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The changing nature of social support for adolescents and young adults with cancer

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ABSTRACT

Purpose: The aim of this study was to explore adolescent and young adult (AYA) experiences and preferences for social support early within the continuum of cancer treatment.

Methods: AYAs aged 15–25 years old at diagnosis were recruited from 6 clinical services that were purposively selected for providing specialist cancer care to AYAs across 3 Australian states and within paediatric and adult services. In-depth, semi-structured interviews were conducted by telephone 6–24 months from diagnosis. The narrative-based interviews included preferences for psychosocial support. Interviews were transcribed and thematic analysis was undertaken using grounded theory methodology.

Results: 60 AYAs were interviewed (mean age 20.52 [SD 2.97] years; 58% male; 72% adult settings). Analysis revealed that parents provided the foundation of emotional, informational and instrumental social support, even for older AYAs and those with partners and children. Informal emotional engagement with cancer peers was strongly appreciated during hospital treatment, while healthy peers provided welcome diversion at this time and during the transition towards their usual life. Nurses and allied health staff provided informational support to hospitalised AYAs and also provided a strong source of emotional support. Formal peer support programs were not endorsed by AYAs early in treatment but appreciated to be of greater interest to some following treatment completion.

Conclusion: Social support was predominantly provided by family, peers and health professionals. The sources and types of support most welcomed by AYAs varied according to the intensity and phase of cancer treatment and where the young person was in their cancer trajectory.

1. Introduction

Social support is intrinsic to happy, healthy and productive lives at all ages (Ertel et al., 2009; Taylor, 2006; Uchino, 2004). Widely used constructs of social support (House and Kahn, 1985; House et al., 1988) describe social support as constituting instrumental, informational and emotional functions. Within this context, instrumental support refers to the provision of material or physical assistance such as housing, transportation, financial support or childcare; informational support refers to the role of information, advice or guidance; and emotional support refers to how emotional engagement by others can support an individual's expression of distress and facilitate coping.

While social engagement underpins healthy adolescent development (Yarcheski et al., 1994), the nature of social support changes during adolescence. In earlier childhood, parents and other primary carers or guardians (hereafter referred to as parents) are the most important providers of all types of social support whether instrumental, informational or emotional in nature. As adolescents mature into young adults, they gradually become more independent from parents. While many adolescents and young adults (AYAs) continue to rely on parents, especially in relation to instrumental support, they also typically expand their social networks at this time and develop more emotionally supportive relationships with peers.

Cancer during adolescence and young adulthood can disrupt normal adolescent development (Barr et al., 2016; Kelly, 2008; Kent et al., 2012; Lewis, 1996). Beyond specific impacts on health, the usual

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trajectories through education to employment are commonly affected (Kosola et al., 2018; Vetsch et al., 2018), and peer friendships and romantic relationships can be impacted. Cancer also challenges adolescents' developing identity, which is believed to be strongly mediated through social engagement with peers (Kent et al., 2012; Neville, 1998). Disruption to social networks is considered a risk for social isolation, with potential impacts on self-esteem and wellbeing (Hokkanen et al., 2004; Kent et al., 2012; Zebrack, 2011).

For AYAs with cancer, social support has been shown to decrease psychological distress (Trask et al., 2003), reduce illness-related uncertainty (Neville, 1998), improve coping (Woodgate, 2006) and increase quality of life (Zebrack et al., 2010). However, while increased dependence by AYAs on family, predominately parents, has been shown during cancer treatment (Hokkanen et al., 2004; Kelly et al., 2004; Lewis, 1996; Lynam, 1995), questions about who provides what type of social support and at what stage of cancer treatment are yet to be explored. For example, a recent systematic review assessed adolescents' needs across widely varying stages of cancer care, but did not explore whether particular types of support may be more valued at particular stages of care (Christiansen et al., 2015).

The aim of this study was to explore the provision of social support to AYAs in the first two years following cancer diagnosis. This analysis focused on who provided social support, and what type of social support was provided. In this study, we distinguish two groups of peers. We refer to 'healthy peers' as friendships established before the diagnosis of cancer, and 'cancer peers' as relationships formed through the shared experience of cancer.

2. Methods

2.1. Design

The Youth Friendly Cancer Care project is a four-stage sequential strategy of inquiry undertaken to determine the degree to which Australian cancer services are meeting the needs of AYAs and their parents. This paper used data from stage one, which consisted of in-depth semi-structured interviews with AYAs, parents and carers. The primary purpose of these interviews was to identify the major psychosocial domains affecting AYAs with cancer and their primary carers across the cancer trajectory to inform the development of a quantitative instrument which was subsequently used to survey a national sample of AYAs with cancer (Sawyer et al., 2016). A stratified, purposive sampling strategy was used to ensure a diversity of participants in terms of age, sex, cancer type, Australian state, and service type (paediatric or adult services), with the goal that this would be sufficient to achieve theoretical saturation around major themes (Sawyer et al., 2016). The approach to sampling was based on four assumptions:

1. There is value in investigating psychosocial support needs across a variety of cancers rather than an individual cancer; AYAs with different cancer types were therefore recruited (Thomas et al., 2006; Zebrack, 2011);
2. Older AYAs managed in adult services are likely to have a greater number of unmet psychosocial service needs than younger adolescents; greater numbers of older participants were therefore sought (Osborn et al., 2013; Thomas et al., 2006; Zebrack, 2011);
3. Participants' needs change with time, even early in the cancer continuum of care; participants within 6–24 months of cancer diagnosis were therefore recruited (Thomas et al., 2006; Zebrack, 2011);
4. Participants will be more able to reflect on their psychosocial needs beyond the immediate time of diagnosis; greater numbers of participants who were 12–24 months beyond diagnosis were therefore sought (Zebrack, 2011).

This paper explores interview data from AYA in the context of social support.

2.2. Recruitment

2.2.1. Participants

Eligible participants were 15–25 years of age at diagnosis, were 6–24 months from a cancer diagnosis and fluent in English. AYAs with cognitive difficulties (due to their inability to participate in an interview) or who had stage 1 melanoma were ineligible.

The project involved six specialist cancer services across three Australian states. Ethics approval was obtained at each site.

Clinical liaison staff identified potential participants, then contacted AYAs to assess their interest in participating. Written consent forms were mailed and completed prior to interview. At paediatric services, parents were contacted and provided consent for AYAs less than 18 years old. Verbal assent was obtained from these participants at interview.

2.3. Procedure

In-depth, semi-structured interviews were conducted by telephone. The interviews were narrative and exploratory in nature and focused on a broad range of issues around the psychosocial impacts of cancer including aspects of AYA health services, information needs and preferences for psychosocial support. Interviews were digitally recorded and transcribed verbatim. A detailed protocol has been previously published (Sawyer et al., 2016).

2.4. Data analysis

The constant comparison methodology (Charmaz, 2006) was employed to allow analytic explanations to emerge from the data. Preliminary content and thematic analyses (Braun and Clarke, 2006) were conducted by the senior qualitative researcher (SD), following which each transcript was independently reviewed by two additional investigators. This iterative process identified additional questions and key themes that were explored in subsequent interviews, consistent with grounded theory methodology (Strauss and Corbin, 1994). A key domain that emerged from the interviews was social support.

Half of the interviews underwent a secondary analysis that enabled the identification of codes under the specific domain of social support. All 60 interviews were then analysed using these detailed codes. Coding of transcripts was carried out in NVivo (version 11, Windows) and conducted by one researcher (ME). Thirty interviews (50%) were independently doubled-coded by another researcher (RM); disagreement between authors was resolved through discussion to reach consensus. Quotes are presented to illustrate the main findings, using participant gender and age as descriptors.

3. Results

3.1. Participants

Seventy-three AYAs met the eligibility criteria and were invited to participate. Thirteen AYAs (three females, ten males) declined to participate, resulting in the study sample of 60 participants (82% response rate), of whom 58% were male. The mean age was 20.52 years (SD = 2.98) and over two thirds (72%) were treated in an adult setting. Fifty-two (85%) reported parents as their main carer, while eight (13%) reported a partner was their main carer. There was heterogeneity of cancers, with the most common being lymphoma, leukaemia and sarcoma. See Table 1 for participant demographic information.

3.2. Key themes

The key themes related to social support, including who provided

Table 1
Participant demographics.

Demographic information	Mean (SD) or n (%)
Age (μ) at interview	20.5 (SD 2.98)
Age (at diagnosis)	
15–19 years	31 (52%)
20–25 years	29 (48%)
Sex	
Female	25 (42%)
Male	35 (58%)
Service type	
Paediatric	17 (28%)
Adult	43 (72%)
Cancer type	
Lymphoma	16 (27%)
Sarcoma	15 (25%)
Leukaemia	12 (20%)
Brain Tumour	5 (8%)
Testicular cancer	3 (5%)
Other	9 (15%)
Treatment centre	
Royal Children's Hospital (Melbourne)	5 (8%)
Peter MacCallum Hospital (Melbourne)	5 (8%)
Royal Adelaide Hospital (Adelaide)	16 (27%)
Women and Children's Hospital (Adelaide)	6 (10%)
Royal Children's Hospital (Brisbane)	12 (20%)
Princess Alexandra Hospital (Brisbane)	16 (27%)
State-based recruitment	
Victoria	17 (28%)
South Australia	22 (37%)
Queensland	21 (35%)

support and the nature and timing of support, are described below. Additional quotes around these themes are provided in Table 2.

3.2.1. Family

The major finding that emerged from the data was the critical importance of family. Family, particularly parents, was central to all aspects of social support, including emotional, instrumental and informational support.

"I think the main thing for me was the support I got from my family … So, if everyone could have like parents like mine, I guess that would be ideal … friends are really important … but I don't think they're as important as the family" (19-year-old male).

The timing of family support spanned the cancer trajectory from diagnosis and acute therapy to transition after treatment when AYAs were trying to return to their previous activities and re-establishing social networks. Many AYAs reported the value of parents accompanying them to medical appointments, acting as medical advocates and helping them make decisions during cancer treatment.

"… especially when I was doing the actual chemo … I was pretty spaced, I was just tired, not even thinking about anything. I missed stuff in appointments. It was better to have a parent there to listen to what the doctor is saying as well, because I was likely to forget everything they said. As soon as we got home, I was like, "yeah can't remember" (19-year-old female)

During intense phases of treatment, which for some included prolonged inpatient stays, AYAs reported that parents were critical providers of emotional support.

"I didn't sleep a night alone in the hospital. One of my parents stayed all the time, and I couldn't imagine them not. I don't know why, I just needed someone there …" (16-year-old female)

Most AYAs also reported being very reliant on parents for various aspects of instrumental support, such as physical and financial assistance.

"… if I was really sick, he [dad] would look after me or if I needed help like in the shower or getting from bed to the shower, because I just really needed support after surgery because my leg was really quite bad still, so he helped me get to my bed and everything" (19-year-old male).

"I mean, I'm pretty lucky, I'm living with my parents. They pay for everything …" (23-year-old male)

Following acute treatment, many AYAs reported that fatigue was a barrier to re-engaging with 'normal' life and parents were important facilitators of instrumental support at that time.

"… she [mother] actually called up one of the unis [universities] and just told them about my circumstances and asked if there were any pathways to get in and they said, "Oh, you could do part-time … my mum was the one that kind of organised that" (20-year-old female)

Notwithstanding the extent and perceived value of support from parents, some AYAs reported that it was difficult to cope with their relative loss of independence and what this meant in terms of the relationship with their parents.

"I'm a very independent person and I was enjoying living by myself down there. Because for the first couple of years of uni [university] I'd come home every weekend because I got homesick …. But I was finally happy, and I had direction, I was making plans … and it all just came crashing down. That was really difficult for me to give that up, and to be so dependent on my family again was hard. There was stages there I couldn't even shower myself so it was very undignifying. To be 21 and have your mum have to shower you was pretty horrific …" (22-year-old female)

Although AYAs reported relationships with parents could be challenging, they almost universally reported greater appreciation of their family as a result of their experience with cancer.

"I think I've grown closer to my family now because I understand better now what's the significance of having your family around, or what really the family means" (23-year-old female)

While eight AYAs nominated a partner as their primary caregiver, parents remained an important source of emotional and instrumental social support for these AYAs.

"[My mum] came down …. .to help out as [partner] had to go back to work. So, she came down for ten days and helped me with the kids and all the housework and that sort of stuff … Then [partner's mum], because she lives here, she came over and took a couple of days off and helped me out too, and everyone sort of did shifts of looking after me and the kids and stuff. So, I had a lot of good support, I was very grateful for everyone for helping me, yeah, for helping us" (25-year-old female).

3.2.2. Healthy peers

Many AYAs reported the presence of healthy peers as beneficial, as it helped them feel more normal during treatment.

"… speaking to people and everyone was sort of like, "oh how are you, is everything okay" and treating you like you're a cancer patient. Those mates kind of just treat you like you're a normal friend and I think that's really important." (22-year-old male)

While some healthy friends also provided valuable emotional support, this was less commonly noted.

"I had some fantastic friends as well, like from uni, …like my best friend, she was always there for me, like through my surgeries, radio, and chemo, she would visit me every day and do stuff that the family would do. She was kind of a family for me during the treatment." (23-year-old female)

Social media was recognised to facilitate relationships with healthy peers while it also enabled AYAs to modulate the extent of emotional

Table 2
Additional quotes to highlight aspects of social support from families, healthy peers, cancer peers and health professionals.

Providers of Social Support		Type of social support
Parents		
The value of comprehensive support	"The friends that I did have … I don't really talk to them anymore. They kind of just backed off. But family was always good if I needed them, and if I needed to talk or whatever they'd be there and listen and help …" (21-year-old female)	Emotional, Informational and Instrumental support
The importance of appraisal support	"I guess it would have been pretty intimidating had I not had that support […] even though I am 23 this time around and I've got a partner of eight years […] I think it sort of helps having them [parents] help me make the decisions […] there is so much information to be handed around, having them there and helping like, take it all in." (23-year-old female)	Informational support
The importance of continuous support	"… my parents were in every day … I was always very appreciative of that." (23-year-old male)	Emotional support
The value of practical support	"My mother, she stayed up and we actually – she moved in with me and she was, because I couldn't drive at the time to get myself to the hospital, she was driving me every day to go get the radiation therapy." (23-year-old male)	Instrumental support
The value of advocacy in relation to practical assistance	"At the beginning a social worker helped us [mum and I] out with Centrelink [government financial assistance], but after that we [mother and participant] had like a six month long battle with Centrelink, but in the end we won and got it backdated and everything" (20-year-old female)	Instrumental support
The AYA cancer paradox	"Yeah. I'd been working since I was in Year 9, Year 8 I started working, so I've had money for quite a while, so I haven't had to ask anyone for money and then suddenly having none, it's a bit of a change …. Yeah, I had to get my mother to pay for a fair bit." (23-year-old male)	Instrumental support
Parents remain important notwithstanding marriage, partnering or parenting	"I always had someone with me, but I wouldn't always take someone in with me, but I did for results, when I was getting results, and my mum and my - my mum or my husband usually came with me." (24-year-old female)." "Yes, yes, just Mum and my Nanna. My Nanna came over heaps and helped out with [my daughter] and stuff like that. So, she was a big help." (21-year-old female).	Emotional support Instrumental support
Healthy peers		
Feeling emotionally overwhelmed can lead to avoiding peer engagement	"… generally, early on I was not well. I didn't really see anyone for probably the first two months of it. I was kind of avoiding it a little bit." (24-year-old male)	Emotional support
The role of social media in distance regulation	"I don't like to air my dirty laundry about my feelings on Facebook, but I certainly kept my friends up to date with my surgeries and stuff. I think it was a good way of keeping everyone [up to date], because not everyone could visit and I didn't really want to talk on the phone, so I'd just post a status, I'm out of surgery, or I'm just being discharged tomorrow, or yeah, visit me, I've got an infection, that kind of thing." (21-year-old female)	Emotional support
The value of peers as a connection to normal life	"Actually, all my friends at the time were [very supportive]. It was sort of an escape. There was sort of a sense of normality … I definitely did want to keep things as normal as possible. The treatment was at the hospital and then when I was home, I was just [me]." (19-year-old female)	Emotional support
The negative impact of cancer on friendships	"She [one of best friends] didn't ask any more questions than what I was going to tell her, because I guess she didn't really want to know - maybe in case it was going to be bad news." (19-year-old female)	Emotional support
Cancer peers		
The value of peer support due to shared experiences	"But then when I started there was this … other girl, she was the same age as me, so our parents, like our mums, got really close and so then we started talking and doing basically heaps of things together. So, we were always causing trouble with the nurses and all that sort of stuff. We were pretty close when she was having treatment." (19-year-old female)	Emotional support
The role of health professionals in facilitating support between cancer peers	"… a whole group of us young guys that have - all have Ewing's sarcoma, at [hospital], and they always try and get us in the same room because there's an adolescent room at [hospital] … it's good. You can get some familiarity, you know, with patients, also you know them, and you don't get stuck with someone who snores at night …" (23-year-old male)	Emotional support
Formal peer support programs were not commonly endorsed	"I felt as though I had enough support with the network that we had already …" "Sometimes I'd say yes, but then I wouldn't end up going, sometimes I just – I don't know, just not interested." (20-year-old male)	Emotional support
The importance of timing around formal peer support programs	"I'll probably go on one [peer support camp] now, while I'm in maintenance …" (21-year-old female)	Emotional support
The value of formal peer support programs	"I do Canteen for that so it's more fun than – basically, they provided the opportunity for it, they provide the setting and they let us talk it out at our own pace." (23-year-old male)	Emotional support
Health professionals		
The value of safety around venting negative issues with health professionals	"… you can be a bit more brutally honest with people that you don't know because you know that you're not going to upset them [referring to nurses] […] I'm pretty open and pretty honest with my family and my friends, but just those things that you don't want them to take on board and be upset by it you can sort of say to someone third party." (23-year-old female)	Emotional support

engagement.

"There were a lot of friends that were writing on my wall [Facebook] and asking how I was and stuff. I kept it pretty simple, but like private message I did talk to some people, like some close friends, about it, yeah." (16-year-old female)

The experience of cancer also helped AYAs to reflect more deeply on

the nature of friendship.

"I used to have a lot of friends, like a lot of friends, but especially going through something like this, you understand that friendship is not just about knowing somebody, it's about actually caring for them. And so, I've started choosing friends a lot more selectively …. " (20-year-old male)

Many longstanding friendships were challenged or lost as a result of cancer. For some, this reflected their friends' difficulties with the experience.

"One friend in particular that I have been friends with since I was seven … she dropped me because she couldn't deal with it. Everyone deals with it in different ways and I'm still a bit bitter – no, I am actually pretty bitter about it. I understand that it was scary for her, but it was bloody scary for me too, I was the one that was going through it." (21- year-old female)

3.2.3. Cancer peers

Many AYAs reported they did not meet other young people with cancer, indicating they were either the youngest among older adult patients, or the oldest among younger children.

"Usually I sit in the waiting room and they're all in their 60's and 70's and I just take my grandma with me and she has a good old conversation with them because they're her age." (24-year-old female)

Many AYAs indicated a desire to be around other AYAs, largely in terms of emotional support.

"… information would definitely help some things, but I just think from the emotional point of view, I'm looking for someone that will - you know, understand what I'm going through, but I think I'm looking for something that's not there. So, I kind of just give up […] I felt pretty alone when it came to age […] I wish I had have met people the same age as me going through the same …" (17-year-old female)

AYAs reported informally meeting cancer peers during a hospital admission or for ambulatory chemotherapy. While only a small number reported meeting other AYA patients in this way, it was universally valued.

"I found like a guy who came into [my hospital] for a couple of visits, who was the same age as me. He had a different [cancer] to me but he was quite mature. I felt like I could relate a lot better to what he was trying to say because I understood." (17-year-old female)

Organizational arrangements and treatment circumstances were reported as important facilitators of informal cancer peer support.

" … we used to have signs up on our doors saying like, you know, [name] is sleeping or [name] is up for visits or whatever. So, it could tell the people, anyone that wanted to come in and visit. So, every now and then if you wanted to go talk to someone or meet other people you could, and that's how I met [AYA cancer peer]." (17-year-old female)

There was widespread familiarity with formal cancer specific peer support programs (such as CanTeen). The potential value of these programs was acknowledged, yet the majority had chosen not to participate. Many explanations were provided for not participating, including physical health constraints and timing.

"I did join CanTeen. I didn't end up, you know, going – I was too sick then to do anything really." (21-year-old male)

Some AYAs did not wish to attend as they reported they did not need additional social support, did not wish to be reminded about cancer, or were simply not interested.

"… I'm not ready to be around lots of sick people and lots of all of that again […] I need to be away from cancer, away from the hospital, away from it all, be with my friends and family […] I'm trying to move on with my life, like move on from cancer …" (20-year-old female)

Yet the few AYAs who had attended formal peer support programs reported the social support that accompanied mutual understanding was valuable.

"… because the nurses, haven't really been through the chemo itself, they're only giving it so they can't sort of really tell a patient how sort of another patient feels. Like I guess it's clearer and more understanding when it's another patient telling you their experience." (23-year-old female)

3.2.4. Hospital staff

AYAs identified hospital staff were an important source of social support during treatment. Continuity of care enabled relationships with staff to develop which facilitated instrumental and informational support. A strong element of emotional support was also described, and many AYAs reported their engagement with various allied health and nursing staff included aspects of friendship.

"I would go see her [occupational therapist] before or after my appointments and stuff […] at the start it was probably more formal, then […] like there was a relationship, like a friendship - it became more informal, like how you'd talk to a friend almost." (19-year-old male)

Some AYAs reported that the relatively young age of staff made them feel comfortable.

"Like you're kind of like in an age group where you're just in the middle, you don't really fit anywhere. When I was in [hospital] I felt like I didn't fit, but at [other hospital], because all the nurses were the same age as me, I felt like I was alright …" (20-year-old female)

Some AYAs reported that the specific value of the relationship with staff was that it was distinct from relationships with family and friends.

"I just needed to have someone [referring to conversations with specific social worker] to vent most days to, instead of confusing my family and friends with how I felt … That was pretty valuable support." (22-year-old female)

4. Discussion

This study affirms that social support from family, peers and health professionals was greatly appreciated by AYAs with cancer, but that the type of support that was most welcomed changed according to different phases of cancer treatment. Support from family, primarily parents, was especially valued as it provided a foundation across the continuum of care, even for older AYAs and including those with partners and children. Informal social support was welcomed from cancer peers during treatment, while social engagement with healthy peers provided welcome diversion during treatment and supported the transition towards a more normal life following the intensity of early treatment. Rather than oncologists, nurses and allied health staff provided additional support during hospital admission.

AYAs highly valued the social support provided by families which, consistent with previous research (Kyngäs et al., 2001; Trask et al., 2003; Woodgate, 2006), spanned instrumental, informational, and emotional functions. Parental assistance was fundamental for remembering and interpreting information within medical consultations, assisting with medical decision-making, navigating the health system, and for wider advocacy including accessing financial aid and reengaging with education and employment. These forms of social support were described in early social support literature (Cohen and Wills, 1985) who referred to 'appraisal' support as cognitive information that assists one's understanding and self-perceptions, and has been further described as "tangible aid, advocacy, directive guidance and social diversion" (Rose, 1990). Appraisal support appears especially relevant for

AYAs given their relative inexperience with medical decision-making, health system navigation, and the complexity of navigating education and employment. These findings suggest that health professionals should explicitly facilitate appraisal support to young people without supportive families who are more likely to lack this support.

Rather than actively providing social support during cancer treatment, healthy peers were mostly seen as important connections to the social networks that characterised AYAs' usual lives. As adolescent identity is formed in the context of such individual peer relationships and social networks (Kent et al., 2013; Neville, 1998), the value of healthy peers should not be underestimated. AYAs' use of social media greatly enabled engagement with healthy peers; social connections could be maintained while controlling the amount of information that was shared and modulating the level of intimacy desired at any time (Kent et al., 2013; Myrick et al., 2016; Rabin et al., 2013). In this context, WiFi in hospitals can be viewed as an important enabler of AYA wellbeing (Myrick et al., 2016).

Yet many AYAs reported that their healthy peers struggled to engage with them, especially when cancer treatment was intense. Consistent with prior research (Palmer et al., 2000), a number of AYAs also expressed hesitancy about engaging with healthy peers, in part perhaps because of the uncertainty of peer responses. Both aspects appeared to act as a barrier to the types of meaningful engagement that underpins social support. These data suggest that appraisal support may be just as indicated for the healthy peers of AYAs with cancer as it is for AYAs themselves as healthy peers will be similarly inexperienced. An example of this is in Denmark, where a model has been developed (Olsen and Harder, 2009) that facilitates social support for AYAs with cancer through engaging the AYA's social network including family, friends, teachers and educators, work colleagues and employers, and health professionals such as GPs. Following nomination by individual AYAs, their social network is invited to meet with the medical team at the beginning of treatment for an information session about the disease and its treatment, which includes discussion about how friends, family, school, and employers can support the AYA and the family.

Cancer peers provide an opportunity for mutual support that is grounded in shared experiences (Kent et al., 2013; Stegenga, 2014). In this study, while AYAs particularly valued informally spending time with cancer peers, it was disappointing that only a minority of AYAs reported having had this opportunity. These results reinforce the value of physically co-locating AYAs (Fern and Whelan, 2013; Sawyer et al., 2019) and the importance of healthcare professionals supporting informal interactions with cancer peers, especially while in hospital. In addition to online approaches that facilitate peer support with cancer peers, including cancer-specific digital media support initiatives (e.g. #Stupidcancer) (Myrick et al., 2016), more intentional methods such as co-scheduling chemotherapy sessions could also promote access to informal support from cancer peers.

Almost all AYAs were aware of formal face-to-face peer support program. While the majority acknowledged the potential benefits, few had participated, consistent with the literature (Campbell et al., 2004; Christiansen et al., 2015; Treadgold and Kuperberg, 2010). Our findings suggest that informal peer support from cancer peers may be most beneficial during cancer treatment, with the timing of formal face-to-face peer support programs better targeted at a later stage.

While hospital staff are well recognised as facilitators of social support for AYAs with cancer (Kelly et al., 2004; Krishnasamy, 1996; Olsen and Harder, 2009; Ritchie, 2001; Shepherd, 2014; Woodgate, 2006), including linking AYAs to family and cancer peers, a somewhat unexpected finding from these data was the extent that hospital staff provided emotional support to AYAs. Social support has been referred to as being received from 'significant others' versus 'similar others' (Thoits, 2011). Significant others such as family typically provide emotional support (caring, valuing, compassionate presence) and instrumental support (accommodation, transportation) that can sustain an individual's sense of connection, belonging and self-esteem and lessen the burdens of cancer. Similar others are those who typically have weaker ties, such as cancer peers, yet whose shared experiences of cancer enable strong emotional sustenance to be received due to their contextual knowledge and empathic understanding. Within this context, our analyses suggest that hospital staff functioned like similar others. In addition to their experiential knowledge of the context of cancer care, the social support provided by particular staff was facilitated by their similarity in age, availability, and continuity of care. Surprisingly, our data also suggest that during intense inpatient treatment, support from hospital staff could be regarded as more important than peer support. The extent to which this engagement reflected lack of opportunities to engage with cancer peers in hospital is not known. Despite intrinsically positive aspects about this engagement with staff, it might also reflect more challenging aspects of healthy peer relationships. For example, during treatment AYAs with cancer might not be sufficiently confident about their cancer and its treatment to be able to put their friends at ease, especially when they are acutely unwell. This might explain why some AYAs experienced social contact with some healthy friends as emotionally and physically overwhelming. Regardless, training around adolescent health, development and wellbeing appears indicated for cancer staff, who may also benefit from formal supervision, given the risks to less experienced staff who may be more likely to experience counter-transference given the closeness of age.

A strength of this study is the large sample size within a narrow age band and, across a range of diagnoses and health care services which provides an in-depth description of the social support experiences of Australian AYAs with cancer. As the interviews were exploratory and iterative in nature, some areas and themes that were identified in later interviews were not asked in earlier interviews. This potential limitation was largely obviated by reaching saturation within the relevant themes. While the retrospective nature of the study means that some loss of detail is expected, we believe that conducting interviews from 6 to 24 months after diagnosis has enabled us to capture relatively accurate recollections of their experiences with minimal burden. Due to ethical constraints, a limitation of this study is the lack of detailed demographic characteristics about eligible AYAs who declined to participate, and their reasons for declining.

In summary, parents provided a foundation of emotional, informational and instrumental support across all treatment stages. The intrinsic value AYAs ascribed to appraisal support provided by parents suggests that models of cancer care for AYAs need to pay attention to how this is provided, particularly in the absence of supportive families. In practical terms, AYA cancer services would benefit from consideration of approaches that broker relationships with informal cancer peers (e.g. physical co-location, social networking) and that better engage families and hospital staff to foster AYAs' existing relationships with healthy peers, earlier in cancer treatment.

Conflicts of interest

The authors declare that they have no conflict of interest.

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