

‘Holistic competence’: how is it developed, shared and shaped by healthcare professionals caring for adolescents and young adults with cancer?

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Abstract

Purpose

In England, specialist cancer services for adolescents and young adults (young people) aged 15-24 are provided in 13 specialist units, with additional care provided in child and adult cancer units in the region. As a result of specialisation, healthcare professionals (HCP) have refined their competence, to deliver holistic care that has become central to the culture of young people's cancer care. We sought to understand and describe how HCPs developed this competence.

Methods

We conducted a multiple case study in four regions across England in 24 hospitals. Data were collected through observation of clinical areas, shadowing members of the multi-disciplinary team, and semi-structured interviews with young people. Data were analysed thematically and triangulated to draw meaning applicable to a range of contexts.

Results

Young people (n=29) and HCP (n=41) across 24 different care settings were interviewed. Holistic competence enabled HCPs to deliver care that considered the age-specific needs of young people, including social, emotional and psychological needs, in accordance with their life stage and psychosocial development. Development of holistic competence was facilitated by the following four factors: the environment, the experience continuum, enthusiasm, and education.

Conclusion

The four factors facilitating holistic competence were interlinked. Working in a specialist/dedicated environment for young people increased HCPs exposure to young people. This enabled them to become experienced in young people's cancer care, supported

through education and training. Without frequent exposure to young people, HCPs were less able to achieve holistic competence, the impact of which was acutely felt by young people.

Introduction

Specialist services for adolescents and young adults (young people) aged 15-24 with cancer have developed over the last 30 years in the United Kingdom (UK) in response to the observation that this population often had poorer survival than children and older adults[1]. The evolution of these cancer services has led to a 'three-population' structure of services in the UK, replacing the traditional child and adult services provided in most medical specialities. Central to specialist cancer services for young people are the dedicated units with essential facilities, not just to deliver cancer care, but to also provide age-appropriate resources and a workforce who are skilled in the developmental and social needs of young people[2,3]. The developmental and social needs of young people are increasingly being acknowledged, with the production of holistic needs assessment tools that are specific to young people, such as the [HEEADSSS \(Home, Education and Employment, Activities, Drugs/Drinking, Sex, Self-harm, depression & suicide, Safety\), a generic adolescent health assessment framework](#)[4,5]. More recently, a needs assessment was developed specifically for young people with cancer: the 'Integrated Assessment Map,' known as the 'IAM,' which has been developed and trialled in a limited number of specialist centres in the UK[3]. The 'IAM' is a framework for conducting a comprehensive, bio-psychosocial assessment of a young person's holistic needs and covers domains such as physical well-being, emotional well-being, relationships and education and/or work[3]: it is yet another step forward in recognising the importance of understanding the wider aspects of a young person's well-being whilst going through cancer treatment.

The workforce who care for young people with cancer has emerged as a discrete cancer speciality. Providing healthcare for this age group requires acknowledgement of a young

person's developmental transition from child to adulthood[6], in addition to meeting their clinical and holistic needs[7]. In England, it was recommended that the multidisciplinary team (MDT) had appropriate healthcare professional (HCP) representation to support treatment planning with the tumour site-specific MDT, and to also provide psychosocial support[8]. Workforce planning within the National Health Service (NHS) required the establishment of staffing levels, as well as role descriptions of appropriate skills, behaviours, attitudes and values[9]. Unique roles were introduced to meet this need, for example, the 'youth support co-ordinator' ~~role~~[3]. These roles, in particular, are noted to be pivotal as a source of emotional support for young people and their families, and in assisting young people to engage with their peers[3,10]. However, outside of the specialist young people's unit there is limited or no access to such specialist HCPs/youth support coordinators, and there can be a lack of access to social and emotional support throughout their cancer treatment, which is often described as an isolating time[7]. The focus to date has been on detailing the core membership of the young person's MDT[8], with less of a focus on articulating contributions to care through descriptions of competence, and the role of education/training [12]; where, until recently, much of the development of the associated skills and knowledge required to care for young people, has been through experiential learning[13].

All HCPs should have the appropriate education and competency to provide high-quality care to young people[12]. Competence has been defined as "the combination of training, skills, experience and knowledge that a person has and their ability to apply them to perform a task safely"[14]. Additionally, factors such as physical ability and attitude can also impact the competence of an individual[14]. An international Delphi study explored the specific competence of HCPs who were experts in working with young people with cancer[12]. This revealed distinct differences in role perception according to professional background; for example, doctors cited traditional medical roles as being more important whereas nurses reported needing competence in areas reflecting the developmental and social needs of young people, such as providing holistic care, the importance of restoring normality, and

allowing young people time to come to their own solutions[12]. Consistency, in terms of education, however remains necessary, which was noted to be challenging in the Delphi study, likely “due to the broad range of HCPs who come into contact with this patient group, their education and training needs will inevitably differ”[15,p.53]. This ‘difference’ in educational requirements of HCPs indicated a need for increased evidence around the knowledge, skills and abilities required by all HCPs, as well as personal qualities, attributes and behaviours: described as the core competencies of practice.

The delivery of care in specialist young people’s cancer units in the UK, and elsewhere, is not mandated. There are many young people who receive their cancer care either in child or adult units, without access to age-appropriate facilities. Thus, they may be cared for by HCPs who may have limited exposure to this population and lack the core competencies to meet their specific needs. The detrimental impact of being cared for by inappropriately qualified and skilled HCPs is well recognised in the care of adolescents with other health conditions[16] and is increasingly being recognised in the care of young adults[17]. Current evidence confirms the importance of HCPs in developing the culture of young people’s cancer care, but this is based on research in specialist young people units only and not in other healthcare settings. This study sought to understand the characteristics of the workplace, and understandings of workplace practices, that influenced the development of competence in the holistic care of young people. It was part of a wider study exploring the culture of young people’s cancer care[18], and therefore this paper presents only the findings related to the development of competence.

Methods

Study design

We conducted a multiple case study using qualitative methods. The case was young people’s cancer care in England, sub-cases were four regions, selected based on our earlier

study mapping the characteristics of each specialist young person's unit[19]. Nested cases were hospitals within the regions (n=24), in which multiple care settings were visited, such as cancer day units, wards, outpatients and radiotherapy departments.

Data collection

Data were collected through semi-structured interviews with young people and HCPs. Interviews followed a topic guide (Appendix 1), were digitally recorded, and field notes captured observational data. Interviews were conducted in a place of the participant's choosing, most commonly a patient's side room, a quiet room, or an HCPs office or clinic space. Giving the participant choice enabled a sense of control and aimed to positively address any potential power balance between the researcher and participant.

Healthcare professionals were purposefully sampled to reflect the young person's MDT, aiming for 10 in each sub-case. The lead nurse and/or clinician for young people's services identified the range of their MDT to participate. Young people were recruited through convenience sampling based on availability and willingness to participate. In addition, methods of data collection included walking tours of hospitals, shadowing members of the MDT, and participant observation in clinical and social spaces of the hospital. Field notes were recorded to document what was observed and these were included in the analysis.

Ethics

This study was approved by the London – Central NHS Research Ethics Committee (Reference: 13/LO/1869). Approval at each hospital R&D department was co-ordinated through the NIHR Coordinated System for gaining NHS Permission and individual hospital approval was required from all the hospitals where young people were interviewed. All participants gave written informed consent, and written parental consent was obtained for patients aged <16 years. As a registered paediatric nurse, an NHS to NHS letter of access was issued by the researcher's NHS employer, and the researcher identified and prepared

for possible issues relating to research conduct with young people, informed consent, protecting confidentiality and balancing risk of harm with potential benefits.

Analysis

Digital recordings were transcribed verbatim and analysed thematically. Field notes were reviewed alongside individual transcripts. Data were reduced, captured as themes, categorised and organised. Miles and Huberman present a staged approach of reducing, displaying, drawing conclusions and verifying data[20]: we followed these steps. The first step involved the generation of initial codes across all transcripts and field notes, undertaken without the use of a soft-ware package, working with printed transcripts and field notes. Alongside memoing and note-taking, codes were grouped into early-stage themes and sub-themes using colour-coding[20]. Tables displaying early data analysis were printed and revised, this allowed for close viewing to aid recognition of associations between the themes and categories; this assisted the process of identifying and drawing initial conclusions from the data[20]. The original themes and categories were further refined and verified through regularly returning to the raw data.

Data triangulation was used, where several perspectives and data sources were combined, giving the researcher opportunity to identify and synthesise both parallels and variations across and within data sets. In this case, this involved sharing a collection of knowledge (triangulated from multiple sources) about the culture of cancer care for young people, with those who cared for them, thus the study provides a contribution that will be valuable across the range of contexts in which it was conducted.

Findings

Interviews were conducted with 41 HCPs (26 nurses and 15 other professionals), and 29 young people. Sample characteristics are presented in Table 1. Healthcare professionals

described how their knowledge, skills and abilities, and overall competence was central to their caring role. Young people wanted to receive care which considered them as a whole person, including their social, emotional and psychological needs, in contrast to care which focussed only on their clinical and physical care needs. Holistic care required holistic competence: this theme emerged primarily in the interviews with HCPs and the field notes. Development of holistic competence was facilitated by the following four factors: the environment, the experience continuum, enthusiasm, and education (Figure 1). These themes are discussed in the following sub-sections, with supporting quotes presented in Table 2.

Environment

The physical space, facilities and tangible infrastructure together created an 'environment of care' which influenced the development of a holistic approach to caring. Specialist environments provided a dedicated platform from which specific knowledge and skills were learned and shared. Healthcare professionals recognised this to be a benefit of having an environment dedicated to young people, where competence in holistic care was more easily developed by delivering care in one 'space'. Both young people and HCPs described the benefits of care in specialist young people units, such as, constant access to an MDT with competence in providing appropriate emotional support. While the specialist environments were more commonly placed within specialist unit, some non-specialist units provide dedicated spaces for young people, which also facilitated emotional support.

The theme 'the environment' is presented as separate to the following three themes in Figure 1, due to its influence on each theme: the environment in which HCPs worked influenced and shaped their approach to care and maintained their enthusiasm for the speciality. Specialist environments provided the space, facilities and atmosphere to enable HCPs to build interpersonal relationships with patients and encouraged an approach that was holistic. The unique aspects of the physical environment in a young people's unit, such

as social spaces, facilitated interpersonal relationships between HCPs and young people and, and this was frequently observed; particularly distinctive were non-clinical interactions observed between nurses and young people (Box 1). It was suggested that staff working in either child or adult cancer services would benefit from spending time in specialist young people's environments of care, to gain opportunities for building experience, witnessing first-hand the importance of the environment. Encouraging such methods to share knowledge could also enhance the competence of those working outside young people's specialist centres, in order to deliver holistic, young person-centred care.

Experience continuum

Experience contributed significantly to the development of professional competence. Whether an HCP had less or more experience was primarily a result of their role and the environment in which they worked. For example, nurses working in dedicated young people's cancer services had regular and consistent exposure to this age group, whereas those in adult/child cancer services had much less. There were young people who described poor experiences of care, particularly when in child or adult-focused settings. In particular, they reflected upon situations where HCPs demonstrated poor understanding of how to communicate with them.

In adult cancer units in the UK, a specific 'lead nurse' was often appointed to oversee and support the care of any young people on the unit, usually as a part-time addition to a tumour site-specific nurse specialist who worked with the more common cancer types for younger patients, e.g. lymphoma. These nurses by default, had the greatest exposure to young people, despite the fact that in many adult units they still only cared for small numbers of young people. Due to these small numbers in some of the adult and children's cancer units, there was variation described in HCPs competence in meeting psychosocial and emotional care needs. On reflection, young people talked about this variation in the context of 'experience', how experienced HCPs were with caring for people of their age and life stage,

influenced the care received. They observed a difference and appreciated how good, age-appropriate communication enhanced their care experience.

Healthcare professionals with regular and frequent experience of caring for young people demonstrated the highest levels of holistic competence. It was also important for staff to have an awareness of the complexity and unique challenges of working with these patients. Healthcare professionals noted that young people who received care in adult units were described as having 'unhindered access' to age-appropriate care, including an expert care team. It was a requirement for young people in adult units to have access to both a tumour site-specific clinical nurse specialist, and a lead nurse for young people's services. While the tumour site-specific nurse specialist could meet all clinical or treatment-related needs, the lead nurse was there to support young people holistically, to ensure their psychosocial needs were also being met.

Enthusiasm

Healthcare professionals in all care settings recognised the delivery of high-quality holistic care to young people required not only competence, but also enthusiasm and passion. Those in specialist young people's units described a "natural migration" of staff away from children's or adult cancer units, to work on their unit. Similarly, those in paediatric oncology shared care units also described how they "love working with teenagers" and spoke passionately about their role in caring for them. This enthusiastic attitude and shared passion to care for this age group was positively recounted by young people. Equally, this was identified by HCPs who advocated the importance of having a workforce with a shared philosophy and passion specifically for caring for this cancer population.

Education

The role of education in developing professional competence emerged across all contexts of care, however it varied in terms of structure and formality. Three categories of education

emerged, which can be described as: 1) raising awareness; 2) in-house education and training; 3) formal education.

Raising awareness

The concern here was raising awareness of both the unique physical and psychosocial needs of young people with cancer, and of the support and services available from the young person's MDT. In children's and adult cancer services, there was an expressed need to heighten the profile of young people's needs and what specialist care for this group encompassed. Raising awareness in hospitals without young people-specific services was a large part of the role of the lead nurses, such as presenting at tumour site-specific team meetings. A further proposed strategy was the creation of "nurse champions" on children's and adult cancer wards to advocate for young people's holistic care, and to raise awareness of their unique care needs. There were clinical teams in neighbouring regional hospitals who had little contact with the specialist young people's MDT, therefore specialist nurses worked to connect hospitals across the region, to raise this awareness to improve young people's care.

In-house education and training

This type of education was utilised in both specialist young people's units and hospitals without specialist services. An example of this 'in-house training' was where expert professionals in the specialist young people's units ran 'clinical skills weeks', which brought together HCPs from both child and adult settings. These involved problem-solving and education about what the young people's services offered to help them to support young people. Training also incorporated information about psychosocial needs, to ensure holistic knowledge was developed. In-house training was described to effectively advance the holistic competence of the staff and promoted team cohesion. In child or adult services, young people lead nurses provided in-house training sessions to both educate their teams

and to promote the service. There were several adult units that lacked young people-focussed education for their team, and this was described as an unmet need.

Formal education

Healthcare professionals discussed the value of formal education programmes. While this was predominantly highlighted by HCPs in specialist young people units, there were those in some adult services who also recognised this need and expressed an interest in supporting their staff to attend formal courses, such as the one provided by a UK university, which was the only academic institution in the UK at the time to provide accredited courses in AYA cancer. Staff in specialist units described having more access to specialist training and education.

Those in management roles noted the challenges of facilitating formal education due to lack of funding and staffing levels. Additionally, issues such as high staff turnover and service reconfigurations presented further challenges. Nurses leading young people's cancer services identified that it would be "impossible" to enable all HCPs who may encounter young people, in every hospital within a region, to access formal education. This further advocated the strategy of having "nurse champions", who would be supported to attend formal education and courses, and then deliver in-house training to share their new knowledge and skills.

All three 'levels' of education and training for HCPs enhanced the development of holistic competence, through increasing the age-specific knowledge and skills of the nursing team and the wider workforce who care for young people with cancer. Additionally, education and training, even at the basic level of raising awareness of young people's developmental care needs, influenced the attitude of HCPs in terms of their enthusiasm for caring for this unique patient population.

Discussion

Cancer services for young people in the UK are often provided in specialist care settings, in which HCPs have refined their holistic competence to work with young people. We present the first national case study that describes how this competence has developed. Our study showed that HCPs recognised the importance of being competent in providing holistic care, and building this competence required experience and education; more easily accessed in specialist young people services. Similar to other evidence-based competencies for AYA cancer care professionals[12,21], the provision of holistic care for young people involved understanding their developmental needs[22]. Specialist young people's cancer units across the UK are staffed by teams of HCPs who are experts in the provision of both clinical and holistic support[23]. However, the challenges of providing care which meets the holistic needs of all young people have been recognised, as they have such wide ranging needs based on their personal circumstances and life stage[22]. This is a challenge for HCPs who have infrequent exposure to young people, where the opportunity to develop their knowledge and experience is limited, clearly characteristics of the workplace has a role to play.

Experience is built through exposure, and clearly in our study this was supported by working alongside colleagues and learning from them. In young people's care, the foundation of this care was through MDT working[11]. Exposure, and working in an environment that provided the right setting for developing and delivering holistic care was clearly beneficial to those in our study. Viner and Barker[25] have previously highlighted the importance of exposure to young people in building this experience, knowledge and skills specific to their care. They have suggested short-term exposure to caring for this age group should be a requirement of all HCP training programmes, enabling HCPs working in either child or adult healthcare settings to have access to caring for young people and receive education around their needs[25].

The 'environment' as a component of care was suggested to facilitate person-centred nursing[26] and the findings of our study showed the environment had an impact on the attitude and interactions HCPs had with patients. Hospitalisation can be a stressful experience for someone of any age, but for young people, extended periods of hospitalisation can be lonely and isolating[27]. Similar to other studies, we found it was important that HCPs recognised young people as a distinct population, with individual needs, desires and opinions[12,19], and this suggests that the environment can act as an enabler for HCPs to adopt a young person-centred approach to care. Additionally, tools such as holistic needs assessments can be a useful enabler for the consideration of a patient's wider psychosocial needs, and for young people the age-specific 'IAM' is being trialled and evaluated as a bespoke, young-person specific holistic needs assessment tool[3]. The usefulness of tools such as this should not be underestimated and could provide a simple and accessible educational resource for HCPs across all services and care settings.

In terms of professional competencies, in nursing it is accepted that the best standards of care are delivered by those who have expertise or specific training in working with this population[13]. The development of a specialist and expert nursing workforce has been integral to the overall development of young people's cancer care within the UK[13], culminating in the publication of a competence framework for young people's cancer nursing in 2014[21]. At present, this is the only formal competency framework for caring for young people with cancer. The nursing profession therefore has a responsibility to share their knowledge, experience and standards for best practice in caring for young people[13,28], and to lead in sharing their expertise to develop the competence of the wider MDT. This is the responsibility of nurses in all care settings but perhaps more so outside the specialist young person's units. Other studies have shown that young people felt that HCPs working on young people's cancer wards had a shared recognition of what was involved when providing expert care to young people[19,29]. The goal should be for the expertise in

specialist young people's units to be shared with the teams across their regional networks[23], which creates a platform for sharing expertise[2]. However, challenges in hospital-to-hospital communication have been identified in other studies, demonstrating the difficulties of team working across a region[30], a barrier which must be acknowledged and addressed.

In terms of training and education programmes, we have highlighted a wide variation across hospitals in access and types of training provided to HCPs working with young people. Learning and experience is often incidental, however if it is more purposeful, it can lead to a more appropriately equipped workforce. Some had access to formal education and training, however, this was more regularly discussed in specialist young people's units. It is in this setting, where the highest numbers of young people were being cared for, and therefore the expertise in caring for this group should be, and is, most concentrated[31]. Local or in-house training and education was developed in some hospitals and was recognised as an important 'next step' for other services to improve the holistic care they provide to young people. Such forms of education can be reinforced and encouraged with the recent generation of evidence-based competencies[12,21], in addition to more recent developments in online and e-learning opportunities making formal education about holistic, young-person centred care more accessible than ever[9].

Strengths and limitations

A major strength of this study was the inclusion of multiple sites, this included young people's services, as well as child and adult services. Of significance to this narrative, there are two main limitations. First, in all of these services working with a convenience sample of young, meant that we only recruited young people who were interested and felt well enough to participate. This may have affected the perspectives gathered as it was likely that those who chose to participate had either very positive or negative experiences to share. While this could have biased the results, this is a known and accepted challenge of recruiting this

population to research[32]. Nonetheless, data collected through the interviews and observations, provided rich data. Second, although a wide range of professional roles within the multi-disciplinary team were interviewed, observed and shadowed, there was a female gender bias in the sample of HCPs. Only 5% of the sample were male. This is reflective of the gender imbalance in the caring professions, particularly in nursing, where only 13% of registered nurses identify as male[33]. While there could be alternative insights into the nature of holistic competence for this group that are gender specific, reflected here are the perspectives, experiences and observations of the largest part of the workforce majority in the healthcare settings.

Conclusion

Both HCPs and young people in our study recounted the challenges of delivering and receiving care, where there was an absence of experience, and specialist education, this impacted on the delivery of holistic care. We would suggest that the development of holistic competence can be built and shaped through experience. For [HCPs](#) who have infrequent exposure to young people, the opportunity to gain experience caring for this patient group was limited as was the exposure to relevant workplace practices that influence competence development. Where clinical exposure to young people is limited, then education has an even more important role to play. Healthcare professionals leading services in children's or adult cancer care must be encouraged to be creative with their approach to educating the workforce, they must find ways to educate HCPs and raise the profile of young people's care across the whole cancer service, and the wider hospital, in order for young people to receive high-quality care, that meets all of their needs. Further research is needed to more fully understand the impact of holistic competence on patient satisfaction, health and quality of life, and overall experiences of care.

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Declarations of interests

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Figure 1: The four themes, which lead to the development of holistic competence

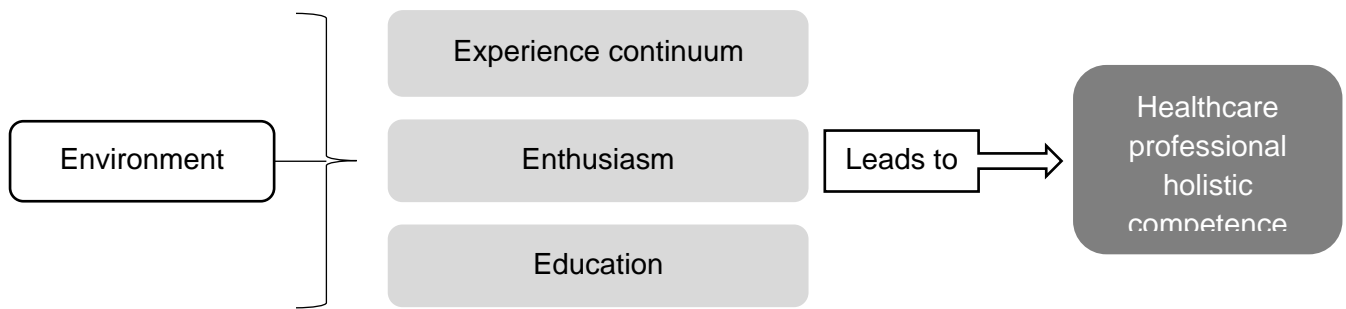


Table 1: Summary table of the characteristics of the study interview participants

	Healthcare Professionals n (%)	Young people n (%)
<i>Total</i>	41	29
<i>Gender</i>		
Male	2 (5)	10 (34)
Female	39 (95)	19 (66)
<i>Age</i>		
Median age [range]	NC	19 [13-24]
13-15	NC	6 (21)
16-18	NC	8 (27)
19-24	NC	15 (52)
<i>Main treatment centre/place of work</i>		
Specialist young people unit	23 (56)	22 (76)
Adult cancer unit	14 (34)	7 (24)
Children's cancer unit	4 (10)	0 (0)

NC: not collected

Table 2. Supporting quotes from participant interviews.

Theme	Supporting quote
Environment	<p data-bbox="448 320 2042 451">“We’re starting to get more exposure to the needs of young adults and exposure for the staff looking after young adults... now that we keep them in one place together because of the nature of the ward.” (HCP19, sub-case 2, specialist young people unit)</p> <p data-bbox="448 523 2042 654">“I think it’s great that the young people are in an environment where most of the people they have contact with feel confident to be able to give them a level of emotional support because they don’t want to wait two days for their CLIC Sargent [charity funded] social worker to be available.” (HCP38, sub-case 4, specialist young people unit)</p> <p data-bbox="448 726 2042 805">“...the difference that the environment has made in making it feel like a unit that sort of looks after people’s needs rather than just gives them treatment.” (HCP19, sub-case 2, specialist young people unit)</p> <p data-bbox="448 877 2042 1008">“I suppose from our perspective what I’ll certainly do is arrange for them to go to other units and it probably will be the Principal Treatment Centre... I would like to get them, sort of, fast tracked, that knowledge, that experience so that they can see how they can really help deliver that A1 service for the young person.” (HCP21, sub-case 2, adult unit)</p>
Experience continuum	<p data-bbox="448 1034 2042 1114">“...we need exposure for the newer staff coming through... you want to build people’s skills up, and at the same time expose them to the young adults.” (HCP19, sub-case 2, specialist young people unit)</p> <p data-bbox="448 1185 2042 1369">“I had a few nights where I was moved to an adult ward. I don’t think they were really used to children, and that was a horrible experience. They weren’t always very nice to you...quite physical, quite unsympathetic about how I was feeling. I don’t think they understood, and it made me feel scared and upset.” (Young person, sub-case 3, specialist young people unit)</p>

	<p>“I think haematology nurses by default tend to take the teenage and young adult role on in the designated hospitals because-, or the lymphoma specialists take it on, because we tend to see the majority of the teenage and young adults... “ (HCP34, sub-case 4, adult unit)</p> <p>“Having health professionals there that are aware of, you know, what they’re going through, with adolescence and going through to young adulthood. Being aware that communication actually is quite difficult, can be very problematic and very complex with those young people.” (HCP14, sub-case 2, specialist young people unit)</p> <p>“What I would like to do is get them fast tracked, that knowledge, that experience so that they can see how they can really help deliver that A1 service for the young person, working with the staff on the floor that deliver that treatment.” (HCP21, sub-case 2, adult unit)</p>
Enthusiasm	<p>“I think you do have to have, definitely, an understanding, and to some degree a bit of passion for young adults.” (HCP19, sub-case 2, specialist young people unit)</p> <p>“There’s definitely the passion and enthusiasm there. It’s about building on that really... the absolute key is that they’re individuals and that we need to be working with them and delivering their health care needs, their holistic assessment and almost their care plan to them.” (HCP21, sub-case 2, adult unit)</p> <p>“it’s about the staff, if the staff don’t get it, it doesn’t matter... it’s just about the whole ethos of it I think...” (HCP29, sub-case 3, specialist young people unit)</p>
Education	Raising awareness

“We wanted to hold a clinical nurse specialist meeting, to generate interest and to highlight the service, for me to talk about my role, my remit, and how I support patients locally... but there was a lack of interest, so it never happened.” (HCP10, sub-case 1, adult unit)

“So, when suddenly we get a patient in [designated hospital] with thyroid cancer, a team who’s never really worked with us before... it’s about trying to educate people about what we’re doing and therefore giving us better access to support the young people.” (HCP38, sub-case 4, specialist young people unit and outreach)

In-house education

“I think teenage and young adult patients have got quite complex needs. They’re different from any other group of patients. I think you need specialist training to care for those patients, from a nursing point of view.” (HCP18, sub-case 2, adult unit)

“Sometimes people ask for advice, or I will help out... I have done teaching sessions for the staff, just about general adolescent oncology, to raise awareness.” (HCP9, sub-case 1, paediatric oncology shared care unit)

“It hasn’t actually been broached at all. I don’t think any of them have had any teenage and young adult training at all. I think that’s maybe something we need to look at in the future, is getting everyone up to the same standard. Teenage and young adult patients have got very different needs from other patients.” (HCP18, sub-case 2, adult unit)

Formal education

“I think education-wise we note that Coventry University do a very good course and we’ve certainly highlighted somebody from our combined day unit which is our chemo suite and the ward will be attending that hopefully this year, so that’ll be really good as well.” (HCP21, sub-case 2, adult unit)

young people: adolescent and young adult; HCP: healthcare professional

Box 1. Supporting observation from field notes

Field note entry 10/07/15

Space: social space in the Principal Treatment Centre on the teenage and young adult ward (sub-case 3)

Actors: the youth support co-ordinator, one young person and one of the CNS's [clinical nurse specialist] sitting at the breakfast table having a chat to begin with

Activity/time: ward 'brunch club', on a Friday late morning

Event: I got there and there was crockery, tea, coffee, juice, pastries, fruit all laid out for everyone to help themselves to. Although the ward was quiet-ish, around the table in the day room there was a 'buzz'. Three more young people came in, two parents, and several nurses came around, hovering, chatting to young people, getting coffee – it was such a relaxed atmosphere. A lot of the conversation was around the upcoming summer holidays and everyone's planned holidays.

Feelings: It was such a lovely, relaxed start to the day – I kind of felt like I was in a coffee shop with a lovely group of people chatting and having brunch – it was as if I forgot I was sitting with patients and nurses.