

RECRUITMENT CHALLENGES IN ADOLESCENT & YOUNG ADULT CANCER
SURVIVORS

by

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RECRUITMENT CHALLENGES IN ADOLESCENT & YOUNG ADULT CANCER
SURVIVORS

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ABSTRACT

The adolescent and young adult cancer population is uniquely difficult to recruit for research studies, leading to a lack of information and clinical trial participation. The purpose of this integrative review was to identify specific limitations to and successful strategies for recruiting this population. These strategies could be implemented in an ongoing study on the effects of physical activity in adolescent and young adult cancer survivors and help general recruiting efforts in the future.

Various databases were searched and reviewed for applicable evidence and current research on the topic of adolescent and young adult recruitment. Barriers identified include the population's developmental stage and their increased mobility leading to the lack of commitment. Successful strategies for recruitment include face-to-face contact by healthcare providers, social media outreach, successful first contact, and continued additional contact.

While multiple barriers to recruitment and successful recruitment strategies were identified, ultimately more research is needed on the subject. The data collected creates a solid base for continued research in this population. The findings in this review are satisfactory to create a plan of action for recruiting the adolescent and young adult cancer population in the current ongoing study on physical activity. A multifaceted approach initiated by the patients' healthcare providers combined with social media outreach and frequent contact will be most effective for this population, based on integrated review findings.

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Recruitment Challenges in Adolescent & Young Adult Cancer Survivors

Adolescent and young adults (AYA) are unique in both their behavior and health outcomes and yet have not been well represented in the current literature. One potential reason they are so underrepresented and understudied is their lack of participation in clinical trials. Traditional recruitment and retention efforts have not proven effective for adolescents and young adults. Consequently, the lack of research in the AYA population has contributed to a shortage of information and understanding of how to treat them both clinically and psychologically. Researchers are faced with challenges when attempting to recruit AYAs for research (Rabin, Horowitz, & Markus, 2012). Adolescents and young adults diagnosed with cancer are not seeing the same clinical improvements that other age groups are experiencing (Harlan et al., 2011). There is currently little data or research on the topic of how to best respond to this issue and best recruit this population, despite the increasing need.

The student investigator was introduced to the topic of recruitment challenges in the AYA population after the primary researchers were having difficulty recruiting participants for their study. Conclusions from this integrative review will be utilized to improve recruiting efforts not only for the primary research project but for future research.

Methodology

The purpose of this integrative review was to identify specific barriers and strategies to successful recruitment of AYAs in clinical trials. These strategies can then be used in the current study on the effects of physical activity on adolescent and young adult cancer survivors struggling to recruit participants and future studies with AYAs.

To address the topic of recruitment in the AYA population, several databases were searched, including CINAHL Complete, PsycINFO, Medline Complete, Joanna Briggs Institute, and PubMed. Key words and phrases used in these searches were “adolescent,” “young adult,” “recruitment,” “retention,” “challenges,” “barriers,” “recruitment strategies,” “research,” “clinical trial,” and “participation.” The strategy in this search was to first identify barriers and strategies and then continue to find more evidence to expand and explain these findings. Grading and ranking of the evidence found through this review can be found in Evidence Table I.

Results

Recruitment Barriers

The AYA oncology population is extremely unique, bringing its own age-specific recruitment challenges. These potential research participants often move, are uninsured, or seemingly too busy to participate in studies.

Developmental considerations. The AYA oncology population can be understood in part through Erik Erikson’s stages of development. According to Erikson, these potential participants are primarily in the “Intimacy vs. Isolation” stage, in which they wish to focus on personal relationships and development. The younger participants may still be in the “Identity vs. Role Confusion” stage, in which they are working to create their own identity and struggling to fit in to society (Learning Theories, 2016). Hendricks et al. (2013) found that one recruitment strategy cannot broadly work to recruit this population, as AYAs have very different perceptions and attitudes to consider depending on their specific ages (e.g., 14 vs. 18 year olds). Researchers therefore must tailor strategies specifically to the different sub-populations within the AYA oncology population. Stages of development can also influence clinical trial enrollment, as many

young people are going through intense emotional and social changes in their lives that can impact their treatment decisions. These potential AYA participants are working through struggles with self-image, peer relationships, social and financial issues, and changes in independence, all of which can influence treatment and participation (Tai et al., 2014).

Mobility. Gorman et al. (2014) identified multiple factors limiting AYA enrollment in studies, notably that they are often geographically dispersed and mobile because of their current stage in life. Going to college in new cities and starting new careers away from home make them difficult to follow and keep in one place long enough to complete a study. The anticipation of these changes can also deter potential participants. Personal life changes such as marriage contribute to this population's frequent movement, as identified in the AYA HOPE Study on recruitment and follow-up of AYA cancer survivors (Harlan et al., 2011). The authors examined the feasibility of recruiting AYA survivors to study issues in their treatment and health outcomes. Gorman et al. (2014) focused both locally and nationally on female cancer survivors, while Harlan et al. (2011) was national and less specific. Both investigations used similar recruitment strategies such as in-person clinic-based recruiting, mailings, and social media.

Insurance. Burke, Albritton, and Marina (2007) noted that a lack of insurance coverage and/or access to healthcare is also a common barrier to participation, especially in clinical trials. Most participants are recruited while they are in the clinic or hospital setting. This age group is one of the largest and fastest-growing uninsured or underinsured population in the US currently, making them much harder to reach. There is no published data supporting a direct link to lack of coverage and lack of research participation but there is a perceived correlation. Lack of insurance coverage may keep patients from continued, consistent medical care and are; therefore, not in a place to be recruited for participation in a clinical trial. In a study conducted at Johns Hopkins

Hospital, researchers found that lack of insurance in all age groups is a major barrier, because even if a patient is insured their insurer may not cover clinical trial costs (Klamerus et al., 2010). Insurance approval was also found to delay enrollment of patients able to participate. Gorman et al. (2014) had similar conclusions regarding insurance as a common factor impacting specifically the AYA participation while studying a social media approach to recruitment.

Time Commitment. Many AYA cancer survivors are particularly concerned about the time commitment that participation will require, as this population is already busy with school, new jobs, and starting families. As German psychoanalyst Erik Erikson concluded, the AYA population is at a stage in life where they wish to “settle down” and are seeking intimacy and satisfying relationships. Participating in research studies does not correlate with the amount of time they wish to spend with friends and family (Learning Theories, 2016). Page et al. (2013) conducted a study examining general recruitment challenges and determined that suboptimal location or time points of study was a major challenge to overcome when recruiting and specifically retaining any research population. The time commitment challenge is a factor in clinical trials for AYA oncology patients, as was concluded by Gul and Ali (2010) in their study on the recruitment and retention challenges in this population. The investigators determined that studies must advertise and provide flexible hours, convenient locations, and work around participants’ work and family schedules for successful recruitment of AYAs in research.

Successful Strategies and Approaches

When examining different studies and challenges that researchers faced, two specific forms of recruitment were reported as successful. The more traditional method of clinic-based recruitment was extremely effective, while the newer social media approach continued to show promise.

Face-to-Face. Rabin, Horowitz, & Markus (2012) examined recruitment strategies in a population of young adult cancer survivors' participation in an exercise intervention. Of the different strategies attempted, in-person clinic-based recruitment and mailings were the most effective. Clinic recruitment was potentially successful due to the close relationship between survivors and health care providers who were the first to approach the potential participants. Clinic-based recruitment was also successful for Hartlieb et al. (2016) when attempting to recruit adolescents in a chronic disease clinical trial. The personal interaction with the health care provider was cited as a likely reason for this success. Rait et al. (2015) compared traditional and Facebook-based recruitment, and determined that provider-referrals was both the most successful and cost effective strategy. These studies show that a traditional clinic-based, provider approach could be a solution to recruitment challenges in this population. A provider approach designates that the patient's physician first approaches the patient about the study, explaining its purpose and the patient's opportunity to participate.

Cantrell et al. (2012) conducted a longitudinal study examining different recruitment and retention methods of the AYA female cancer survivors, and encountered similar success with site-based research facilitators. In a National Children's Study focused on recruitment outcomes of provider-based approaches, provider-based recruiting was found to be successful if researchers could overcome the challenge of providers often being unwilling to participate in recruitment (Hale et al., 2016). Serge, Buckwalter, and Friedemann (2010) examined strategies to engage clinical staff to recruit research participants. These investigators concluded that clinical staff often do not facilitate research or approach patients about their willingness to participate, usually focusing strictly on clinical care instead. Clinical staff already have a connection with patients, and along with investigators can facilitate the successful recruitment of

AYAs in research. This strategy was shown to be one of the most successful methods of recruitment. Effectively educating and training clinical staff on research recruitment could also lead to increased research participation.

Social Media. Social media, specifically Facebook, can also be an effective method for recruiting AYAs, as was found in a research study focused on specific issues in recruitment for young participants (James, Taylor, & Frances, 2014). They reported that Facebook can be utilized as a means of communication and connection, and using it can create a snowball effect when recruiting participants. Brown et al. (2015), examined the recruitment of college students and also determined that web-based recruiting could be more effective than traditional methods for this population. Fazzino et al. (2015) specifically evaluated the feasibility of recruiting college students for research through Facebook and Twitter postings. Social media provided the investigators a broader access to this population, and determined that Facebook, but not Twitter, is feasible for recruitment. Rait et al. (2015) found while comparing traditional recruiting to Facebook that Facebook could draw the greatest volume of potential participants, but that technology-based recruitment may result in higher costs. Gorman et al. (2014) discovered while examining different recruitment approaches for young adult female cancer survivors nationally that social media can often be the most successful method of recruitment. This systematic review of the use of Facebook as a recruitment tool for adolescent health research found that Facebook has great potential value for research recruitment. Utilizing Facebook allows researchers a greater reach when searching for potential eligible participants.

Other Successful Strategies. In addition to specific recruitment strategies already discussed, other strategies were found to be necessary for successful recruitment. In a study conducted on the challenge of recruitment and retention of participants in clinical trials,

investigators discovered that the “first contact” is extremely predictive for how the potential participant will view the research (Gul & Ali, 2010). During an AYA HOPE study on recruitment of AYA cancer survivors, a majority of potential participants required additional contact to eventually enroll them in the study (Harlan et al., 2011). A single point of contact is often not enough for this particular population, and additional recruiting can be necessary for successful recruitment.

Discussion

After this integrative review of the current literature, multiple barriers to recruitment and successful recruitment strategies have been identified, as shown in Table II. The most notable barriers to recruiting the AYA population are their developmental changes, frequent mobility, insurance problems, and the perceived time commitment (Burke, Albritton, and Marina, 2007; Gorman et al., 2014; Gul and Ali, 2010; Harlan et al., 2011; Hendricks et al., 2013; Klamerus et al., 2010; Tai et al., 2014). Investigators determined that face-to-face recruiting (a healthcare provider-based approach) and social media will produce the best recruitment results for this population, as well as factors such as successful first contact and continued follow-up contact (Cantrell et al., 2012; Gorman et al., 2014; Gul & Ali, 2010; Harlan et al., 2011; Hartlieb et al., 2016; James, Taylor, & Frances, 2014; Rabin, Horowitz, & Markus, 2012). A complex, multi-faceted approach will create optimal recruitment outcomes for the unique AYA population. Ultimately, more research is needed on the topic of best recruitment strategies, as was reported by many investigations as part of this integrative review. Grisby et al. (2014) attempted to assess the attitudes of young adult oncology patients toward clinical trials, but only could conclude that the drivers of these attitudes are not well understood and future work should focus on defining them in order to increase positive perception. The information reviewed and summarized by the

student investigator provides a foundation to understand this population better and to begin more personalized a recruitment practices. Based on these results, a specific plan of action can be created to better recruit AYA oncology participants in the ongoing study regarding physical activity.

Implications

The AYA oncology population is extremely unique as many researchers have discovered. To best recruit these participants, one must have an understanding of the barriers and challenges of this task and also the strategies that have shown the most success. After doing so, investigators can apply the knowledge and information to create a plan of action for the currently struggling research study on the effects of physical activity in AYA oncology survivors. A multi-faceted approach will be most successful, with the patient's physician and other healthcare providers personally approaching first about the opportunity to participate. This first contact from a known and trusted individual will create the best first impression of the study. The clinical staff in the office/clinic will need to help facilitate contact with researchers and encourage participation. Social media (Facebook) is another new avenue to explore for recruiting participants and should be used in conjunction with the clinic-based recruitment. Finally, researchers can continue to approach the AYA survivors in clinic, by telephone, and by postal mail to inquire about participating in the study addressing physical activity, emotional health, and fatigue. This multi-faceted approach will lead to an increase in the number of and quality of AYA studies. More research will lead to improved treatment outcomes and a better understanding of this population as a whole.

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APPENDIX

Table 1

Evidence Summary

Article	Purpose	Design	Results	Evidence Level/Grade`
Brown et al. (2015)	Various recruitment strategies used for enrolling college students in a research study.	Quantitative, empirical	<ul style="list-style-type: none"> - Traditional recruitment strategies (newspaper ads and flyers) may not be the best approach for recruiting college students. - Web-based efforts proved to be a better recruitment strategy. 	Level III Good quality
Burke et al. (2007)	Recruitment challenges in adolescents and young adults for cancer clinical trials.	Descriptive	<ul style="list-style-type: none"> - Challenges: access to insurance or healthcare (largest and fastest-growing un-insured or underinsured population in the US), more likely to see providers who are not part of research institutions, are less likely to be referred to clinical trials. - Solutions to overcome limitations: increase number of trials, change age eligibility limits, increase collaboration between cooperative groups, advocate for education initiatives, insurance coverage, and research funding, and education of the general public and medical personnel to increase AYA oncology awareness. 	Level III Good quality
Cantrell et al. (2012)	Challenges in recruitment and retention of a sample of older adolescent and young adult female survivors of childhood cancer	Descriptive	<ul style="list-style-type: none"> - Site-based research facilitators are crucial - Challenges: perceived extensive or inconvenient requirement, multiple demands on time and resources, lack of trust in research, and lack of understanding of the importance of research. 	Level III Good quality

Article	Purpose	Design	Results	Evidence Level/Grade`
Fazzino et al. (2015)	Evaluated feasibility of recruiting students via free message postings on Facebook and Twitter to participate in a web-based brief intervention study.	Quantitative, empirical	<ul style="list-style-type: none"> - Social media provides a broader access to this population - Facebook recruitment was feasible and free and resulted in a large number of participants - Twitter was not as successful - Social media allowed researchers to extend web-based intervention access to students in the United States and Canada. 	Level III Good quality
Gorman et al. (2014)	Specific recruitment strategies used in recruiting AYA-aged female cancer survivors and. Challenges and recommendations discussed.	Quantitative, empirical	<ul style="list-style-type: none"> - Social media and internet strategies are effective, especially on a national level. - This population is difficult to recruit because they are geographically dispersed and mobile, are less likely to be insured, and less likely to regularly visit a single doctor. - Locally the best method is HCP or clinic referral. 	Level III Good quality
Grigsby et al. (2014)	Assess attitudes toward clinical trial participation in young adults with a history of cancer.	Quantitative, empirical	<ul style="list-style-type: none"> - Drivers of attitudes toward clinical trial participation in AYAs are not well understood and may impact cancer trial participation. - Future work should focus on defining attitudes toward cancer clinical trials in the AYA population and developing interventions to increase awareness, knowledge, and positive attitudes toward participating in cancer research. 	Level III Good quality
Gul et al. (2010)	Importance of recruitment and retention of research participants, the associated barriers and challenges, and various strategies to overcome these barriers	Descriptive review	<ul style="list-style-type: none"> - Demographics: low income/education/health awareness contribute to high refusal and attrition rates, psychosocial and emotional variables - motivation, fear of loss of insurance benefits, influence of family, negative research perceptions, and personal values/beliefs, lack of 	Level III Good quality

Article	Purpose	Design	Results	Evidence Level/Grade`
			<p>interest/time/transportation/physical limitations and not wanting to be bothered, cultural factors, political and media-related factors, and research-related factors.</p> <ul style="list-style-type: none"> - Effective strategies: eliminating participant-related barriers, minimizing cultural and contextual barriers, dealing with research-related barriers. - The "first contact" is extremely important for how the potential participant will view the research. 	
Hale et al. (2016)	Tested whether provider-based recruitment could improve recruitment outcomes compared with household-based recruitment.	Quantitative	<ul style="list-style-type: none"> - Provider-based recruitment can be successful if researchers can overcome certain challenges: time-intensity of engaging the clinical practices, differential willingness of providers to participate, and necessary reliance on providers for participant identification. 	Level III Good quality
Harlan et al. (2011)	Feasibility of recruiting a population-based sample of AYA survivors to examine issues of treatment and health outcomes.	Quantitative, empirical	<ul style="list-style-type: none"> - Challenges: mobile and difficult to follow population due to educational and employment opportunities, marriage, and other personal life changes. - Researchers used mailing as their primary form of recruitment, and included a LIVESTRONG bracelet in each mailing packet to add interest. - Majority of potential participants required additional contact to eventually enroll them. - Population-based cancer registries are a good source to find potential participants. 	Level III High quality
Hartlieb et al. (2015)	Examined recruitment and retention rates of adolescents for study by	Quantitative, empirical	<ul style="list-style-type: none"> - Clinic-based recruitment is effective because of the personal interaction with a medical clinic health provider 	Level III Good quality

Article	Purpose	Design	Results	Evidence Level/Grade`
	the 3 recruitment strategies used: clinic, informatics, and community.		<ul style="list-style-type: none"> - Clinicians' negative feelings about approaching patients about research must be overcome - Community-based enrollment can also be effective - Opt-out letters (instead of opt-in) can be successful. 	
Hendricks-Ferguson et al (2013)	Overview of factors related to recruitment of adolescents and young adults (AYA) into research.	Randomized control trial	<ul style="list-style-type: none"> - Participants choose to participate because of altruism and the distraction - Patients choose not to participate because of the time commitment, other interferences, competing studies, an unwillingness to be randomly assigned, and emotion/symptom distress 	Level I Good quality
James et al. (2014)	Examined issues encountered when recruiting participants for a research project on the lived experiences of young people aged 16-24 years with diabetes 1.	Qualitative, descriptive	<ul style="list-style-type: none"> - Social media, specifically Facebook, is a very effective form of recruitment for this particular age group - Researchers must know their participants and tailor their recruitment strategies to them 	Level III Good quality
Lane et al. (2015)	Reviewed the literature on online recruitment for, and retention in, mobile health studies.	Literature review	<ul style="list-style-type: none"> - Online methods of recruitment are promising but come with challenges such as participant retention - Little research noting which types of online recruitment are successful and cost-effective, so more consistent data needs to be collected and recorded 	Level III Good quality
Moe et al. (2015)	Evaluated effectiveness of a research study for college students.	Quantitative, descriptive	<ul style="list-style-type: none"> - Recruitment strategies: mass emails and poster advertisements on college campus, referrals, "word of mouth", monetary incentives 	Level III Good quality

Article	Purpose	Design	Results	Evidence Level/Grade`
	Described the methods used to recruit and retain the colleges and their students. Discussed recommendations.		<ul style="list-style-type: none"> - Retention strategies: outlining specific expectations, obtaining multiple forms of contact info, having flexible scheduling, and providing incentives for follow-ups 	
Page et al. (2013)	Reviews challenges and alternative strategies associated recruiting, retention, and blinding in clinical trial activities.	Quantitative	<ul style="list-style-type: none"> - Challenges: unexpectedly low estimate of participants needed or available, unfriendly study design, suboptimal location or time points of study, untimely or late recruitment planning - Alternative strategies: overestimate number of participants that must be recruited, prioritize endpoint and outcome measures most relevant to study aims, locate the study team and selected resources at a clinical center for access to participants is vast 	Level III Low quality
Rabin et al. (2012)	Assessed strategies used to recruit young survivors for an exercise intervention.	Quantitative, descriptive	<ul style="list-style-type: none"> - Strategies assessed: clinic-based, recruitment at cancer-related events, mailings, telephone-, advertising on the internet, radio, television and social networking media, brochures and word-of-mouth referrals - Effective strategies: recruitment at an oncology clinic (due to the relationship between survivors and physicians, who first approached them about the study), mailings, and online/social media advertising 	Level III Good quality
Rait et al. (2015)	Examined and compared traditional and Facebook-based recruitment strategies on reach, enrollment, cost, and retention.	Quantitative, longitudinal, empirical	<ul style="list-style-type: none"> - Facebook drew the greatest volume but resulted in fewer enrollees compared to traditional methods because of the high rate of ineligible contacts - Referrals (a traditional strategy) were the most successful and cost-effective 	Level III Good quality

Article	Purpose	Design	Results	Evidence Level/Grade`
			<ul style="list-style-type: none"> - Technology-based recruitment can expand a study's reach but may yield higher costs 	
Serge et al. (2010)	Described research strategies that improved staff engagement in different studies conducted in US clinical settings.	Descriptive	<ul style="list-style-type: none"> - Clinical staff members should be utilized to form connections to research recruiters - Without the engagement of clinical staff members it is very challenging to gain access to potential participants 	Level III Good quality
Stanton et al. (2013)	Tracked cancer patient recruitment to identify ways to increase recruitment efforts.	Quantitative, empirical	<ul style="list-style-type: none"> - Successful recruitment strategies: call center standard service program, "call-to-action" emails, and cancer registries - Eventual participants were more likely to be educated, middle-upper class, and Caucasian - Use registries of individuals who are motivated to participate in research - Programs that attract cancer information-seekers can be a resource for recruitment - A sense of trust and reciprocity can facilitate willingness to participate in studies. 	Level III Good quality

Table II

Barriers and Successful Recruitment Strategies

Barriers to Recruitment	Successful Recruitment Strategies
Developmental Changes	Face-to-Face
Mobility	Social Media
Insurance	Successful first contact
Time Commitment	Continued contact