Supportive Care in Cancer (2019) 27:467–475
https://doi.org/10.1007/s00520-018-4337-4

ORIGINAL ARTICLE

Health professional perceptions of communicating with adolescents and young adults about bone cancer clinical trial participation

Verna Lavender[1] · **Faith Gibson**[2,3] · **Alexandra Brownsdon**[4] · **Lorna Fern**[4] · **Jeremy Whelan**[4] · **Susie Pearce**[5]

Received: 29 January 2018 / Accepted: 26 June 2018 / Published online: 5 July 2018

Abstract

Purpose Low recruitment of adolescents and young adults in cancer clinical trials is widely reported and may be linked to limited improvements in survival. Research to date does not adequately explain all underlying reasons for poor trial accrual. This paper reports health professional perceptions of communicating with adolescents and young adults with bone sarcoma about clinical trial participation.

Methods This study used narrative inquiry. Findings are reported from thematic analysis of in-depth interviews with 18 multidisciplinary health professionals working in a supra-regional bone and soft tissue sarcoma centre.

Results Participants described professional expertise, the development of specialist knowledge and skills and strategies used to develop trusting relationships with adolescents and young adults with bone sarcoma. These factors were perceived to facilitate communication about clinical trial participation. Emergent themes were having credibility through expertise of the team, developing specialist communication skills through reflection on practice, having inclusive approaches to education and training about clinical trials, individual communication styles used to form trusting relationships, using a patient-centred approach to connect with adolescents and young adults, creating time needed to form trusting relationships and effective team working.

Conclusions We aligned findings of this study with characteristics of patient-physician trust and provide a basis for transferable recommendations. Our findings can be used to inform the development of age-specific, specialist communication skills and highlight health professional education needs about clinical trials. Additional research is needed to explore which elements of team working optimise improved clinical trial participation, in what contexts and why.

Findings reported in this manuscript arise from a study, where findings related to other aspects of the participation of adolescents and young adults in bone cancer trials have been reported in a separate manuscript: Pearce, S., Brownsdon. A., Fern, L., Gibson, F., Whelan, J., Lavender, V. The Perceptions of Teenagers, Young Adults and Professionals in the participation of Bone Cancer Clinical Trials. *European Journal of Cancer Care.* Version of Record online: 3 MAR 2016, DOI: 10.1111/ecc.12476

A poster presentation was given at the Royal College of Nursing International Nursing Research Conference, April 2017, Oxford, UK.

A paper was presented at the UK Oncology Nursing Society Symposium at the National Cancer Research Institute Cancer Conference, November 2017, Liverpool, UK.

✉ Verna Lavender
vlavender@brookes.ac.uk

Faith Gibson
faith.gibson@gosh.nhs.uk; f.gibson@surrey.ac.uk

Alexandra Brownsdon
a.brownsdon@nhs.net

Lorna Fern
lorna.fern@nhs.net

Jeremy Whelan
jeremy.whelan@nhs.net

Susie Pearce
Susie.pearce@plymouth.ac.uk

Extended author information available on the last page of the article

Keywords Adolescents · Young adults · Cancer · Narrative inquiry · Clinical trials · Patient-professional communication

Introduction

Bone sarcomas (primary bone cancers) have a peak incidence during adolescence and young adulthood [1, 2] and a 5-year survival rate of 50–60% [3]. Survival improvements over the last 30 years have been modest and may be related, in part, to fewer adolescents and young adults (AYA) participating in clinical trials than other age groups [4–6].

Similar to other countries, England has set a target that at least half of AYA with cancer are entered into trials by 2025 [7], with the aim of improving patient outcomes. There is some way to go to achieve this target for sarcoma, because only one in four British adolescents with soft tissue sarcoma was included in a recent European study [8].

Potential barriers to recruiting AYA to clinical trials include developmental considerations [9], AYA and parent perspectives [10], healthcare system factors [11] and research design issues [12]. Successful recruitment is also thought to be dependent on the acceptability of the trial, which is influenced by AYAs' perceptions of the trial [6, 12]. Since a person is presumed to have consent from the age of 16 years in England [13], there is a need to understand more fully the relationship between AYA patients and health professionals, which can influence decisions about participating in a research study [14].

We report here additional findings from our study that sought to gather perceptions from AYA and health professionals regarding participation in two bone cancer trials [12]. In this paper, we explore professional expertise, specialist knowledge and skill development and strategies described by the health professionals for communicating with AYAs about participating in two large, collaborative, international, randomised bone sarcoma clinical trials for newly diagnosed patients: EURAMOS-1 (E-1) [15] and EUROEWING-99 (EE-99) [16]. These trials were chosen to understand what influences AYA trial participation, because deficits in AYA accrual to E-1 and EE-99 have been observed [17] and osteosarcoma and Ewing sarcoma have peak incidence in AYA [1, 2] with little improvement in survival over the past two decades.

Methods

Study design

Narrative interviews were undertaken with health professionals and AYAs aged 15–24 years with bone cancer using an interpretative, qualitative approach [18], which explored the "whats" and "hows" of participants narratives from their experience [19]. The age range of the AYA recruited to the study was determined by age criteria for AYA specialist care used in England [20]. In this paper, we will focus on the health professionals in the study; the methods and findings of interviews with the AYAs are reported elsewhere [12].

Study setting and sample

This was a single-centre study conducted at a supra-regional bone and soft tissue sarcoma centre that conducts clinical trials and hosts one of the largest principal treatment centres for young people in England. We used purposeful sampling [21] to invite 29 health professionals representative of this service configuration and who treated and cared for AYAs who were eligible to be recruited to the E-1 or EE-99 clinical trials. Eighteen health professionals agreed to participate. This included nine who were directly involved in recruiting AYAs to the E-1 or EE-99 trials (medical oncologists, oncology trainee doctors, clinical nurse specialists [CNS] and research nurses) and nine participants who treated and cared for AYAs on these two clinical trials (orthopaedic surgeons, chemotherapy nurses, ambulatory care and oncology ward managers and clinical trial pharmacists).

Informed consent

Ethical approval was obtained from a National Health Service research ethics committee (study reference: 11/LO/0523).

Data collection

The research team included experienced qualitative health researchers. Semi-structured narrative interviews were conducted by AB and took place with the professionals in a setting of their choice. An illustration of the open questions used for interviewing health professionals is shown in Table 1. Participants were asked to describe their perceptions about, experiences of, and role in, recruiting, treating or caring for AYAs invited to, and enrolled in, E-1 and EE-99 clinical trials. Interviews lasted an average of 40 min and, with permission, were digitally recorded.

Data analysis

Interviews were transcribed, and the transcripts were analysed by memoing, coding and constantly comparing codes to identify emergent themes, using an interpretative approach similar

Table 1 Question guide for health professional interviews

Can you tell me a little bit about your role (in the care of patients with bone cancers/ soft tissue tumours)?

What involvement do you have with the bone sarcoma clinical trials?

How long have you been involved with these trials/ caring for people undergoing these trials?

What do you understand about clinical trials in general?

What are your thoughts about treating patients on clinical trials?

What do you think are the specific issues around recruiting young people (15–24 year olds) with cancer to clinical trials?

What is your understanding of the bone cancer specific trials, Euramos-1 and EE-99?

What do you perceive are factors that influence participation in Euramos-1 and EE-99 for AYA?

Can you tell me about how AYA patients are recruited to the bone sarcoma clinical trials?

Can you tell me what you discuss when talking to young people or their parents, about clinical trial participation?

What support is there for patients making decisions about entering these clinical trials?

How do you feel about discussing randomisation?

What sorts of things do you think (would) help support young people through the clinical trial?

What do you think might support the professionals involved in this process?

to that described by Charmaz [22]. All transcripts were read and coded by AB and SP. To validate the coding process, a sample of interviews was independently conducted by two experienced healthcare qualitative researchers, VL and FG. VL independently coded all health professional interview transcripts. Initially, thematic analysis of interview data from health professional participants was conducted separately from analysis of the AYA interview data to generate two analytical frameworks: an AYA framework and health professional framework [12]. SP and VL re-checked coded transcripts by comparing coding of all interviews against the analytical frameworks to ensure no findings had been missed and data sufficiency had been achieved, which added another level of rigour to the analytical process. A combined analytical framework including both AYA and health professional data were developed by integrating themes common to both data sets (where there was a high level of agreement between coded data) [12]. Themes that emerged from coded health professional data that were distinct from those arising from the AYA data were re-examined by SP and VL.

Results

Participants described aspects of professional expertise and specialist knowledge and skill development that were perceived as important for effective communication with the AYA, as well as strategies used to communicate with AYAs about clinical trial participation.

Professional expertise and specialist knowledge and skill development

Having credibility through expertise of the team

Professionals spoke about being part of an experienced team that was "used to dealing with AYAs" and working in a centre "very driven towards research". The time in their current role ranged from newly appointed to more than 20 years in post; most participants had multiple years' experience of working with AYAs, in cancer services and/or cancer clinical trials.

Some health professionals spoke about the team's experience and nature of the centre influencing the perception of the AYA. One health professional said, "Obviously because this is a specialist centre, they (the AYA) are just very happy to be somewhere where they know they're getting very good quality treatment." [Health Professional #02 (HP02):p2] The experience and expertise of team members was identified as an asset in providing information with sensitivity, "There are some people who are very sensitive and very capable at judging what's enough…And experience teaches people that" [HP13:p5].

Developing specialist communication skills through reflecting on practice of, and with, others

More junior health professionals referred to learning from observing senior professionals in practice. "Well for me it was helpful to sit in (on clinical trial and consent appointments), and then you learn techniques" [HP06:p12]. "Learners" either regarded a senior practitioner as a role model and someone's practice they aspired to, or they "learned from the mistakes" of others and identified behaviours that they would not wish to emulate. "It's very good to have videos of deliberate mistakes, well mistakes. And then the video stays in your head very well" [HP06:p12].

More senior professionals commented on the lack of opportunity to learn from observing the practice of peers: "Once you're a consultant you never, you don't see other people's practice, and you don't see other people doing consultations with patients" [HP07:p6]. Instead, consultants spoke about receiving feedback from nursing colleagues. "I've learnt most from getting feedback from clinical nurse specialists who say, 'That went really well,' or them saying, 'That didn't go so well, they were shocked to hear this,' or whatever. That's what I've based, that's how my practice has evolved in the way I give information" [HP08:p5].

Need for inclusive approaches to education and training about clinical trials

Systems were in place to provide education and training about the trials to health professionals. This training was often as part of the trial initiation process. "Sometimes there's the launch of a new trial, and there's a formal teaching session arranged. […] Sometimes it's less formal" [HP13:p2]. Professionals who were not able to attend formal training sessions described being "updated" by colleagues who could attend. Some health professionals also spoke about ongoing training opportunities: "There are various different teaching sessions and opportunities throughout the pattern of the week. And yes the staff are encouraged to go to those sessions" [HP13:p3].

However, health professionals not directly involved in trial recruitment felt less well informed about trials and had less opportunity to receive education. Health professionals identified a lack of knowledge of the trials as an issue: "[If educated] we know how the trial works, what the arms mean and all that sort of thing… then we can actually answer questions from the patients…. there's nothing worse than someone being on a trial and even we don't really know what's going on, which, you know, has happened before" [HP09:p7]. To ensure credibility across the team, health professionals thought education and training should be more inclusive and accessible to the wider multidisciplinary team.

Individual communication styles used to form trusting relationships

With the exception of one health professional who thought all professionals would probably structure clinical trial consultations in the same way, informed by their trial training and shared philosophy of care, most professionals had views that each professional had a unique style of communication and thus conducted consultations differently. This created a sense of needing to observe a range of colleagues in practice to develop optimal communication skills. "We all have our different ways and means of saying things, you know, and we all have our different ways of, you know, approaching patients… I don't know whether that does affect how many patients are recruited and how many patients aren't. But I'm sure it may do" [HP04:p6].

The level of sensitivity and skill health professionals perceived were needed to provide accurate and honest information to AYAs about the E-1 and EE-99 trials without causing undue alarm or distress were highlighted. "I've certainly seen some doctors explain things just amazingly and I've seen others kind of be slightly—not brash, perhaps is a little bit too harsh, but kind of a bit too kind of straight pointed with it, a bit too blunt" [HP09:p5].

Strategies health professionals used to communicate with AYAs about bone cancer trial participation

Using a patient-centred approach to connect with the AYA

Health professionals talked about strategies to facilitate openness and sharing with the AYA to reinforce the patient-centred philosophy they practiced and, in doing so, fostered trust. One method of demonstrating patient-centred care was by asking the AYA "if there was anything they wanted to talk about or ask?" [HP02:p7–8].

Another strategy used by one health professional to demonstrate patient-centredness and "make them feel comfortable" was to identify common ground with the AYA. "Well every time I'm about to discuss the trial with somebody, I'm trying to relate with them and I mean I'll try to find something in common […] or I'm trying to find something that interests them, so they feel at ease and sort of comfortable chatting to me" [HP06:p5]. This might involve honing in on a specific interest, like commenting on "something they're watching or their opinion about a gadget or if they're wearing a football shirt, just to try to relate to them really" [HP06:p6].

Many health professionals emphasised the need to individualise the approach when respecting autonomy of the AYA and meeting the needs of family members. Health professionals acknowledged the need for family-centred care, communicating with parents (particularly of younger adolescents) and partners (of older adolescents and young adults), but they reported taking care to maintain patient-centred communication. "We are quite careful about talking to parents without the patient there. We do talk to them, but more specific questions about outcomes and more personal questions, we'll be very careful to make sure that the patient was involved in those" [HP10:p5]. Sometimes, it was a legal requirement to involve parents in decision making: "For the younger ones, the parents have to consent as well. So one has to make sure that the parents are on the same level as the patient, because they have to put their name to it as well… if they're under 16, but one tries to talk to the patient first rather than the parents" [HP03:p9]. Health professionals also highlighted that for some AYAs, partners needed to be considered: "It's not just the young person themselves, it may be …partner, that maybe have questions?" [HP04:p3].

Creating time needed to form trusting relationships

In addition to referring to a lack of time to interact with the AYA [11], health professionals described some strategies they used to "make time". One strategy was to meet the young person as soon as it was convenient to do so. "I think the earlier you can meet them and develop some sort of rapport; I mean it does help (in discussing clinical trial participation)" [HP14:p5]. Other professionals talked about being committed to working a longer day if needed, "We're all prepared to do longer consultations and repeat consultations, even though that's going to make our clinics longer and bigger" [HP07:p7]. Making time to work around the needs of AYAs demonstrated person-centred care: "You need to go when they are not in pain. Or if they are about to have lunch, if they're having guests…Or just woken up. Simple things like that. … That's why you need plenty of time…But respecting the individual and sort of make time, even if it's after hours, before hours, I think it helps" [HP06:p5].

One health professional described their ideal approach: "In a perfect world, what it would be is, you meet them the first time, you go through all the illness and you'd say to them, you know, 'There's a clinical trial, I really want to talk with you about it, but why don't you go and have some tests and then I'll come back and meet you and talk to you again,' and then you can, then you have a much greater amount of time to focus purely on the clinical trial aspect. So basically I do need three meetings with them… More often than not one has two" [HP03:p6].

Effective team working to facilitate the development of a trusting patient-professional relationship

Health professionals coherently articulated their own roles and involvement in the recruitment, treatment and care of AYAs participating in the bone sarcoma clinical trials. They were conscious that having discussions about participation in clinical trials often within 2 weeks of diagnosis, and sometimes at the same time as sharing their cancer diagnosis, was overwhelming for the AYA.

Doctors recognised the challenges of having difficult conversations with AYAs within the clinic environment and the importance of team work, for example seeking support and "reassurance" from nurses: "If you've had a clinical nurse specialist in with you and it's been particularly difficult, then you'll, afterwards you'll say, 'That was difficult.' […] You might reflect for a few minutes, but usually there's another patient to see" [HP07:p10].

For AYAs with a new diagnosis of bone cancer, there was an additional challenge of meeting a range of different health professionals, which could detract from developing trusting patient-professional relationships. "I think they almost meet too many people at the beginning and there can be a rather overwhelming number of new faces and new roles" [HP2:p9]. One strategy was to delegate core communication to one or two members of the team, often the consultant and the CNS.

Health professionals talked about the CNS having a pivotal role in clinical trial participation: "With the input of the CNS, sometimes if it's not appropriate to meet me, the CNS will hand out information sheets and go through what's required rather than think, 'Oh someone else to see,' and they'll follow that up and keep me in the loop and everything. So it is about working as a team" [HP18:p9]. Similarly, CNSs utilised team members as a source of information about the clinical trials.

Discussion and conclusion

Discussion

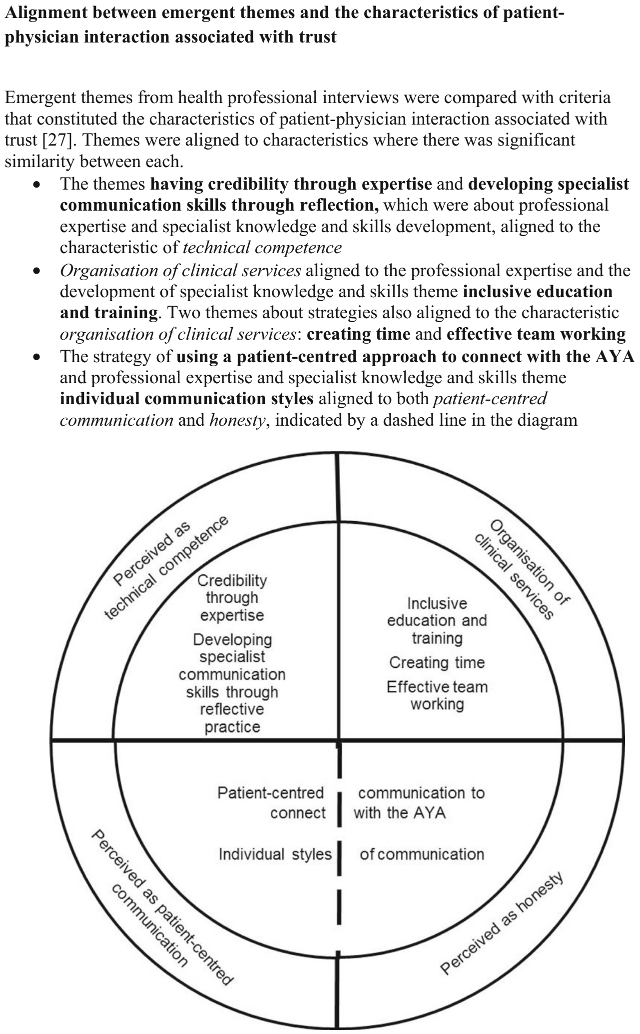
Our findings identify the perceived importance of professional expertise and development to support specialist communication about AYA clinical trial participation and expand on strategies that go some way towards detailing how clinical trials can be "effectively presented" as part of the pathway to enrolment [23].

A recurrent finding was that health professionals attempted to form trusting patient-professional relationships to aid communication with AYAs, while recognising the importance of the family and the need for family-centred care. Trust is widely recognised as being central to the doctor-patient relationship [24] and discussing clinical trial participation with AYA [12]. It is also described as a foundation for AYAs and health professionals to establish clear communication [25] and a virtue of Good Clinical Practice (GCP) [26].

We aligned the emergent themes presented here with four main characteristics of "physician-patient" interaction associated with trust [27] (see Fig. 1). Three characteristics are based on the patient's perception of the physician including *perceived technical competence*, being straightforward and "telling the truth" (*honesty*) and *perceived patient-centred communication.* The fourth characteristic, the *organisation of clinical services*, includes allocation of time and continuity of care needed for the establishment of patient-physician relationships.

Having the specialist technical competence to form trusting patient-professional relationships was perceived as highly important by the participants in our study, which Sawyer and colleagues [28] identify as an indicator of adolescent-friendly health care. Health professionals described developing specialist knowledge and skills through experiential learning. In some instances, this provided a sense of interprofessional and interdisciplinary support and encouraged reflection on their own practice. In particular, consultants talked about developing their communication skills based on feedback from nursing colleagues working alongside them in consultations.

Fallowfield [29] recommends that health professionals learn advanced communication skills by predominantly experiential training methods rather than apprenticeship models of learning [29, 30]. In addition to developing advanced



Alignment between emergent themes and the characteristics of patient-physician interaction associated with trust

Emergent themes from health professional interviews were compared with criteria that constituted the characteristics of patient-physician interaction associated with trust [27]. Themes were aligned to characteristics where there was significant similarity between each.

- The themes **having credibility through expertise** and **developing specialist communication skills through reflection,** which were about professional expertise and specialist knowledge and skills development, aligned to the characteristic of *technical competence*
- *Organisation of clinical services* aligned to the professional expertise and the development of specialist knowledge and skills theme **inclusive education and training**. Two themes about strategies also aligned to the characteristic *organisation of clinical services*: **creating time** and **effective team working**
- The strategy of **using a patient-centred approach to connect with the AYA** and professional expertise and specialist knowledge and skills theme **individual communication styles** aligned to both *patient-centred communication* and *honesty*, indicated by a dashed line in the diagram

Fig. 1 Alignment between emergent themes and the characteristics of patient-physician interaction associated with trust. Emergent themes from health professional interviews were compared with criteria that constituted the characteristics of patient-physician interaction associated with trust [27]. Themes were aligned to characteristics where there was significant similarity between each. The themes **having credibility through expertise** and **developing specialist communication skills through reflection,** which were about professional expertise and specialist knowledge and skill development, aligned to the characteristic of *technical competence*. *Organisation of clinical services* aligned to the professional expertise and the development of specialist knowledge and skills theme **inclusive education and training**. Two themes about strategies also aligned to the characteristic *organisation of clinical services*: **creating time** and **effective team working**. The strategy of **using a patient-centred approach to connect with the AYA** and professional expertise and specialist knowledge and skills theme **individual communication styles** aligned to both *patient-centred communication* and *honesty*, indicated by a dashed line in the diagram

communication skills, health professionals working in AYA services require age-specific communication skills [31].

Adolescence and young adulthood is a life-stage transition [32, 33] characterised by cognitive, emotional and social developments. Having a cancer diagnosis during adolescence and young adulthood intensifies the biopsychosocial challenges of these developmental stages and requires specialised care [9]. For young adults, cancer causes a shift in their life narrative, resulting in desire to stay in control, retain independence and autonomy and retain their former identity [34]. This range of complex, individual, age-specific needs means experiential learning opportunities need to be created within the context of specialist AYA services.

Patient-centred care is an essential element of the recruitment process [26] and was identified as one of five "top competencies" needed to provide specialised AYA care [35]. Key communication skills that aligned to these competencies were listening to AYAs' concerns, talking about difficult issues, using familiar terminology while maintaining professional boundaries, telling AYA about all aspects of their disease and acting as an advocate [35]. In our study, health professionals used patient-centred communication to facilitate the development of a trusting and open relationship to help put the AYA at ease; one strategy described was to attempt to make a connection with the AYA by finding a common topic of conversation.

Using more familiar language might be regarded as "small talk"; however, strategies that actively engage AYA in conversations is thought to help in their understanding of the complexity of the trial, the risk-benefits and burden, and what it will mean to them if they do, or do not, consent to enrol [26]. Bora and Kim [36] also recommend using "humanistic engagements" such as 'small talk' to promote open and engaging communication with AYA.

The health professionals in this study described discussing trial participation with parents and other family members using a family-centred approach [37]; however, they took care to maintain patient-centred care. Sometimes, inclusion of parents was necessary, as the parent was required to provide consent if the adolescent was under the age of 16 years; sometimes, this was at the request of the AYA. It was evident that managing competing information needs of AYA and their family was sometimes difficult, highlighting a need for AYA-specific communication skills. Detailed findings about family-centred care and patient autonomy from this study have been previously reported and discussed [12].

The organisation of clinical services in this study was based on a multidisciplinary team approach to cancer care, which is widely advocated [7, 38]. Sharing both learning and roles and responsibilities in communicating with AYAs about clinical trial participation reinforced the notion of effective team work. For example, CNSs worked closely with other members of the multidisciplinary team, particularly consultants and research nurses. French and Stavropoulou [39] also reported that close team working between the CNS and research nurses was beneficial for trial recruitment [39], where the CNS can facilitate information exchange between research nurses and patients as part of their key worker role in coordinating treatment and care [40–42].

Receiving education and training about the trials was valued and helped the professionals in this study feel more credible. Health professionals thought education and training should be more inclusive and accessible to the wider multidisciplinary team, for example at trial initiation. However, not all health professionals involved in the treatment and care of AYAs with bone sarcoma received GCP training, and only some health professionals involved in recruitment received additional age-specific or advanced communication skills training. In the UK, senior medical professionals and senior cancer nurses, such as CNSs, have access to advanced communication skills training, but these training opportunities are not widely available and AYA age-specific training opportunities are limited [43].

Professionals also suggested methods to support AYA communication skill development such as learning from mistakes, watching videos of scenarios where things fell short of good quality care and practicing communication skills in a "safe" learning environment. We propose that all professionals working with AYAs with cancer should have access to age-specific communication skills training, which includes interdisciplinary, experiential learning. Furthermore, supporting health professionals to develop age-specific communication skills should be seen as a priority if current AYA trial recruitment targets are to be met. Since completing this study, a simple strategy introduced at the centre hosting this research is for professionals attending a monthly sarcoma trial operational team meeting to routinely share experience of, and reflect on, discussions with AYAs who have subsequently declined to consent to participate in a clinical trial.

Strengths and limitations of the study

This study was conducted at a single study site, which represents a familiar model of caring for AYAs with bone sarcoma in the UK and other countries with similar models of AYA care. This study recruited health professionals treating and caring for AYAs recruited to two complex, first-line, bone sarcoma-specific trials, which limit the transferability of all findings. Some findings, however, resonate with literature from other areas of cancer practice, which suggests transferability. We included a range of professional roles in this study, and although not all were directly involved in trial recruitment, the participants gave insight into the experiences of health professionals involved in the treatment and care of trial eligible AYA across care settings. Although participants were not invited to comment on coded transcripts, study findings have been shared at the study site. Exploring the dynamic of working across teams highlights the necessity of effective multidisciplinary team working in providing trustworthy and consistent information to AYAs about clinical trial participation.

Conclusion

This study provides insight into the perceived importance of professional expertise and development and strategies for communicating with AYAs about bone cancer trial participation. An underpinning concept was the need to build trusting patient-professional relationships. Our findings can be used to inform the development of specialist knowledge and skills needed to communicate with AYAs with bone cancer and their families about clinical trial participation. Research exploring which elements of team work most effectively support clinical trial participation and why is warranted.

Acknowledgements We thank all healthcare professionals who gave up their time to participate in this study. Thanks also to Professor Helen Dawes, Oxford Brookes University, for reviewing early drafts of this manuscript.

Funding information We thank the Bone Cancer Research Trust for funding this study (Grant Number BCRT 21/10) and the National Institute for Health Research, Teenage Cancer Trust and Oxford Brookes University for financially supporting the authors of this study.

Compliance with ethical standards

We e-mailed invitations with participant information packs to health professionals inviting them to participate in an interview and followed the e-mail with a telephone invitation. We obtained written and informed consent from potential participants. We assured anonymity and confidentiality, and participants were informed they could withdraw from the study at any time without giving a reason.

Statement of confidentiality We confirm all personal identifiers have been removed or disguised, so the persons described are not identifiable and cannot be identified through the details of the story.

Conflict of interest The authors declare that they have no conflict of interest.

References

1. Bleyer A, Barr R. & Ries L.A.G. (2006) Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000. NIH, Bethesda, MA, USA
2. Andritsch E, Beishon M, Bielack S, Bonvalot S, Casali P, Crul M, Bolton RD et al (2017) ECCO essential requirements for quality Cancer care: soft tissue sarcoma in adults and bone sarcoma. A critical review. Crit Rev Oncol Hematol 110:94–105. https://doi.org/10.1016/j.critrevonc.2016.12.002
3. Whelan J, McTiernan A, Cooper N, Wong YK, Francis M, Vernon S, Strauss SJ (2012) Incidence and survival of malignant bone sarcomas in England 1979-2007. Int J Cancer 131:E508–E517. https://doi.org/10.1002/ijc.26426
4. Bleyer A (2005) The adolescent and young adult gap in cancer care and outcome. Curr Probl Pediatr Adolesc Health Care 35: 182–217
5. Birch JM, Pang D, Alston RD, Rowan S, Geraci M, Moran A, Eden TOB (2008) Survival from cancer in teenagers and young adults in England, 1979-2003. Br J Cancer 99:830–835. https://doi.org/10.1038/sj.bjc.6604460

6. Fern LA, Lewandowski JA, Coxon KM, Whelan J (2014) Available, accessible, aware, appropriate, and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials. Lancet Oncol 15:e341–e350. https://doi.org/10.1016/s1470-2045(14)70113-5
7. Independent Cancer Taskforce (2015) Achieving world class cancer outcomes, A Strategy for England 2015–2020. https://www.cancerresearchuk.org/about-us/cancer-strategy-in-england. Accessed 30 June 2018
8. Ferrari A, Trama A, De Paoli A, Bergeron C, Merks JHM, Jenney M, Orbach D et al. (2017) Access to clinical trials for adolescents with soft tissue sarcomas: enrollment in European pediatric Soft tissue sarcoma Study Group (EpSSG) protocols. Pediatr Blood Cancer 64. doi: https://doi.org/10.1002/pbc.26348
9. Docherty SL, Kayle M, Maslow GR, Santacroce SJ (2015) The adolescent and young adult with cancer: a developmental life course perspective. Semin Oncol Nurs 31:186–196. https://doi.org/10.1016/j.soncn.2015.05.006
10. Read K, Fernandez CV, Gao J, Strahlendorf C, Moghrabi A, Pentz RD, Barfield RC, Baker JN, Santor D, Weijer C, Kodish E (2009) Decision-making by adolescents and parents of children with cancer regarding health research participation. Pediatrics 124:959–965. https://doi.org/10.1542/peds.2008-2878
11. Bleyer A (2007) Adolescent and young adult (AYA) oncology: the first A. Pediatr Hematol Oncol 24:325–336
12. Pearce S, Brownsdon A, Fern L, Gibson F, Whelan J, Lavender V (2016) The perceptions of teenagers, young adults and professionals in the participation of bone cancer clinical trials. Eur J Cancer Care (Engl). https://doi.org/10.1111/ecc.12476
13. NHS Choices (2014) Consent to treatment—children and young people at: https://www.nhs.uk/conditions/consent-to-treatment/children/ (accessed 09.05.18)
14. Broome ME, Richards DJ, Hall JM (2001) Children in research: the experience of ill children and adolescents. J Fam Nurs 7:32–49
15. Whelan JS, Bielack SS, Marina N, Smeland S, Jovic G, Hook JM, Krailo M, Anninga J, Butterfass-Bahloul T, Böhling T, Calaminus G, Capra M, Deffenbaugh C, Dhooge C, Eriksson M, Flanagan AM, Gelderblom H, Goorin A, Gorlick R, Gosheger G, Grimer RJ, Hall KS, Helmke K, Hogendoorn PC, Jundt G, Kager L, Kuehne T, Lau CC, Letson GD, Meyer J, Meyers PA, Morris C, Mottl H, Nadel H, Nagarajan R, Randall RL, Schomberg P, Schwarz R, Teot LA, Sydes MR, Bernstein M, EURAMOS collaborators (2015) EURAMOS-1, an international randomised study for osteosarcoma: results from pre-randomisation treatment. Ann Oncol 26:407–414. https://doi.org/10.1093/annonc/mdu526
16. EUROpean_Ewing_tumour_Working_Initiative_of_National_Groups (2017) Combination chemotherapy with or without peripheral stem cell transplantation, radiation therapy, and/or surgery in treating patients with Ewing's sarcoma. ISRCTN Registry at: http://www.isrctn.com/ISRCTN61438620 (accessed 09.05.18)
17. Fern L, Davies S, Eden T, Feltbower R, Grant R, Hawkins M, Lewis I, Loucaides E, Rowntree C, Stenning S, Whelan J, National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Development Group (2008) Rates of inclusion of teenagers and young adults in England into National Cancer Research Network clinical trials: report from the National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Development Group. Br J Cancer 99:1967–1974
18. Schwandt TA (2000) Three epistemological stances for qualitative inquiry: interpretivism, hermeneutics, and social construction. In: Denzin NK, Lincoln YS (eds) Handbook of qualitative research, 2nd edn. Sage Publications, Thousand Oaks, pp 189–213
19. Squire C (2008) From experience-centred to socio-culturally narrative approaches to narrative. In: Andrews MSSCTM (ed) Doing narrative research. Sage, London, pp 41–64
20. National Institute for Health and Clinical Excellence (2005) Guidance on cancer services: improving outcomes in children and young people with cancer, the manual. NICE, London, p 8
21. Patton QM (2002) Qualitative research and evaluation methods. Sage, Thousand Oaks, p 230
22. Charmaz K (2000) Grounded theory objectivist and constructivist methods. In: DNA L (ed) Handbook of qualitative research, 2nd edn. Sage Publications, Thousand Oaks, pp 509–536
23. Freyer DR and Seibel NL (2015) The clinical trials gap for adolescents and young adults with cancer: recent progress and conceptual framework for continued research. Current Pediatric Reports 3: 137–145 doi: DOI 10.1007/s40124-015-0075-y
24. Thom DH, Hall MA, Pawlson LG (2004) Measuring patients' trust in physicians when assessing quality of care. Health Aff (Millwood) 23:124–132. https://doi.org/10.1377/hlthaff.23.4.124
25. Bahrami M, Namnabati M, Mokarian F, Oujian P, Arbon P (2017) Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study. Support Care Cancer 25:1587–1596. https://doi.org/10.1007/s00520-016-3561-z
26. Nuffield Council on Bioethics (2015) Children and clinical research: ethical issues. Nuffield Council on Bioethics, London, pp 131–175
27. Hillen MA, de Haes HC, Smets EM (2011) Cancer patients' trust in their physician—a review. Psychooncology 20:227–241. https://doi.org/10.1002/pon.1745
28. Sawyer SM, Ambresin AE, Bennett KE, Patton GC (2014) A measurement framework for quality health care for adolescents in hospital. J Adolesc Health 55:484–490. https://doi.org/10.1016/j.jadohealth.2014.01.023
29. Fallowfield L (2005) Learning how to communicate in cancer settings. Support Care Cancer 13:349–350. https://doi.org/10.1007/s00520-004-0765-4
30. Fallowfield L, Langridge C, Jenkins V (2014) Communication skills training for breast cancer teams talking about trials. Breast 23:193–197. https://doi.org/10.1016/j.breast.2013.11.009
31. Essig S, Steiner C, Kuehni CE, Weber H, Kiss A (2016) Improving communication in adolescent cancer care: a multiperspective study. Pediatr Blood Cancer 63:1423–1430. https://doi.org/10.1002/pbc.26012
32. Erikson EH (1995) Childhood and society. Vintage Books, London
33. Havighurst R (1972) Developmental tasks and education. David McKay Co Inc., New York
34. Soanes L, Gibson F (2018) Protecting an adult identity: a grounded theory of supportive care for young adults recently diagnosed with cancer. Int J Nurs Stud 81:40–48. https://doi.org/10.1016/j.ijnurstu.2018.01.010
35. Taylor RM, Feltbower RG, Aslam N, Raine R, Whelan JS, Gibson F (2016) Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer. BMJ Open 6:e011361. https://doi.org/10.1136/bmjopen-2016-011361
36. Bora K, White K (2017) How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review. Int J Adolesc Youth 23:198–218. https://doi.org/10.1080/02673843.2017.1330696
37. Corlett J, Twycross A (2006) Negotiation of parental roles within family-centred care: a review of the research. J Clin Nurs 15:1308–1316. https://doi.org/10.1111/j.1365-2702.2006.01407.x
38. Borras JM, Albreht T, Audisio R, Briers E, Casali P, Esperou H, Grube B et al (2014) Policy statement on multidisciplinary cancer care. Eur J Cancer 50:475–480. https://doi.org/10.1016/j.ejca.2013.11.012
39. French C, Stavropoulou C (2016) Specialist nurses' perceptions of inviting patients to participate in clinical research studies: a qualitative descriptive study of barriers and facilitators. BMC Med Res Methodol 16:96. https://doi.org/10.1186/s12874-016-0204-5

40. Ling J, McCabe K, Brent S, Crosland A (2013) Key workers in cancer care: patient and staff attitudes and implications for role development in cancer services. Eur J Cancer Care (Engl) 22: 691–698. https://doi.org/10.1111/ecc.12079
41. Martins A, Aldiss S, Gibson F (2016) Specialist nurse key worker in children's cancer care: professionals' perspectives on the core characteristics of the role. Eur J Oncol Nurs 24:70–78. https://doi.org/10.1016/j.ejon.2016.08.009
42. National Cancer Action Team (2010) Quality in nursing excellence in cancer care: the contribution of the clinical nurse specialist. Department of Health, London
43. Coad J, Smith J, Pontin D, Gibson F (2018) Consult, negotiate, and involve: evaluation of an advanced communication skills program for health care professionals. J Pediatr Oncol Nurs 1043454218765136:296–307. https://doi.org/10.1177/1043454218765136

Affiliations

Verna Lavender[1] · **Faith Gibson**[2,3] · **Alexandra Brownsdon**[4] · **Lorna Fern**[4] · **Jeremy Whelan**[4] · **Susie Pearce**[5]

[1] Department of Nursing, Faculty of Health and Life Sciences, Oxford Brookes University, Jack Straw's Lane, Marston Road, Oxford OX3 0FL, UK

[2] Centre for Outcomes and Experiences Research in Children's Health, Illness, and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH, UK

[3] School of Health Sciences, Faculty of Health and Medical Sciences, University of Surrey, Guildford GU2 7XH, UK

[4] Cancer Division, University College London Hospital NHS Foundation Trust, 1st Floor Central, 250 Euston Road, London NW1 2PG, UK

[5] School of Nursing and Midwifery, Faculty of Health Sciences, Plymouth University, 10 Portland villas, Drake Circus, Plymouth PL4 8AA, UK