

**“This is the first time I’ve talked about this”:** Considerations when conducting qualitative research interviews with adolescents and young adults with cancer

Authors

Dr Jane P. Davies PhD LLM PGCE RGN RSCN  
Senior Lecturer  
School of Healthcare Sciences  
Cardiff University  
Room 13.91 Eastgate House  
35-43 Newport Road  
Cardiff  
CF240AB  
UK.  
Email/Ebost: [daviesjp3@cf.ac.uk](mailto:daviesjp3@cf.ac.uk)  
Online/Ar-lein: [www.cardiff.ac.uk/](http://www.cardiff.ac.uk/)

Brittany C. McGill M Psych (clin).  
School of Women's and Children's Health, UNSW Medicine, UNSW Sydney,  
Sydney, Australia.  
Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital,  
Sydney, Australia.  
Sydney Children's Hospital, Kids Cancer Centre,  
Level 1,  
High St, Randwick,  
NSW, AUSTRALIA, 2031.  
Ph: +612 9385 9870 Fax: +612 9382 1789  
Email: [b.mcgill@unsw.edu.au](mailto:b.mcgill@unsw.edu.au)

Ursula M. Sansom-Daly, PhD, MAPS  
Clinical Psychologist & Senior Research Fellow  
Deputy Head, Behavioural Sciences Unit  
School of Women's and Children's Health, UNSW MEDICINE, UNSW Sydney,  
Sydney, Australia, Kids Cancer Centre  
Level 1  
South, Sydney Children's Hospital,  
High St., Randwick,  
NSW 2031, Australia.  
T: +61 (2) 9382-3114  
F: +61 (2) 9382-1789  
E: [ursula@unsw.edu.au](mailto:ursula@unsw.edu.au)  
W: [www.med.unsw.edu.au](http://www.med.unsw.edu.au)

Claire E. Wakefield, PhD MPH  
Professor, School of Women's and Children's Health, UNSW MEDICINE, UNSW  
Sydney, Sydney, Australia.  
Head, Behavioural Sciences Unit,  
School of Women's and Children's Health, UNSW MEDICINE, UNSW Sydney,  
Sydney, Australia, Kids Cancer Centre  
Level 1

South, Sydney Children's Hospital,  
High St., Randwick,  
NSW 2031, Australia.  
T: +61 (2) 9382 3113 (Mon-Wed)/ 0425 336 571 (Thur-Fri)  
F: +61 (2) 9382 1789  
E: [c.wakefield@unsw.edu.au](mailto:c.wakefield@unsw.edu.au)  
W: [www.med.unsw.edu.au](http://www.med.unsw.edu.au)

Professor Daniel M. Kelly PhD RN FRCN  
Royal College of Nursing Chair of Nursing Research,  
School of Healthcare Sciences  
Cardiff University  
Eastgate House  
Newport Road  
Cardiff CF 24 0AB  
UK  
Phone: +442920688565  
Email; [kellydm@cardiff.ac.uk](mailto:kellydm@cardiff.ac.uk)

Corresponding author

Dr Jane P. Davies PhD LLM PGCE RGN RSCN  
Senior Lecturer  
School of Healthcare Sciences  
College of Biomedical and Life Sciences  
Cardiff University  
Room 13.91 Eastgate House  
35-43 Newport Road  
Cardiff  
CF240AB  
UK.  
Email/Ebost: [daviesjp3@cf.ac.uk](mailto:daviesjp3@cf.ac.uk)  
Online/Ar-lein: [www.cardiff.ac.uk/](http://www.cardiff.ac.uk/)

Keywords

Interviewing

Communication

Experiences

Reflection

Adolescents and young adults

## Cancer

### Abstract

Qualitative research is a useful and important way to describe and analyse the experiences of adolescents and young adults with cancer. However, undertaking qualitative research with adolescents and young adults living with, or beyond, a cancer diagnosis requires careful planning and a well-informed approach for participants with a high level of vulnerability and who are at a crucial stage developmentally. This article reflects on the challenges of including adolescents and young adults with cancer between the ages of 16 and 25 in qualitative research. By drawing on each author's own experiences of engaging in qualitative research interviews with adolescents and young adults with cancer, the article provides suggestions regarding how best to manage challenges and yield valuable data describing their experiences. Insights that are shared between qualitative researchers in this field may assist in preparing for the challenges posed by conducting qualitative research with this group and may help researchers to manage this activity successfully.

## Introduction

Qualitative research plays an important role in describing adolescent and young adults' (AYA) cancer experiences.<sup>1</sup> Qualitative research can provide explanations for quantitative findings and unearth new facets of the AYA cancer experience that are important in improving care. One useful example is the little explored area of AYAs' pre-diagnostic experiences, with qualitative work revealing how AYAs coped with undiagnosed cancer symptoms, sometimes for extended periods of time.<sup>2</sup> There are an increasing number of studies and commentaries which have highlighted the unique challenges that may impact qualitative research carried out with AYAs with a diagnosis of cancer.<sup>3-6</sup> However, there is a scarcity of guidance about how investigators might approach working with this age group during the qualitative research interview in an optimal, age-appropriate manner.<sup>7</sup>

Adolescence between the age of 16 and 25 is a dynamic 'time of transition' across all domains of an individuals' experience. This has implications for those in this age group with cancer.<sup>8-11</sup> In addition to significant physiological changes adolescents are called upon to navigate several key social challenges including individuation from their parents and the family system, solidification of peer groups and formation of romantic relationships.<sup>12,13</sup> Key psychological developmental tasks include identity formation, the ability to understand and regulate one's own emotions, and movement towards more complex abstract thinking.<sup>12,13</sup> Many mental health disorders have onset in the adolescent years, and account for a significant proportion of disease burden in this age group worldwide.<sup>14</sup> Understanding adolescent developmental theory may be useful in achieving an effective relationship with AYAs. Tonorezos and

Oeffinger have highlighted the challenges of undertaking research with AYAs with cancer, many of which are related to their transitional stage of social, cognitive and emotional development.<sup>15</sup> These developmental considerations may impact both the *content* of qualitative interviews (that is, what is asked by the interviewer, and what is revealed by the AYA) and the interview *process* (that is, how these questions are posed, and how the interview is set up).

Undertaking qualitative research with AYAs living with, or beyond, a cancer diagnosis therefore requires preparation and a careful and measured approach given their pre-existing developmental and psychological vulnerabilities.<sup>16,17</sup> It is important that mechanisms are put in place to support young people taking part in qualitative research that may evoke strong emotions or memories, and to ensure that they are protected from feeling burdened as a result of the research process.<sup>18</sup> Although not in the same way, this sense of emotional burden can also emerge for qualitative researchers who witness the emotional impact of cancer on this age group.<sup>19</sup> Insights that can be shared between qualitative researchers in this field may assist in preparing for the challenges posed by conducting qualitative research with this group and managing this activity successfully. This article will consider how to manage these challenges by drawing on each author's own experiences of having engaged in qualitative research interviews with AYAs with cancer.<sup>20-27</sup>

### **The nature of cancer in the AYA age group**

Cancer diagnosed during the AYA years (sometimes defined as between the ages of 16 and 25) presents a range of unique psychosocial issues.<sup>28-30</sup> Young people facing such a serious illness at this point in the life course will experience a number of unfamiliar transitions, 'layered' one upon another.<sup>30</sup>

Two major, and simultaneous, transitions facing a young person with cancer include the shift from childhood to adulthood, and from a life free from a cancer diagnosis to one where they are required to live with its impact (whether as a current patient, a cancer survivor, or at the end of life). Within each of these possible scenarios, AYAs with cancer will face a number of additional transitions on an everyday level such as moving from one school year to the next, the transition towards independent living, sexual and relationship experimentation, and achieving freedom from parental control.<sup>31</sup> This transitional complexity is compounded further by the fact that many AYAs have not yet developed sufficiently mature experiential or cognitive frameworks, informed by life experiences such as prior serious illness. AYAs may also lack an appropriate array of emotional skills to find meaning in their cancer experience. Thus, psychosocial care that is appropriate in terms of meeting the needs of the age group is a prime consideration in this field of practice.<sup>32</sup> As a group of researchers, we also suggest here that similar considerations should also be addressed when planning qualitative research involving AYAs affected by cancer.

### **The nature of qualitative research**

Some researchers may assume that effective qualitative interviewing can be undertaken with minimal preparation; especially given the view that interviewing is somewhat akin to the skills of everyday conversation which, when successful, is a universally-familiar human interaction. However, this not the view of authors in this area.<sup>33</sup> Additionally, the relational nature of qualitative interviewing means that the intentional nature of the interaction is imbued with complexity and may present challenges even to the most experienced of qualitative researchers.

Qualitative interviewing of any vulnerable population requires the skills of active listening, interpretation of non-verbal cues and understanding the need to tolerate silences during the interaction.<sup>33,34</sup> Employing these skills is particularly critical, when working with AYAs with cancer who have a dual vulnerability: serious, possibly life-limiting illness, and mental health risks characteristic of their developmental stage. In this article, we present several examples, drawing on actual in-depth interviews with individual young people affected by cancer during their AYA years, alongside theoretical perspectives that may assist in preparing for best-practice qualitative data collection.

We present three cases relating our experience of conducting qualitative research interviews with AYAs diagnosed with cancer from the United Kingdom and Australia. This analysis draws illustrative cases from three separate research studies, which were each initially analysed in the context of the original studies. This collaborative, secondary analysis aims to illustrate the unique developmental processes that can emerge when undertaking qualitative interviews with AYAs, regardless of the research focus and interview content. We use each case to highlight one key developmental consideration, and then use each case as a departure point from which to explore relevant theoretical perspectives to help to explain processes observed and experienced within the interview encounter. We also focus on some of the more complex, relational issues that can arise during qualitative interviews with AYAs, for which there is less clear methodological, clinical and ethical guidance surrounding qualitative research 'best practice'. Each case draws on our experiences of interviewing AYAs from a range of contexts. To protect these individuals, we have adopted pseudonyms throughout. Our intention is not to make recommendations for practice but rather to explore propositions and strategies



that might be helpful to consider when conducting such interviews with this age group before, during, or after cancer treatment.

### **CASE STUDY 1: Will**

Will was 20 years old and had recently completed a college programme at a local sports academy. Will had a girlfriend who he had been seeing for six months and had a wide social circle of friends. He enjoyed a number of sports and played football and rugby for local teams.

As a result of his cancer diagnosis, Will required surgery resulting in an above knee amputation. At the time of the interview, he was working with a physiotherapist as part of his rehabilitation and was receiving chemotherapy which was due to be completed in two months. His cancer treatment required significant changes to his daily life, particularly with reference to sports, which he had hoped to incorporate into his future career plans. He was also hoping to move out of his parent's home as soon as possible.

#### **The study context**

Will was participating in a research study exploring his experience of decision-making during cancer treatment. This study was undertaken in the UK with the data collected between February 2014 and February 2015 and was approved through the NHS UK research ethics committee (REC reference number 13/WS/0293). The aim of the study was to explore choice and control in treatment decision-making and to observe how this fluctuated during cancer treatment. The study included a series of three face-to-face semi-structured interviews lasting no longer than one hour.

Participants could choose the location of their interview. Will preferred to be interviewed at home in his bedroom, lying on his bed.

### **Reflection**

In the early part of the first Interview, Will's answers were short and, when invited to, he did not seem to want to expand on his responses. He commented to me prior to the interview that this was, 'the first time I've talked about this'. This may have accounted for his short replies early on the series of interviews. This quote illustrates the value of a qualitative in-depth interview where the methods/process takes into account the unique developmental considerations of the group/participant and how these may affect an interview. In later interviews, he talked more openly and was also more animated. His mother had taken leave from work and had remained downstairs during the interview but knocked on the door more than once to see if he required anything (such as a drink). He told the interviewing researcher he wished she would just 'F...ff' and stop interrupting him.

### **Theoretical insights**

Reflecting on this interview experience it was apparent that conscious personal agency emerged as a concern in determining the degree of autonomy and freedom that Will had to control his environment.<sup>35</sup> His depth of response to questions in the early interviews and his use of privacy and personal power controlled the extent of his disclosure. This attempt to maintain control and privacy in his environment contrasted with how cancer had already altered his body and had impacted negatively on his lifestyle.

As is common with the AYA age group, Will was making the transition to a state of established adulthood and as this is a dynamic period, it is often identified as 'emerging adulthood'.<sup>31</sup> Closely aligned to this process is the ongoing development of personal autonomy. Zimmer Gembeck and others refer to autonomy as being mainly task orientated.<sup>36</sup> They emphasise the importance of the development of autonomy, arguing that this contributes to the general wellbeing of AYAs, and commenting that moving from reliance on adults towards self-reliance is a feature of coping during this phase of development. The move towards autonomy in adulthood represents a time of significant change, when individuals engage in several new activities, including leaving home and separating from parental influence. Part of the move towards independent living may involve key changes in relationships with parents, including differences in communication routines. These will alter as and when the young person begins to occupy a place in the wider community in their own right, whilst developing, for instance, the tools for social independence, such as financial stability and moving into the labour market.<sup>37-39</sup> This does not always signal an end to communication with parents but may denote a new emphasis on becoming more autonomous as an individual with expectations around privacy and expression of opinions.

In Will's case, he was now unable to leave the parental home as he had planned prior to cancer. He not only had to cope with the effects of chemotherapy, he was also having to learn how to mobilise with a prosthesis following the amputation. Despite this, he still sought to enact some autonomy. It has been suggested that the process of 'letting go' can be difficult for parents, particularly between mothers and sons, with mothers sometimes feeling a desire to keep supporting young men despite their desire for increasing independence.<sup>40</sup> In the context of a cancer diagnosis, parents may be experiencing high levels of stress, fear, anxiety and even anticipatory grief. Added to

this, parents must also navigate a range of complex family dynamics whilst also coping with the relationships required with those professionals providing healthcare.<sup>41,42</sup> This scenario provided a brief glimpse into each of these factors.

### **Further considerations**

It is not surprising that Wills' mother wanted to check on the interview process. Although the interviewer had sought to establish a trusting relationship with the mother, this had only been for a short time and she was perhaps anxious about the situation. Importantly, a qualitative interview taking place at home with one's child about their cancer, is very different to talking to healthcare professionals in a hospital or more public setting. Will had also only recently left hospital, where his mother had constantly supported him and had been involved in most conversations that took place between himself and his healthcare team. Therefore, recovering from cancer was not only a time of change and transition for Will, but also for his mother and the wider family.<sup>43,44</sup> Nevertheless, his mother's desire to be present to support him was exemplified by her making an enquiry as to his wellbeing but this was not welcomed by Will. Instead, he was keen to maintain his privacy and not be interrupted. Had this happened, then Will would perhaps not have felt the need to express anger at his mother in light of her interruption when he was engaging in a private conversation.

In Will's case there were a number of matters which may have further influenced the interview situation, not least that he was exhibiting symptoms of grief both at the loss of his leg and that he was unable to participate in traditional sport in the short and longer term.

### **Practice implications/considerations**

It is important for the qualitative researcher to be attuned to the nuances of the AYAs broader family system and to link this to relevant theoretical perspectives that will underpin the interview encounter, such as agency and autonomy.<sup>20</sup>

This level of awareness can help the interviewer to understand the dynamic existing between parents and the AYA and by doing so enable the interviewer to recognise the tension between autonomy and the drive for parents to support and protect their child.

We also suggest that it would be helpful for qualitative researchers to discuss openly the need for privacy and confidentiality between young people and their parents. Researchers may find that by first explaining a study's focus, intent, and implications jointly with AYAs and their parents, they are able to convey a sense of respect and understanding of the parental role in their child's life, clarify the AYAs autonomy and provide clarification/reassurance to both parties about confidentiality. Importantly researchers could also openly acknowledge the parent's difficulty or discomfort with the interview situation set against the AYAs need for some sense of control. This may help to prevent apparent 'interfering' or 'blocking' behaviours on the part of the parent and may be especially useful when working with AYAs who are legally minors and/or still living together with their parents.

### **CASE STUDY 2: George**

The second study was carried out in the UK between 2007-2009. The reviewer noted that we had mentioned twice 'in the UK' in this sentence so we deleted a repeat of in

the UK and was granted ethical approval in 2007 by the UK NHS Research ethics process (Reference number 07/Q0806/59). The focus was on the pre diagnostic experiences of adolescents and young adults within one year of a cancer diagnosis. The interview interaction with George provides the focus for this section.

George was 19 at the time of the interview. He was undergoing chemotherapy for a pelvic cancer and was being 'boarded' in an adult oncology unit. The researcher had arranged the interview for the late morning and arrived to find a bare clinical room with few personal possessions. George sat on top of the bed with his posture suggestive of being resigned to his situation. George was alone in this room having to endure a lengthy course of chemotherapy over several days.

### **The study context**

This interview took place as a part of a study investigating the pre-diagnostic experiences of AYAs with cancer. The aim was to gain insight into the symptom experience, the transition towards a definitive diagnosis and the impact of this experience when undergoing treatment in a specialist AYA cancer centre. The study consisted of single face-to-face interviews with young people with a range of cancers and with different personal experiences of receiving a cancer diagnosis. Some follow up communication with each young person took place towards the end of the study by phone or text. A range of experiences emerged during the research including some accounts that described ongoing and sometimes severe symptoms as well as repeated attempts to have these taken seriously. It was not uncommon for the AYAs in the study to live with burdensome symptoms, such as ongoing pain for several months or even years, until a diagnosis was made. The impact of this experience

was found to influence AYAs subsequent views about how their symptoms had been viewed by those from whom they had sought help.

## **Reflection**

Having carried out several other interviews for the study, this meeting struck the researcher as completely different to those that took place in a specialist AYA unit where personal artefacts acted to emphasise the individuality of each young person and signified their identity. Apart from George himself, who was lying on the bed in the hospital room, it was actually the intravenous chemotherapy stand that dominated the room. His demeanour was resigned boredom and he seemed to be focused on getting through the challenge of his treatment. He seemed unsure about what taking part in an interview might entail.

During the interview itself, which focused on the lead up to his diagnosis, he revealed that his home life was always “full of family politics” and that his parents told “everyone his business.” This sense of privacy being breached infused the interview and he needed specific encouragement to open up and provide more details. The approach taken by the researcher was to encourage him to talk. His responses were often brief but, when offered, were detailed and insightful. He spoke repeatedly of disappointment at losing his sense of privacy through cancer and by being thrust back into his family when he had hoped to move away. He also spoke of having only one good friend who was currently away travelling. He gave an impression of coping with all of this alone.

## Theoretical insights

The practical and theoretical challenges that underpinned this interview event revealed George managing responses that highlighted grievance and resentment toward his family, primarily as a result of the impact of cancer on his independence and his now uncertain future. According to Young and Gibb experiences with others that may evoke frustration or anger from figures who are significant early in life may evoke a recurring sense of unfairness if needs are unfulfilled.<sup>45</sup> This dynamic may then characterise an AYA's subsequent relationships with peers or adults, including interactions with an adult researcher who is trying to engage them in an interview.

George spoke very clearly about how much he resented his family's tendency to talk about him with others, signifying a loss of trust, and he disliked having to repeatedly tell the 'back story' of his cancer (which made it challenging to address this topic during the interview; especially at the start). This meant that a different approach was needed to establish rapport. To address this, the researcher focused on what he was looking forward to in the future. This seemed to evoke a more engaged response, as the future became less threatening than the present and this shift in focus managed to carry the remainder of the interview forward.

This qualitative interview ended on the topic of regrets. George shared that he had been unable to provide a sperm sample prior to chemotherapy due to pelvic nerve damage, and thereafter developed an infection when a sperm sample was sought via a surgical incision in his groin. This 'failure' seemed to represent another of his attempts towards independence being thwarted, as though he was again "at the mercy of his cancer". As Briggs suggests such events can be catastrophic for young people who feel that their body has already failed them, whilst healthy peers



may be focussing primarily on the future and establishing an identity with which they can relate.<sup>46</sup> The threat of cancer in the AYA population can be seen to include challenges to relational capacities and the impact of these were played out openly in this interview situation between George and the researcher.

### **Further considerations**

Establishing rapport early in an interview is a significant challenge in any qualitative research study, and we suggest that more attention needs to be paid to this issue. In AYA age groups, the rapport that is needed to allow disclosure about sensitive issues, such as the threat of a cancer diagnosis, relies on what Knox and Burkard suggest is a central concern: how to conduct an incisive interview that yields rich and meaningful data while simultaneously helping participants to feel safe to explore often difficult experiences with a relative stranger.<sup>47</sup> Whilst Knox and Burkard are coming from a psychotherapeutic perspective, there are echoes with interview situations with AYA cancer participants who are invited to explore emotionally challenging topics verbally, and always with the (often unspoken) existential threat associated with cancer.

### **Practice implications/considerations**

Researchers seeking to establish a rapport with AYA participants during qualitative interview situations should be mindful of the challenges that they may face. Establishing rapport may require several strategies to allow engagement with a young person, such as viewing the interview situation from their perspective, or trying different ways to ask questions in a way that matches with what is important to them. This case also suggests the need for qualitative researchers to be able to 'read' AYAs relationship with their cancer experience, as different AYAs may

experience challenges envisaging/imagining their futures after cancer in great detail.<sup>24</sup> Being asked to do so in a study context may therefore be both difficult, and potentially distressing and researchers should be aware of this.

### **CASE STUDY 3: Abbey**

Abbey was 16 years-old at her time of participation in a qualitative interview delivered over the telephone. She had recently completed curative treatment for acute myeloid leukaemia, and the research team was aware that Abbey had a history of mental health difficulties including major depressive disorder and episodes of superficial self-harm (i.e., 'cutting') in the context of school and interpersonal stress. She had recently returned to school full-time, close to her home in a rural area several hours' drive from where she was originally treated for cancer. Here, she was hoping to continue her schooling together with her original year-group (after having missed much of the previous year). Abbey lived with her parents and younger brother, all of whom she described as being close to.

#### **Study context**

The purpose of the interview was to investigate young cancer survivors' perceptions of the impact of their cancer diagnosis by asking them to recount a narrative of their lives and to reflect on their visions and goals for the future. This study was undertaken in Australia, with data collected between March 2014 and December 2016 and was approved through the South Eastern Sydney Local Health District Ethics Committee (Reference number 12/068). Abbey completed the telephone interview from her home in a rural area of Australia.

## Reflection

From the beginning of the interview, Abbey's slowed and flat tone of speech caused the researcher to wonder whether she might be sad or experiencing low mood. She was not easily engaged by the researcher early in the interview, responding to inquiries about the events of her day and current psychological state with statements such as "It doesn't matter" and "I'm fine". As the interview progressed, and Abbey talked about events in her life to date, she mentioned a significant family history of mental illness as well as personal experience of suicidality and self-harm. Abbey also described current periods of recreational drug use, such as cannabis, during her cancer treatment for pain management, although she mentioned that this was not endorsed by her oncologist. When discussing her hopes and visions for her future, Abbey described feeling hopeless. Abbey told the researcher that she was reluctant to believe that her future life could entail any positive achievements or events, and therefore she felt that she had "nothing to look forward to". At the end of the interview the researcher was left with significant concern for Abbey's wellbeing. Enacting the steps defined by the IRB approved research study's psychosocial risk management protocol, the researcher conducted a follow-up phone call with Abbey to determine her current psychosocial supports and needs. By using Abbey's own described experiences as an entry point for 'checking in' further with her, this process was able to be both sensitive and responsive, whilst still adhering to IRB-approved safety protocols to ensure participant safety. This telephone-based risk assessment to assess Abbey's level of suicidality or self-harm ideation identified that although she was feeling low in mood, she was not at any acute risk. This conversation resulted in Abbey and the researcher determining a safety-plan for the next steps, which included Abbey

agreeing to make an appointment with her general practitioner (GP) to discuss her psychological symptoms.

### **Theoretical insights**

This case study revealed that some AYA patients and survivors who participate in qualitative research interviews will be experiencing distress or have a current (or past) diagnosable mental health disorder. The AYA years are developmentally-complex, and are known as a time of mental health risk.<sup>48,5</sup> Within the framework of the Adolescent Resilience Model, a highly stressful life event such as a cancer diagnosis may precipitate reduced quality of life and mental health outcomes with risk factors located in the individual (e.g. maladaptive coping styles, genetic predisposition to mental illness, and/or a personal history of mental illness).<sup>49</sup> Abbey's case highlighted several risk factors including a personal history of suicidality and self-harm and family history of mental health difficulties. It was possible from the symptoms reported at the time of the interview that she was experiencing a major depressive episode. However, as the ARM illuminates, protective factors were also likely at play for Abbey, including her close family relationships, and possibly a supportive school environment.

Although it is clear that qualitative researchers should hold in mind useful theoretical models of adolescent health to inform the processes taking place in the interview, this case also highlights that qualitative research studies should have pre-defined psychosocial risk management procedures that can be followed if information about an AYA's mental health or mental health risk comes to light through the interviewing process. When working with populations vulnerable to poor mental health outcomes, such as AYAs with serious, possibly life-limiting illness,

there are cases where the researcher has an ethical duty to not only function as an observer or 'witness' to the AYA's unique experiences of physical pain and emotional distress, but actually intervene if/when needed.<sup>17</sup>

### **Further considerations**

This case study also illuminates several considerations in interviewing AYAs when the qualitative data collection does not take place face-to-face. Telephone and telehealth (e.g., videoconferencing, 'Skype') interviews are increasingly more common in qualitative research and allow the opportunity to access the perspectives of some 'hard to reach' populations, including those living in remote geographical areas.<sup>50</sup> In the Australian context, the perspectives of AYA cancer patients and survivors who live in such areas are important to capture. Further, some have argued that telephone interviews may allow individuals to more freely discuss sensitive, personal material that they may be reluctant to address face-to-face.<sup>50</sup> We can speculate that Abbey may not have engaged in a face-to-face interview about her experiences. Nevertheless, this case illustrates that building rapport may be different, possibly requiring more effort, when interviews are conducted over the telephone as important social cues have to be perceived aurally.

### **Practice implications/considerations**

Qualitative researchers working with AYA cancer patients or survivors should be aware that participants may express distress, with the threat of death being a universally distressing experience. Qualitative researchers working with AYA cancer patients/survivors should assume that at least some participants in their research will be experiencing clinical levels of distress, or possibly a diagnosable mental health disorder. It is therefore important for qualitative researchers to be trained in basic

psychosocial risk management. As part of this risk management, researchers should have an understanding of psychosocial supports and referral options available to the young person in their area.

We also suggest that telephone interviews are a useful method of data collection in this population to access AYAs living in remote geographical areas, and/or to collect data on sensitive subjects, however a prior plan to build rapport over the telephone might be valuable to ensure that the interviews yield in-depth data. Qualitative researchers using these technologies to conduct interviews remotely should familiarise themselves with safety practices used in other forms of remotely-conducted research, such as in digital/telehealth-delivered psychological interventions.<sup>51,52,18</sup> In Abbey's case specifically, following a referral through her GP, Abbey's psychological needs continued to be monitored by the research team alongside her ongoing participation in an online psychological intervention. As such, she was linked in with several forms of support concurrently, illustrating the way in which it is sometimes necessary and important for an AYA's research participation and their 'real world' to intersect to effectively support them.

## **Discussion**

The quality and richness of the data obtained from interviews is integral to the success of qualitative inquiry. Interviews are brief but important social encounters, carried out with a purpose. Done well, they have the potential to yield rich descriptive data and interviews can provide nuanced insights into the experience of young people living with a cancer diagnosis. As the title of this article highlights and as stated previously, this may be the first time that an AYA with cancer has spoken to someone at length about their experiences. It is therefore important that interviewers

support AYAs to feel at ease in attempting to retrieve rich sources of data. This article argues that the interview encounter with AYAs affected by cancer can be a complex and sometimes challenging activity for both parties. To fully realise the potential benefits of qualitative interviews requires practical skill, insight and theoretical understanding of the issues involved. An appreciation of the aforementioned factors is relevant for researchers who approach AYA participants wishing to undertake a successful interview. Furthermore, we argue that further matters require consideration in this field with regard to interviewing.

Each case described here occurred in a different context in terms of the location, method of interviewing, and the type and stage of cancer involved, and each presented different factors for consideration, and a range of tensions that required some degree of balancing. In Will's case, there was a clear need for autonomy alongside the need for privacy and the capacity to talk freely. However, the perspective of the parent was also important, and the interviewer was required to strike a balance between the needs of mother and her son to achieve the best outcome. The researcher needed to view the AYA in isolation, but within the context of their family unit. In George's case, there was a similar need for independence for George as he struggled to establish a rapport with the researcher, and the researcher tried to establish a rapport with him, so that his story could be told. This indicates the need for researchers to sensitively gauge AYAs' current relationship with cancer and their own personal futures. In George's case he was also concerned for his privacy which he felt was being compromised by his family when recounting detail of his illness to others. In Abbey's case, the interview took place by telephone. As described, there is some evidence that those being interviewed by phone can be more likely to disclose richer or more emotionally challenging issues than being

interviewed face to face. In this case, Abbey disclosed her level of distress and some of the strategies that she adopted to manage these feelings. On this occasion, the researcher was left concerned for Abbey’s wellbeing; an outcome that is challenging for qualitative researchers who seek to maintain participant’s privacy but also protect them from harm. Abbey’s case highlighted the need for researchers to be aware of when they need to shift from a more passive, ‘observer’ role, and when the research process may need to intersect with the AYA’s ‘real world’. The table below suggest some possible ways in which researchers may think about useful approaches which can overcome the challenges described in the cases.

Table 1 propositions and strategies in enhancing interviews with AYA cancer patients.

<b>Challenges in the interview process</b>	<b>Potential propositions and strategies</b>
Finding and maintaining privacy	<ul style="list-style-type: none"> <li>• Negotiate a private space beforehand and ensure others know that privacy is required (e.g. parents and siblings, other clinical staff if in a clinical space).</li> <li>• Acknowledge parents may find it difficult to not become involved in the interview.</li> </ul>
Building rapport and relational awareness	<ul style="list-style-type: none"> <li>• Familiarise yourself with the participant</li> <li>• Allow time to get to know what the participant is interested in</li> </ul>



	<ul style="list-style-type: none"> <li>• Employ active listening skills</li> </ul>
<p>Having awareness of the psychosocial context of the interview (for example, recent news re diagnosis, treatment issues)</p>	<ul style="list-style-type: none"> <li>• Ensure that any relevant clinical permissions are in place</li> <li>• Communicate with relevant clinicians and ensure they are aware of the study</li> </ul>
<p>Recognise individual agency</p>	<ul style="list-style-type: none"> <li>• Focus on participant’s individual situation</li> <li>• Ensure that all data is valuable and individual perspective welcomed</li> <li>• Allow enough time for individual priorities to emerge alongside focus of the interview questions</li> <li>• Do not judge responses</li> </ul>
<p>Addressing and assessing mental health concerns</p>	<ul style="list-style-type: none"> <li>• Normalise the experience of distress, both in terms of thoughts and feelings, in AYAs who have/have had cancer throughout the interview.</li> <li>• Openly explore expressions of distress without judgment, providing opportunities for the young person to pause, or leave the interview, and</li> </ul>

	<p>giving them the agency to choose to continue (e.g., <i>“It sounds like this is bringing up some difficult feelings for you. This is really common when reflecting on such a challenging period of your life. But I do want to make sure you are OK to continue?”</i>)</p> <ul style="list-style-type: none"><li>• Be prepared with a plan to manage acute distress or mental health risks (e.g., expressed suicidal ideation), including immediate and short-term supports for the young person during and after the interview.</li></ul> <p>Ensure that you also help the young person consider the way in which their research participation may have helped contribute towards research and future patients (e.g., helping to develop better services for young people with cancer) - to strengthen the young person’s sense of agency, self-efficacy, and sense altruism for having taken part in the interview.</p>
--	---

Theoretically, there are also several different perspectives described here. These range from the use of conscious agency, as well as theories associated with rapport building and independence and resilience awareness in the AYA cancer population. These frameworks can help situate the needs of young people during the interview process and can help us to better understand the ways in which researchers can gather important qualitative data more effectively. We suggest that qualitative interviewing is essentially a relational activity and one that requires skills of empathy to the other. As MacNamee (2014, 74) usefully summarises:

*'If ours is a relational constructivist view, the 'thing' (or entity) we are examining is the interactive processes of people in relation with each other and their environments. We are curious about what sorts of worlds can be made possible through particular forms of interaction, particular ways of talking and acting.'*<sup>53</sup>

## **Conclusion**

For researchers seeking to understand the AYA cancer experience, it is imperative that the interview encounter is recognised as an opportunity to connect and explore. To do so successfully, however, requires relational skills that are appropriate to this age group and a readiness to adopt a flexible approach to assist in accessing data that can help answer the research question. We hope that our reflections on this process can assist other researchers planning to engage AYAs with cancer in qualitative interviews. By attending to the underlying factors impacting on successful qualitative interviewing, the data collected may be of a higher-quality, and may better capture AYAs' perspectives, generating greater insight into the lives of AYAs living with cancer.

## **Acknowledgements**

Dr Sansom-Daly, Ms McGill, and Prof Wakefield wish to acknowledge that the original study from which their case was drawn was supported by a *beyond blue*/Cancer Australia co-funded grant (ID:1022868), and Cancer Institute NSW (IDs:14/ECF/1-11; 11/ECF/3-43) and NHMRC Fellowships (IDs:APP1111800; APP1067501). The Behavioural Sciences Unit is proudly supported by the Kids with Cancer Foundation, the Kids Cancer Alliance, and a Cancer Council NSW Program Grant PG16-02 with the support of the Estate of the Late Harry McPaul.

Thanks to Professor Ben Hannigan in contributing to the final reading of this article.

All research originally undertaken met with the requirements for appropriate informed consent in research.

Author disclosure statement

No competing financial interests exist.

## REFERENCES

1. Wong AWK, Chang TT, Christopher K, et al. Patterns of unmet needs in adolescent and young adult (AYA) cancer survivors: in their own words. *J Cancer Surviv.* 2017; 11(6): 751-764.
2. Gibson F, Pearce S, Eden T, et al. Young people describe their pre-diagnosis cancer experience. *Psycho-Oncology.* 2013; 22,(11): 2585-2592.
3. Hinds PS, Drew D, Oakes LL, et al. End of life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology.* 2005; 23 (36): 9146- 9154.
4. Hokkanen H, Eriksson E, Ahonen O, Salanterä S. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nursing.* 2004; 27: 325 335.
5. Morgan S, Davies S, Palmer S, Plaster M. Sex, drugs, and rock 'n'roll: caring for adolescents and young adults with cancer. *Journal of Clinical Oncology.* 2010; 28(32): 4825-4830.
6. Olsson M, Jarfelt M, Pergert P, Enskär K. Experiences of teenagers and young adults treated for cancer in Sweden. *European Journal of Oncology Nursing.*2015; 19(5): 575-581.
7. Heathcote LC, Loecher N, Spunt S.(in press). Do qualitative research interviews cause distress in adolescents and young adults asked to discuss fears of cancer recurrence? Accepted by *Psycho-Oncology*, 31st August 2020.
8. Leffert N, Peterson AC. (1999). Adolescent development: Implications for the adolescent alone. In: Blustein J, Levine C, Neveloff Dubler N (Eds).*The Adolescent Alone, Decision Making in Health Care in the United States.* Cambridge: Cambridge University Press, 1999; pp.31-49.

9. Ressler IB, Cach J, McNeill D, et al. Continued parental attendance at a clinic for adult survivors of childhood cancer. *Journal of Pediatric Haematology/Oncology*. 2003; 25(11): 868-873.
10. Grinyer A. Young adults with cancer: parents' interactions with health care professionals. *European Journal of Cancer Care*. 2004; 13(1):88-95.
11. Downs JS, Fischhoff B. Theories and models of adolescent decision making. In: DiClemente RJ, Santelli JS, Crosby RA. (Eds.), *Adolescent health: Understanding and preventing risk behaviors*. San Francisco: Jossey-Bass; 2009; pp. 77-90.
12. Christie D, Viner R. Adolescent development. *BMJ (Clinical research ed.)*. 2005; 330(7486): 301–304.
13. Tarrant M, MacKenzie L, Hewitt LA. Friendship group identification, multidimensional self-concept, and experience of developmental tasks in adolescence. *Journal of Adolescence*. 2006; 29(4): 627-640.
14. Erskine HE, Moffitt TE, Copeland WE, et al. A heavy burden on young minds: the global burden of mental and substance use disorders in children and youth. *Psychological Medicine*. 2015; 45(7):1551–1563.
15. Tonorezos ES, Oeffinger KC. Research challenges in adolescent and young adult cancer survivor research. *Cancer*. 2011;117(10 Suppl):2295-300.
16. Sansom-Daly UM, Wakefield CE. Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Translational Pediatrics* 2013; 2:167-197.
17. Viner R M, Ross D, Hardy R, et al. Life course epidemiology: recognising the importance of adolescence. *J Epidemiol Community Health*. 2015; 69(8): 719–720.

18. Sansom-Daly UM, Wakefield CE, McGill BC, Patterson P. Ethical and clinical challenges in delivering group-based cognitive-behavioural therapy to adolescents and young adults with cancer using videoconferencing technology. *Australian Psychologist Special Issue: Tele-Psychology: Research and Practice*. 2015; 50(4): 271-278.
19. Stahlke S. (2018). Expanding on Notions of Ethical Risks to Qualitative Researchers. *International Journal of Qualitative Methods*. 2018; 17: 1-9
20. Davies J, Kelly D, Hannigan B. 'Life then', 'life interrupted', 'life reclaimed': The fluctuation of agency in teenagers and young adults with cancer. *European Journal of Oncology Nursing*. 2018; 36:48-55.
21. Davies, J. The experience and role of partners in helping to meet the support needs of adolescents and young adults with cancer. *Journal of Advanced Nursing*. 2019; 75(5): 1119-1125.
22. Kelly D, Pearce S, Mullhall A. 'Being in the same boat': Ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies*. 2004; 41(8): 847-857.
23. Pearce S, Gibson F, Whelan J, Kelly D. Untellable tales and uncertain futures: The unfolding narratives of young adults with cancer. *International Journal of Social Research Methodology*. 2020; 23(4): 377-390.
24. Sansom-Daly UM, Wakefield CE, Robertson EG. et al. 'Adolescent and young adult cancer survivors' memory and future thinking processes place them at risk for poor mental health'. *Psycho-Oncology*. 2018; 27: 2709 - 2716
25. Sansom-Daly UM, Baenziger J, McGill B, Wakefield CE. 'Impact of physical appearance changes reported by adolescent and young adult cancer

- survivors: A qualitative analysis'. *European Journal of Cancer Care* 2019; 28(4) e13052.
26. Vetsch J, Wakefield CE, McGill BC, et al. 'Educational and vocational goal disruption in adolescent and young adult cancer survivors'. *Psycho-Oncology*. 2018; 27: 532 – 538.
27. Wakefield CE, McLoone J, Fleming C, et al. 'Adolescent Cancer and Health-Related Decision-Making: An Australian Multi-Perspective Family Analysis of Appointment Attendance and Involvement in Medical and Lifestyle Choices'. *Journal of Adolescent and Young Adult Oncology*. 2012; 1:173 – 180.
28. Bellizzi K M, Smith A, Schmidt S, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*. 2012; 118 (20): 5155-5162.
29. Stern M, Krivoy E, Foster RH, et al. Psychosocial functioning and career decision-making in Israeli adolescent and young adult cancer survivors. *Pediatric Blood & Cancer*. 2010; 55 (4): 708-713.
30. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*. 2012; 30(11): 1221-1226.
31. Arnett, JJ. *Emerging adulthood*. (2nd ed). Oxford: Oxford University Press, 2015.
32. Fern LA, Taylor RM, Whelan J, et al. The art of age-appropriate care: Reflecting on a conceptual model of the cancer experience for teenagers and young adults. *Cancer Nursing*. 2013; 36(5): E27-E38.



33. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*. 2008; 204(6): 291-295.
34. Kvale, S Learning the craft of qualitative research interviewing. (3rd ed). London: Sage Publications, 2015.
35. Bungay V, Halpin M, Atchison C, Johnston C. Structure and agency: Reflections from an exploratory study of Vancouver indoor sex workers, *Culture, Health and Sexuality*. 2011; 13(1): 15-29.
36. Zimmer-Gembeck MJ, Skinner EA. Review: The development of coping across childhood and adolescence: An integrative review and critique of research. *International Journal of Behavioral Development*. 2011; 35(1): 1-17
37. Chiuri MC, Del Boca D. Home-leaving decisions of daughters and sons. *Review of Economics of the Household*. 2010; 8(3): 393-408.
38. Jones G. *Leaving home*. Buckingham: Open University Press, 1995.
39. Seiffe-Krenke I. Leaving home or still in the nest? Parent-child relationships and psychological health as predictors of different leaving home patterns. *Developmental Psychology*. 2006; 42(5): 864-876.
40. Lashlie C. *He'll be OK: Helping adolescent boys become good men*. New Zealand: Harper Collins, 2011.
41. Stewart JL, Pyke-Grimm KA, Kelly KP. Parental treatment decision making in pediatric oncology. *Seminars in Oncology Nursing*. 2005; 21(2): 89-97.
42. Stewart JL, Pyke-Grimm KA. Making the right decision for my child with cancer. *Cancer Nursing*. 2012; 35 (6): 419-428.

43. Wakefield CE, McLoone JK, Butow P, Lenthen K, et al. Parental adjustment to the completion of their child's cancer treatment. *Pediatric Blood & Cancer*. 2011; 56(4): 524-531.
44. Wakefield CE, Butow P, Fleming C A, Daniel G, et al. Family information needs at childhood cancer treatment completion. *Pediatric Blood & Cancer*. 2012; 58(4): 621-626.
45. Young L, Gibb E. Trauma and grievance. In: Garland C (Eds). *Understanding trauma: A psychoanalytic Approach*. (Tavistock Clinic Series). London: Routledge; 1998; pp. 81-95.
46. Briggs S. *Working with Adolescents and Young Adults. A Contemporary Psychodynamic Approach*. (2<sup>nd</sup> edn). Basingstoke: Palgrave Macmillan; 2008.
47. Knox S, Burkard A. Qualitative research interviews. *Psychotherapy Research*. 2009; 19: 566-575.
48. Merikangas KR, He JP, Burstein M, et al. Lifetime prevalence of mental disorders in US adolescents: results from the National Comorbidity Survey Replication–Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry*. 2010; 49(10): 980-989.
49. Haase J E. The adolescent resilience model as a guide to interventions. *Journal of Pediatric Oncology Nursing*. 2004; (21) 5: 289-299.
50. Mealer M, Jones J. Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Researcher*. 2014; 21(4): 32-37.

51. Sansom-Daly UM, Wakefield CE, McGill BC, et al. Consensus Among International Ethical Guidelines for the Provision of Videoconferencing-Based Mental Health Treatments. *JMIR Mental Health*. 2016; 3(2): e17.
52. Chalmers JA, Sansom-Daly UM, Patterson P, et al. Psychosocial assessment using telehealth in adolescent and young adults with cancer: A partially-randomised patient preference pilot study. *JMIR Research Protocols*. 2018; 7(8): e168.
53. MacNamee S. Research as relational practice: exploring modes of inquiry. In: Simon G, Chard A. (Eds), *Systemic Inquiry: Innovations in Reflexive Practice Research*. London: Everything is Connected Press; 2014; pp. 74-94.