

Challenges Conducting Qualitative Psychosocial Research for Adolescent and Young Adult Patients and Survivors

The field of adolescent and young adult oncology (AYAO) is developing and evolving, providing fertile ground for debate, discussion, and the exchange of opinions. In the "Controversies" feature of each issue of Journal of Adolescent and Young Adult Oncology, we will pose a key AYAO question to people from various organizations, geographical locations, and professions.

In this issue, we asked respondents about the challenges they encounter conducting qualitative psychosocial research for AYA patients and survivors.

—Editors

I PERSONALLY ENCOUNTER two types of difficulties when conducting psychosocial research with AYAs. The first one relates to methodology and the second to funding and publication opportunities.

Regarding methodology, the aspects I mostly struggle with concern the design of questions sensitive to the developmental, existential, and psychosocial realities of AYAs while maintaining "scientific rigor" or standardization in the process of questioning across subjects interviewed individually. Due to the varying age-related degree of maturity from one AYA to another with respect to their perceptual, introspective, and expressive abilities, my challenge lies in trying to obtain a detailed narrative following a previously defined set of open-ended questions with as little prompting or guidance as possible. For example, while some may elaborate on their experiences with cancer, other AYAs may struggle not only to self-reflect but also to verbalize about their inner cognitive, emotional, or existential processing of these experiences. Furthermore, an additional challenge I face concerns the analysis and determination of information that appears impertinent or unrelated to the question being asked. For example, I find that some AYAs that are not familiar or experienced with open-ended, introspective questioning often have difficulties staying on task and have a tendency to provide tangential responses to questions.

The other challenge I find myself struggling with concerns ongoing problems with the recognition of the scientific value of qualitative research, limiting the ability to both obtain funding and get published. For example, I often find that unless I present a study with a mixed-data design integrating qualitative with quantitative methods, the opportunities for funding remain limited in Canada. This seems especially true if I intend to apply to federal or provincial-based research institutes or programs in health, such as the Canadian Institutes of Health Research. The same applies for the scope of journals in which qualitative research can be published. Aside from journals specific to qualitative research, other journals that may be receptive to publishing qualitative research are within the realm of the social sciences, generally within the area of psychosocial oncology. I rarely see qualitative studies published in more medically or clinically oriented journals such as the *Journal of Clinical Oncology*.

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Qualitative psychosocial research has challenges in its own right, but it becomes even more complicated when conducting it in the specialized field of AYA oncology. Although an important first methodological approach or step is to collect qualitative data when little is known about a construct or question to be studied (i.e., quality of life or psychosocial functioning in AYAs with cancer), qualitative research still seems to take a back seat with regards to oncology funding and publication opportunities when compared to studies that rely heavily on quantitative data collection, for which the primary focus is understandably

on cure (i.e., laboratory analyses, and morbidity and mortality rates). In a medical setting, qualitative psychosocial research is sometimes misunderstood or viewed as lacking scientific rigor, objectivity, salience, or impact.

This viewpoint may be magnified in the context of an oncology specialty that is in its infancy, such as AYAO. Despite gaining momentum, it continues to be difficult to build a strong rationale for the scientific impact of conducting research, especially qualitative psychosocial research, with AYAs with cancer. Grant reviewers may critique your methodological

approach, as there is not necessarily one "right way" of conducting qualitative research depending on the research aims.

Study recruitment is also particularly challenging in this age group for many hypothesized reasons. My hypothesis is that there are underlying developmental issues, such as the increased need for control and autonomy in emerging adulthood, that contribute to the lack of AYA participation in research (i.e., it is something AYAs can say "no" to during a time when they feel they have lost emotional and physical control due to cancer). It is not only difficult to recruit AYA participants for cancer clinical trials, it sometimes feels like "pulling teeth" to recruit for qualitative studies that utilize focus groups or interviews during which participants are asked to share their feelings or cancer experiences. I have found, particularly in this age group, that many AYAs avoid talking about their cancer experiences and isolate themselves in their clinic or hospital rooms during treatment; for some of them this shifts after treatment ends, when they are more readily able or willing to look back and reflect on their experiences. I am concerned that AYAs who do participate in qualitative psychosocial research may not be representative of the larger AYAO population and may have different opinions or perspectives than AYAs who do not participate, resulting in a

biased sample or collection of skewed data. This, coupled with Institutional Review Board policies secondary to the U.S. Health Insurance Portability and Accountability Act that limit investigators' recruitment methods to (1) sending informational letters with reply cards indicating whether the individual may be contacted or (2) approaching eligible patients in the clinic or hospital if part of the treatment team, hamper AYA recruitment and enrollment in qualitative psychosocial cancer studies.

As a practicing psychologist and researcher in a pediatric cancer center that functions separate from the adjacent adult cancer center, I feel it is essential to overcome the institutional barriers by forming multidisciplinary pediatric and adult oncology collaborations to conduct studies successfully (from recruitment to data collection) with AYAs with cancer.

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Qualitative psychosocial research is not unlike other research approaches in that it presents researchers with particular sets of challenges. These challenges are not insurmountable, but certainly require careful navigation coupled with perseverance. Two of the most salient challenges I have encountered in conducting qualitative psychosocial research relate to writing for publication and simple logistics (i.e., time, effort, funding).

Writing for publication has been difficult from the perspective that qualitative psychosocial research is not universally accepted as a research approach worthy of publication. Although this point of view seems to be gradually shifting over time, there are still some reviewers who believe that the qualitative approach is subjective to a fault and lacks scientific rigor. At the other end of the continuum are those reviewers who are qualitative researchers themselves but from a differing or opposing qualitative tradition or approach. Given the substantial heterogeneity in qualitative methods as reflected through various qualitative traditions (e.g., ethnography, phenomenology, constructivism) and approaches (e.g., life stories/narratives, individual interviews, focus groups), it is not uncommon for reviewers to be very familiar and experienced with their particular tradition or approach of choice, yet completely uninformed and biased against others. These misinformed perspectives can represent substantial barriers to publishing qualitative psychosocial work.

The logistics of conducting qualitative psychosocial research can also be quite cumbersome. Whether conducting focus groups or in-depth interviews, qualitative data collec-

tion requires much more time and effort than simply administering a set of questionnaires. The group moderator or interviewer must be skilled at both establishing rapport and gaining useful information. The amount of data collected through a qualitative encounter is vast, and these data must be transcribed and subsequently analyzed. The time required to interpret qualitative data can be quite extensive and often involves much back-and-forth interpretation. In order to be able to provide this level of time and effort, funding is critical. However, it can be difficult to obtain funding for qualitative psychosocial research. Major funding agencies will typically only fund qualitative research in the context of a larger mixed-methods (i.e., qualitative and quantitative) study. Foundation grants may represent a more fruitful option, yet may result in a much smaller grant award that may not be sufficient to implement the qualitative study.

Although challenging at times, qualitative psychosocial research is also immensely valuable. As a psychosocial researcher in the area of AYAO, qualitative research has been tremendously useful in capturing the experiences of this underserved and neglected population.

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There are numerous challenges I have faced when conducting qualitative psychosocial research with AYA cancer survivors.

First and foremost, obtaining funding for qualitative work has been, and continues to be, a challenge. I am currently fortunate enough to have a career award from the American

Cancer Society, which is funding our recent qualitative work, allowing us to conduct numerous individual interviews and focus groups with AYA survivors. However, obtaining enough resources to conduct rigorous qualitative research, which can be extremely time consuming and labor intensive, has been quite challenging.

Logistics and practicality of recruitment have been a consistent challenge. Individual interviews have been easier to recruit for and conduct within this young population. They are also advantageous in that they have allowed us to explore, in depth, the unique experiences of each AYA survivor, but do not allow for group discussion or consensus. It has been an ongoing challenge to assemble focus groups of AYA survivors, especially given the other demands in their lives (e.g., school, extracurricular activities, lack of flexibility at work due to being "junior," etc.). This has resulted in smaller than ideal sample sizes for our groups. However, focus groups provide a meaningful personal experience for our participants, in addition to rich data. As each method has unique strengths and provides meaningful data, we remain committed to both qualitative methods. Aside from some of the practical issues of recruitment, interest and motivation to be part of our qualitative research has not been an issue with AYAs.

One of the other major methodological challenges we have encountered in conducting this type of research relates to survivors' developmental stage versus their chronological age. We have generally conducted separate focus groups for AYAs because they typically each face unique issues and challenges. However, we have found that developmental stage varies widely within each group and appears related not only to individual differences (as one might expect to find

when conducting research with any group of adolescents or young adults), but also to each AYA's particular cancer history. Some participants who have had extensive or prolonged treatment, with a large amount of school and personal life missed as a result, have had significant developmental delays, while others have displayed greater maturity. Some of our older participants might have been better suited in a younger group, which was virtually impossible to predict in advance. Despite this, there are many key psychosocial issues similar across the AYA spectrum, such as feeling different from peers and concerns about fertility.

Therefore, conducting focus groups, as well as subsequent data analysis of thematic content, is achievable. This developmental variability also necessitates large enough sample sizes to flesh out differences and obtain thematic agreement. This is not only challenging in terms of conducting qualitative research, it is also one of the biggest difficulties we face when designing psychosocial interventions.

Despite all these challenges, I continue to find conducting qualitative research with AYA cancer survivors both rewarding and essential if we are going to advance our understanding of their unique challenges and needs.

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Qualitative research methods, which are specifically designed to study the in-depth lived experiences of understudied populations, are a critical tool for understanding AYAs with cancer. This cluster of methods (which includes ethnographies, individual interviews, focus groups, case analyses, and detailed survey questionnaires) offers us, as scientists and clinicians, important opportunities to learn about AYAs who have been significantly underrepresented in prior cancer studies and clinical trials. This understanding can and should ultimately lead to the design of intervention-focused research and clinical tools that will enhance their lives. However, qualitative researchers face unique challenges to conducting effective and rigorous studies different from those encountered in quantitative research. Specifically, qualitative research must contend with issues of recruitment and sample size, transparent description of methods, and rigor enhancement.

Recruitment has long been a challenge in AYAO research. In qualitative studies, it is not necessary to have sample sizes that are powered for statistical significance, but it is critical to have samples that are representative of the population, homogeneous enough to establish conclusions, and large enough to reach data saturation. In my own qualitative studies, I have found these challenges to be significant while working with this population. Recruitment is a particular struggle because AYAs may not be interested in participating in research studies and may also be difficult to locate. I have found this to

be especially true in recruiting AYAO survivors, who often do not want to come back to the treatment center to discuss their cancer experience. And those who do participate may represent only a specific subset of the population of AYAO survivors.

Another barrier in recruiting representative samples in AYA oncology is the wide age and developmental range of 15 to 39 years. While it is completely acceptable in qualitative studies to have a final *N* of 10–15 participants, I struggle to ensure that the age range of those final participants is tight enough to make sense of the final themes that emerge from the data. Consequently, when designing a study I try to limit the recruitment to a targeted range (such as 15–21 year olds) so that my final sample is representative of my population of interest. However, this further limits my recruitment ability and is a tension that must be weighed during the initial design. In determining a final *N* for a study, qualitative researchers recruit until the data reach a saturation point, such that there are relatively few new emerging themes in analysis. This can also challenge recruitment efforts, as it may take a significant time commitment to reach saturation.

As someone who conducts both qualitative and quantitative studies, I have found that detailed and transparent descriptions of methods and rigor enhancement strategies are useful in successful publication of qualitative studies. Strategies to enhance rigor include prolonged engagement,

triangulation, peer debriefing and support, member checking, negative case analysis, and audit trails.¹ I attempt to utilize as many of these strategies as possible in my qualitative studies and to describe them in detail in my methods section to assist readers' understanding of how I came to the conclusions in my data analysis.

As the field of AYA oncology continues to emerge, we must utilize all of our scientific tools to best understand the needs of this population. Despite their inherent challenges, qualitative studies of AYAs with cancer can provide us with the rich, detailed stories of their lives, which are needed as we seek to improve diagnosis, care, and survivorship.

My biggest challenge in conducting qualitative research with AYA oncology populations is the difficulty in publishing with small sample sizes, an issue not unique to this population. There are limited guidelines for identifying a sample size in qualitative research. One oft-cited methods paper suggests at least five subjects per variable of interest, meaning if one intends to examine male versus female perceptions then there should be at least 10 subjects.¹ Each additional variable (e.g., cancer type, marital status, race, etc.) would require an additional five subjects per variable. However, sample size quality is best achieved through attention to saturation—the point during data collection at which no new information is emerging. It is not difficult to imagine that some concepts saturate early on in the research phase. Asking participants to identify the emotions they experienced when they learned of their diagnosis or to describe their concerns about recurrence produces similar themes and stories. While the adjectives used may vary, there is a strong thread of continuity that the experience produced fear, numbness, disbelief, and so on. However, I know that if there is any hope of publishing these data, I will continue to recruit until I have at least 25–30 participants, even if I stopped hearing new information after the first five.

Qualitative research is not meant to be generalizable. It is meant to tell a story, identify emergent themes, and explain *why* instead of *what* from the perspective of the person who lived the experience. A quantitative survey can identify that patients are satisfied with their healthcare experience, but only about those facets the survey designer selected to ask about. Asking a focus

Qualitative research is an important method of inquiry that can contribute meaningful information to research questions that seek to understand the dynamic, multiple realities inherent in certain phenomena, which are best answered through naturalistic approaches. When conducting qualitative research with AYAs with cancer, several challenges must be carefully considered to maximize the potential impact of research findings.

One such challenge relates to recruitment of participants for interviews or focus groups, two common data collection methods in qualitative research. The AYA population is extremely transient, moving frequently from ages 15 to 39 with limited continuity in their healthcare. Thus, standard recruitment efforts may frequently result in a lower than ex-

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group of AYA cancer survivors an open-ended question about what their healthcare experience was like increases the likelihood that respondents will tell you about things that matter to them rather than pre-selected content areas.

Rigorous methodology exists in good qualitative research. Much of this rigor is built into an appropriate recruitment plan, a solid question guide with consistent prompts, and a detailed analysis plan that addresses the theoretical underpinnings of the study aims. Further elements of bias reduction such as using multiple coders, member checking, and debriefing also aid in producing solid, reliable results. It is my hope that in the future editors and reviewers will consider these elements of rigorous qualitative methods and pay more attention to authors' discussion of saturation than to the specific number of subjects who participated in the research.

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pected recruitment yield due to contact information that is not current. Efforts to recruit AYA cancer patients and survivors may benefit from a systematic, multi-modal approach whereby tumor registries and academic and community-based cancer centers are utilized but augmented through support and advocacy groups (e.g., LIVESTRONG, I'm Too Young for This! Cancer Foundation, and Imerman Angels) and online research panels. Over-sampling based upon key clinical and demographic characteristics can minimize any concerns regarding the representativeness of the sample and enhance generalizability of findings. Also, given how technologically savvy the majority of AYAs are, making use of internet-based social networks may be particularly fruitful and could even provide opportunities for online focus groups.

A second and perhaps equally challenging aspect of qualitative data collection with AYAs is how best to assure different developmental cohorts of AYAs are being uniformly represented. With AYAs, there are a number of developmental changes and a wide range of fertility, educational/vocational, emotional, interpersonal, and even existential issues impacting them. Focus groups are used frequently in qualitative research to capitalize on the group dynamic of a given population and allow the collective story to unfold amongst group members. Focus groups benefit from some degree of homogeneity, which can facilitate cohesion, trust, and openness. However, focus groups arranged around age bands or cancer types may obscure more fundamental similarities such as life stage. An 18-year-old female college student with thyroid cancer will likely prioritize different needs than a 38-year-old married male with lymphoma who is raising two teenage children. Specific research aims should inform and guide the selection of group characteristics to maximize cohesion while permitting some degree of heterogeneity.

A third challenge in conducting qualitative research with AYAs can simply relate to how a participant self-identifies, which can vary widely depending on a person's age, stage, or current developmental status along the cancer continuum. For example, some participants do not relate to the title "young adult" while others do not resonate with the label

"patient" or even "survivor." When trying to reach this target population to participate in open-ended group discussions or individual interviews, it is important to be able to effectively "market" the research opportunity without offending potential participants or missing them completely because they do not think it applies to them.

Being mindful of some of these possible challenges can help minimize factors that would compromise the integrity of qualitative studies and provide a necessary foundation that may yield informative results about the unique challenges for AYAs with cancer. In turn, these findings can be used to impact standards of care, improve assessment methods, and enhance potential intervention efforts, positively impacting the lives of AYAs with cancer.

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AYA cancer patients and survivors are a historically understudied group with distinct psychosocial and developmental issues exacerbated by their cancer diagnosis. As the clinical and scientific communities recognized the importance of understanding AYA patients' experiences, research substantially increased. Though many psychosocial and health-related quality of life domain areas have been hypothesized as meaningful to AYAs with cancer, it is unclear which are most important and deserve additional exploration. There is also a dearth of valid and reliable psychosocial assessment instruments appropriate for AYAs.

In 2008, the National Cancer Institute, with funding from LIVESTRONG, initiated the population-based Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study (www.outcomes.cancer.gov/surveys/aya). The survey was designed to assess broad health service use and psychosocial experiences to identify better key domains for future research. Survey items came from existing instruments or were developed by our research team. To develop and modify the instrument, we conducted several rounds of cognitive interviews to elicit information about participants' comprehension, retrieval, judgement, and response regarding items under development. Through this distinct form of qualitative research, we were able to revise our instrument and also encountered several implementation and content challenges.

Initial implementation challenges were with recruitment: we needed a local sample stratified by age and gender, and diagnosed with one of five cancer types. Additional challenges were logistic and specific to participants' age or stage of life (e.g., for minors, parental consent/assent and transportation; for older AYAs, childcare or bringing young children). Age-specific

challenges with instrument content emerged from the interviews; item relevance and comprehension varied immensely. Several questions did not apply to all participants (e.g., school/education for older AYAs and marital plans or relationships with children for younger AYAs). Younger AYAs knew less about insurance coverage—though this was not strictly a linear finding (e.g., some 18 year olds could respond while some 24 year olds could not). Further, comprehension and word recognition difficulties by age led to item changes or deletion.

A major result of our qualitative research was the detection of potential retrospective bias. One of our key questions was whether AYAs experienced delays in their cancer diagnosis, a common anecdote. Our discussions revealed that participants' understanding of their pre-diagnosis symptoms changed once they had heard the word "cancer." With too much potential for recall bias and no way to verify reports, we decided to drop this line of inquiry from our larger study, believing that other study designs (e.g., medical record review from institutions where pre-diagnosis information was available) could better examine this question.

Many personal stories were shared in the interviews, such as: confusion about where to go for treatment; discomfort in medical settings where most patients were older; interests in social connections with other AYA survivors; frustrations with insurance coverage; and challenges with family, peers, and employers. As a result of these anecdotes, we decided to include an open-ended question at the end of our survey to allow respondents to provide additional information. These qualitative data will be analyzed for important themes to be addressed in future studies.

Overall, some challenges we observed were specific to participants' age or developmental status, whereas others

were more related to the cancer itself. Our experience suggests that AYA cancer survivors are complex and have unique challenges. Qualitative exploration into these complexities yields important implications for studies of this population—results that should better inform quantitative research of national trends.

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I would spin this question to address how qualitative research may be useful in overcoming some of the challenges of conducting studies involving AYAs with cancer. First, what are some of the challenges?

Locating and recruiting a geographically mobile population is difficult. I utilize a fundamental principle from social work: be where the client or patient is. In a literal sense, I have found that going to the patient, as opposed to asking the patient to come to me, establishes trust and engenders good faith. It conveys the message that I value the AYA's response enough to make the effort to come to him or her.

Establishing trust with AYAs is critical. Authority figures are often suspect, so investigators' *bona fides*—evidence of good faith or genuineness—must be established and demonstrated if AYAs are going to share the deep and honest truths that we seek. In some of my earlier research involving young adult survivors of childhood cancer, I at first decided not to disclose my own cancer history of having been diagnosed with Hodgkin lymphoma at the age of 25. I happened to mention I was a cancer survivor after one interview, to which the respondent said, "I wish you would have told me that *before* the interview" and explained that she "probably would have been more open and comfortable at the beginning, knowing that you knew what it was like to have cancer." An existing body of research suggests that investigator-subject matching on age, gender, or race/ethnicity elicits greater trust, openness, and truth.

I consider AYAs as a culture, with a shared sense of normative behaviors and attitudes. Therefore, my ability to engage this population, this culture of young people, involves my ability to communicate in ways they understand. I often look to young adult undergraduate and graduate students

that I employ as research assistants, as well as AYA survivors expressing an interest in my work, to help me phrase questions and develop topics for discussion. I have found that peer group interviews involving 8–10 teens and young adults can engender rich discussions. However, I have also learned that group composition is important. Once, while conducting focus groups in Los Angeles with both male and female Latino survivors, we noted afterward that the women spoke a lot less than the men, perhaps out of deference to male authority as a cultural norm. Subsequently, we conducted separate group interviews with males and females, and my female collaborator led the discussion.

Qualitative research overcomes the limitation of conventional survey approaches to research that often exclude racial and ethnic minority groups. Conventional approaches to research (e.g., surveys, structured interviews) are often experienced as irrelevant or discomforting for sub-populations who do not share the same beliefs or values that underlie the rationale for using questionnaires as simple and appropriate means for gathering information. I have found that engaging people in face-to-face interviews, or equipping them with cameras to document the impact of cancer on their lives, offers enriching opportunities for both AYAs and investigators as both move toward a better understanding of how having had cancer has affected their lives.

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