.

Online Clinical Forums

While not typically accessed by patients, secure online clinical forums may provide a useful setting for physicians and other professionals to discuss challenging clinical cases. A recent example of such a forum is the American Society of Blood and Marrow Transplantation Clinical Case Forum, which serves as a professional discussion forum for experts in stem cell transplantation (22). In the first year since its launch in early 2014, 137 cases have been posted and discussed.

List of online resources for/by AYA

Below is a brief description of some of the organizations for AYA patients with cancer (Table 1). Many of these organizations originated from efforts of individual AYA survivors who recognized an unmet need and were determined to develop solutions for their peers and future patients. The reader should note that the list is not meant to be exhaustive, and that several other organizations and online resources exist.

CancerFightClub (www.cancerfightclub.com)

Cancer*Fight*Club is the young adult cancer program at Hope & Cope, Jewish General Hospital/McGill University. This innovative support program offers in-person opportunities for young adult cancer patients, their caregivers and supporters in Montreal, Quebec, Canada. These programs include retreats, café nights, Bro's Club, cooking club classes, exercise evenings, Club Mets (a support group for young adults living with metastatic and/or advanced cancer), dance classes and more. Their website includes information on resources and support services, an events calendar and a blog that features written work from AYA cancer patients, caregivers and healthcare professionals.

Critical Mass – The Young Adult Cancer Alliance (www.criticalmass.org)

The LIVESTRONG Foundation created the LIVESTRONG Young Adult Alliance (Alliance) in 2006. After rapid growth in the following five years, the Alliance was spun off in 2012 as an independent organization and named Critical Mass: the Young Adult Cancer Alliance. The organization is involved in advocacy and provides information on patient resources. Its “Mission Control” search engine helps identify resources by geographic location and type of resource. The organization also organizes an annual meeting, which is unique in that it serves as a forum that brings together patient advocates, clinicians, investigators, as well as representatives from government organizations and professional societies.

Hope for Young Adults With Cancer (www.hope4yawc.org)

Hope for Young Adults With Cancer, founded by Cara Paymaster (@CaraPaymaster) and Billy Paymaster (@ukfann00), is a non-profit organization headquartered in St. Louis, MO. In addition to providing information and organizing social networking events, it also provides direct financial support to AYA patients through the “Giving Hope Fund”, which accepts applications twice a year.

Lacuna Loft (www.lacunaloft.org)

The main focus of Lacuna Loft, founded by Mallory Casperson (@mallorycaspersn), has been the development of an online magazine with daily articles on lifestyle maintenance and psychosocial support for young adult patients with cancer or other chronic illnesses, survivors and caregivers. The site offers tips, advice and resources on how to cope with the diagnosis and its impact on the life of young adults.

The Samfund (www.thesamfund.org)

The Samfund, founded by Samantha Watson (@theSamfundCEO), focuses on the financial impact of cancer diagnosis and treatment. It provides direct financial support in the form of grants, as well as online education and support. Since 2005, the organization has awarded \$1.35 million in grants. It also provides a free Webinar series, “*Moving Forward With Your Financial Health*”, and a Finances 101 Toolkit program.

Stupid Cancer (www.stupidcancer.org)

Stupid Cancer is a nonprofit organization founded by Matthew Zacchary (@StupidcancerCEO) and Kenny Kane (@KennyKane) focused on young adult cancer that has taken on an advocacy role, promoting outreach and awareness, particularly through mobile social media. In particular, they host podcasts (www.stupidcancershow.org) that feature patients, clinicians and caregivers, and focus on multiple issues relevant to AYA patients. For example, one of the authors (MAP) participated in a podcast on stem cell transplants (<https://soundcloud.com/stupidcancershow/understandingtransplants>). Stupid Cancer also organizes CancerCon (@CancerCon), a conference and social networking event for AYA patients with cancer, survivors, caregivers and advocates. In addition, the organization co-sponsors the “OMG! Cancer Summit for Young Adults” with the Leukemia and Lymphoma Society (www.lls.org, @LLSusa). Finally, Stupid Cancer also released a mobile messaging platform (www.instapeer.org) and app that allows young adult cancer patients to reach out to peers for support.

In addition to the above organizations, there are others that serve more specific constituencies, for example specific types of cancer, or geographic locations.

Young Survival Coalition (www.youngsurvival.org)

Young Survival Coalition (YSC) is an organization that focuses on young women diagnosed with breast cancer.

Testicular Cancer Society (<http://www.testicularcancersociety.org/>)

The Testicular Cancer Society is a nonprofit organization founded by Mike Craycraft (@pharmacistmike) to raise awareness for testicular cancer. They are dedicated to increasing awareness and education about testicular cancer and providing support for fighters, survivors and caregivers.

AYA cancer patients on social media

As noted in Table 1, the organizations described above all have social media channels on Twitter and/or Facebook in addition to their main websites. Many of these organizations participate in regular tweet chats. Adolescent and Young Adult Cancer Societal Movement (#ayacsm) is a monthly live Twitter event that takes place on the fourth Thursday at 9pm EST. It was co-founded in 2013 by Emily Drake (@EK_Drake), Maureen Sweet (@maureensweet) and Billy Paymaster (@ukfann00). Examples of recent tweet chat topics include current books/articles/journals of interest to the AYA cancer community (09/24/2015); favorite Twitter communities and hashtags (08/27/2015); social media tools (8/23/2015) and supporting LGBTQQ young adults with cancer (6/25/2015). Since its founding in 2013, #ayacsm has generated 32,719 tweets from 3618 participants (data obtained through analytics on www.symplur.com as of 11/02/2015). Emily Drake also launched #mayacc (Metastatic & Advanced Young Adult Cancer Community), another AYA monthly tweet chat for young adults living with metastatic/advanced/chronic cancer. Among the advantages of tweet chats is the ability to reach a large audience with different levels of participation based on individual's needs and preferences. Furthermore, these can be archived and searched for later use, thus creating a useful reference library. The Young Adult Program at Dana-Farber/Brigham (see below) archives their tweet chats on their website, while some of the recent #ayacsm chats have been archived by @DrMiguelPerales using Storify (<https://storify.com/DrMiguelPerales/ayacsm-4-2-15-tweetchat>).

Medical Centers with AYA focus on social media

A number of medical centers have a presence on social media that is focused on AYA patients with cancer. The Young Adult Program at Dana-Farber/Brigham (@DanaFarberYAP) hosts live tweet chats (#YAPchats) aimed at AYA patients with cancer. Recent chats have included "Getting Your Needs Met through Effective Communication" (9/3/15), "Strengthening Identity After a Cancer Diagnosis" (8/6/15) and "Movement, Meditation, and Mood" (6/9/15). Other programs include the Oregon Health and Science University Knight Cancer Institute Adolescent and Young Adult Oncology Program (@ohsuaya), and the Seattle Children's Teen and Young Adult Cancer Program (@SCHAYAOncology).

Interactions between patients/survivors and clinicians on social media

Physicians in general and hematologist/oncologists in particular, are increasingly integrating social media into their professional life. Various applications demonstrating the utility of social media were recently reviewed by Thompson et al. (23) The presence of clinicians on social media, either through institutional accounts (as described above) or through personal accounts, provides an opportunity for direct interactions with patients, survivors, and caregivers. Social media has provided a novel method for patients with cancer to obtain information and discuss various aspects of the cancer patient experience in real-time. (24) Online interactions with healthcare providers have the potential to become a key benefit of clinician engagement. This may enrich conversations with clinicians having the ability to inform online conversations based on data, while at the same time learning the concerns of

AYA patients that may not readily come up in the routine clinical interactions with patients. Clinicians can become part of broader AYA communities that go beyond patients and include survivors, advocates, researchers, philanthropists, etc. This is a bigger conversation than the clinic-based doctor/patient encounter and it is important for the clinician voice to have a role, and in turn to provide context to the clinician that can then inform his/her clinical practice.

There are additional implications of patients on social media. For example, discussions of side effects may provide a venue for industry and regulators to monitor post marketing drug safety. (25) The impact of social media on clinical trials also deserves a particular mention. The NCI estimates that less than 5% of adult newly diagnosed with cancer in the US are enrolled onto clinical trials, and there a clear need to improve on this statistic. (26) Social media may represent a great vehicle to raise awareness about the critical importance of clinical trials in developing new cancer treatments and also direct patients to specific trials that they may be eligible for. However, patients still need to consult with their medical team to understand the multitude of trials that may be posted and determine which if any may be the most appropriate one. Furthermore, discussions of specific trials on social media need to take into account FDA regulations, and a general recommendation is to just list the name of the study and refer patients to specific links on www.clinicaltrials.gov in order to avoid the risk of promoting inaccurate statements based on preliminary and often anecdotal data. Finally, with the presence of many patients on clinical trials on social media, there is significant risk that preliminary and even blinded data may be revealed while studies are still ongoing. This may significantly impact the study endpoints by introducing potential biases in recruitment and retention on studies. Furthermore, there may be a financial impact on study sponsors as many analysts, journalists and other stakeholders monitor blogs and other social media platforms to obtain early information on trial results. There is no easy solution to this quandary and it is unrealistic to expect or require patients to comply with the same types of confidentiality agreements that investigators routinely sign.

Summary

Adolescent and young adults aged 15 to 39 years (AYA) who are diagnosed with cancer each year represent a unique population with many specific medical characteristics. At the same time, this age group also has very high rates of social media usage. Many of them turn to the internet and social media for information about cancer or to interact with their peers and others about their diagnosis and its impact. A number of organizations, many founded by patients and/or their caregivers, have a web and social media presence specifically aimed at AYA patients with cancer. In addition, physicians and other healthcare professionals are increasingly on social media and interacting with patients and their caregivers. Given the fact that AYA are often early adopters, it is critical for healthcare professionals to also stay up to date in this area and ensure that AYA patients have access to reliable information about health issues as well as forums to communicate and exchange their concerns.

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Table 1

Examples of online resources for AYA patients and survivors

Organization	Website	Twitter	Facebook
CancerFightClub	www.cancerfightclub.com	@CancerFightClub	TheCancerFightClubCommunity
Critical Mass – The Young Adult Cancer Alliance	www.criticalmass.org	@heycriticalmass	CriticalMass
Hope for Young Adults With Cancer	www.hope4yawc.org	@hope4yawc	Hope4YAWC
Lacuna Loft	www.lacunaloft.org	@Lacunaloft	LacunaLoft
Samfund	www.thesamfund.org	@TheSAMFund	TheSAMFund
Stupid Cancer	www.stupidcancer.org	@Stupidcancer	stupidcancer
Young Survival Coalition	www.youngsurvival.org	@YSCBuzz	Youngsurvivalcoalition
Testicular Cancer Society	www.testicularcancersociety.org	@TCSociety	testicularcancersociety

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