DETERMINING DOMAINS OF PRACTICE FOR YOUTH SUPPORT CO-COORDINATOR WORK IN TEENAGE/YOUNG ADULT CANCER CARE IN THE UNITED KINGDOM

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Purpose: Youth Support Coordinators (YSCs) provide youth focused psychosocial support to teenagers and young adults (TYA) with cancer within multidisciplinary teams (MDTs) in National Health Service (NHS) specialist cancer environments. This action research project aimed to provide insight into the work of YSC with TYA with cancer within MDTs in clinical settings, and to develop a knowledge and skills framework for YSCs.
Methods: An action research approach was taken involving two focus groups (FG), with Health Care Professionals (n=7) and TYA with cancer (n=7), and a questionnaire with YSCs (n=23). Data were analysed using a thematic analysis approach. A research steering group ensured consistency with the participatory methodology.
Results: The positive value of YSC contribution to patients and MDT was echoed across the data sets. Four domains of practice were identified for inclusion in a YSC knowledge and skills framework: 1. Adolescent development; 2. The TYA with Cancer; 3. Working with TYA with cancer; and 4. Professional practice of YSC work.
Conclusion: Findings highlight the interdependence of YSC domains of practice. For example, the impact of cancer and its treatment must be considered alongside biopsychosocial knowledge relating to adolescent development. Similarly, skills for running youth focused activities need adapting to the professional cultures, rules and practices of working in healthcare systems. Further questions and challenges are raised, such as: the value and challenge of therapeutic conversations; practice supervision; and the complexities of the 'insider/outsider' perspectives YSCs bring. These insights potentially have important transferability to other areas of adolescent healthcare.

Keywords: Youth, young people, teenagers, adolescents, young adults, cancer, psychosocial support, youth support coordinator

Introduction

Adolescence is a time of rapid physical, psychological and social change as children become young adults[1,2]. Cancer and its treatment in adolescence and young adulthood challenges this developmental process, at a time when Teenagers and Young Adults (TYA) may not yet have developed the personal and social resources to cope[3,4]. Consequently, TYA have particular support needs when faced with navigating a cancer diagnosis alongside the more expected experiences and challenges accompanying adolescence[5,6].

Teenage Cancer Trust (TCT), a charity in the United Kingdom (UK), provides dedicated support to TYA (13-24 years) with cancer, working in partnership with many stakeholders including NHS, where

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they have contributed to the building of 28 specialist clinical environments/wards[7,8]. They also fund specialist services, resources and multi-professional roles to provide a unique service for these patients[9,10]. One such role, which is fully funded by TCT, is that of Youth Support Co-ordinator[11].

The YSCs (numbering 29 at the time of this research) have no dictate for a discipline specific background and come from a variety of professional backgrounds, examples of which include teaching, nursing, youth work and counselling. As the number of YSCs across the UK has grown, role variations have become apparent, with evident differences as regards their day-to-day practices and a lack of consistency in relation to the knowledge and skills deemed important to enact the job. All bar a few posts are remunerated at the same level as a registered nurse, though a few have negotiated a higher pay banding at a local level. Given the uniqueness of the role, it is also evident that there are limited career progression routes for YSCs in this field.

Whilst the experience brought to the service from the range of YSC professional backgrounds is seen as being creative and valuable, the juxtaposition of this is that there is no baseline knowledge and skills framework to map against to ensure YSC work is carried out with consistency and to an agreed minimum standard. This has important implications for individual practitioners, the charity, the NHS and the TYA and families the YSCs work directly with. The TCT commissioned an external university research team to help understand the core business of the role of YSC and to develop a knowledge and skills framework to support internal and NHS recruitment practices, and any subsequent training and development initiatives. The study aimed to identify the knowledge and skills required for YSC working with TYA with cancer so that a knowledge and skills framework can be created.

Study design

An action research methodology[12] was taken. The research team collaborated with a Steering Group (SG), acting as critical companions in the ‘diagnosis’ of the research problem and in the development of a ‘solution’ through collaborative working[13]. YSCs made up the majority of Steering Group (SG) members, with other members chosen for their intimate knowledge of the role, or for the management responsibility they held within the organisation. As such, YSCs were central to a process of reflective enquiry[14], which sought to better understand their role and the key knowledge and skills underpinning it. YSCs, therefore, directed key areas of the action research process, such as: refining the research ‘problem’; initiating action to bring about change in relation to the ‘problem’; collecting and analysing data and evaluating the action research process. Figure 1 provides an overview of the four phases of the research, which reflect an iterative cycle of ‘plan, act, observe, reflect and re-plan’[15] within the research process.

Preliminary Work	**Research Proposal and ethics approval**	
Phases of Data Collection and Analysis	1. Documentary Analysis of charity documents, NHS job descriptions and scoping review of wider literature.	Initial drafting of framework
	2. Focus group with health care professionals (n=7).	⬇
	3. Focus group with young people (n=7).	Re-drafting of framework ⬇
	4. Online survey of YSC (n=23)	Finalising of framework ⬇
Guidance and direction of Steering Group Throughout		

Figure 1: Overview of the phases of the YSC research project

Study Participants and Recruitment

A purposive sampling approach was adopted to ensure opportunities were created to include the perspectives of TYA with cancer, the healthcare professionals who worked with YSC, and the YSC themselves[16]. TYA and members of the multi-professional team were invited to participate in FGs through promotional fliers, with study information being visible on all of the Units (in staff and non-staff areas). YSCs were invited to participate by direct e-mail.

We aimed to recruit 5-10 TYA aged 13–24 years with a cancer diagnosis, treated within the previous 5 years. Participants had to be able to communicate in English. Eligible TYA were identified and recruited by their health care teams. For the HCP FG, we aimed to recruit 5-10 HCPs, targeting professionals from a mix of different professional backgrounds. All TCT funded YSCs were invited to complete the YSC questionnaire by direct e-mail.

Ethical approval

The study was approved by the Health Research Authority, (IRAS229263). Written informed consent was obtained from all the participants, and where the TYA was <18 years old, parental consent was also obtained.

Data Collection

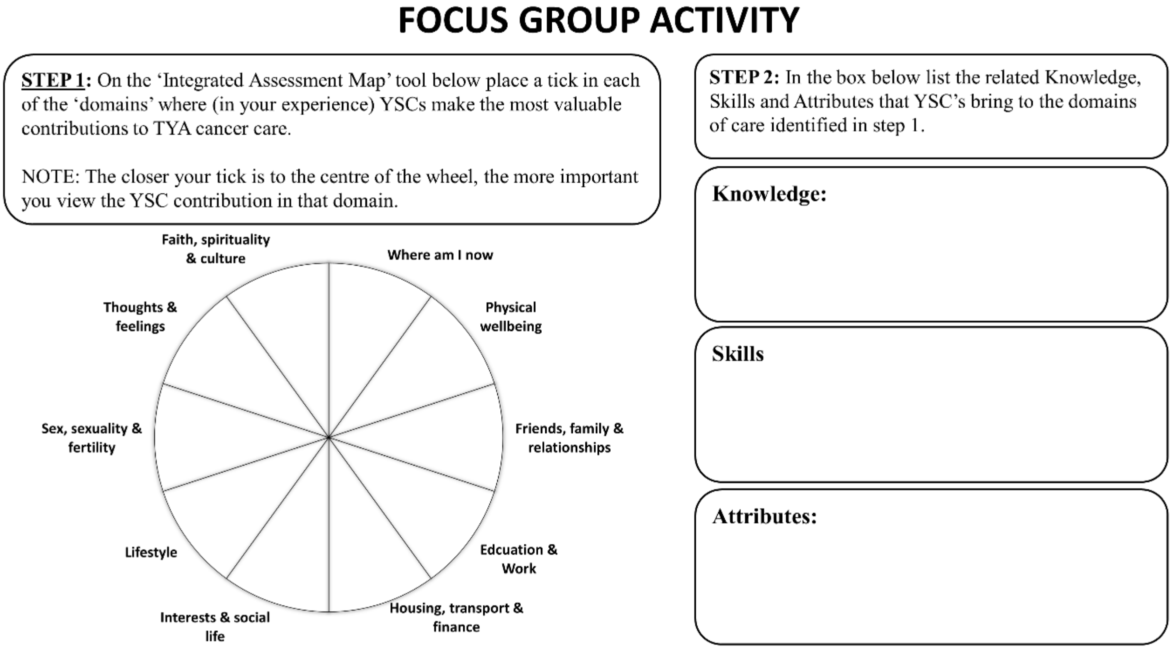
Phase 1 of data collection involved undertaking a documentary analysis of relevant literature. The analysis spanned two main areas: internal TCT documentation relating to the role of the YSCs, and external literature relating more broadly to age specific cancer care for TYA. Insights from the analysis were presented at the first steering group meeting to assist in refining the direction for the overall research, and to assist in narrowing the focus for enquiries within the first FG.

Phase 2 of data collection was an online FG with a mix of nurses (n=7) working with YSCs, in a range of settings. The FG was conducted using web conferencing and was facilitated by the researchers. The purpose was to explore their perspectives on what constituted important aspects of the knowledge and skills required of the YSCs they work with.

Phase 3 of data collection was an in-person FG held with TYA (n=7) who were receiving, or who had recently received, support from YSCs. A range of discussion-based activities were used to prompt reflection on participant experiences of support received from YSCs. The aim of these activities was to encourage TYA to articulate the knowledge and skills considered important for YSCs. A semi-structured schedule was followed, derived from the documentary analysis and early findings from FG 1.

Lastly, phase 4 of data collection involved an online questionnaire, circulated to all YSCs. The purpose was to assess the extent to which the key features of the YSC role set out within the emerging draft framework had broad consensus across the YSCs nationally.

An important resource used across the two focus groups and the questionnaire was the Integrated Assessment Mapping tool (IAM)[17]. Participants were asked to consider which areas of the IAM wheel they considered YSCs made the most significant contribution to TYA care. Figure 2 illustrates how the IAM wheel was used as the basis for a FG activity. Subsequent questions explored why particular areas were considered more important than others, and the knowledge and skills that were considered important for these given areas of care. This resource was very productive in stimulating thought and discussion around a range of aspects of the YSC role.



FOCUS GROUP ACTIVITY

STEP 1: On the 'Integrated Assessment Map' tool below place a tick in each of the 'domains' where (in your experience) YSCs make the most valuable contributions to TYA cancer care.

NOTE: The closer your tick is to the centre of the wheel, the more important you view the YSC contribution in that domain.

STEP 2: In the box below list the related Knowledge, Skills and Attributes that YSC's bring to the domains of care identified in step 1.

Knowledge:

Skills

Attributes:

Figure 2: Focus group activity

Data Analysis

Data were analysed using thematic analysis, combined with a process of triangulation[18] to add robustness. Data triangulation was undertaken by reviewing and consolidating themes identified across researchers and across data sets[19]. The transcripts from the FG were read initially for overall understanding of content and context. Initial categories and codes were identified, validated and mapped by the two researchers (MC, MW). The resulting categories were added to a thematic table, which provided the basis for an evolving knowledge and skills framework. Where additional categories or subcategories emerged, these were added to the table iteratively. The themes identified through this process were further explored with the SG and used to develop a conceptual knowledge and skills model.

Findings

7 TYA, 7 Nurses and 23 YSC participated in the study (Table 1).

Table 1: Participant Demographics

Characteristic	*N=*
Focus Group 1: HCP	
Gender	
Female/Male	7/0
Role Type	
Clinical Nurse Specialist	4
Lead Nurse	2
Staff Nurse	1
Focus Group 2: TYA	
Gender	
Female/Male	6/1
Age	
16yrs	2
20yrs	1
21yrs	1
22yrs	2
26yrs	1

Cancer Type	
Lymphoma	4
Brain cancer	2
Sarcoma	1
Not known	1
Status at participation	
Off treatment	5
Unsure of status	2
Questionnaire: Youth Support Coordinators	
Gender	
Female/Male	3/20

The complex nature of YSC work within multiple interconnected systems was evident in the findings, as illustrated in the conceptual framework in Figure 3. Findings highlighted the perceived value of the role, whilst also suggesting specific aspects of YSC practice requiring greater clarity, along with the structures and processes needed to ensure consistent and safe practices. The key outputs from this research- the identification of the YSC domains of practice and a YSC knowledge and skills framework- represent important findings in relation to the YSC role, in addition to offering the funding organisation a number of practical enhancements to the role and, by implication, the consistency of the support YSCs offer to TYA with cancer.

The Domains of Practice and Knowledge and Skills Framework

Four key domains of practice were identified for the YSC work, which provided an overall structure for key areas of YSC contribution to the support of TYA with cancer. Within each of these domains of practice key knowledge and skills, considered essential to be achieved within a timescale of one year of commencing the role, were also identified. In the absence of any professional regulation of this role, a proposed code of ethical practice was identified to strengthen the ethical underpinnings of the role. Personal Development Planning (PDP) and Continuing Professional Development (CPD) requirements were also identified to offer clearer practice development expectations and pathways, both for individual YSC practitioners and for those with responsibility for supporting and resourcing their practice development. Lastly, the framework set out guidance in relation to reflective practice requirements and supervisory support within YSC day to day practice. The following section offers some more focused insights on the core building blocks of the framework- the YSC domains of practice.

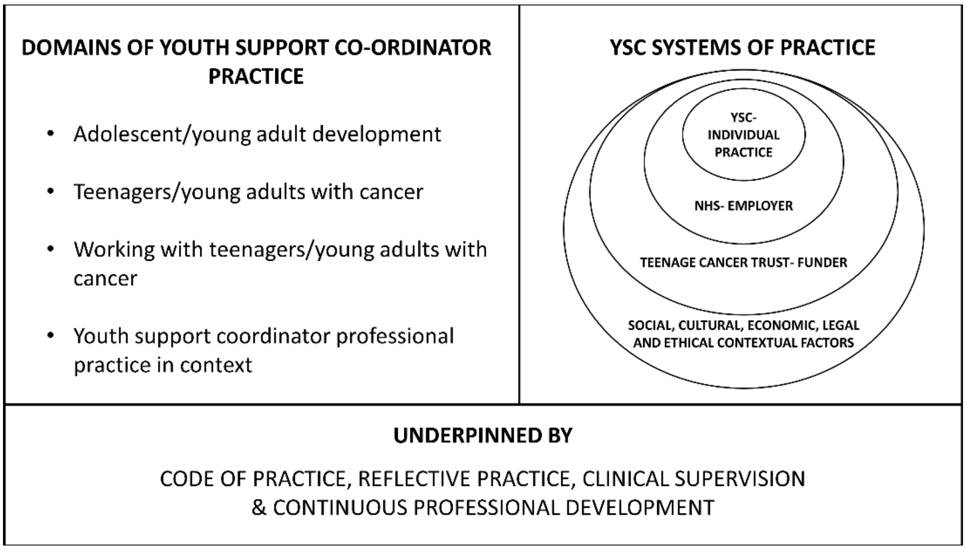


Figure 3: Conceptual Framework of Youth Support Co-ordinator Professional Practice

Domain 1: Adolescent/Young Adult Development

This domain focuses on knowledge and skills related to adolescent development, from biological and psychosocial perspectives, as these areas are considered essential within healthcare and health promotion work with TYA. Within the FG TYA emphasised the importance of YSCs being able to understand, and respond to, their experience of cancer treatment within the context of the wider social and cultural youth transition they were experiencing.

'*Everyone knows about paediatrics, and everyone knows about adult treatment…people don't realise that experiencing treatment at our age is completely different because it interrupts your life at a really formative stage'* (FG2P1)

This domain emphasised the need for YSC to have knowledge of adolescent developmental theories, approaches to promoting resilience, and the importance of changing relationships with families, peers and partners.

Domain 2: The TYA with Cancer

Research findings highlighted the need for YSCs working with this patient group to have an understanding of cancer, its treatments and how it impacts on the lives of TYA, their significant others and social networks. However, some of the significant discussion around this topic centred on acceptable limitations of knowledge in this area. That is, while TYA emphasised a base level knowledge as important, they also acknowledge the value of YSC as non-clinical roles and were open to them learning with TYA through the treatment process. While HCPs acknowledged these acceptable boundaries of YSC knowledge in this area, they also emphasised the significance of certain base level understandings in order to ensure safe working practices.

'*…medication times for example, there was a time when a patient was taken to have pizza in another unit…I think they should have more understanding on the disease and even the possible side effects…and how to help patients on those effects…definitely end of life is a challenge.*' (FG1P3)

This domain had a strong knowledge orientation and emphasised the expectation for YSCs to have knowledge around areas such as common cancers, diagnostic procedures, various cancer treatments and their side effects, and the purpose and function of the MDT. Having this knowledge at the point of starting the role or as a priority within induction was considered important.

Domain 3: Working with TYA with Cancer

As a non-clinical core MDT team member, the knowledge and skills of the YSC should enable them to actively focus on the distinct age-specific psychosocial needs of TYA with cancer within NHS settings. Day to day working with TYA with cancer in the context of NHS settings was seen as requiring a particular knowledge and skills set, likely to be distinctive from the knowledge and skill set required for working with TYA in other contexts.

'*It has a really nice balance between a professional relationship and also feeling like you can confide in them…being able to talk to them but also like they remind you that you're not just this emotional like thing, because you're also like probably gonna want to relax a bit and chill and not talk about cancer all day long when you're sat on a drip'* (FG2P1)

The knowledge and skills areas emphasised within this domain include an ability to: assimilate basic cancer/treatment related knowledge about a newly diagnosed patient in preparation for a first meeting; engage with and form a professional relationship with the TYA, their family, significant others and wider social networks; respond appropriately and empathetically to the emotional needs of the TYA with cancer; plan and prioritise workload in consultation with the clinical team; and knowledge of the purpose of different forms of activities work, and related outcomes, when working with TYA with cancer.

Domain 4: YSC Professional Practice in Context

YSC work across organisational boundaries and in a variety of settings that have different expectations in relation to professional practice. YSC are accountable for their actions and are required to understand, manage and justify their decisions regarding competing demands in their day-to-day practice. As a non-clinical role operating within a heavily clinically informed environment, the YSC's perspective was seen as adding a valued dimension to the overall care offered to TYA, but this was also seen as presenting particular challenges in relation to aligning this role with the professional practice requirements and practices of the NHS.

'*All members of the MDT have their skill sets and attributes to bring to the table in supporting TYA's, and often the relationship built between YSC and an individual can offer insight into many areas of their life. Advocating for Young People through the MDT.*' (QNRP32)

This domain emphasised the knowledge and skills required for YSCs to work across organisational boundaries and in a variety of settings that have different expectations in relation to professional practice. Examples of knowledge and skills required in this domain include having an ability to manage oneself physically and emotionally to maintain health and wellbeing; to maintain accurate records in line with local policy and procedures; knowledge of organisational policy and procedures in relation to lone working and an ability to implement risk and governance processes relating to the YSC role.

Discussion

YSCs stem from a multiplicity of professional backgrounds, which can be viewed as both a value in terms of richness of professional perspectives and a limitation, as there are no single points of reference on how to approach their work. By dividing the work of the YSCs into four key domains, the YSC framework provides a more refined and focused resource for reviewing YSC job descriptions, person specifications and recruitment processes, which also offers the capacity to enhance outcomes for patients[20]. Furthermore, the framework provides guidance in identifying the types of qualifications and previous experience that may be most suited for new appointees.

Our findings suggest that YSCs make a valuable contribution to a range of areas of support provided to TYA with cancer, requiring of them to draw on a broad range of knowledge and skills. Even with the most thorough recruitment practices in place it is expected that, over the first year in post, CPD opportunities will be important to learn and develop essential knowledge and skills. Beyond that, it is expected that YSC will continue to access CPD opportunities to either refresh or further enhance key knowledge and skills areas. The draft YSC framework highlights some important areas for consideration in relation to a CPD programme for YSC, but equally importantly it places YSC CPD priorities in context, allowing for consideration at individual, team, organizational and service levels[21].

The perceived informality of the YSC role is considered to be both a strength and a challenge, offering YSCs the opportunity to occupy a dual position of 'insider/outsider' within the clinical environment. Research findings suggests a clear purpose to the 'informality' of the role, and along with this comes a distinct need for the YSC and MDT to fully understand and manage this and any potential risk. TYA told us that YSC really helped with their feelings and this was in part due to the fact that they were not in uniform, were not performing a specific clinical role and (from TYA's perspective) appeared to be able to spend a lot of time with them, either 'hanging out' or undertaking activities. The nature of the relationship seems to be productive in opening up 'therapeutic conversations'[22,23] that are important to TYA, which otherwise might not happen. However, this sense of informality also raised important considerations around boundaries of the role and the emerging conversations, which have been actively addressed within the Framework. This challenge of balancing the valued contributions of unlicenced roles alongside the need for clear professional boundaries is echoed in the wider literature[24,25].

This study is limited by its scale and scope. Further representation, for example, from the wider range of HCPs within the MDT in FG1 would have added to the depth of insight gained on the YSC role from a range of professional perspectives. Future research, with YSCs and other HCPs, extending the scale and scope of this study would enable further exploration and refinement of the practice domains, and the related knowledge and skills, particularly in relation to their application to similar healthcare roles.

In conclusion, the insights gained through this research offer structure and guidance for the YSC role, allowing for the uniqueness and flexibility of the role to be retained, at the same time as ensuring a baseline of knowledge and skills to map against in order for YSCs to carry out their work with consistency and to an agreed minimum standard. These insights may offer valuable transferable learning for other areas of healthcare where youth workers are increasingly employed as part of multidisciplinary teams such as adolescent health care in general and youth violence management in emergency departments[26,27].

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Authorship

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Declaration of Conflicting Interests

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