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Health Promotion for Adolescent Childhood Leukemia Survivors: Building on Prevention Science and eHealth

Diane L. Elliot, MD[1], **Susan J. Lindemulder, MD, MCS**[2], **Linn Goldberg, MD**[1], **Diane D. Stadler, PhD, RD**[3], and **Jennifer Smith, MPH**[1]

[1]Division of Health Promotion & Sports Medicine Oregon Health & Science University Portland, Oregon 97239

[2]Division of Pediatric Hematology and Oncology Oregon Health & Science University Portland, Oregon 97239

[3]Graduate Program in Human Nutrition Oregon Health & Science University Portland, Oregon 97239

Abstract

Teenage survivors of childhood acute lymphoblastic leukemia (ALL) have increased morbidity likely due to their prior multicomponent treatment. Habits established in adolescence can impact individuals' subsequent adult behaviors. Accordingly, healthy lifestyles, avoiding harmful actions, and appropriate disease surveillance are of heightened importance among teenage survivors. We review the findings from prevention science and their relevance to heath promotion. The capabilities and current uses of eHealth components including e-learning, serious video games, exergaming, behavior tracking, individual messaging, and social networking are briefly presented. The health promotion needs of adolescent survivors are aligned with those eHealth aspects to propose a new paradigm to enhance the wellbeing of adolescent ALL survivors.

Keywords

adolescent survivors; prevention science; eHealth; health promotion

INTRODUCTION

Almost 90 percent of children with acute lymphoblastic leukemia (ALL), the most common childhood malignancy, achieve cure [1]. However, approximately two-thirds of those survivors experience future adverse consequences, including obesity, premature cardiovascular disease, and second malignancies, resulting in a nearly 25 percent reduction in life expectancy [2, 3].

Ameliorating these adverse outcomes presents challenges. Survivors can be geographically dispersed and at long distances from their original therapy site. Their primary care providers may be unaware of the implications of a prior ALL diagnosis [4]. Although interventions for childhood cancer survivors exist, they primarily are aimed at correcting problems once they have occurred. A recent review described survivors' health promotion as in its infancy [5].

Enhancing ALL survivors' wellbeing can be informed by two fields: 1) evidence-based prevention science and 2) technology-enabled health care (eHealth). We present a rationale for intervening with adolescents, followed by a review of prevention science principles and the rapidly advancing field of eHealth. The information is combined with the needs of ALL survivors to propose a new paradigm for improving their health, a format that might be applicable with other survivor groups.

ADOLESCENCE: A CRITICAL WINDOW FOR HEALTH PROMOTION

Adolescence is a time when healthy habits often decline and harmful behaviors increase. For example, teenagers' fast food and sugar-added beverage intake increase, while fruit and vegetable consumption is reduced [6, 7]. During this period, physical activity levels diminish, especially for females [8], and chronic sleep deprivation is common [9]. The prevalence of alcohol and drug use doubles from middle to high school graduation [10]. Adolescent childhood cancer survivors engage in harmful health behaviors at rates similar to their siblings, and their treatment experiences and more frequent medical contact do not appear to protect them from unhealthy actions [11].

These unhealthy changes occur when lifelong behavioral trajectories are being established, and those habits can persist into adulthood [12-14]. Prospective trials to test that relationship are uncommon, but we and others have demonstrated that programs to increase adolescents' healthy behaviors can have durable positive outcomes [15, 16]. A well-designed health promotion program has the potential to attenuate teens' adverse behavioral trends and initiate a path toward healthy habits.

In addition, adolescence is when individuals are highly influenced by peers [17]. Prevention programs for older adolescents that target bonded peers groups can alter attitudes, intentions, and behaviors [18]. Accordingly, this age is ideal for a program designed for teens sharing the empowering experience of ALL survival.

Adolescents also are high technology consumers. The average teen texts more than 100 times a day, and more than three-quarters frequent social networking sites [19]. They perceive the Internet as their primary source of health related information and prefer technology-enhanced educational programs [20]. An eHealth promotion format fits well for geographically separated teens, bonded by their shared ALL experience. Finally, later adolescence is a time when many youth transition to adult care, where few receive appropriate risk-based surveillance [21]. A program designed for older adolescents also could provide links to facilitate better adult-focused survivorship care.

PREVENTION SCIENCE CAN INFORM HEALTH PROMOTION

In general, health promotion efforts among adolescents have had limited efficacy, and recent reviews conclude with calls for new implementation strategies and larger multifaceted studies [22]. Contrary to that experience, 30 years of research deterring harmful habits, such as preventing drug use and violence, provide clear principles of effective behavior change. The National Registry of Evidence-based Programs and Practices was established in 1997 as

a repository for proven prevention programs, and it has more than 230 entries (www.nrepp.samhsa.gov/).

The shared characteristics of effective prevention have been identified [18, 23]. Evidence-based interventions are based on shared principles to affect components in the domains of knowledge, skills, attitudes, and social support for change. Although knowledge alone does not change behavior [24], certain facts may have a permissive although not sufficient influence. For example, preventing performance-enhancing drug use was mediated in part by learning those substances' adverse effects as a component of a sport team-centered drug prevention program for high school football players [25]. For teens, information is best retained with peer instructors using methods that allow active learner involvement [26].

For adolescents, important influences result from their conforming to group behavioral norms, such as their social interactions in school and with other existing peer groups. Teens also can select to affiliate with those sharing common attitudes and interests, and these selected social influences also can have major influences on behavior [27].

Rather than focusing on distal outcomes, science-based prevention programs enhance protective and reduce risk factors [23]. To illustrate, instead of spotlighting disordered eating's harmful effects, which paradoxically can increase those habits [28], a program that reduced those behaviors taught skills to prevent depression and avoid social pressures to be thin, while increasing peer support for a healthy diet [29].

Focusing on proximal influences has additional benefits, as risk and protective factors typically relate to several behaviors [30]. As a result, addressing antecedents can impact a range of outcomes [23]. For example, the science-based intervention that deterred disordered eating also reduced new sexual activity and riding with drinking drivers, neither of which were explicitly targeted [29]. Evidence-based programs also increase teens' adult competency abilities, including skills in communication, problem-solving, and decision-making; which can assist in making future healthy choices [31].

Although intuitively appealing, fear arousal by overstating adverse consequences can have adverse effects [32]. For some adolescents, riskier behaviors may seem more attractive, and programs focusing on unhealthy outcomes may stigmatize participants, enhance experimentation, and promote bonding with deviant peers [33]. The same appears true for health promotion. Teens asked about what would change their nutrition habits thought images of unhealthy foods would make them want to eat them [34]. Successful programs are empowering and enhance teens' self-efficacy [35]. An effective wellness program for adolescents could be designed with these principles, targeting youth bonded by their shared experience and building on their self-efficacy as ALL survivors.

TECHNOLOGY–ENABLED HEALTH PROMOTION

Technology-enabled health care has rapidly expanded during the last decade. The field has its own journals and national meetings (e.g., gamesforhealth.org/, mobilehealth.org/, mhealthsummit.org/, medicine20congress.com). Mobile health is its latest dimension (mHealth), and it has a projected annual market of more than 4.5 billion dollars. We provide

an overview of eHealth components that could be applied to a wellness program for ALL survivors.

e-Learning

e-learning broadly comprises all forms of electronically supported teaching and learning [36]. For this discussion, e-learning refers to technology to increase knowledge, which for adolescents usually involves simple games, quizzes, graphics, comic-type stories, and short instructional videos. These are exemplified by educational Internet sites for teens. The National Institute on Drug Abuse has a link for adolescents (www.teens.drugabuse.gov/NIDA) that houses games, video clips, and downloadable materials; and the Centers for Disease Control and Prevention lists almost three dozen sites (www.cdc.gov/family/kidsites/index.htm). Because teens often look to the Internet for confidential information regarding sexuality, contraception, and STDs, those sites are especially common and demonstrate e-learning's creative potential (e.g., www.avert.org, www.teensource.org/ts/, www.iwannaknow.org/teens/index.html, and www.canyoufixit.sense.info/) [37, 38].

Video Games

For adolescents, video games can have both negative and positive health effects. Sedentary screen-based activities may substitute for physically active pursuits and contribute to the increased prevalence of obesity [39]. Also some game content may encourage violence and other anti-social behaviors [40]. However, serious video games can encourage healthy habits and assist disease management [41, 42]. Particularly relevant to pediatric oncology is the action-adventure game Re-Mission. When assessed in a prospective randomized trial, Re-Mission enhanced adherence to chemotherapy and resulted in a three-fold increase in the intervention group's self-efficacy to manage their illness [43].

The video game industry has annual revenues of more than 10 billion dollars, and users have high expectations for their games [44]. Mainstream video games usually are funded by a publisher, and they require millions of dollars in production costs. Consequently, health promotion games are limited by the need for large upfront investments, generally exceeding other types of health promotion interventions [44]. Without a potential market to recoup expenses, complex and intricate games have had limited application to health promotion.

Physical Activity Technology

Exergaming is combining a computer and physical activity, such as Wii Fit, Kinet games, dance-simulations, cyber-cycling, and other virtual reality interfaces. Exergames, especially those that use the lower body, can produce moderate levels of energy expenditure [45]. However, as with exercise equipment in general, this technology has limited ability to motivate increased physical activity [46]. Their greatest use appears for special populations and in rehabilitation [47]. The Robert Wood Johnson Foundation supports health games research, and their website provides comprehensive resources (www.healthgamesresearch.org/).

Behavior Tracking

Tracking behaviors can assist individuals in identifying patterns and moving toward behavioral goals [48]. Pedometer use has been shown to increase physical activity among adults, adolescents, and children [49]. Personal activity monitors have advanced in their abilities, and higher-tech tools, such as Zamzee, Fitbit, Jawbone UP, and Nike+ Fuelband have additional capabilities, including monitoring sleep, connecting to the Internet, adding inputted nutrition information, and interfacing with social networks.

Apps (applications) for smartphones and tablets have added to tracking abilities. More than half a million apps have become available since 2008, with more than half relate to physical activity (33%) or nutrition (20%) [50]. Most health promotion apps offer information and tracking comparable to a self-help guide. Nutrition apps often are combined with fitness apps, and they provide food tracking, nutrition analyses, recipes, and recommendations for dining out and specific health needs. Apps are introduced daily, and some; such as Fitocracy, Healthper and SuperBetter; have social networking components. Those features add engagement and have the potential of moving apps from self-help tools to providing the social support that could motivate and reinforce change.

Pushed and Pulled Messaging

eHealth promotion web or app platforms can *push* out scheduled text messages or have participants *pull* messages with their texts. That format fits well for teens, as texting is their preferred form of communication. Older adolescents spend an average of 90 minutes texting each day [19]. Teen programs to promote physical activity, alter diets, and enhance disease management have been designed that incorporate text messaging [51], and adding that component can augment the interventions' efficacy [52]. A push/pull system offers some variability as participants can set their push schedule and determine what messages are pulled, and more individualized interactions can be driven by algorithms [53].

Social Support

Web-based social networking sites (SNSs) are forums were individuals create a visual personal profile and share it with friends and to a limited degree, other site members. Users can communicate with status updates, postings, instant messages, chat rooms, blogs, and file sharing. SNSs support a wide range of interests and are a part of most adolescents' lives. SNSs also are a means to generate vicarious experiences and social support for behavioral change [54]. SNSs exist for teens and young adults with cancer; e.g., www.teenslivingwithcancer.org, www.teenagecancertrust.org, and www.planetcancer.org. Participants can obtain information, share stories and making connections. In general, these are directed toward teens and young adults with cancer or recently completing therapy, rather than a focus on health promotion for teens with ALL as a younger child.

A team is a microcosm of a social network, and worksites have recognized that bonded employee teams can increase productivity and job satisfaction [55]. Worksite wellness programs can benefit both workers and their employers, and that economic incentive has led to companies marketing worksite wellness computer platforms that build employee teams to support healthy behaviors [56]. As might be expected from the importance of bonded-peers

for adolescents, computer-based teams for health promotion have been effective with younger adults [57].

HEALTH PROMOTION NEEDS OF ALL SURVIVORS

Proposed components of a comprehensive health promotion program for adolescent ALL survivors are shown in Table I. As discussed, knowledge may be a necessary, albeit insufficient for behavior change. ALL survivors could benefit from information about their illness, its long term health implications, and their future health care needs. These facts alone may motivate behavior change, as younger cancer survivors indicated that greater understanding of how exercise benefits survivors might motivate their increased physical activity [58].

The majority of the health behaviors listed in Table I are aspects of the Healthy People 2012 goals and especially applicable for ALL survivors due to their increased risk for obesity, hypertension, metabolic syndrome, premature cardiovascular disease, and second malignancies [2, 3]. In addition to heightened risk, these survivors may have behavioral profiles more unhealthy than other adolescents. Adult childhood cancer survivors were less likely than their siblings to meet physical activity recommendations [59]. While some reduction in physical activity may be related to the neuropathy and late musculoskeletal effects of therapy [60], those effects generally are not limiting, and their determinants of physical activity similar to the general population [61]. Survivors' nutrition profiles are less well examined. Limited studies found that less than one-third met recommendations for vitamin D and calcium intake [62], and their diets were high in "sweets" and fats, while low in fruit, vegetable, and fiber intake [62, 63].

Studies have documented an increased risk of obesity among childhood ALL survivors [64], and in cross-sectional study, their average BMIs were higher than their siblings [65]. However, obesity is not listed in Table I. Not all survivors are obese, and programs that focus on weight control can have unintended adverse effects. Longitudinal studies indicate that teen dieting behaviors, even if not obese are related to greater weight gain over time [66]. In addition, pressure to lose weight may lead to smoking and disordered eating habits [67], and a link between smoking and disordered eating habits has been observed among teen survivors [68]. Effective weight loss programs increase physical activity, augment health eating habits and engage social support for those behaviors [69]. The proposed intervention would focus on those activities without explicitly targeting obesity.

Sleep often is deficient among adolescents [70]. Studies of adult childhood cancer survivors have reported higher rates of fatigue, daytime sleepiness, and self-reported poor sleep quality compared to siblings [71], and chronic sleep deficiency has been linked to an increased risk of malignancies [71]. Finally, lack of sun protection is a common behavioral risk factor among childhood cancer survivors [72], and both adequate sleep and sun safety/skin self-surveillance would be promoted.

ALL survivors' unhealthy behaviors have received limited study. Although their smoking rates may be lower than age-matched controls [73] and their siblings [11], a substantial number of adolescent and young adult childhood cancer survivors smoke [11]. This is

particularly concerning as smoking at a younger age is predictive or adult smoking among US cancer survivors [74]. In prior programs, simply providing survivor–related information concerning tobacco's risk helped motivate quitting [75].

Overall rates of alcohol use among adolescents who had malignancies before age four in the Childhood Cancer Survivor Study cohort was comparable to their siblings, with approximately half of teens reporting past or ongoing alcohol use [76]. However, Rebholz et al. [77] examined alcohol use among more than 1,000 Swiss childhood cancer survivors and found their binge drinking was double that of controls. Drinking is of particular concern among childhood cancer survivors, as teen alcohol use was more predictive of later heavy use than among the general population [76]. Alcohol also may have unique risks for ALL survivors due to its augmenting anthracycline cardiotoxicity [78], increasing risk for certain malignancies [79], and adversely affecting bone health [80].

A third content category would relate to mental health. Recognizing that most adolescent ALL survivors report good present and expected future mental health [81], these could be elective aspects. ALL survivors are at risk for problems related to executive function [82] and also have a higher prevalence of depression, anxiety, and PTSD compared to their siblings [83]. Management of these disorders is critical for health promotion, as they are associated with being less physically active, using alcohol, and smoking [11, 68, 84].

TECHNOLOGY-ENABLED HEALTH PROMOTION FOR ALL SURVIVORS

eHeath promotion provides a means to unite ALL survivors as a bonded group of adolescents and deliver the content shown in Table I. The program's core is a web-based platform that could be accessed by geographically dispersed ALL survivors. The need for web-based networks to improve the knowledge of childhood cancer survivors and their long-term care is not a new concept [85]. The 2012 launched AYA Cancer Survivorship iPhone application provides text information about survivor health topics and survivorship plans. Designed for a broad range of malignancies and ages, it has useful information and links, but lacks e-learning activities tailored for adolescents, social networking and a focus on teenage survivors.

The e-learning aspects would involve games, quizzes, graphics and brief instructional videos addressing the program's knowledge objectives. An advantage is the site's ability to use animation as a tool to make knowledge content relevant, engaging and understandable for teens [86]. Health topics and survivor risks would be presented without "scare tactics" and kept appropriate for adolescents' risk literacy. Motivation to complete the activities could be built in with challenges, feedback on mastery and gaining access to deeper aspects of the site. The platform could link to resources to be shared with their health care providers concerning future medical care needs [87].

A bonded network of teens and building on their self-efficacy as ALL survivors is an instrumental feature of this paradigm. The mobile component would include access to useful apps, such as identifying healthy foods at fast food restaurants and tools for personal monitoring. Both the apps and website would build a network of social support, and healthy behavioral norms would be enhanced by instant polls and mentoring by older teens [88].

Postings by survivors would enhance the content. Peer teaching was effective for smoking cessation among adult cancer survivors [89], and teen survivors indicate that peer support is an important factor for getting regular physical activity [90]. In other settings, the social commitment to healthy behaviors that could occur through a website has motivated teens' healthy actions [91]. The experience would be individualized based on self-identified goals, such as personalizing text messages and accessing elective components of the platform. For example, computer programs for adolescents can improve neurocognitive function [92] and prevent depression [93], and these could be linked as elective resources.

Creating an engaging platform for teenagers is a challenge, as they are demanding Internet users. However, successful websites illustrate components that can satisfy teens and be blended into an ALL survivor platform. For example, Beinggirl.com is a popular website for teenage girls. Launched in 2000, it has more than one million registrants. It has a unique niche and presents information not available elsewhere [94]. Visitors must read relevant articles before they can join, and only members can generate posts for peer interactions. Beinggirl.com also engages through pushed connections at least once a month. It leverages partnerships to build interest, such as featuring a different music artist each month. By analogy, an ALL survivor website could identify partners for its pro-social mission with music artists, athletes, and well-known cancer survivors.

The National Cancer Institute's quit site for teen smokers (www.teen.smokefree.gov) demonstrates the potential of mobile apps and individualized messaging. Visitors can link to social media and access a text messaging service that provides round-the-clock encouragement and advice. In keeping with effective prevention emphasizing empowerment and choice, their tagline is "Your Life. Your Health. Your Call."

BodiMojo (www.bodimojo.com) is a wellness site for teens that offers web information, health apps and personalized messages. Tools include games, quizzes, social networking, and customized user pages. Visitors create a personal profile, track goals, take health challenges with friends, and earn points and rewards. BodiMojo is a newer site and aims to monetize its activities through advertising and a virtual economy of points and merchandise. An ALL survivor site would have the advantage of an existing bonded participant group and uniquely relevant content.

CONCLUSION

The principles of prevention science inform health promotion and when combined with the expanded abilities of eHealth could provide a new paradigm to deliver a wellness program for ALL survivors. Editorials have drawn attention to the need to use new technology for health promotion [95]. Adolescent ALL survivors could be connected in an interactive eHealth network. Those selecting to join the site at age 14 or 15 would have several years to learn about their health, interact and bond with other survivors, as they age mentor younger teens just accessing the site and be influenced by healthy behavioral norms. The overall narrative of the platform would be building on their self-efficacy from surviving leukemia to establishing lifelong healthy habits. The format would be in keeping with studies indicating that survivors' resilience is increased by focusing on their strengths [96]. The intended

outcomes would be healthier lifestyles, reduced risk of the morbidities of their prior therapy and appropriate transition to lifelong survivor-specific surveillance.

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Table 1

Health Promotion for Adolescent ALL Survivors

Knowledge
• Health topics for teens
• Survivor-specific risks and risk reduction
• Longitudinal care needs
Healthy Behaviors
• Regular physical activity
• Healthy nutrition
• Adequate sleep
• Sun protection
• No tobacco and alcohol use
Mental Health (optional content)
• Executive function
• Depression and/or anxiety
• Post traumatic stress disorder