

**The experiences of Early Career Nurses Working in
Specialist Adolescent/Young Adult Cancer Units: A
Narrative Inquiry**

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Summary

This thesis applied a narrative inquiry methodology to explore the experiences of the early career nurse (ECN) working in adolescent/young adult cancer (AYAC) specialist settings in the United Kingdom. Nine nurses came forward and their stories were elicited over Zoom technology during the COVID-19 pandemic. Individual and whole cohort data were analysed using Clandinin and Connelly's three-dimensional framework of temporality, sociality and space. Meanings were developed and synthesised that drew on wider theoretical perspectives such as emotional labour, intergenerationality and competence development theory.

The findings revealed the work of these nurses as multi-faceted, involving a complex range of effort and labour. Significantly, this study highlighted the emotional labour enacted by the ECNs as a consequence of working with AYAC (aged 15-25yrs) and their parents, whose cancer treatment extends over prolonged periods of time. The ECNs, some of whom are of similar age to patients, contend with managing physical, organisational and cognitive demands in the highly pressurised NHS where nursing shortages are at an all-time high. The need to develop competence and strategies to manage the emotional burden of this work has been revealed along with tensions and risks, not only for ECNs, but also for managers and funders.

The study places emphasis on recognising and learning how to nurse AYAC and attend to their developmentally appropriate healthcare needs.

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Go raibh míle maith agat and may you all live happily ever after.

The End.



Seals in the bay at the foot of Muckish Mountain, Co. Donegal Ireland

Abbreviations

AA	Age Appropriate
AYA	Adolescent/Young Adult
AYAC	Adolescent/Young Adults with Cancer (used interchangeably with TYAC)
AYACC	Adolescent/Young Adults with Cancer Care
CF	Compassion Fatigue
CNS	Clinical Nurse Specialist
CYP	Children and Young people
DAH	Developmentally Appropriate Healthcare
DOH	Department of Health
ECN	Early Career Nurse
EOL	End of Life
FP	Fertility Preservation
HCP	Healthcare Professional/Provider
HSCC	Health and Social Care Committee
MDT	Multi-Disciplinary Team
NHS	National Health Service
NI	Narrative Inquiry
NMC	Nursing and Midwifery Council
NQN	Newly Qualified Nurse
RN	Registered Nurse
ScR	Scoping Review
SLE	Shared Learning Experience
TCT	Teenage Cancer Trust
TYA	Teenage/Young Adult
TYAC	Teenager/Young Adult with Cancer
UK	United Kingdom
USA	United States of America
WBN	Ward Based Nurse
YSC	Youth Support Co-ordinator

Chapter 1 Introduction

1.1 Introduction

This chapter sets out the rationale for the study. Background information is provided to orientate the reader to the context of the phenomenon being examined. The rationale, methodological approach and scope of this study will be introduced. This study seeks to generate meaning from the narratives of early career nurses (ECNs) who care for adolescents/young adults (AYA) with cancer in specialist age-appropriate settings/units. This study is based in the United Kingdom (UK) where 28 of these cancer units have existed within National Health Service (NHS) oncology settings with financial and political support from the charity Teenage Cancer Trust (TCT) since the early 1990s. I am a cancer nurse academic in a UK university who has worked alongside this charity since 2005 developing and delivering accredited and non-accredited interprofessional education programmes; thus, I have watched this specialism emerge and develop over this time. Nurses who work in these units can be a registered nurse (RN) (Adult) or RN (Child), unlike most other clinical areas where sick adults can only be cared for by a RN (Adult) or in paediatrics where only a RN (Child) can work. These units usually care for adolescents/young adults with cancer (AYAC) between the ages of 15 and 24 years old. Given the variation in terms that can be used and seen in the literature, adolescent and teenager are taken to mean the same and are used interchangeably, thus AYA/AYAC are same as TYA/TYAC.

1.2 Current issues in nursing and healthcare

The timing of this doctoral study, which took place over the COVID-19 pandemic of 2020-21 cannot be ignored. Healthcare across the world has been severely affected by the pandemic, making it even more challenging for healthcare professionals (HCPs) and services to meet the health needs of all communities. Regulators and healthcare service providers have experienced a serious shortfall of healthcare professionals which was evident before the pandemic, but the pandemic has added further strain on staff and services. A recent report said the government needs to exceed its target of 50,000 new nurses in England by 2024/25 if it wants the NHS to fully recover from the coronavirus pandemic

(Buchan et al., 2020). According to recent analysis of current trends, in 10 years' time there will be a shortfall of around 108,000 full-time equivalent nurses in the NHS (Beech et al., 2019).

These nursing shortages are across the board in nursing and no specialism appears to have escaped their impact. Some clinical and geographical areas appear worse hit and some cancer services in London were stopped because of these shortages, even before the pandemic (Wise, 2018). Reasons for this situation include poor workforce planning; insufficient funding for training places; challenging immigration policies that have been exacerbated by Brexit; capped pay increases; and very high numbers of nurses exiting the profession well before retirement age (The Kings Fund et al., 2018). The personal cost to those nurses who remain in practice against the backdrop of this extreme shortage is that they experience higher workplace stress caused by excessive workload demands and highly emotive and stressful work conditions (Challinor et al., 2020; Currie and Hill, 2012).

Stress and coping in caring work are not new phenomena and, over time, theoretical perspectives have been applied to many specialisms of healthcare, professions as well as life in general. In the book *The Primacy of Caring in Nursing* (Benner and Wrubel, 1989), the transactional model of stress and coping (Lazarus and Folkman, 1984) is used, and they argue that stress occurs when things that matter to the individual are under strain. In essence, when things that matter to the individual are threatened or challenged, stress is the result.

These negative personal positions impact on the HCP's own well-being (Health and Safety Executive, 2020; Health and Social Care Committee, 2021) as well as their ability to cope with or manage work-related stress which have been linked with poorer patient outcomes (Francis, 2013; Maben et al., 2012). Additionally, there are negative workload and well-being consequences for other team members (Westman and Bakker, 2008). Stress and burnout also result in an economic cost to organisations in terms of absenteeism and in poor retention (Dyrbye et al., 2017; Knapp and Lemmi, 2014). Growing evidence of the association between health professionals' well-being and patient and organisational outcomes draws attention to the need for effective staff support.

1.3 Cancer nursing workforce

Cancer nursing as a specialism that is evolving to meet the global cancer burden (Bray et al., 2018) with its growing incidence and prevalence, and complex treatment options. Cancer nursing is a term recognised in high-income countries, and the principles of care along the cancer continuum worldwide strive to provide optimal care within the context of healthcare settings (Young et al., 2020). The need for generalist, specialist and advanced roles in cancer nursing is also increasing (Charalambous et al., 2013). Challinor et al. (2020) advise that in addition to the implications from the COVID-19 pandemic, challenges to a robust oncology nursing workforce still exist. These include nursing shortages, recruitment barriers (e.g., perceptions of a demanding specialty with complex care and hazardous work environments) and burnout. Arguably, the strength of the cancer nursing workforce determines the quality of cancer care and patient outcomes in all settings, so these risks are ever more present. Srivastava et al. (2021) recognised the substantial shortages in oncology nursing and the wider multi-disciplinary team (MDT), all of whom are key to successful patient outcomes, and identified that cancer nursing recruitment is difficult because the profession is emotionally, physically and cognitively demanding.

Research shows that working in professional caring roles can be gratifying but also emotionally challenging (Bowden et al., 2015; Kinman and Leggetter, 2016) and caring for patients (adults or children) with cancer is viewed to be innately stressful for healthcare professionals. This leads to a negative personal impact which can be labelled using any number of terms such as stress, burnout, compassion fatigue and emotional suffering (Boyle and Bush, 2018; Cañadas-De la Fuente et al., 2018; Pfaff et al., 2017).

Causes of stress and burnout in cancer nursing are multifactorial. They can include the nature of the disease; complexity of cancer treatments; high-acuity patients; dealing with death; communication issues; intense patients and family involvement; interdisciplinary conflicts; ethical challenges/decision-making; end of life (EOL)/palliative care issues; workload and workplace; role strain; and work environment issues (Barnard et al., 2006; Duarte and Pinto-Gouveia, 2017; Isikhan et al., 2004; Mazzella Ebstein et al., 2019). These do not include any additional personal or intrinsic factors that nurses may also face.

Early work by Hinds et al. (Hinds et al., 1994; Hinds et al., 1998; Hinds et al., 2003) and others asserts that nursing children and young people (CYP) with cancer has the potential to cause significant emotional distress to professional caregivers (Bowden et al., 2015; Mukherjee et al., 2009). Despite this evidence, a survey of children's oncology Principal Treatment Centers in the UK revealed there is wide variation across these centres and amongst staff groups in the number and types of staff support interventions that exist (Beresford et al., 2018). This also shows the lack of understanding given to the need for staff support and subsequent interventions in paediatric oncology, which would merit further robust evaluation. The picture is similar in adult oncology and haematology where recent literature revealed that RNs who worked in substandard staffing units often express job dissatisfaction, stress and burnout, which prompt them to seek new employment out of the oncology specialty (Cañadas-De la Fuente et al., 2018; Ortega-Campos et al., 2020; Toh et al., 2012). Clearly, this is a problem for health services, the nursing profession, as well as nurses themselves.

Nurses are not the only professional group who are personally impacted by caring for patients with cancer. Banerjee et al. (2017) surveyed 737 young oncologists (up to age 40 years) in Europe to investigate prevalence of stress, work and lifestyle factors that potentially affect burnout they experienced. They arrived at the conclusion that burnout is a significant problem among young oncologists. Despite there being some geographical variations, they also revealed that work/life balance, access to support services, living alone and vacation time were identified as being key factors that contribute to burnout. Banerjee et al.'s (2017) findings echoed those reported from earlier studies undertaken in the USA and France (Blanchard et al., 2010; Shanafelt and Dyrbye, 2012; Shanafelt et al., 2014). Without doubt caring for patients with cancer is emotionally demanding work for different reasons, and for many disciplines.

Compassion fatigue (CF) is a form of secondary traumatic stress and burnout (Figley, 1995). CF is thought to be experienced mostly during and/or following prolonged interactions with distressed individuals and to be the result of stress when combined with ongoing self-sacrifice (Potter et al., 2013; Potter et al., 2010). There seems to be high prevalence of CF in cancer settings (Arimon-Pagès

et al., 2019; Potter et al., 2013; Yu et al., 2016) where MDT members have regular interactions with patients and families who are suffering the physical, emotional and spiritual traumas caused by cancer and its treatments. As with stress and burnout, the phenomenon of CF exists in both adult and paediatric oncology settings across the world (Hesselgrave, 2014; Sullivan et al., 2019). However, little is known about any of these challenges for nurses in an AYAC setting thus far.

1.4 Adolescent and young adult cancer care

The specialism of adolescent or teenage/young adult cancer care (AYACC or TYACC) has developed over the past 20 -30 years in the UK and has gathered pace internationally (Cable and Kelly, 2019). Some might say it's currently in its own adolescence. The age of the AYA population has been defined in various ways: in the USA, the National Cancer Institute's AYA Oncology Program proposed an age range from 15 to 39 years, but there are still inconsistencies, particularly as regards the upper age limit (Close et al., 2019; Geiger and Castellino, 2011). However, for the UK, most of Europe and Australia the age ranges that are referred to are 13-24 yrs. and services have developed to cater for these requirements (McCabe, 2018). The inconsistencies in defining an age range for AYA exist primarily because of the realities of the complex biologic and psychosocial developmental processes experienced in the lengthy transition from childhood to adulthood in Western cultures. The implications of this can create a broad set of challenges, particularly in terms of service provision and cancer outcomes in this group. Included in these challenges are biologic variations in tumours, treatment effectiveness and tolerance, adherence, fertility preservation, and early death (Geiger and Castellino, 2011).

In the UK, where this study is based, the clinical service provision for AYA cancer is based on a patient range of 15-24 years (National Institute for Health and Clinical Excellence, 2005). In 2005, the Improving Outcomes Guidance document (National Institute for Health and Clinical Excellence, 2005) first set out recommendations for the care of CYP with cancer based on the best available evidence. This guidance suggested that TYAC/AYAC should receive tailored treatment and support specific to their needs, but subsequent data show that

this has not been the case for all those affected (O'Hara et al., 2015). Updated UK government guidance is awaited at the time of writing.

Cancer in AYAs aged 15-24 years is uncommon, with 2,490 new cases of cancer diagnosed and 270 deaths each year (2015-2017) in the UK. This accounts for 1% of the total cancer population (Cancer Research UK, 2021). Despite the relatively small numbers of AYAs affected by cancer, the specialism would not have developed without a combined contribution from nursing and other HCPs, researchers, policymakers and philanthropists. The UK charity TCT started in 1990 by building a specialist ward within a London Hospital (Whiteson, 2003) and since then, a further 27 specialist wards/units have been opened. Whilst the momentum may have started because of a building programme, further service developments have occurred that acknowledge that the unique needs of AYAC cannot be met by buildings alone. Hence the emphasis on specialist multi-professional AYAC teams who acknowledge the transitional life stage issues for AYAs that are fundamental to meeting their specific clinical and care needs. Integral to this has been the contribution of nurses and their leadership (Cable and Kelly, 2019; Morgan and Soanes, 2016; Olsen and Smith, 2018; Smith et al., 2016; Taylor et al., 2016). The emergence of the specialism was viewed through the perspective of Michel Foucault by Cable and Kelly (2019) at the start of this doctoral journey (Appendix 1), arriving at the conclusion that because of an initial process of problematisation, the subsequent generation of an evidence base has helped shape health policy to develop a new cancer specialism that is distinct from paediatric or adult oncology care. The multiple perspectives of different disciplines and stakeholders has resulted in the creation of new discourses and practices which have led to the acceptance of AYA cancer services in the UK, with the distinct difference being an emphasis on the youth element of the lives of AYAC. This transitional life stage, whether from biological or psychosocial perspectives, will continue irrespective of a cancer diagnosis and is seen to shape the distinct needs of this patient group (Chisholm et al., 2018).

What is globally acknowledged, however, is that what makes AYA care unique is the chronological transitional life-stage involved, during which individuals are undergoing remarkable bio-psychosocial changes. Not only are AYAs (with or

without cancer) trying to make sense of these bio-psychosocial changes, but they are also living through an ever-changing global landscape that is undergoing significant economic, demographic, societal and technological change. These challenges are of particular importance for those at the lower end of the broad age range that is noted in the literature. The needs for those who are in the higher age bracket, 25-39 are very different to those aged 13-24, with those in the upper age limit capable of being the parents of those in the younger age bracket; another reason for challenging the age bracket of the AYA population. Biologically, financially and socially those in the upper age bracket are also remarkably different and they have reached adulthood and independence (Sawyer et al., 2018). For those nursing AYAC, particularly in the 15-25 age range, they must remember that these insecurities and realities of life remain constant as AYAs progress through bio-psychosocial development which is shaped further by cancer and its treatment. Thus, it is important that approaches to service delivery and care provided for this age group, are set against an age-appropriate and evidence-informed model (D'Agostino et al., 2011; Morgan and Soanes, 2016; Smith et al., 2016). Nurses who care for AYAC are urged to have insight into these foundational issues when approaching their care (Smith et al., 2016).

1.5 Rationale for the study

Whilst research has explored the emotional impact on nurses caring for adult and paediatric patients, little is yet known about the experience of all types of nurses caring for adolescents with cancer and the emotional challenges that it may bring. This study hopes to illuminate this area to provide better understanding of the needs of nurses caring for AYAC. In particular, the focus will be on frontline, early career (ECN) caring for patients in the 15-24 age category. In turn, this could inform potential support strategies to minimise the impacts. Additionally, it may contribute to understanding factors that affect the retention of nurses caring for AYAC. It may be helpful to enquire what makes those nurses who continue to care for AYAC stay in their roles, and what is it about caring for these young people that interests them. As so little research on nursing AYAC has been done to date and given this is a distinct specialism within

oncology care with nurses at the helm of much of the care that is provided, it is fitting that nursing continues to develop its own body of research. This research will contribute to AYAC literature and to the wider general cancer nursing care evidence base.

If these issues are considered in relation to AYAC nursing, we begin to see some of the daily stresses facing nurses in this field. Whilst this may appear obvious, it is an under researched area from which we can learn and offer an original contribution to knowledge.

1.6 Why early career nurses?

My interest is in the experiences of junior nurses in frontline clinically oriented roles rather than those in specialist or formal management posts. In the UK, Band 5 is the entry band for a person who has studied to become a registered nurse. Thereafter, levels of pay are calculated according to experience and qualifications within pay bands that are determined by the structured pay system of Agenda for Change (NHS Employers, 2021). Nurses can choose to stay at this pay band or progress to higher banded jobs where they are expected to take on more specialised roles such as clinical nurse specialist (CNS) or more line-management responsibility in clinical settings. I wanted to focus on nurses who remained at this pay grade/band and had at least six months of experience where they were more established in their preceptorship period of being newly qualified. I did not wish to assume that all Band 5 nurses would be newly qualified as some may choose to stay at that pay band indefinitely. I wanted to focus on nurses whose primary function was to give direct clinical care to AYAC and I felt that higher bands of nurses would have had other responsibilities that would take them away from this; therefore, their time with these patients may be less. I did not want to make any assumptions about these nurses' gender, age or length of experience as a RN. For the purpose of this thesis, I refer to these nurses as ECNs as I felt it reflected where they were on their career trajectory. I could have chosen several potential labels to categorise them and I outline reasons why I discounted them in Table 1.1.

Table 1.1 Discounted potential labels of ECN

Potential label	Reason for discounting
Band 5 staff nurse	Not recognisable beyond the UK
Ward based nurse	This could have included senior staff nurses with management responsibilities who I did not want to include.
New graduate/newly qualified	Some of the nurses I could have interviewed may have chosen to remain at this band for many years and would therefore no longer be considered 'new'.
Junior staff nurse	I felt that this was slightly derogatory, especially to those who may have chosen to work at this band for several years and may be at the top of their pay scale within Band 5.

As I was recruiting in the UK, the language I used during recruitment was Band 5 so that nurses would know exactly the type of nurses I wished to engage. However, for the most part in the thesis I used the term ECN as it may be better understood beyond the UK.

1.7 Research question and aims

The research question that evolved was, *What are the experiences of early career nurses (ECNs) who care for adolescents/young adults (AYAs) with cancer in specialist age-appropriate settings?*

The aims were:

- a) To generate meaning of the experiences of ECN who care for AYA with cancer in specialist settings by exploring their narrative accounts.
- b) To identify aspects of uniqueness attributed to the nursing care of AYAC.

c) To examine the personal and professional impact on ECNs associated with caring for AYAC.

d) To identify training/education and support needs for ECNs to support them in their care of AYAC.

The research question is generic and open, thus I purposefully steered away from directional, leading questions such as, 'To what extent does caring for AYAC cause you emotional distress or burnout?', which could have been considered given what has been outlined in the earlier background literature. What was key for me was that participants had an opportunity to tell me about their experiences of this type of work. Arguably, the question itself held some of my assumptions - that the experiences of these nurses would have meaning for them. This assumption was based on my past experience of being an ECN who cared for AYAC as well as more recently, when I educated and supported ECNs, that this type of work would be emotive because of the patients' ages. In this study I believed that the nurses would consider the meaning of their work before telling me their story, which I would then reflect upon and interpret. This is termed as 'double hermeneutic' (Brogden, 2010) and the meaning of nurses' experiences posed in this thesis are co-constructions of nurses' stories and my interpretations.

My axiological stance in this research was that I hoped to make a positive contribution to my profession and that knowledge identified would be of value to nurses, managers, healthcare professionals, researchers, educator and ultimately for the benefit of AYAC.

1.8 Methodological approach

This study lends itself to taking an interpretivist or constructivist approach, thus adopted a qualitative research design. The methodological choice is based upon my ontological belief about what is real and what is valuable. I believe that reality is subjective and that the meaning of an experience can only be told by one who has had an experience, that everyone has a past which shapes their present experience, thus has the likelihood of influencing any future experience. I felt that the most appropriate methodology to address the research question was to take a qualitative approach and selected narrative inquiry (NI), as

proposed by Clandinin and Connelly (2000) and Kim (2015). This approach values the stories of individuals and is based on the work of John Dewey (1938) who notes that experience is understood to be relational, interactional, continuous and social . This will be further described in Chapter 3.

The research design could have taken several qualitative research approaches, such as grounded theory, discourse analysis, phenomenology or action research to name but a few. However, this qualitative study used a narrative research approach to describe the personal stories of 8-16 AYA ECNs, which was explored in-depth to derive meaning from those experiences. I believe that every individual has a past which shapes current experience and has the potential to influence future experience.

1.9 Thesis overview

Chapter 2 outlines the literature review process and findings that justify the rationale for undertaking this study.

Chapter 3 sets out the methodology and methods from theoretical and practice perspectives, clarifying the processes undertaken and highlights the ethical considerations.

Chapter 5 discusses inquiry findings in the context of theoretical perspectives and previous nursing and AYAC care research, as a means to bringing new understanding to the experiences of ECNs who care for AYAC. Recommendations for research, practice, education and policy are presented.

Chapter 6 concludes the study.

Chapter 2 Literature Review

This chapter aims to contextualise the study within the existing knowledge base by describing and reporting on a systematic scoping review (ScR). Debate exists on the inclusion of literature reviews within NI methodology theory. Holloway and Freshwater (2007) warn of the influence of pre-existing literature, whilst others prefer to locate the review after the narratives (Clough, 2002). Kim (2016) advises the review should include theoretical and methodological literature and as such, I elected to review literature before collecting data. This pragmatic decision was in part due to time constraints of the doctoral course and the fact that I was a part-time student.

ScR, an increasingly prevalent method for synthesising research evidence, can be particularly valuable when a topic has not yet been extensively explored or is of a complex or heterogeneous nature (Daudt et al., 2013; Peters et al., 2015). ScRs are particularly relevant to disciplines with emerging fields of evidence where the paucity of randomised controlled trials makes it difficult for researchers to undertake systematic reviews (Levac et al., 2010).

Often criticised as having little systematic critical appraisal because of resource constraints and lack of time (Aveyard et al., 2016; Gough et al., 2017), ScRs are frequently used to describe the nature of a research field rather than present an exhaustive synthesis of findings (Arksey and O'Malley, 2005). As is customary with ScRs, in this review an assessment of methodological quality was not conducted (Armstrong et al., 2011; Levac et al., 2010) and this is considered a limitation of the review. However, a critical lens approach was applied throughout and used to draw conclusions.

The structure of this review followed the six-step methodological framework set out by Arksey and O Malley (2005), further developed by Levac et al. (2010) (see Table 2.1). This review stopped at stage 5.

Table 2.1 Steps taken in the search

1. Identifying relevant studies
2. Study selection
3. Charting the data
4. Collating
5. Summarising and reporting the results
6. Knowledge translation component of scoping (optional)

The chapter begins with detailing the search strategies used and follows with a discussion of the identified themes that support the justification for this study.

2.1 Identifying the research question

Levac et al. (2010) recommend that researchers combine a broad research question of the literature with a clearly articulated scope of inquiry. Arriving at the review question was supported by using a tool/framework (Booth, 2004; Booth et al., 2016) - see Table 2.2. for the key concepts included in the search strategy. In this case I focused on setting, perspective, interest, context and evaluation (SPICE).

Table 2.2 Formulating the question using the SPICE framework

Setting	Perspective	Interest	Context	Evaluation
Hospital, community or hospice settings	early career/ward-based nurses (WBN)	Caring for	Adolescents/young adults with cancer	Age-specific care at any point in the cancer experience

The research question was, *What are the experiences of early career nurses (ECNs) who care for adolescents/young adults (AYAs) with cancer in specialist age-appropriate settings?*

The aims of this ScR were:

- a) To identify recent empirical research that investigated ECNs' experiences or perceptions of caring for AYAs with cancer (AYAC) in a variety of clinical settings.
- b) To produce a narrative account of existing evidence defining the experiences or perceptions of nurses working with AYAC in healthcare and any challenges that have been documented.
- c) To identify gaps in the current literature in terms of methodology, perspective and design that may inform future studies.

2.2 Identifying relevant studies

Methods adopted for identifying literature in a ScR ideally need to achieve in-depth but broad results (Arksey and O'Malley, 2005). This leads to the outcome stemming from an iterative, rather than a linear process with the researcher engaging with the available literature in a reflexive and comprehensive way.

In outlining the parameters of the ScR from the outset (Arksey and O'Malley, 2005; Levac et al., 2010), I took an intentionally wide approach to include nurses within HCP data sets to generate a breadth of coverage of the literature. The terms early career/ward-based nurses (WBN) and nurse are used interchangeably with ECN, as the focus of this study is on these types of junior nurses working with AYAC and as such I would only include studies where these nurses were easily identifiable.

The international age range of AYAC spans a large range in the literature, from 13-44 years. For example, in the USA, the age range for AYAC spans from 13-44 years, whereas in the United Kingdom it is 13- 24 years (National Institute for Health and Clinical Excellence, 2005). Therefore, this ScR included both adult and paediatric literature, looking for where AYAC care (AYACC) is clearly delineated, to gain a consensus of relevant issues. This follows Levac et al. (2010) who advise that researchers justify their decisions and acknowledge the potential limitations of their studies.

2.2.1 Database searches

Several health and social care, subject-specific and journal databases were explored with the advice of a librarian (Aveyard and Sharp, 2017) - see table 2.3.

Table 2.3 List of databases searched

Academic Search Complete (EBSCO)
CINAHL(EBSCO)
Cochrane Library
PubMed
Psycharticles (EBSCO) & Psychinfo (EBSCO)
SCOPUS
The Joanna Briggs Institute (COnNECT)

2.2.2 Grey literature and hand searching

Sources used for searching grey literature include direct contact with experts and organisations in the field of AYACC and nursing, to identify any ongoing studies or other unpublished data, e.g., (Kelly et al., 2004); (Olsen and Harder, 2011); and (Avery et al., 2019). Other search strategies included reviewing reference lists of retrieved papers, hand-searching of key journals, engaging existing networks and exploring relevant organisations for outputs.

2.3 Study selection

I conducted the study selection and extraction processes independently and clarification was sought on processes and outcomes with librarians and doctoral supervisors as good practice suggests (Arksey and O'Malley, 2005; Gough et al., 2017; Levac et al., 2010). Whilst books/chapters and editorials have been written about AYACC more recently, these have not been included because whilst they refer to research, they are often opinion-based publications, not peer reviewed nor identified in the electronic searches. They were held for possible inclusion in the discussion chapter. Unpublished theses and conference papers were excluded for the same reasons. The initial review was conducted June 2020 and updated March 2021.

2.3.1 Eligibility criteria

Inclusion and exclusion are presented in Table 2.4

Table 2.4 Inclusion and exclusion criteria for scoping review papers

	Inclusion Criteria	Exclusion Criteria
Types of participants	Studies where ward-based or early career nurses and HCPs were involved in the care of AYAC.	Studies where ward-based or early career nurses or AYAC were not clearly identified. Infants, young children or elderly. Student or assistant nurses, nursing associates or nursing auxiliaries/ healthcare support workers. Care of AYAs with non-cancer illnesses. Transition or survivorship of AYAC.
Types of interventions /phenomena of interest	Nurses and HCPs who care for AYAC. Experiences, motivations and perceptions of HCPs and nurses working in AYAC settings. The emotional impact, discomfort, distress or suffering of caring for AYAC. Any nuances outlined by nurses and HCPs that are specific to caring for AYAC.	
Context	Nurses and professionals who care for AYAC in a variety of clinical settings to include hospitals, hospices, home settings and community.	Student, assistant nurses, nursing associates or nursing auxiliaries, healthcare support workers. Care of AYAs with non-cancer illnesses. Studies where AYAs were not clearly identified within the papers.
Time limits	2000-2021 given the recent emergence of the specialism.	Studies older than 21 years.
Language	Only studies published in English.	Non-English publications.

2.3.2 Search terms

Table 2.5 outlines the search terms that were used whereby truncation, spelling variations and Boolean operators were considered. In Medline, MESH headings were searched and in CINAHL databases, subject headings were searched. Limiters are also described.

Table 2.5 Identification of search terms and limiters

	Perspective	Interest	Context 1	Context 2
Terms used in research question →	Registered nurses	Experience of caring	Adolescents/ young adults	Adolescents/ young adults with cancer
Alternative phrases →	nurs* or "health* professional*" or "health care professional*" or "health* provider*" or "health care provider*" or clinician	impact* OR effect* OR perspectiv* OR attitude* OR percepti* OR experienc* OR distress* OR stress* OR burnout OR impact* OR affect* OR suffer* OR retention OR recruit* OR attrition OR retain* OR motivat*	teen* or adolesc* or "young adult*" or youth or "young person" or "young people"	cancer or neoplasm* or tumor or tumour or oncol*
Limiters	2000-2021 Peer reviewed articles only English language only			

2.3.3 Search results

An initial yield of 8,235 references were retrieved. The titles and abstracts for these citations were screened and 477 (with 34 duplicates noted) were considered for further assessment of the full paper, resulting in 85 papers read in full text for eligibility, three of these were located through hand searching. Twenty-five papers were selected for review. The PRISMA extension for scoping reviews checklist (PRISMA-ScR) was used to guide reporting (Tricco et al., 2018). The search results are presented in a PRISMA diagram in Figure 2.1.

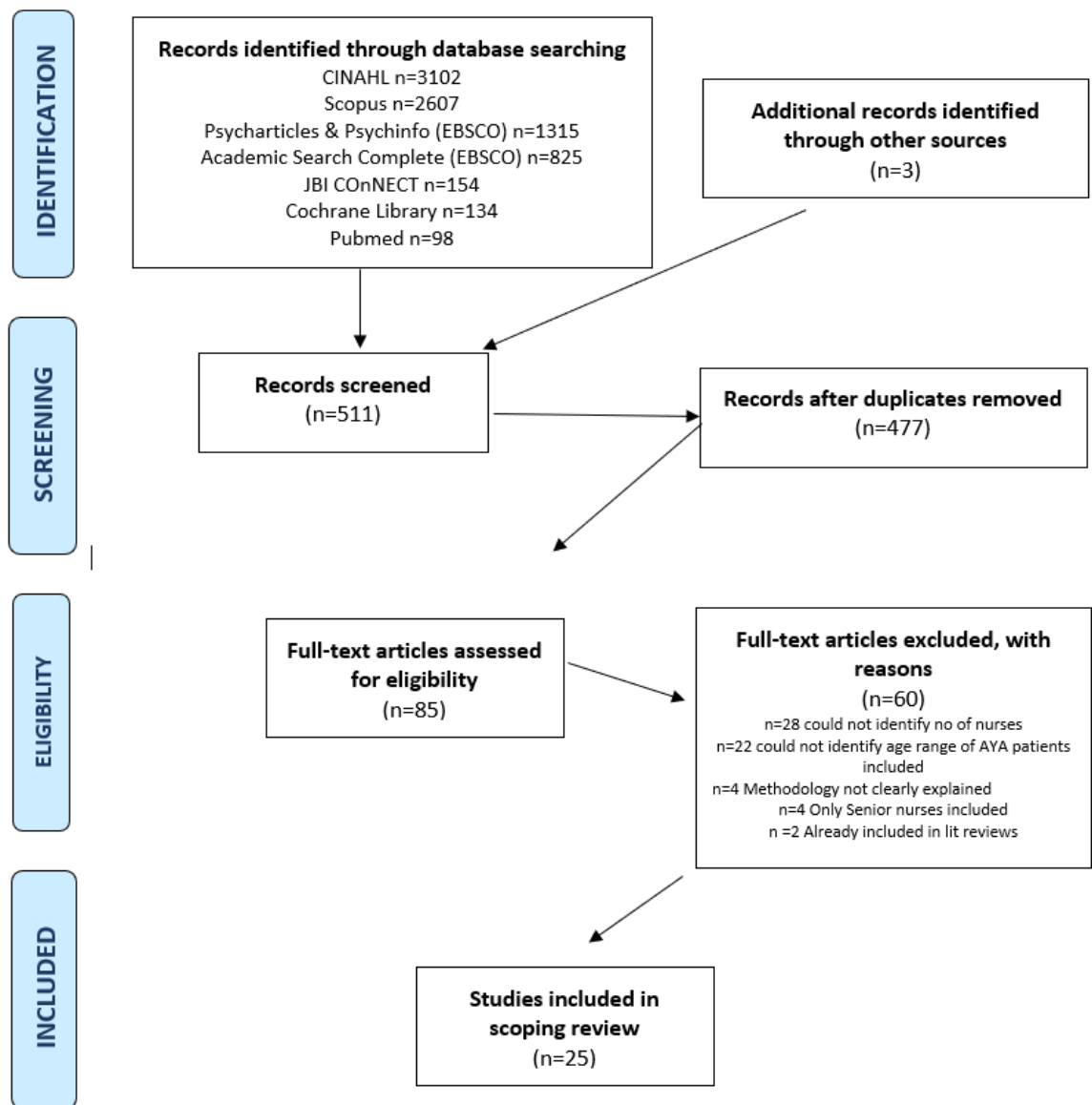


Figure 2.1 PRISMA diagram (Moher et al., 2015)

2.4 Charting the data

A data charting summary (section in Appendix 2) recorded information related to database(s) sourced from author(s), publication year, article title, journal or publication title, type of source, type of publication, target population, intervention, research design, methods, sample size, major themes/findings and recommendations. This iterative data synthesis process was led by me as there is little clarity on how best to achieve this, or what should be included (Levac et al., 2010; Peters et al., 2015). Discussion with doctoral supervisors clarified inclusion and exclusion of papers.

2.5 Collating, summarising and reporting the results

The data charting summary helped develop a narrative account of the papers (Arksey and O'Malley, 2005). In reporting this narrative account, I present a characteristic analysis of the papers illustrating the paper type, geographical location of the studies and dates of publication. Further review of the papers identified the study types, sample used, sample sizes and research approaches used. This analysis helped to identify key themes which were checked and refined at doctoral supervision meetings, thus demonstrating the importance of checking the validity and reliability of results and these are featured in the Summary of Included Papers (see Appendix 3). This iterative process led to the identification of two main themes, which are discussed further in this chapter.

2.5.1 Review characteristics

Twenty-one empirical studies and four literature reviews were included - see Table 2.6. The empirical papers were heterogeneous in methods and approach, the nature of the data presented, types of experiences and perceptions of nurses and HCPs, and issues studied.

Table 2.6 Review characteristics

Empirical Studies	Literature reviews
Albers et al., 2020a; Albers et al., 2020b; Avery et al., 2019; Bahrami et al., 2017; Berger et al., 2019a; Bradford et al., 2018; Day et al., 2018; Essig et al., 2016; Essig et al., 2019; Gibson et al., 2012; Kelly et al., 2004; Laryionava et al., 2018; Lavender et al., 2019; Norton and Wright, 2020; Olsen and Harder, 2011; Pearce et al., 2018; Smith, 2017; Taylor et al., 2016; Thompson et al., 2013; Tutelman et al., 2019; Williamson and Rumsey, 2017	Barlevy et al., 2016 ; Smith, 2004; Tennyson and Griffiths, 2019; Vindrola-Padros et al., 2017

2.5.1.1 Country of study/authorship

Table 2.7 shows countries of authorship. Several papers were written by authors from two countries highlighting the absence of literature from the East/Orient, South Americas and Africas, though one from Iran is co-authored.

Table 2.7 Country of study/Authorship

Country(ies)	Authors
Australia	Berger et al., 2019 Bradford et al., 2018 Thompson et al., 2013
Canada	Avery et al., 2019 Tutelman et al., 2019
Denmark	Olsen and Harder, 2011
Germany	Laryionava et al., 2018
Netherlands	Albers, Bergsma et al., 2020 Albers, Haj Mohammad et al., 2020
Switzerland	Essig et al., 2016 Essig et al., 2019
United Kingdom	Day et al., 2018 Gibson et al., 2012 Kelly et al., 2004 Lavender et al., 2019 Norton and Wright, 2020 Pearce et al., 2018 Smith, 2004 Taylor et al., 2016, Tennyson and Griffiths, 2019 Williamson et al., 2016
USA	Smith, 2017
Co-Authors from multiple geographic locations Iran and Australia Switzerland and Canada UK and USA	Bahrami et al., 2017 Barlevy et al., 2016 Vindrola-Padros et al., 2017

2.5.1.2 Population

Three empirical papers engaged with nurses solely, but not especially in AYA units (Norton and Wright, 2020; Olsen and Harder, 2011; Smith, 2017). The

remainder explored the views of nurses (of varying role types) within wider groups of HCPs, patients and/or caregivers. Of the four literature reviews, none focused specifically on nursing though nurses did feature within all. No study referred specifically to early career nurses although those that are included here did include ward-based nurses as a group.

Ten studies engaged HCPs who predominantly work with AYAC in age-specific specialist settings as opposed to caring for AYAC in adult or paediatric oncology settings (Berger et al., 2019b; Bradford et al., 2018; Gibson et al., 2012; Kelly et al., 2004; Lavender et al., 2019; Norton and Wright, 2020; Olsen and Harder, 2011; Pearce et al., 2018; Thompson et al., 2013). This highlights the paucity of research on nurses in AYAC settings.

2.5.1.3 Chronological order of papers

The numbers of papers and the year of publication are presented in Figure 2.2. This highlights that the contribution of specialist care for AYAC has been researched steadily and increasingly over the past 20 years, particularly between 2016 and 2020.

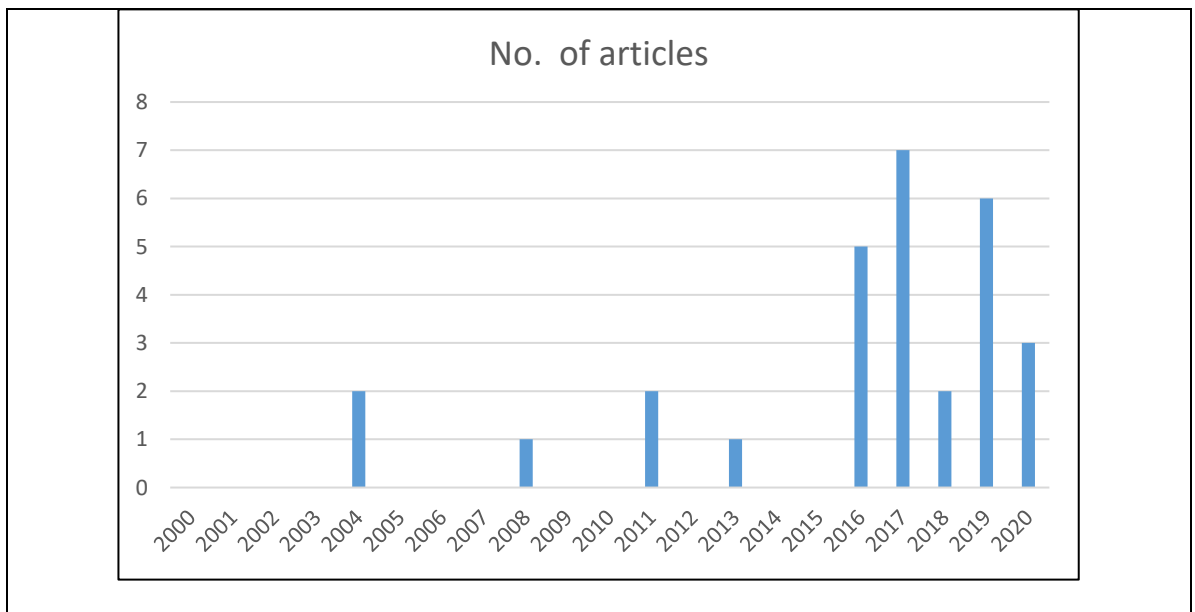


Figure 2.2 Chronological order and number of papers selected

2.5.2 Thematic analysis

From the data charting summary, a thematic matrix was developed (Appendix 4). Two overarching themes, each with sub-themes were identified. The first is *working in AYA cancer care* with the sub-themes: recognising AYA specific issues, decision-making and the emotional impact of the work. The second theme is *communication/conversations* with sub-themes: sexuality/oncofertility, parents and EOL care.

The development of these themes and sub-themes were aided using a digital mind map, represented in Figure 2.3, because it reflects our natural thinking patterns, which can be non-linear (Buzan and Buzan, 2006). These themes are discussed separately and presented forthwith.

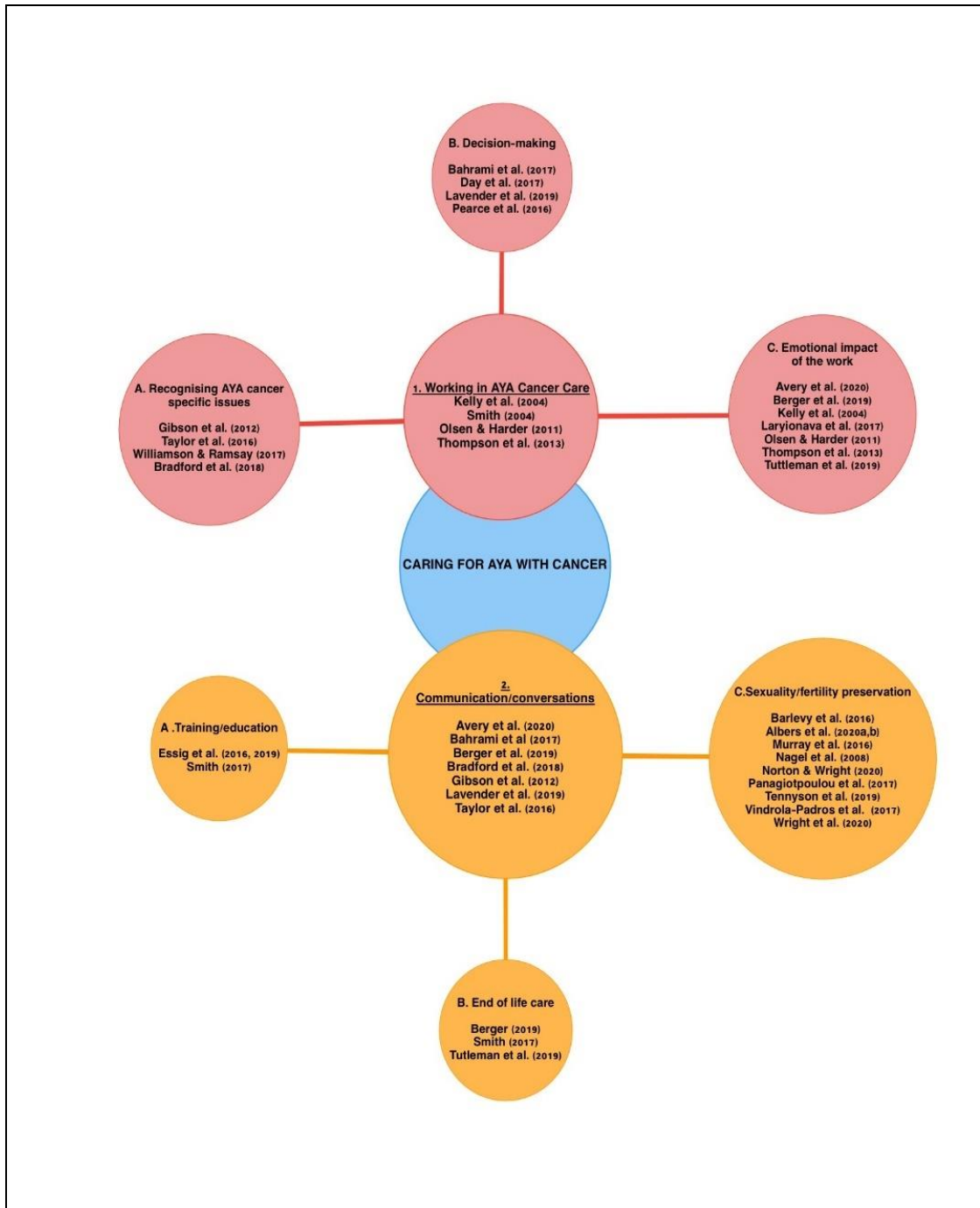


Figure 2.3 Mind map representation of themes

2.5.2.1 Working in AYA cancer care

Varying perceptions of those who work with AYACC appear in all selected papers. Smith (2004); Kelly et al., (2004); and Olsen and Harder (2011), three nurse researchers, focused specifically on working within AYAC units. Smith’s (2004) literature review on quality nursing and AYACC reported in the same year as Kelly et al.’s (2004) ethnographic study in one of the early AYAC units in the UK. Kelly et al. (2004) interviewed 14 HCPs including nurses of undisclosed

levels. Olsen and Harder's (2011) grounded theory study included nurses (n = 7) and explored network-focused nursing in a youth cancer unit in Denmark.

Smith (2004) highlighted the unique needs of AYAs and sought to explore the evidence base as to what would constitute quality nursing care in these clinical areas. From 27 papers, she identified key themes, including the significance of the specialist environment, attitudes and knowledge of HCPs and adolescent development issues. Until that point, adolescents were treated in children's or adult wards, neither of which were equipped for adolescents. She added that the approach to care for AYAC was as important as the environment. She highlighted that the literature on the hospital experience for AYAC was both inadequate and fragmented, with no published evaluation of existing services, and that there was a lack of research activity in adolescent oncology.

Smith (2004) postulated that staff attitudes and specialist knowledge have a direct impact on the hospital experience for adolescents. Additionally, she espoused that staff caring for these patients must have an interest and commitment to this age group and that continuing education was required for those working in these units. She concluded that AYAC patients should be cared for within an adolescent unit, nursed by staff with experience and expertise specific to this client group.

From the title of Smith's (2004) paper, one would not determine that it was a literature review; similarly, the type of literature review is not stated. It provided an overview of the state of knowledge in the early 2000s when the specialism was still in its infancy, thus arguably, Smith was attempting to generate debate and champion this emerging specialism.

At a similar time to Smith (2004), Kelly et al. (2004) reported on the first ethnographic study of the first TCT unit in the UK. Kelly et al. (2004) recognised the complexity of challenges facing AYAC and were keen to establish the extent to which specialist AYAC units were more effective, or more acceptable than general cancer settings. Two data themes, cancer and the cancer care unit, and changes over time, were presented in their paper.

The fact that the unit was concerned solely with AYAC emerged as highly significant. Kelly et al. (2004) revealed that the unit appeared to help people

cope with negative images of cancer, which had impacted on these adolescents and their families. All participants agreed that there were merits in caring for AYAC in one area, encapsulated when one participant referred to it as “being in the same boat” (p. 847). The relationship between patients, families and staff appeared central to the creation of an atmosphere of mutual support and reaction to what could be an optimistic or pessimistic situation. Kelly et al. (2004) identified that professionals clearly set the tone of the service but were also required to manage the emotional demands of their work. This required a balance to be struck between purposeful informality and maintaining professionalism - with Kelly et al. (2004) suggesting there was a high level of emotional labour when working in this care setting.

The second theme related to time and highlighted how patients and staff interact together over long periods (Kelly et al., 2004). This interaction was particularly difficult for adolescents, families and staff when cancer recurred. This, along with fear of death in adolescence, was also noted to be particularly challenging for nurses. One said “the downside is they can’t be protected when someone comes back with a relapse, somebody dies on the ward... they come in feeling well and you look around and everyone is suffering, you want to run out” (p. 854). The perceived informality of the unit seems to be a very strong finding; as it allowed AYAs to ‘be adolescents’ during cancer treatment. They noted differences such as late waking times, a more recently well-recognised adolescent developmental need (Bartel et al., 2015).

The culture of the unit also emerged as a pivotal source of support and expertise which was perceived to be more beneficial than having facilities or professionals available. Of equal importance were the values, skills and personalities of the staff, as well as the contribution made by patients and families treated on the unit over time. Kelly et al. (2004) felt that this resulted in the creation of a ‘therapeutic milieu’ which captured the essence of the setting. What is not clear from this paper is the relationship the researchers had with the ward team or the patients and families. The professional disciplines of the researchers are also unclear which could have led to bias of findings depending on their previous professional experiences.

Olsen and Harder (2011) explored the processes and strategies of oncology nurses engaged in a specialist AYAC nursing programme in Denmark that strived to maintain, establish and strengthen support from the social networks of AYAs during the cancer treatment period. They established that it was challenging for the nurses to create ways to help AYAs continue with their normal growth and development during the treatment phase. They conceptualised this nursing act as 'bridging'. The relationship building and communication between nurses and patients was fundamental. Some nurses in this study were as young as the patients and others were older and may have been considered as a mother figure. These age-related perceptions were proffered as potential challenges to breaching professional boundaries, though conversely, they were also perceived as advantages in developing therapeutic relationships with patients.

As with Kelly et al. (2004) and Smith (2004), Olsen and Harder (2011) recognised that nurses had exceptional commitment and involvement with young cancer patients and their significant others. Establishing a trusting and respectful partnership with an emerging independent young person and their family requires a highly sensitive approach, assessment and cooperation. Olsen and Harder (2011) add that specialist care that embraces the lives and close involvement of the others impacted by AYA cancer is a complex and highly demanding practice that needs to be addressed by nurses, educators, researchers and health policymakers. Olsen and Harder (2011) also recommend AYAC be cared for in specialised units and that nurses use their unique position to carefully consider and facilitate involvement of the patient's social networks and focus on the AYA's developmental needs and youth culture, all of which are underpinned by the need for high quality professional communication skills. It is interesting that these authors see nurses as taking the responsibility for promoting patients' social networks without questioning whether this might be achieved alternatively by other disciplines, such as social or youth workers. Taking a grounded theory approach to arrive at this conclusion may be ambitious, particularly as the sample size was small and taken from the only youth cancer unit in Denmark, leading to questions of the practicability of all young people with cancer being treated on specialist units. Indeed, it is arguable that aside from geographical distance, some young people may not want to be cared for in such environs at all.

Thompson et al. (2013) undertook an exploratory study of oncology HCP's understanding of the preferences of AYAs living with cancer in one Australian AYAC unit that was embedded within a generic cancer centre. More than 50% of the HCPs recruited (n = 60) were nurses. Data were collected via a questionnaire and investigated professionals' top five perceived issues for AYAC. Results highlighted that with a strong focus on survival and physical well-being, professionals significantly underestimated the breadth of AYAs' psychosocial concerns. In a previous study by this research group, AYAs reported different healthcare concerns compared with HCPs, (Palmer et al., 2007). Thompson et al. (2013) add that there are varying levels of professional skill, experience and confidence; significant workforce development and support needs for HCPs; and AYAC models of care require rigorous evaluation to ensure the improvement of outcomes for AYAs living with cancer. This study showed there is wide recognition among HCPs of the challenges and cumulative impact of working within this field of complex, clinical multidisciplinary AYAC practice in this unit and arguably it is not representative of broader Australian services for young people with cancer. They advocated the need to invest in strategies that focus on workforce development, education and training, and support.

Whilst AYAC services appear to be slowly growing internationally, these studies remind us of the emotional challenge for nurses and HCPs working with this age group. They suggest improvements in the quality of care for AYAC occurs if professionals are specifically trained in the elements that define this field of practice. The results of these studies indicate that recognition and commitment by organisations are essential to ensure appropriate infrastructure is put in place to monitor the impact of this work and support those delivering care. Additionally, there is also a need for ways to enhance staff support in this field, such as through multidisciplinary peer groups and supervision models. It is worth noting that the sample sizes are also small, and it is difficult to generalise on the impact of this work on ECNs.

Recognising AYA cancer specific issues

All papers refer to the specific needs of AYAC. Some of these are described further in the ScR such as communication and conversation issues, altered appearance, EOL, sexuality and fertility preservation (FP). In this section, four

papers will be discussed, Gibson et al. (2012); Taylor et al. (2016); Williamson and Rumsey (2017); and Bradford et al. (2018) which broadly refer to AYA cancer specific issues.

Gibson et al.'s (2012) scoping exercise identified the preferred competencies of HCPs, including nurses involved in AYA cancer care in the UK. Data were generated during two workshops and from an education day with AYAC HCPs, dated as far back as 2006. Knowledge, attitudes and 13 principal skills were derived from using the participatory visual research method, a diamond activity, at the workshops. The top two competencies were expertise in treating paediatric and adult cancers and understanding cancer. Further cataloguing of key competencies noted that being an expert was the most important area of competence with communication skills as the second. Whilst findings from participants led to generation of themes, arguably only those who were motivated or empowered attended these events, participated. They also had insight into the unique needs of AYAC, when it was already known that not all AYAC are treated in specialist units, meaning that some education needs to be considered for those areas that treat AYAC but are not specialist in delivering age-appropriate care. Yet this is not considered in the paper, however the ambition to work and develop an international set of competencies is mooted. Findings from this study were used to inform an international electronic-Delphi study (Taylor et al., 2016) aimed at determining what the international community believed to be the competencies required for working with AYAC. It has been enlightening to see this team of researchers generating and reporting on evidence on the work of HCPs in the UK.

The Delphi study reported by Taylor et al. in 2016 used an electronic survey, which included 87 closed questions with responses on a 9-point Likert scale and further open-ended responses to identify other skills, knowledge and attitudes. In round one, 158 participated. Round two contained only items with no consensus in round one, with additional items on competency. The areas of competence rated most important were agreed as: identify the impact of disease on AYAs' lives (skill); know about side effects of treatment and how this might be different to those experienced by children or older adults (knowledge); honesty (attitude); and listen to AYAs' concerns (aspects of communication).

What is apparent in Taylor et al.'s (2016) study are the lists and themes that were presented to participants in round one and two that feature AYA specific aspects of care such as having knowledge of adolescent development, paediatric oncology and adult oncology; knowledge of how side-effects of treatment might differ to those experienced by adults or children; having specific communication skills; understanding and having the skill to consent AYAC to clinical trials; to address AYAs' concerns on spirituality; and to be able to discuss sensitive subjects such as sexuality and fertility. Gibson et al. (2012) and Taylor et al. (2016) espouse that the outcomes of these studies could help when designing new AYA services and forming workforce planning for new and established clinical teams, directing national and international education and training, be used as a benchmark against which expectations about standards can be assessed and lastly, to inform a competency-based assessment of performance. Again, because of the generic inclusion of nurses within the HCP demographic, it is difficult to determine what specifically is required for nursing as a distinct discipline.

Bradford et al. (2018) undertook two surveys of the educational needs of HCPs, including nurses, in a different Australian youth cancer service to Thompson et al (2013), discussed earlier. The first survey (n = 122, of which nurses = 52) was used to develop an education programme, delivered between 2013-2017 and the second survey (n = 73, of which nurses = 36) was completed in 2017. The most prominent educational needs in 2013 focused on palliative care and biomedical topics such as understanding AYA growth and development as well as specific AYA cancers and treatments. The second survey identified that palliative care education remains important; however, there was a shift towards health professional requests for more psychosocial and practical education on topics including fertility, sexuality and managing late effects.

Interesting to note is the shift of focus from biomedical AYA cancer topics in 2013 to more psychosocial and practical topics in 2017. This may be attributed to the emphasis of the educational programme during the preceding years, indicating that HCPs are more aware of adolescent specific issues such as normal growth and development. Findings from this study identified that there is an ongoing need for the provision of educational opportunities and support for

professionals who provide care to AYAC. It is surprising that Bradford et al (2018) did not refer to Thompson et al's (2013) research from another Australian state given the similarities of findings. However, they did allude to the fact that their findings may not be generalizable to other settings.

Thompson et al (2013), Gibson et al. (2012); Taylor et al. (2016); and Bradford et al. (2018) all highlighted the generic knowledge skills and competencies required of HCP's as a broad group. Each research group took a systematic approach to elicit information from a variety of stakeholders through surveys and interviews. From this review, it can be seen that a picture of educational need and the potential content for curricula began to emerge across the UK and Australia.

As discussed, we can see research emerging that highlights generic AYAC psychosocial needs that nurses and HCP should be educated about. Another specific aspect of this psychosocial need was examined by Williamson and Rumsey (2017). They explored perspectives of HCP on the psychosocial impact of an altered appearance on AYAC using a sequential exploratory mixed method design, drawing from 62 HCPs including nurses, from a range of UK oncology care settings. Of the participants, 87% believed appearance related distress was common amongst AYA cancer and that although both boys and girls experience concerns, boys may appear more reluctant to discuss these. Participants felt that at the heart of appearance distress is the experience of looking and being treated differently by their peers, feeling unattractive compared to society's beauty norms and fear of negative evaluation by others, including being teased. Here we see some very specific adolescent development issues: appearance and peer relationships. Fundamental to this, they maintained that HCPs needed to develop trusting relationships, using a patient-centred approach to hold discussions about appearance concerns.

Participants felt appearance can be difficult to discuss, particularly in the context of practical and emotional pressures associated with managing vulnerable AYAs with a life-threatening illness and their parents (Williamson and Rumsey, 2017). Organisational constraints and reluctance to discuss appearance concerns were identified more frequently than barriers associated with personal competence. Training and education were also acknowledged as a barrier to

information sharing, communication and support strategies to address psychosocial concerns around appearance changes for AYAC.

The studies reported in this section all point to the need for further AYAC-specific education for HCPs, though the operationalising and evaluation of this situation appears to be lacking.

Decision-making

Four studies have focused specifically on information needs/decision-making relating to AYA cancer treatment.

Bahrami et al. (2017), based in Iran, assessed the viewpoints, experiences and preferences within the clinical communication triad (parent, adolescent, HCP team) concerning the information sharing process for AYAC. In-depth, semi-structured interviews with 33 participants including AYAs aged 15-20, their parents and HCPs (which included six nurses) were conducted and data were analysed using constant comparative analysis. They identified three main themes: disaffiliation of adolescents in information-sharing processes; barriers to information-sharing; and cornerstones in information-sharing processes. Participants believed information-sharing processes need to be gradual and based on the adolescent's need and mental capacity, thereby signalling the need for age-appropriate information. They noted that the cultural background of the research setting may have created an obstacle during the information-sharing process, with the medical team holding a negative attitude towards information sharing. They stated that the Iranian culture is rich in feelings and emotions and accordingly, parents avoid giving information to adolescents to protect them from bad news. This is the first study to refer to geographical culture in any way.

A barrier identified was the negative attitude of HCPs towards sharing information with adolescents. Nurses often tried to avoid situations requiring their response to adolescents' questions and referred them to the physicians believing that adolescents do not have adequate spiritual and psychological capacity for tolerating news related to their disease, would lose hope and abandon treatment. Nurses believed that, sometimes, giving information to the adolescent would interfere with the treatment process. This contrasts with a study from the West where the absence of adolescents from initial information-

sharing leads to more tension and anxiety in adolescents (Gibson et al., 2010). Gibson et al. (2010) proposed that an AYA shifts positions with their parent(s) and only adopts the role of primary communicator in consultations once autonomy has been gained (or regained). It can be argued that this is a key goal in AYA cancer care, particularly transitioning to self-management in survivorship (Smith et al., 2020). In particular, the more involved parents are in care, the less control and interest AYAC may have in their own disease management. Bahrami et al. (2017) suggested that adolescents' and parents' information requirements be considered along with adopting a culturally sensitive approach for HCPs to facilitate triadic communication to clarify information-sharing preferences using a validated context-based tool. The notion of culturally sensitive communication approaches is not included elsewhere in AYACC literature so it is of value to see this highlighted in the Bahrami et al study.

Day et al. (2018) examined the role of HCPs in the involvement of teenagers with leukaemia in decision-making in a tertiary referral hospital in the UK. Data were collected by observations of MDT meetings and semi-structured interviews with HCPs. Within the dataset, 19 nurses were included. HCPs revealed principles relating to the involvement of teenagers with leukaemia in decision-making to do the right thing, to act on the care and treatment preferences of the teenager and openly disclose information about the teenager's condition. These principles were prioritised and utilised uniquely in each situation and were reliant on three mediating factors: family communication styles, stage of the illness and the nature of the disease. regarding 'doing the right thing', HCPs spoke explicitly and implicitly about this when making decisions about care and treatment and accepted that the decisions where there is little possibility of long-term cure lies mostly with HCPs rather than teenagers and their families. These decisions would be made where possible with active engagement with the teenager to help elicit their preferences. Open communication was essential to enable the teenager and HCP team to come to the right decision, though it was acknowledged this could very difficult.

Common tensions about the influence of parents and families on a teenager's choice were noted by Day et al. (2018). They recognised that the family and teenager were inextricably woven together and attempts to separate treatment

and decision-making from each other were not always possible. Day et al. (2018) felt that any combination of these factors could lead to sub-optimal HCP communication and that such barriers need to be understood before any interventions are proposed. This highlights the need for the MDT to be aware of the individual situational preferences of teenagers and their families; an additional complexity when working with AYAC not often seen in the care of children or adults, where adults generally take all the responsibility for decision-making. Arguably, as this was a single site study, these findings are not generalisable. In addition, only adolescents with haematological malignancies were included which does not represent those who are being treated for other cancer types, particularly where treatment regimens differ in their approach and complexity.

Pearce et al. (2018) and Lavender et al. (2019) reported on different elements of a study investigating the participation of AYAs in bone cancer trials. The former reported on the perceptions of AYAs and HCPs in the study whereas the latter reported on the HCPs' perceptions in greater detail. The research team conducted semi-structured interviews using narrative enquiry with 21 AYAs aged 15-24 years and 18 HCPs. HCP participants included oncologists, registrars and various nurse types. Pearce et al. (2018) outlined the following influencing factors were identified in both datasets: perceptions and understanding of clinical trials, communication and information, support and coping, in the context of clinical trials and the culture of AYA specialist care. Trust, support and rapport developed over time with other staff, including medical staff, being highly valued. Pearce et al. (2018) remind us of the importance of working within an ethical framework and that nurses and HCPs develop high levels of awareness and reflexivity within themselves and across teams when obtaining clinical trial consent.

Lavender et al. (2018) established that having credibility within the professional expertise of the team was central to supporting AYAs with bone cancer in clinical trial participation. This is especially needed in order to improve trial accrual for this cancer type, which has well-documented low survival (Stiller et al., 2013). The study findings based on interviews with 18 HCPs (including nurses of unknown quantity and type) showed this credibility develops through

reflecting on the practice of others in the healthcare team. A second theme identified that developing strategies to communicate with AYAs about bone cancer trial participation was important. Key to all of this appears to be patient and family-centred conversations that emphasise the need to individualise the approach when respecting autonomy of the AYA and their family. The timing of this is important and may not be achieved at the first meeting. An effective team approach to facilitating the development of these trusting patient/professional relationships is key to the success of trial participation. Like Day et al. (2018), this study was conducted with patients with a specific tumour type and only in one cancer centre, so are not generalisable. However, findings from such studies are of benefit and can help the wider HCP team to consider key issues when communicating with AYA with cancer, in particular regarding decision-making about cancer treatments.

Across all these studies, key aspects of developing therapeutic working through effective communication and relationship-building are evident, taking note of the developmental needs of AYAC. The cultural difference within countries and built environments are notable also.

Emotional impact of the work

A broad theme from this ScR is that there are aspects of caring for AYAC that nurses and HCPs report as being emotionally challenging.

Kelly et al. (2004); Olsen and Harder (2011); and Thompson et al. (2013) are the only studies that were undertaken in specialist AYA cancer services that refer to some of the emotional challenges. Olsen and Harder (2011) described the continuous and demanding challenge of balancing professional and personal involvement with AYA patients and families. They established that the nurses felt a long-term commitment and profound knowledge of the AYA and their family created conditions for bonding. The primary care nurse often became an anchor, a trusted person the AYA and their significant others turned to when overwhelmed by feelings or practical problems which could extend beyond the treatment period.

Olsen and Harder (2011) noted that young nurses who experienced friendly communication with the AYA could confuse their perception of the nurse's role. These young nurses felt they sometimes moved into a 'grey zone', partially

because of the informal nature of the purposefully created clinical environment making them feel at risk of behaving unprofessionally. This showed how they tried to balance being professional and part of a more informal social network.

Several participants from across HCP groups in the Thompson et al. (2013) study, commented on the challenge of working with AYAC which were greater than those associated with working with adults. These included having a lack of confidence and clinical skills in working with this age group, poor understanding of AYAs' developmental life stage and limited AYAC-specific knowledge. These HCPs added that workload pressures, delivering complex and prolonged treatment regimes, exposure to death and dying, and the intensity of the emotional involvement with families without appropriate support mechanisms in place, can have a significant personal and professional impact.

HCPs in this study demonstrated there is wide recognition of the challenges and the cumulative emotional impact of working within the complexity of the AYA cancer specialism. HCPs journey alongside AYAC for a very long time and Thompson et al. (2013) and Olsen and Harder (2011) recognised the absence of research into the accumulative emotional impact of caring for AYAC, which supports the rationale for undertaking this study.

Laryionava et al.'s (2018) study of 22 oncologists and seven oncology nurses sought to understand their perceptions of treatment decisions when cancer was incurable in young adult patients (18-40yrs) and to investigate the extent to which age was a factor in these decisions. Participants reported that decisions about limiting cancer treatment with AYAs are the most challenging and stressful in clinical practice. They noted that overtreatment in AYAC often occurred approaching EOL. Three major reasons for overtreatment were identified: patient's preference for further treatment, the oncologist's perception of unfairness of dying at a young age and identification with the patient. The patient's age was a significant factor in oncologists' reluctance to discuss treatment limitations with patients. Laryionava et al. (2018) advocated the importance of starting a timely discussion with AYAC about treatment limitations. However, they argued that oncologists act in accordance with the ethical principle of respecting patient autonomy, a key value in western medical ethics, and see conflict between autonomy and non-maleficence. Another key

factor from Laryionava et al. (2018) was the identification and emotional entanglement with the patient being some of the most common countertransference reactions. Younger oncologists in the study appeared to be especially vulnerable to countertransference in comparison to older oncologists when treating AYAs. These emotions increase the risk of acting for the sake of action and the patient-doctor relationship, and the consequent overuse of chemotherapy near EOL. Whilst much of this appears to focus on doctors, it highlights the emotional labour associated with caring for AYAC and that communication is key to managing ethical dilemmas.

Laryionava et al. (2018) used a grounded theory approach to analysing these data, yet no theory development is seen in the reporting of this study, as might be expected, leading to questions as to the use of this particular research approach (Charmaz, 2014). That said, in this paper they have not justified this qualitative research method so may never have had an ambition to generate new theory. This adds to the suggestion that a grounded theory method, although widely applied, is often mis-understood (Timonen et al., 2018).

Three other studies explore HCPs' experiences caring for AYAs with incurable cancer: Avery et al. (2019); Berger et al. (2019); and Tutelman et al. (2019). Avery et al. (2019) conducted semi-structured interviews with 19 HCPs, including doctors and nurse practitioners that relate to difficulties they experienced when dealing with AYAs (15-39yrs) with advanced cancer, as opposed to adults. Four key themes were identified: challenges helping AYA/families to engage in and accept palliative care, uncertainty as to how to involve the family, a sense of tragedy for the HCP and the HCP's sense of emotional proximity.

Participants recognised some similarities in caring for adults, but it was challenging when AYAs were less accepting of incurable cancer, making it difficult for HCPs to approach the topic of palliative care. One nurse noted that "AYA were more willing to undergo additional treatments to maintain hope of living a normal life because it remained inconceivable from the patient's perspective that they would die of cancer at a young age" (Avery et al., 2019, p. 4). There was more resistance, hesitancy and uncertainty when introducing and discussing palliative care with AYAs and the family, particularly around death and dying. This was further compounded by uncertainty regarding how to involve

family and that appeared to make it more challenging for the AYA to remain autonomous and make decisions for themselves as they deteriorated. Participants described feeling a sense of loss, sadness and shock when knowing they were treating such young patients. HCPs expressed feelings of helplessness at not being able to fix or cure the cancer and the sense of failure was linked to a feeling of frustration that cure was not possible.

These participants experienced a different sense of identification with connection to AYAs than with other populations, which caused them to reflect on their own experiences as a young adult or as a parent of a young adult. Avery et al. (2019) noted the sense of relatedness or emotional proximity that increased the burden of care for HCPs. This type of proximity amplified the emotional duress HCPs already felt when providing palliative care to AYAC. They suggest the findings support the development of dedicated training and support for HCPs involved in palliative care for AYAC.

This study was conducted in two hospitals in one city in Canada, which is a limitation. The lead author acknowledged that most of the coding was done by the lead author, which could suggest the presentation of a potential single perspective on the findings. However, the paper further indicates that there was a whole team approach to data analysis and interpretation which adds some confusion on this matter.

Tutelman et al. (2019) revealed similar findings to Avery et al. (2019) when they interviewed four nurses and five physicians in a single Canadian hospital so may not be comparable with other larger cancer centres, or those with specific AYAC units. Data were analysed using interpretive phenomenological analysis. The first of four themes highlighted, were that there are many unknowns and uncertainties in providing care for AYAs. Participants noted that even when education or training is available, it can still be difficult to maintain their skills and expertise due to the infrequency of having AYAC at the EOL. The second finding focused on the intense emotional experience compared with caring for patients of other ages and was described as more difficult. This seemed to be particularly difficult for those caught off-guard given the relatively low incidence of terminal illness in this population. The third theme revealed challenges in responding to and identifying with AYAs and their families. Some

reported an acute wish to avoid as much patient/family suffering to avoid a negative outcome. Similar to Avery et al.'s (2019) findings, participants recounted how the nature of their identification with patients evolved over their careers, identifying more closely with people their age when they were younger and with patients' parents now that they were parents themselves. The last theme focused on trying to make sense of the experience where a cognitive dissonance appeared for the HCP. Participants suggested that younger children live more fully in the moment and do not have the lived experience that AYAs have to understand the opportunities they will miss in the future. AYAs had the perspective of what their life could have been which was difficult to witness and make sense of.

The HCPs interviewed may not have had much experience of caring for AYAC as compared with those that might work in a specialist AYAC unit so their experiences may not reflect general AYAC care. Given the low numbers of AYAC who die from cancer, it is likely that these are rather unique professional experiences to those who might work in specialist units where this sadness is more commonplace. However, it must be acknowledged that whilst AYAC death is uncommon, it can occur in specialist and non-specialist setting so these perspectives are important to be explored.

Berger et al. (2019) used semi-structured interviews with 12 HCPs working in medicine, nursing and allied health caring for AYAs with incurable cancer in a major cancer centre in Australia. They identified HCP challenges and enablers to this work. HCPs lack of professional knowledge and experience was reported as the greatest challenge in caring for adolescents at EOL. This was further compounded by an absence of professional development, education, training opportunities and clinical practice guidelines. Another theme, communication, was felt to be central to the delivery of quality care with AYAs and families. There appeared to be a lack of sufficient care-planning forums to discuss AYAC that involve joint decision-making, in addition to having limited age-appropriate information. Another challenge identified was the lack of institutional, formalised support structures and lack of skill-building opportunities for HCPs.

Three main enabling themes were identified by Berger et al. (2019). The first was the benefits of multidisciplinary care, which considered shared decision-

making and promoting collegial support at critical time points. The second was age-appropriate care delivery by utilising a developmental framework that was recognised by all the HCP team. This included understanding the life stage in the context of incurable disease and the role of the specialist AYA oncology service. The last theme was HCP support, which recognised the emotionally burdensome impact of this work and that the role of senior colleagues in providing support was imperative. Maintaining professional boundaries was seen to promote quality AYA palliative care and clinician self-care. They highlight that for younger nurses who may be of a similar age to patients, the need for greater awareness as to how to maintain professional boundaries was important.

These four studies, though small in participant numbers and the types of clinical settings represented, highlight the complex and emotionally taxing nature of this work for nurses and HCPs. The significance of multidisciplinary team support and the need for specialist education on adolescent development, EOL care and communication skills is mooted as key to improving practice and care outcomes.

2.5.2.2 Communication/conversations

So far in this review we have already seen where information sharing, effective communication skills and knowledge appear to be central to AYACC practice (Avery et al., 2019; Bahrami et al., 2017; Berger et al., 2019; Bradford et al., 2018; Gibson et al., 2012; Lavender et al., 2019; Taylor et al., 2016). All these papers suggest that further dedicated training and information for HCPs is needed to enhance practice and care for AYAC regarding specific communication needs.

Thompson et al.'s (2013) study highlighted that HCPs often do not communicate well with adolescents. Adolescents have a desire to understand their condition, be involved in decision-making, be treated respectfully and to feel supported in trusting relationships. It would appear from the literature that some HCPs find communicating with adolescents and their parents particularly difficult (Bahrami et al., 2017; Smith, 2017; Thompson et al., 2013). Laryionava et al. (2018) and Avery et al. (2019) were the only groups to report on the ethical challenges that accompany difficult communication conversations. Other aspects of communication skill are presented forthwith.

Communication skills training

Three papers in this review focused specifically on developing communication skills training for HCPs working with AYAC. Smith (2017) focused on simulated advanced care planning communication training, whilst Essig et al. (2016, 2019) reported on two studies they undertook with professionals working with AYAC.

Essig's (2016) multi-perspective study draws from patients, parents, doctors and nurses (n = 54) to gather suggestions for improving communication in AYACC. Eighteen nurses participated in a series of focus groups. Three themes were identified including the framework in which professionals communicate with AYAC; communication difficulties between professionals, patients and parents; and effective professional communication. All parties agreed that the framework in which communication occurs was unique and different for AYAC particularly around regression in a time of detachment, what they know about cancer, the discrepancy between cognitive and legal maturity and lastly, negotiating transition between paediatric and adult oncology.

Doctors and nurses found it hard to communicate with adolescents who responded to their situation by withdrawing and showing indifference. This made it particularly difficult to communicate when the adolescent's priorities conflicted with their treatment, often leading to tensions for parents and HCPs. Doctors, nurses, patients and parents thought that nurses should be effective go-betweens for doctors and patients. There was an expectation that nurses would spread good humour and cheer, balance professionalism and close relationships with parents, and check to make sure patients have all that they needed. The nurses felt they communicated more effectively when they showed respect for adolescent autonomy and were connected with patients by explaining what they were doing, reading between the lines and taking advantage of quiet times to make personal contact and give massages. This study shows that good communication by nurses and HCPs overlaps with the therapeutic alliance, the collaborative bond between provider and patient. Nurses tend to focus on building a strong relationship with AYAs and their parents rather than imparting information. What this study shows is that the type of relationship AYAs seek may differ from AYA to AYA but also between professionals (e.g., doctors and

nurses). Therefore, it is paramount that all HCPs working with AYAs develop the relevant skills to support relationship-building over long periods of time.

Later in another study, Essig et al. (2019) reported on a pilot study to evaluate communication skills training (CST) for HCPs (n = 50, doctors 26, nurses 24) based on the discipline's needs. A two-day CST programme for doctors and nurses in adolescent oncology was delivered to those who volunteered to participate. The training programme consisted of presenting role-plays with simulated patients where the HCP participated in simulated training. Self-assessed questionnaires on skills were collected before, immediately after and six months after training. Thematic analysis identified that the training's practical orientation and intensity increased self-confidence and assisted in the application of communication techniques. Arguably, it could be proffered that education in this may in part assist nurses and HCPs cope in these emotive situations. What is unknown from this study is whether having more clinical experience in the self-selecting participants influenced findings.

End of life conversations

Tutelman et al.'s (2019) study with five doctors and four nurses in one small adult oncology centre in Canada, highlighted the need for further education and research on the impact that HCPs can have on the perspectives of AYAs with terminal cancer. They argued that training in palliative care alone does not always meet HCPs' information and emotional needs around caring for AYAs with terminal cancer, revealing a need for specialised training and support. They add that whilst guidelines for palliative care education for HCPs of AYAC may exist (Wiener et al., 2015), there are few formal opportunities to receive this type of specialised training. Again, these findings about a very specific element of AYACC reflect what Berger et al. (2019) found in relation to lack of specialist education and communication skills training for HCPs who care for AYAC at EOL. These studies may not reflect what nurses and other HCP may experience in larger specialist centres where AYAC are cared for at EOL, though arguably, there is a need to recognise the education and development needs of all those who care for AYAs in many clinical areas, as to ignore them would be at a disservice to AYAs with cancer and indeed the HCP who care for them. With so few AYAs at EOL overall, it may be difficult for many HCP to develop

competence, skill and confidence at holding these difficult conversations, particularly those who work in areas where they are cared for infrequently, as seen in these reported studies.

Smith (2017) reported on a simulated learning experience (SLE) for 18 paediatric nurses using an advanced directive guide (*Voicing My Choices*) to initiate communication about advanced care planning for AYAs with high-risk cancer. A pre-test-post-test non-experimental design was used to describe the nurse's confidence and attitude towards the advanced directive guide as well as satisfaction with the guide to use within the SLE. There were overwhelmingly positive responses to the simulation activity. Participants felt that the SLE should be held routinely, and that advance care planning should be a regular part of conversations with patients. They felt that advanced-care planning was often missing in the care of young adults with a life-limiting condition. However, few nurses said they had training or experience in having these difficult conversations. Smith (2017) advocates that offering a SLE enables the learner to develop competence and confidence in the communication skills required for these conversations in a safe environment. These nurses expressed a significant increase in self-confidence and skills, not only to discuss advanced care planning but to also initiate the conversation. *Voicing My Choices* was reported as being a beneficial guide to structure the conversation. A larger, more diverse sample that included nurses of AYA cared for in other settings (to include nurses who care for adults, and with varying years of experience) including specialist AYAC and/or adult oncology would enhance the transferability of the research and the application of findings to other contexts.

Sexuality/fertility preservation conversations

Three literature reviews (Barlevy et al., 2016; Tennyson and Griffiths, 2019; Vindrola-Padros et al., 2017) and three studies focused on aspects of discussing sexuality/fertility preservation (FP) care among patients, parents and adolescent HCPs (Albers, Bergsma et al., 2020; Albers, Haj Mohammad et al., 2020; Norton and Wright, 2020,) are presented. The three literature reviews outline their systematic approaches to literature screening and arrived at similar themes which are outlined in Table 2.8

Table 2.8 Summary of literature reviews (sexuality/FP)

Author	Number of studies reviewed	Themes				
		AYA factors	Parent factors	HCP knowledge/ beliefs	HCP Education	Institutional issues
Barlevy et al., 2016	96	x	X	x	x	x
Vindrola-Padros et al., 2017	16	x	X	x	x	x
Tennyson et al., 2019	15	x	X	x	x	x

These reviews capture thinking of a total of 127 studies up to 2019, many of which are duplicated and will not be discussed here. As it is not the purpose of this ScR to focus specifically on discussing matters of sexuality, sexual health or FP conversations with AYAC, papers by these authors are not included here. Suffice to say, from these three reviews important conversations between HCPs, AYAC and their parents on these matters are not straight forward. They comprise multiple factors to consider such as barriers and facilitators to holding the conversation and HCPs' own discomfort, attitudes, beliefs and education.

Many HCPs were cognisant of the various challenges that impede successful oncofertility discussion and strive to overcome them, despite HCPs and parents underestimating the information and counselling needs of patients (Barlevy et al., 2016). Some challenges lay in determining who holds these conversations and which professional group takes the lead. How to have these conversations was also identified, with HCPs reporting numerous elements that help facilitate

oncofertility discussion despite various barriers. When armed with adequate education, as well as an informed approach and practice guidelines/standards, HCPs can well meet patient and parent needs in oncofertility discussions. Barlevy et al. (2016) identified that more research to understand the needs and preferences of both patients and families, as well as their decision-making processes regarding FP is needed.

Vindrola-Padros et al.'s (2017) review identified five factors that influence HCPs' discussion of FP with AYAs: (1) HCP knowledge; (2) HCP's sense of comfort; (3) patient factors (i.e., sexual maturity, prognosis, partnership status, and whether or not they initiate the conversation); (4) parent factors (i.e., HCP's perception of the extent of their involvement); and (5) availability of educational materials. They identified that HCPs reported embarrassment at discussing FP with children, AYAs and/or their parents. HCPs can feel uncomfortable questioning the AYA about their sexual practices, either in private or with their parents present. Concerns were also raised about proposing the use of FP procedures, such as sperm banking, which could require the use of erotic materials. Vindrola-Padros et al. (2017) recognised that most studies were not specific on the ages of the patients the HCP cared for, making it difficult to extrapolate variance in the factors affecting the discussion of FP with children and AYA patients.

Another research group sought to understand the barriers and facilitating factors to having these conversations given the risk of impaired fertility during cancer treatment (Tennyson and Griffiths, 2019). They established that the rates and timing of fertility discussions and a broad range of factors influenced fertility discussion. These were further divided into patient, parent and professional factors. This ScR only focuses on the professional factors. Professional discomfort when discussing infertility was related to the emotive and intimate nature of the subject matter. Lack of knowledge and false beliefs were highlighted as barriers to discussing fertility issues with confidence, which suggests a need for HCP education and development (Tennyson and Griffiths, 2019). Who took responsibility for these conversations was also identified with some contention as to whether it is the place of the doctor, nurse or other allied HCPs, as Barlevy et al. 2016 also found. So, in general whilst this review established that HCPs recognise fertility issues as important, there are varying

views as to how well this is conducted, by whom and what level or type information should be provided. HCPs sometimes find these conversations difficult, though it is reported that it is easier to have conversations with males than females. Tennyson and Griffiths (2019) acknowledged this may be because more FP options for males than females exist. It was not clear to what extent these barriers may be due to HCPs' own values and judgements or lack of knowledge. They leave this paper with an interesting and unanswered research question which is to understand why these factors prevent the conversations from happening. The extent to which they do so and the complex interaction between factors are unclear and require further qualitative exploration. Understanding this, as well as examining the differences across professional groups and services, would help guide the professional development of education and training and would be welcomed by many professionals.

These literature reviews outline a systematic approach to exploration of the literature up to a given point in time and whilst they recognised limitations within each paper, they remind the reader of how difficult it can be to truly analyse literature as gaps can occur, particularly around determining age of AYAC patients, as highlighted in chapter 1. It also reminds the reader of how much in its infancy this specialism is and the lack of in-depth analysis of participants' accounts of their clinical experiences.

Since 2019, several other studies on this have been reported and are worth noting. Norton and Wright (2020) reported on the barriers and facilitators to fertility related discussions with 11 nurses working in TCT units in the UK using semi-structured interviews. Parents and family were identified as self-appointed informal gatekeepers who were perceived to hold power to control nurses' access to communicate with AYAs about fertility issues. The supportive role nurses adopted was enhanced by the nature of their professional relationship with these AYAs. However, there was uncertainty expressed as to whether the AYAs had been fully informed of their infertility risk and potential FP options. The emphasis in this paper was that nurses should manage parental involvement sensitively if AYAs are to make informed decisions regarding their future fertility and reproductive health. The need for clear role identification for infertility discussions prior to commencing treatment was highlighted. Norton and Wright

(2020) advocate that nurse can cultivate the primacy of the relationship to improve fertility care. What appears significant in this study was the sense of the nurse's willingness to engage with AYAs and contribute in a useful way that was personally meaningful to them, providing ongoing support along the continuum of their cancer experience. This study offered new insight into this contemporary issue and is one of few studies that focuses on work in an adolescent cancer unit in the UK specifically, despite it being a small-scale study in one centre from a self-selecting group of nurses. This highlights the need for more knowledge and education to assist nurses in holding these discussions.

Two qualitative papers from the Netherlands led by same author in 2020 report on HCP communication around intimacy, sexuality and sexual health with AYAC (Albers et al., 2020a; Albers et al., 2020b). Small numbers nurses participated in both studies yet similar findings are reported here.

Albers et al. (2020a) reported on semi-structured interviews with doctors and nurses (N = 14). They identified five themes concerning the discussion of sexual health: (1) being responsible for bringing up the topic of sexual health; (2) finding optimal timing to discuss sexual health; (3) acquiring knowledge to enable discussion of sexual health; (4) facilitating communication about sexual health; and (5) providing informative material for AYAs. They advocated that to facilitate discussing sexual health, clearly defined responsibilities within the MDT and sufficient knowledge are important. Self-report questionnaires, handout material, a checklist for HCPs and knowledge of different communication strategies are mooted as needed when discussing sexual health. By applying such means, communication with AYAs might be improved. This paper was the only one to consider the inclusion of a sexologist in the healthcare team. They also recognised that not all HCP may be comfortable or competent in discussing the subject, which might lessen the expectation of everyone in the team feeling they had to do it.

Albers et al. (2020b) reported on a cross-sectional survey conducted among self-selecting AYAs and HCPs in the Netherlands (Albers et al., 2020b); 90% of AYA and HCPs believed communication about sexuality was important. HCPs felt that doctors and nurses were responsible for discussing sexuality and AYAs preferred nurse practitioners and sexologists to have these conversations. The main

barriers reported by AYAs to initiate a discussion on sexuality included the feeling of shame; however, the presence of a third party such as parents was the most challenging for healthcare professionals. HCPs also noted that written material and additional training to assist in having these conversations would be helpful. As in many of the papers in this review, the authors recognised the limitations, notably that the sample size was small and most participants were female.

So as time progresses, it appears that attending to the sexual health needs, which can be as far reaching as discussing intimacy through to FP, remains a challenge for nurses and HCPs. The evidence, though small in terms of sample size, reveals there are many personal, professional and institutional barriers for HCPs. These patients' needs cannot risk going unmet by HCPs who may be well educated on how to hold these conversations. Albers, Bergsma et al. (2020) and Albers, Haj Mohammad et al.'s (2020) studies pointed to a feeling of discomfort for both the AYAs and the HCPs in discussing this sensitive topic. Overall, it seems a juxtaposition between HCPs' sense of discomfort and their duty to explore sexual health and FP conversations. There are some barriers identified that explain this, such as lack of services, educational materials, recognition of who within teams takes the professional lead on these conversations, as well as general gaps in professional education on this matter. It appears that this theme is a dominant one in this ScR given the papers that have been identified and presented. Arguably, to have missed key discussions and actions around FP can leave a negative legacy for AYAC survivors. Given the clinical advances in FP for AYAC in recent years (Burns et al., 2018; Diesch et al., 2017), it is not surprising that more research is emerging given the emotive nature of the topic. This review identified that the need for more education and research on FP and sexual health advice is one aspect of communication that needs to be improved as well as the need for training nurses on how to hold these sensitive conversations. Consideration of the nuanced details of managing parental involvement, and cultural and ethical matters need to be considered when approaching AYAC nursing care.

2.6 Chapter conclusion

The aim of this ScR was to contextualise this study within the existing knowledge base to produce a broad map of the literature, relevant to the insights investigated in this study.

The results confirmed the initial observations of a paucity of empirical data in the experiences of ECNs and nurses in caring for AYAC in specialist units. This ScR included 25 papers published over a 21-year period that investigated or described issues related to the experiences of caring for AYAC. Most studies were conducted in the late 2010s, all in the west bar one from Iran.

Of the studies and papers examined, nurses were often referred to within HCP teams and were not always presented clearly within studies and rarely studied as a distinct discipline on their own, except for three papers (Norton and Wright, 2020; Olsen and Harder, 2011; Smith, 2017). Of these, only two studies (Kelly et al., 2004; Norton and Wright, 2020) were conducted on a TCT Unit in the UK. Rarely are the ages or seniority of nurses mentioned enabling full extraction of the views of ECNs.

Findings in this ScR indicate that overall there is a series of similar and intertwined themes that are important for professionals, including nurses, in the delivery of age-specific care of AYAC. Gaps in education for nurses that relate specifically to AYACC are highlighted but less so, are supportive care strategies for nurses who may find this work emotionally challenging, which is another aspect of practice that is reported.

Often the emotional impact of AYA cancer caring work on nurses and HCPs was difficult to extrapolate from papers' abstracts or titles, but when all papers were read, 11 of them focused quite clearly on some of these challenges, particularly around conversations about oncofertility and EOL care. It was clear from the general literature that professional caring work is emotionally demanding and caring for adults and children with cancer brings distinct challenges (Davis et al., 2013; Kendall, 2007; Wilkinson, 1994). It appears that caring for young patients is both rewarding and demanding in nature and this is reflected eloquently in Olsen and Harder's (2011) study when one participant

stated “I simply couldn’t let go...the family had so much confidence in me. I couldn’t break. They were in such pain” (p. 156).

It was noted that developing relationships with AYAC built on trust can take time and require significant investment on the part of the nurse. It appears that in working with these AYAs, particularly where there was a specialist AYA cancer service (Kelly et al. 2004; Olsen and Harder 2011; Thompson et al. 2013) the purposeful culture of the perceived informality in the ward environment could pose challenges for those who worked in it. The perceived informality lends itself to meeting the developmental needs of AYAC but has the potential of inadvertently prompting the HCP to over engage and breach boundaries, which could lead to emotional distress.

Although there is currently little empirical evidence of the impact of emotional distress and burnout on nurses, in particular ECN, in AYAC settings, professional experience and insights from this ScR suggests the likelihood of its existence. Similarly, few studies referred to the age or the experience of the nurse caring for the AYAC, though it was more apparent as an issue for younger less experienced nurses in the papers that referred to EOL.

Adolescence as a distinct time of rapid development, featuring surges in physical, cognitive and bio-psychosocial growth as the young person moves into adulthood. A common thread throughout the literature was that nurses and HCPs needed to be aware of age factors. The age of these patients gives rise to different challenges for nurses that do not appear for children or adults. This was established early on in Smith’s (2003) review. Kelly et al. (2004); Olsen and Harder’s (2011); and Thompson et al.’s. (2013) studies in specialist AYAC units placed stronger emphasis on the psychosocial needs of AYAC and the value of physical space when being cared for.

Other age-specific issues were identified that pose some challenges and thus require some education for nurses and HCPs. These include holding conversations on sexuality and FP (Barlevy et al., 2016; Tennyson and Griffiths, 2019; Vindrola-Padros et al., 2017); EOL care (Berger et al., 2019; Tutelman et al., 2019); and facilitating decision-making (Pearce et al. 2016; Bahrami et al., 2017; Day et al. 2018; Lavender et al., 2019). There appear to be notable gaps in

the confidence and knowledge base of nurses in having these conversations, as well as research on specific information/educational materials for AYAC.

A key feature in many of the papers was recognition of need for specialist education and staff support for HCPs, including nurses who care for AYAC. In several papers, aspects of what should be taught in curricula for all HCPs, including nurses, was presented and included age-appropriate care (Bradford et al., 2018; Gibson et al., 2012; Smith, 2004; Smith, 2017; Taylor et al., 2016; Thompson et al., 2013). Without this understanding, the needs of AYAs may go unmet and lead to poorer outcomes for patients. Little was found on the supposed content of accredited and non-accredited AYA cancer education, just an acceptance that it is needed and many challenges prevent staff from accessing it (Bradford et al., 2018; Taylor et al., 2016).

None of the papers reviewed addressed the motivation of the nurse or HCP to work with AYAC; therefore, a gap in this knowledge exists. Much is written in the broader literature about types of support systems for nurses working in paediatric or adult cancer services, but no others were found in this ScR about nurses who care for AYAC, hence there is a gap in the literature as to what may or may not be helpful for nurses caring for this group beyond what is available in general.

2.6.1 Limitations

The results presented in this ScR are limited by the specified combination of search terms. The age range and definition of adolescent or teenager varies in the literature internationally, so this also questions generalisability.

Much of what is presented is based on literature reviews (n = 4) or small-scale studies (n = 25). Some studies are pilots, several are small qualitative studies with low sample sizes. Qualitative descriptive studies, which represent most of the available evidence, have been useful in highlighting some distinct experiences of nurses (and other HCPs) in the work associated with AYAC. This is reflective of the relatively low numbers of AYAs who get cancer and the specialist workforce commensurate with this. Most studies employed qualitative methodologies which are pertinent to understanding experiences and insights of nurses and HCPs in this field. Few studies used mixed methods which added

some quantitative perspectives, and it is difficult to see how quantitative approaches alone would solely illuminate the phenomena to be explored. Given the lack of formal quality assessment of the papers reviewed, a relatively wide range of papers was included which could have introduced selection bias. Attempts to reduce this were made by the supervisors acting in a review capacity throughout the review process.

Additionally, there is a dearth of longitudinal studies, which in part may reflect the recent emergence of the specialism and challenges that have become apparent for HCPs who care for AYAC. The literature could also benefit from studies that incorporate multiple sites and/or that use methodologies that would allow generalizability. Most articles included in this review are single-site studies. For the limited number of multi-site studies included, the sample sizes are small, and sites are always within the same country. International comparative studies could shed light on how contextual differences influence stakeholders' perspectives and professionals' practices. Such studies could also assist in developing culturally specific guidelines.

2.7 Evolution of research questions from the literature review

This ScR reveals some of the nuanced work nurses and HCPs who are involved in the care of AYAC are exposed to. It is apparent that there is a paucity of research on the distinct work of WBNs/ECNs in AYACC. This specialism is still emerging, and specialist AYACC environments do not exist in every western country, unlike the UK, Denmark and Australia. Little is known about the experiences of WBNs, junior nurses or ECNs in AYAC or the impact of this caring work when it appears from the ScR that there are different factors these nurses may have to contend with that adult or children's nurses do not. Therefore, this justifies the rationale for proceeding with this study to explore the experiences of ECNs in AYACC.

What appears fundamental in many of the studies is that education and training is required for HCPs who care for AYAC, yet none of this is mandated. Little by way of strategy to support the emotional needs of these staff is described. However, there is some evidence to suggest that formal education for nurses is helpful, but it is unknown if this helps with the emotional aspect of this work.

What motivates nurses to stay in this clinical environment has not featured in the literature and if we are to seek to retain nurses in the profession, we need to reveal this so we can build on the knowledge thereafter to retain them in safe and healthy work environs. Adopting a qualitative methodological approach, using NI to determine this, is fitting with my epistemological stance. This approach will enable me to hear how nurses construct meaning from their systems of belief, attitudes, values and experiences that shape their sense of self and identity as an ECNs. It will allow me to move between the internal and external world of these nurses as they recount their stories to me (Clandinin, 2006), more of which is described in the next chapter.

Chapter 3 Methodology and Methods

3.1 Introduction

This chapter outlines the philosophical and practical considerations regarding this study's design. I present the rationale for the methodological approach and methods used in this research, and articulate the theoretical frameworks through which I view the data in seeking to address the research question, *What are the experiences of early career nurses (ECNs) who care for adolescents/young adults with cancer (AYAC) in age-appropriate specialist settings?*

Firstly, I outline how my ontological, epistemological and axiological positions informed and contributed to the methodological decision-making and guided me in crafting this thesis (Kim, 2015; Savin-Baden and Major, 2013; Schneider et al., 2016).

3.2 My philosophical/theoretical perspectives

I start with how I make sense of reality and portray my worldview. Philosophical perspective is important because it influenced subsequent choices as to how my study was conducted. Therefore, I needed to attend to the congruence of the nature of knowledge and being, and how I uncovered those views.

When I entered the world of academia in 2000 to teach cancer nursing, how I learned and how I shaped the learning of others was brought to a new level of self-consciousness. Along with it came a real sense of responsibility. Move forward 20 years and that has been reshaped by studying philosophy where I began to explore the fundamental nature of knowledge, reality and existence. I understand and accept that my knowledge is drawn from a variety of sources which includes evidence derived from science plus my personal and professional experience, including intuition and tacit knowledge. It may be easier to explain and justify scientific knowledge when compared to intuition and tacit knowledge, as these both lack objectivity and an ability to rationalise them. Nonetheless, I cannot abandon this completely as it is inherent in the way I practice and think about a given situation.

My philosophical realm has evolved over time, and I accept that my truths are not static and they can be transformed by many things such as science, fact, culture, politics and social organisation, thereby situating me as a postmodern thinker. I believe there is little point in understanding for the sake of understanding and that knowledge is purposeful and must be, otherwise there is no point in generating or knowing it. That said, as a postmodern thinker and early career researcher, I am mindful of organisational, professional and external processes that impede this somewhat. Examples include the professionalisation of nursing as a career, the Research and Teaching Excellence Framework agenda that drives UK universities, and the expectation from my own university that academic staff will all hold doctorates to help them become more credible and score highly in league tables. I am also conscious that my own knowledge production and thinking will be modified by those opportunities and constraints.

3.2.1 Postmodernist thinking

Postmodernism is a philosophical and social movement against the intellectual foundation of truth, meaning, knowledge and universal values. The postmodern historical phase, developed in the mid-twentieth century, is aligned with the ending of the 'modern' period known as the Enlightenment (Lyon, 1999). The terms postmodernity, postmodernism and postmodern are used inconsistently and definitions of each filled with ambiguity. This makes for often difficult engagement and interpretation. Postmodernism mostly emanated from France and Europe, from the thinking of the following philosophers: Foucault, Derrida, Lyotard and Baudrillard, to outline but a few (Kim, 2015). It has served to grapple with human experience and beyond, striving to disown theory, method and dominating systems (Kroeze, 2012; Watson, 1995) which has resulted in a discourse formation that primarily serves political ends, often linking to notions of power, gender, sexuality, language and feminism.

Early in the doctoral programme through the development of an academic assignment and subsequent publication (Cable and Kelly, 2019) (Appendix 1), I became introduced to Foucault's thinking (Foucault, 1977) and examined how AYACC has evolved and progressed. It appears to have stemmed from a process of problematisation, to one that has increasingly become the focus of

philanthropic support and empirical research, where it attracts the attention of policy-makers, health services and professionals on a global scale. In our published article, Cable and Kelly (2019) argued that this shifted attention away from cancer purely as a biological malfunction, towards one where 'the person' is recognised with, in this context, the requirement to cope with a cancer diagnosis in a social sense (as a member of kinship or friendship groups) during a specific phase of the human life course (as an AYA). During this analysis I attended to the power dynamic that Foucault asserts and arrived at the conclusion that the power base of AYA cancer care (AYACC) is not static and is opened to further challenge despite many forces it must contend with. Taking a temporal view and looking to its future, Kelly and I (Cable and Kelly, 2019) suggest the specialism may benefit from understanding the ways that power and associated discourses have been challenged successfully to allow it to arrive at its present situation.

The experience of taking this postmodern lens whereby there is no single grand design to the world, is in keeping with a Popperian view that our knowledge of the world is conjectural, falsifiable, challengeable and changing (Popper, 2005). Taking the lead from these philosophers led me to adopting this philosophical stance.

Postmodernism and its principles have gained traction in nursing research and practice, which is important for me to bear in mind given that I am exploring the experiences of nurses. Watson (1995), a nursing scholar, asserted that postmodernism became a worldview that became associated with deconstruction of reality that stemmed from the quest for new meaning of the human science, (p. 61). Nursing recognises the importance of what it means to be human. To examine this goes beyond the view that the universe is a system that yields truths through careful observation and analysis, that any knowledge acquired is universal, singular and constructive, and that our practices are shaped by, and aspire to, the ideals these imply (Holmes and Warelw, 2000).

This acknowledgement of complexity thinking as a postmodernist comprises multiple formations of thought, sources of ideas, multiple thinkers and their influencers from multiple disciplines (Peters, 1998). Having this freedom to consider a worldview outside the boundaries of grand discourses gives me

opportunity to embrace multiple ways of knowing. Whilst Cheek (1998 cited in Holmes and Warelow, 2000) asserts that the views of postmodernists strive to be both atheoretical and post-disciplinary, I cannot be completely atheoretical in my approach to research and knowledge. To understand the world around me, critical thinking is required. Accordingly, it is espoused that qualitative researchers consider a systematic approach (of varying levels) about the general world; the justification of their belief (epistemological position); and the theory of value (axiology), though this can lead researchers to struggle to determine their own philosophical stance.

My ontological position of what is 'real' and what is 'valuable' in that reality is subjective and may have multiple meanings. By this I mean that the meanings of experience can only be described by the person who has had those said experiences, that everyone has a past which influences current experience and this may influence any future experience. Therefore, this is a relational and temporal perspective which supports the study of experience based on Deweyan thinking (Dewey, 1938). Axiologically, aside from that mentioned in Chapter 1, for me, another value in this research will be if, by drawing attention to the experiences of ECNs, it has a direct effect on practice. I will see my research as of value if it influences the way people teach, learn or practice - for the better.

Epistemology concerns the nature of knowledge and what is possible to know (Braun and Clarke, 2013). I believe that knowledge is subjective and in constructing knowledge I am mindful that in qualitative research the relationship between me, as the researcher and those with whom I collect data is integral to generating an understanding of the phenomenon under investigation (Savin-Baden and Major, 2013). It has been discerned that "all qualitative researchers are philosophers" (Denzin and Lincoln, 2011, pg. 12). This perspective suggests that research is more than a technical act that follows systematic processes. Kim states that qualitative researchers are guided by highly abstract principles which includes their ontological beliefs, epistemology and methodology, (Kim 2015, p. 32). She argues that these researchers operate within one or more theoretical paradigms and as such they employ philosophical, theoretical frameworks or paradigms to shape their studies. She suggests that theory is integrated at three levels: macro, meso and micro. Theoretical considerations thread through my

research approach and I portray how I integrate levels of theory as per the model in Figure 3.1.

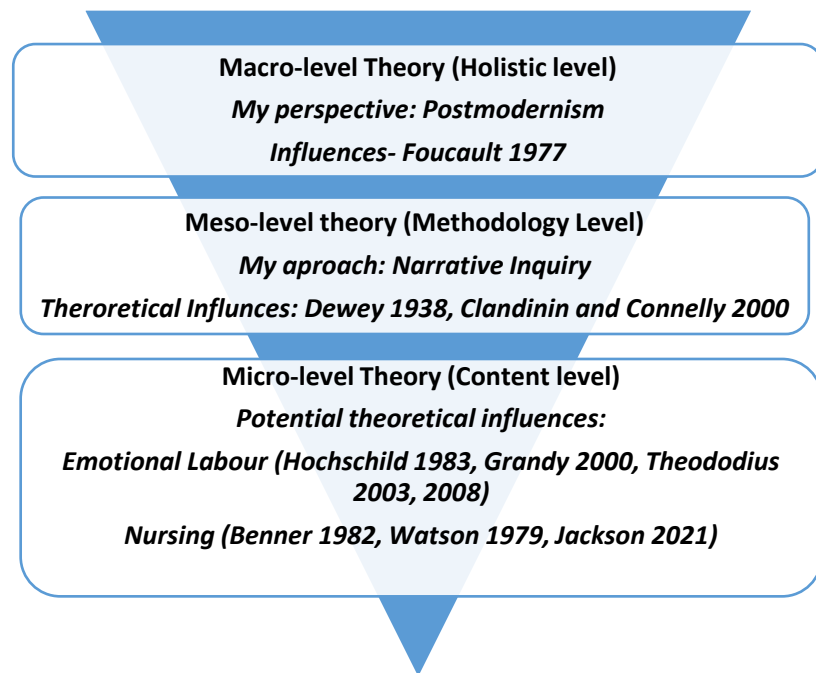


Figure 3.1 My theoretical integration based on Kim's (2015) Levels of Theory

It is important to point out that the integration of theory aids in the understanding, analysis and evaluation of stories (Bal and Van Boheemen, 2009). However, arguments have been proposed that NI 'is not theoretical enough' (Clandinin and Connelly 2000, p. 42) or that many NI studies fail to bring to the fore methodological and theoretical frameworks that underpin their conclusions (Hollingsworth and Dybdahl, 2007). Kim (2015) adds that theories should be used to 'construct meanings of stories with conscious attention to the three levels of theory, but this is not to say that theory is more important than story', (p. 34).

It is suggested that theory, theoretical frameworks, theory of method and conceptual frameworks are terms that have blurred lines within qualitative methods literature and either suffer or benefit from widespread nuanced differences (Collins and Stockton, 2018, pg. 2). They determine that inclusion of a theoretical framework is considered valuable as it renders theory a valuable tool to the coherence and depth of a study, although others would contest this. It has been asserted that at times the exploratory nature of a study overrules the benefits of a theoretical framework (Guba and Lincoln, 1994), so I assert that theory-free research does not exist.

There are multiple ways in which theory can be used to frame a study, primarily either by testing an existing theory or by theory building, (Sim and Wright, 2000). In this study no hypothesis or existing theory was to be tested. I used my theoretical propositions described earlier to consider the experiences of these ECNs so that concepts and themes were identified through induction. During the process, theoretical propositions were generated leading to theorising or theory building, with little emphasis on generalisability. I was mindful of Kim's (2015) words: "we cannot make sense of stories told without the help of theory or the intersection of multiple theories" (p. 77). In this case, theory was used to guide sensemaking of the stories that were told by these nurses.

3.3 Reflexivity

Reflexivity is the process of reflecting upon the relationship between the researcher and the research. It is viewed as a means to assist researchers in considering their position and influence during the study by examining their own beliefs, judgments and practices during the research process as to how these may have influenced the research (Coolican, 2018; Savin-Baden and Major, 2013). This is a personal, ongoing and nebulous process.

I constantly enacted this practice across the research process through the design, fieldwork and interpretation phases as I viewed and generated new knowledge. It is an inherent part of my research practice as a qualitative researcher. Reflexivity grounded me in terms of establishing my philosophical positioning to arrive at the research question which underwent constant refinement. This is known as epistemological reflexivity (Willig, 2013). It was important to remember that reflexivity should be used in the service of the research question, not instead of it (Lazard and McAvoy, 2020). I was cognisant of my position as researcher and participant in the process of knowledge construction. I was not seeking to establish a single truth, as my epistemological approach is interpretative rather than reductionist. It was the meaning from the stories of ECNs' experiences that I sought: the truth of their experience and not an objective decontextualised truth (Bailey and Tilley, 2002).

In NI, Kim (2015) highlighted the risk of becoming too self-reflexive and shifting the gaze to one's own narrative and beliefs rather than those of the

participants. By being reflexive in the early analysis I sought to listen to the individual narratives from the outset, as opposed to identifying themes too early in the process. I needed to listen to their story with as little impediment as possible, yet also recognise my potential personal influences and narratives which are pertinent to the listening and ‘retelling’ of narratives (Clandinin and Caine, 2013).

I used a variety of reflexive strategies to assist with this process to ensure rigour in the application of my methodology. Examples include peer support, attending lectures and having doctoral supervision. I kept a reflective diary capturing thoughts at key moments, such as after supervision sessions and after each zoom conversation with participants. Examples of these are in Appendix 5, which were sometimes shared with supervisors.

3.4 My research paradigm, question and methodological alignment.

A research paradigm is considered as a worldview, a general perspective on the complexities of the world around us and is often characterised by our ontological and epistemological positions (Polit and Beck, 2017). As mentioned earlier, I adopt a constructivist approach (often referred to as the naturalistic paradigm), which is a counter approach to positivism or quantitative research, by offering an alternative system for research approaches in the social sciences and health. Like me, the naturalistic researcher believes that reality is not fixed but a construct of those participating in research, that reality exists within context and that many constructions of that reality are possible (Coolican, 2018; Polit and Beck, 2017). Moule espouses that constructivists, or interpretivists, believe that to understand and make meaning of the world, researchers need to interpret human behaviour in natural settings (Moule, 2020). To accomplish this, they employ distinctive research approaches and methodologies using analysis of qualitative material that are narrative and subjective (Parahoo, 2014; Polit and Beck, 2017). In this way, they interrogate data to develop a theory or description to understand more about a phenomenon under observation. It was my aim to meet ECNs in their natural settings at work, on a specialist unit. However, with this research being conducted during the COVID-19 pandemic,

this became impossible, so I had to meet them online. This is discussed further in this chapter.

By being clear on our paradigm we sharpen our focus on a phenomenon. That said, both qualitative and quantitative approaches seek to understand more about phenomena and both types of research generate and gather evidence for analysis. Where humans are involved, both will be bound by having to have human interaction and with that, comes ethical constraints. Irrespective of which approach is used, in my view imperfection is not avoidable.

Therefore, whilst it is important to recognise that researchers' perspectives in general may be paradigmatic, knowledge itself is not, which is why I believe both paradigms are important and can sit side by side.

3.4.1 My primary research question and methodology

My primary research question was, *What are the experiences of early career nurses (ECNs) who care for adolescents/young adults (AYAs) with cancer in specialist age-appropriate settings?*

My aim was to take an interpretative approach to understanding this using qualitative research. This would help determine what types of experiences these nurses have, what motivates them to stay in this type of work and understand the emotional impact of that work. Once understood, measures can be put in place to support and educate them to continue in their jobs effectively and with a sense of fulfilment, a reduction in job attrition and support the therapeutic value in working with AYAC and their families.

Methodology is often confused as meaning the same as method. The methodology of any study determines the quality of the research and encompasses much more than the methods and techniques of data collection and analysis (Cordeiro et al., 2017; Parahoo, 2014). Assembling my methodology was important as it bridges theory (my research strategy) and my research practice (methods) (Cordeiro et al., 2017; Trafford and Leshem, 2008).

As discussed earlier, I could have used other qualitative research approaches but after much reflection, I settled on adopting a narrative research approach to describe the personal stories of 8-16 AYAC nurses.

3.5 Narrative inquiry

Narrative Inquiry is an overarching phrase that encapsulates personal and human perspectives of historic experience and acknowledges the relationship between cultural context and individual experience (Clandinin and Connelly, 2000). I felt NI's underlying philosophy and accessibility illuminated the stories of real people in real settings by acknowledging their human experiences as dynamic entities which are in a persistently fluctuating state (Wang and Geale, 2015).

Furthermore, it helps understand issues such as personal identity, life course developments and the cultural/historical domains of the narrators, which fitted with the perspectives I sought to explore. People's lives are filled with stories, so the participants in this study had an opportunity to tell me theirs so that I could make meaning from their narratives.

It is postulated that narrative approaches are theory, processes, data and product combined to create a unique form of inquiry (Savin-Baden and Major, 2013; Savin-Baden and Niekerk, 2007). I believed it would help to depict the richness of data within the real stories that these nurses shared in a meaning-making and systematic way. Gilbert adds that a narrative approach takes account of both the content and the form of the interviewee's explanation and engagement with the interviewer (Gilbert, 2008).

NI was therefore posited as an appropriate form of inquiry as it offered a unique way of developing knowledge in this field. This sits comfortably with my ontological belief that reality is subjective; that the meaning of any experience can only be told and owned by the person who has experienced it and that it is relational and temporal. I chose this methodology as it can apply interpretive lenses through multiple theoretical and philosophical approaches which pivot from the centrality of stories as told by the nurses.

3.5.1 Narrative thinking

Becoming a narrative enquirer requires more than learning about various data collection techniques or understanding research standards (Connelly and Clandinin, 2006; Kim, 2015). Despite NI bearing some resemblance with other qualitative enquiry such as ethnography or phenomenology, Connelly and

Clandinin (2006) suggest that the following help us to learn to think narratively. These include imagining a life space; living and telling as starting points for collecting field texts; and balancing what they term as three commonplaces (temporality, sociality and place). I also considered my own investment in the enquiry as this is a process of making a story out of the experience of another, on which I reflect upon my experiences to construct new stories (Robinson and Hawpe, 1986). Thinking narratively began well before nurses were invited to tell their stories and this process extended throughout the research. The ECNs were viewed as narrators of their own stories as opposed to interviewees. In fact, I considered these as research conversations rather than interviews.

Three components in the process of narrative thinking as outlined by Robinson and Hawpe (1986) were adopted. Firstly, the storyteller creates a *narrative schema*, a plan or a roadmap which organises various pieces of information that usually have causal relations. By that I mean considering what happened, to whom, why and so forth; in effect recalling relevant facts. This *schema* is drawn from the second component which acknowledges the *storyteller's prior knowledge and experience*. The third component is *cognitive strategies* where the storyteller actively extrapolates, arranges, compares and postulates their facts to create a story, thus facilitating an understanding of the actions of others and oneself in relation to others (Kim 2015). This form of thinking is described by Robinson and Hawpe (1986) as a *heuristic device* enabling a perpetual construction of stories generated between “the particular and the general” (p. 21) in human experience.

My narrative thinking was strengthened by drawing on two key principles of narrative research as identified by Chase (2003). Firstly, that narration is a major way in which people make sense of experience, construct the self and create and communicate meaning, and secondly, that narratives are social as they have an interactional component (Chase, 2003, pg. 79). Therefore, these nurses' stories must be socially recognisable if they are to be meaningful to them, me as a researcher and to others.

The recruitment and data collection processes are described further in this chapter. In preparation for conversations with the nurses, I developed my own loose guided conversation schema (Appendix 6), which invited responses to

open-ended, broad questions, as opposed to closed questions that would not allow for free-flowing conversation (Holloway and Freshwater, 2009; Kim, 2015). During the guided conversations, there were times when the stories being told were purposefully not interrupted to allow free flow of the participants; as if the interview dyad had been 'travelled together', where the nurses told me of their 'lived world' (Kvale, 2008). Thus, I had some degree of control over the process and content of the interview, taking into account my desire to have the flexibility to illicit unexpected stories from these overarching questions.

I felt that it was important not to interrupt the nurses per se, but to merely guide the conversation and think narratively. I did this by using my transferable skills of using verbal/nonverbal prompts for encouragement to keep the conversation on track so that they spoke in their own voices; expressed themselves freely (creating their own narrative schema); and their stories became fluid and unexpected. I felt that this supported the development of rapport and a positive relationship between us (DiCicco-Bloom and Crabtree, 2006).

By following Robinson and Hawpe's (1986) second component of the process, I factored in my own prior knowledge and experience. My current role is as lecturer and researcher in AYACC. I no longer work in clinical practice, but I teach and support registered healthcare professionals whose day-to-day work is in AYACC. I have worked alongside AYAC senior nurses to deliver education programmes since 2006, so am connected vicariously with clinical practice, though no longer directly involved with patients. This positions me in a place where I hear from students (such as these ECNs) about their day-to-day practice through our online discussions. I have a symbiotic relationship with senior clinical colleagues from the field who co-teach with me. I hear first-hand of clinical service developments from them, whilst at the same time they glean critical thinking perspectives from me as regards education and research developments. We work together on research projects on competency development for nurses and youth support co-ordinators (YSC) in AYACC. So, my working life is in and around frontline carers for AYAC patients and families as opposed to working directly on the frontline.

It is 22 years since I was a clinical nurse specialist (CNS) and nurse manager in haematology and oncology in a district general hospital and there was no AYAC service then. To that end, I could not relate to this specialist environment the ECNs in this study were working in. Over the years, as a nurse academic in AYACC I am conscious that I have helped shape a significant part of the workforce development in this field through my teaching, research and consultancy work. The online course that I am responsible for is the only AYAC course outside of Australia. Over this time, I have taught more than 1,000 learners from across the world in AYACC through accredited and non-accredited learning events I have developed and delivered. I was mindful that I had a reputation for doing this type of work and had to consider how I might manage this with participants.

I was conscious of the 'asymmetry of power' between myself and the ECNs I was conversing with (Kim, 2015), and wanted to give the ECNs control over their story. I felt that an important way to manage this was to build a rapport based on trust early in the recruitment process (McGrath et al., 2019). This was important because it involved human interaction upon which the ECNs' openness, trust and generosity to share their stories with me would be based. I was reminded that rapport is not a commodity and that it is relational (Darlington and Scott, 2020). I recognised that whilst I was to enable free-flowing conversation that avoided responses concerning my opinion, I felt it important for them to know that I too was a cancer nurse so that we had common ground. In my attempt to avoid an over-rapport, I had to manage how I showed my genuineness and interest in their work as nurses and as human beings, and that they were treated with dignity and respect (Shea, 2000).

The cognitive strategies suggested by Robinson and Hawpe (1986) were for me as the researcher to select, compare, contrast, infer and make decisions about these experiences to help guide me in determining relevant data to create new stories. Therefore, this helped me to understand my actions in relation to the nurses. All of these helped guide my narrative thinking as a foundation for data collection for NI which differentiates narrative methods from other qualitative methods (Kim, 2015). Narrative inquiry research seeks to explore depth and breadth of a chosen phenomenon, it requires a more holistic exploratory

approach from recruitment to data collection and analysis (Lindsay and Schwind, 2016) and this is what I sought to do.

3.6 Recruitment to the research

I was interested in stories of particular nurses' experiences which meant that I needed to engage with people with the required role, knowledge and experience for the study aims, in keeping with narrative research (Holloway and Freshwater, 2007). This is known as purposive sampling and is a non-probability sampling method (Braun and Clarke, 2013; Coolican, 2018). A key feature in NI literature is that the relationship that develops between the researcher and the participants is what is important, rather than paying attention to the process of recruitment and sampling, unlike other research designs (Clandinin and Connelly, 2000; Clandinin and Rosiek, 2007; Holloway and Galvin, 2016; Kim, 2015).

3.6.1 Recruitment process

In July 2019, ethics approval from Cardiff University was granted to proceed with seeking appropriate approvals from the Health Research Agency (HRA) as it was my intention to recruit 8-16 nurses from specialist AYA cancer wards in four specific NHS hospital sites across England. I aimed to interview them either onsite or via web conferencing software. I was granted HRA approval (IRAS project ID: 265008) (Appendix 7) in October 2019 and I was asked to engage further with the four NHS organisations to confirm capacity and capability. By February 2020, I had succeeded in acquiring a research passport so that I could go on to each site.

I circulated an eye-catching paper-based flyer (see Appendix 8) to be pinned up in various sites on each of the four specialist units, as guided by Braun and Clarke (2013). By the end of March 2020, the COVID-19 crisis emerged and all non-essential research in the NHS was stopped. I was asked to suspend my study and not access any NHS sites.

On discussion with supervisors, and working within the timelines of the doctoral course, I revised my recruitment approach. I switched to recruiting using social media only, using my Twitter feed (circa 1,800 followers) and offered to interview participants by secure web-conferencing/Zoom only. Using social

media platforms has gained popularity in healthcare research and has multiple uses such as sharing and discussing content among diverse audiences (Arigo et al., 2018). Doing this meant that I would not be accessing NHS property and thus not require further HRA approvals. I revised my ethics application at Cardiff University to this effect, which was accepted. I communicated with the four NHS Trusts to advise them of this change, and they agreed this was acceptable and the only viable option available to me at that time.

This also meant that I could open recruitment from any specialist AYA cancer unit in the UK. Clandinin and Caine (2013) speak of “negotiating entry” on the participation in research. I was conscious of my desire to minimise the power differential linked to my role, especially if any participants were already known to me through my professional networks or my teaching. ‘Entry’ was initiated via two routes: posters at each of the four specialist units advertising my research pre-COVID-19, and secondly via Twitter post-COVID-19.

I commenced online recruitment in September 2020 with a series of tweets and retweets (Appendix 9). The first tweet generated 42 ‘likes’ and 54 re-tweets. In November 2020, a further tweet generated 13 likes and 10 retweets. Through my clinical networks, I understood that many NHS staff were redeployed away from AYA cancer units and that the NHS was under unprecedented pressure. By December 2020, nine Band 5 ECNs working in specialist settings had come forward. I had just exceeded the minimum target of eight nurses and with the agreement of my supervisory team, we accepted this was sufficient for data collection. This discussion was not entered lightly and required thoughtful justification on the limits of accessing nurses amidst the COVID-19 crisis. In essence, I was not seeking to achieve data saturation to assess the sample size. The sample size used in qualitative methodological approaches are often deliberated (Kim, 2015; Newell and Burnard, 2010) These researchers suggest there is no definitive number requirement, and that the emphasis should be on whether the sample will “yield sufficiently meaningful data” (Kim, 2015, p. 160) which we felt would be achievable.

In NI methodology, the values of the story of each individual are what yield rich data as opposed to looking for large sample sizes in order to generalise results. Data saturation, the point at which no new information, codes or themes are

yielded from data is often seductive (Braun and Clarke, 2021). In qualitative inquiry, there has been a move away from this being the unquestioned acceptance as the gold standard. Braun and Clarke (2021) concur with others who argue that saturation, “is a logical fallacy, as there are always new theoretical insights to be made as long as data continues to be collected and analysed” (Low, 2019, pg. 131). Given my methodological approach and epistemological stance, I concur. I felt that the number of participants in a study does not necessarily translate into quality of findings, particularly when each participant in this study has a different story to tell, even if they work in the same environment or care for the same patients. Meaning can be generated in many ways. Furthermore, a large cohort of research participants was not anticipated for this study, which was an important factor in selecting NI as a methodological approach.

3.6.2 Inclusion and exclusion criteria

It is important to offer an opportunity to participate in research to all those who fulfil the criteria of the research. In this case, the nurses had to have had a particular experience (Holloway and Freshwater, 2007; Holloway and Freshwater, 2009; Holloway and Galvin, 2016; Macnee and McCabe, 2008) and meet certain criterion as outlined in Table 3.1.

Table 3.1 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
<p>RN must be working regularly (or have worked with AYA with cancer in the past six months to allow for recall) on specialist AYA cancer clinical settings or day care facilities for at least one year continuously.</p>	<p>Not open to those qualified less than six months.</p>
<p>Must be more than six months since qualified as a RN.</p>	<p>Not open to those with less than six months' experience of working with AYAC to allow for AYA cancer nursing experiences to have been developed for recall.</p>
<p>Be a RN, child or adult</p>	<p>Not open to nursing auxiliaries/assistants/associates or student nurses as they will not have completed the rigour of nurse education and professional regulation that registered nurses have.</p>
<p>Be working in the UK</p>	<p>Not open to those who occasionally work with AYAC so that regular contact with AYAC can enable the nurse to select from a range of experiences.</p>
<p>Be Band 5 nurses working on specialist AYA cancer clinical settings</p>	<p>Not open to those working outside UK as this is beyond where the researcher works, and ethical approvals will have been sought for.</p>
<p>Be Band 5 nurses working on specialist AYA cancer clinical settings</p>	<p>Not open to nurses other than Band 5 Not open to clinical nurse specialists, nurse managers or nursing assistants.</p>

When nurses contacted me to register their interest in the research, I sent them a participant information sheet (Appendix 10) and asked them to contact me again if they wanted to continue. When they had agreed to participate, we negotiated a time to meet online to share their story. At the beginning of our

online meeting via Zoom, I revisited the information sheet and confirmed they were willing to continue. The consent to participate form was signed as an agreement to continue and returned by email prior to the online meeting (Appendix 11).

3.7 Data collection

3.7.1 Interview/conversations

Advocates of NI based on Dewey's theory e.g., Clandinin and Connelly (2000) and Clandinin and Caine (2013), encourage several meetings between the researcher and participants so that the 'continuity' of experience is encapsulated. Clandinin and Caine (2013) recommend there should be several opportunities to have relational conversations with the participants to gain as much insight as possible on the past and present influences on their interpretation of the experience, thus gaining relational insight. As this study was undertaken within the timeframe of a professional doctorate amidst a pandemic, I had to modify this. We only had one conversation and I offered them the opportunity to have a second should they wish to. I added that I may contact them to check for clarification of points after I had transcribed each conversation. This is a limitation; the ECN's story was 'time limited' to one, which may have limited their selection of what to tell me.

All nine interviews were conducted via Zoom using Cardiff University's licenced Zoom account. The functionality of this meant that I could record both video and audio of the conversations. Zoom's transcription function meant that I had a basic transcript of each conversation.

The conversations lasted from 46 minutes to 93 minutes. The first meeting was the shortest. In part, this was because the nurse was less conversational than some of the others, and I acknowledge that I was developing my confidence in terms of allowing the conversation to flow naturally, whilst attending to the conversation schema that I had prepared (Appendix 6). In principle, open questions were used and all interviews used starting questions such as: "Tell me how you came to work with AYA with cancer."

As the conversation developed to thinking about what it is like being an AYAC nurse on a day-to-day basis, each conversation ended in asking where the nurses

saw their future so that I could attend to the temporal aspect of their experiences. As stories and experiences unfolded, new questions arose such as “You mentioned that XYZ happened earlier; can you explain more about that?” I was keen not to interrupt the flow of the conversation but to delve further into aspects of the conversations as they went on. This allowed thoughts, feelings and other experiences to emerge.

As I progressed, I became more confident in facilitating the conversations. I was conscious that I would build trust and rapport with the participants, as the act of collecting data or stories now depended on this (Kim, 2015). Holloway and Freshwater (2007) reminded me that I needed to suppress my own desire to speak so that the participant could tell their story of their “lived world” (Kvale, 2008). In the first conversation, I felt I had held back, almost too afraid to speak; that I perhaps curtailed the expression of the stories. I reflected on this with my supervisors and in my diary and reframed my thinking. I had separated my practice from being an experienced teacher of communication skills in healthcare work to that of a novice researcher. By reattending to my experience as a nurse, communicator and educator, I reminded myself of my capability to hold open facilitative conversations using warmth, empathy and genuine concern, and drew on this as I progressed with the conversations. I sent a copy of each transcription to the supervision team, and I recalled feeling positive when one of them commented that my conversation technique was “splendid” as I progressed.

Clandinin et al. (2011) encourage narrative inquirers to avoid thinking about expected outcomes of stories and to work with them whilst they are being told. Given that both the nurses and I were “in the midst” (Clandinin and Caine, 2013, p. 43) of our personal and professional lives, and situated within the institutional and professional contexts, I was reminded of how complex stories were. I encouraged them to tell me their story of their AYAC nursing experiences in the midst of being an ECN.

3.7.2 Data collection and storage

Collecting data was an enjoyable part of the research process. The ECNs were willing, keen to share their stories and seemed comfortable with having an online conversation. They knew they were being video and audio recorded and

that I would be transcribing their data verbatim. They also knew that I would return each transcript for them to certify and I would check in with them regarding their well-being because of our conversation. As was I, the participants were in their own homes in a room where no one could hear us to maintain confidentiality. They knew their files would be kept on a password protected site that was only accessible by myself and the data would be destroyed at five years, all in keeping with good clinical practice guidelines (National Institute of Health Research, 2020).

3.7.3 Transcription

After each conversation, I reviewed each video recording before I started to review the automatic Zoom transcription but did not expect it to be word perfect and it was not. This meant that I had to listen intently and ensure the recording was accurate and audible, pick up on nuances as well as mis-quotes. During this time, I went over my own field notes/diary to ensure I had acknowledged facial expressions, body language, audible changes, silences and pauses. To further enhance the accuracy of the transcripts, I watched the video recordings of the interviews twice more, over a three-month period, making sure that I accounted for every word, ensuring anonymity of participants.

3.7.4 Rigour

All transcripts were sent to the three doctoral supervisors, helping me to reflect on my interview technique. I found their feedback helpful, and I was keen that my data were being reviewed by other academics who would also be noting their own thoughts on them. In addition, each participant was sent the full transcript of their recorded conversation for verification of accuracy as part of the process to further ensure rigour.

By doing this, each of the participants story was given a voice and I was keen to ensure that the narratives were an authentic representation of the experiences as the nurses told them (Clandinin and Connelly, 2000). All participants agreed that my transcript was a true and accurate representation of the conversation, and several said they enjoyed the process. They added that they found it “*almost therapeutic*” and helped them reflect on the work they did. To ensure other aspects of assessment of rigour in this study, I deferred to the Four-

Dimension Criteria (FDC) of Lincoln and Guba to establish trustworthiness (Lincoln and Guba, 1986) as outlined in Table 3.2.

Table 3.2 Key FDC strategies adapted from Lincoln and Guba (1986)

Rigour Criteria	Purpose	Strategies used
Credibility	To establish confidence that the results (from the perspective of the participants) are credible and trustworthy.	Discussion with supervisors that I was a capable interviewer. Regular debrief sessions with supervisors. Maintained reflexive diary. Participants had opportunity to check transcripts for accuracy. Supervisors reviewed themes independently and these were discussed as a group.
Dependability	To ensure the findings of this inquiry are repeatable if the inquiry occurred within the same cohort of participants, coders and context.	A study protocol was developed prior to commencement. Rich description of methods is outlined. Digital recordings of conversations were transcribed immediately and checked for accuracy by supervisors against video and written formats. Codes were checked by the supervisory team.
Conformability	To extend the confidence that the results would be confirmed or corroborated by other researchers.	I kept a reflexive journal. I had regular documented doctoral supervision meetings.
Transferability	To extend the degree to which the results can be generalised or transferred to other contexts or settings	ScR completed to check that this study has not been undertaken previously or repeated elsewhere. Detailed descriptions of experiences documented. Final report written to include data extracts to provide evidence to support analysis.

3.8 Ethical considerations

Ethical approval from Cardiff University was gained. I have described other practical ethical issues such as informed consent, confidentiality and data storage elsewhere. Other moral judgements I made included balancing the need to obtain valid data against the rights of individuals and groups to privacy and autonomy. I agreed with each participant that I would anonymise their data by giving them a pseudonym and remove any patient or place name that might potentially make them identifiable. Holloway and Freshwater (2007) acknowledge that in narrative research there may be times when anonymity is difficult to ensure because of the holistic and contextual nature of this type of research. I was mindful of this, given the small number of participants that were recruited from such a small pool of potentials. I was also conscious that they may refer to some patients by name and that I had a moral and professional obligation to manage this according to the Nursing and Midwifery Code of Conduct (Nursing Midwifery Council, 2018).

I respected the principle of beneficence by committing to the academic integrity of the research design which when upheld should ensure benefit by creating outputs that merit dissemination. An aspect of non-maleficence that I addressed was the small risk that emotional harm or discomfort would occur during the conversation, particularly if speaking about patients that had died or were dying or if it related to participants' personal experiences. To address this, I checked they were content to continue during the conversation. At the end of the conversation, I asked again and offered a follow-up telephone call. I checked again in an email that asked them to verify the transcript. No participant was visibly distressed during the interview, requested a follow-up call or expressed this by email. I had a list of support services I could have signposted them should this have been the case.

There has been extensive debate about the clarification of researchers' roles in their research where they position themselves as 'insiders' or 'outsider' to the communities they study (Teusner, 2020). Insider researchers generally are those who chose to study a group to which they belong, whilst outsider researchers do not belong to the group under study. Whilst I did not work directly with any of

these nurses in clinical environments (I was an outsider to them), I had taught three participants on an online course but had never met them in person.

I debated with the supervision team whether I should include them in my study or not. I attended to my exclusion and inclusion criteria, and I had not accounted for this. Yet on a broader scale, I felt I was an insider because of the duality of my role in the research. I was aware of my position within the field, having contributed to the development of national nursing competences (Teenage Cancer Trust, 2014); published several publications; and speak often at national and international AYAC conferences. I was conscious that I was the curriculum leader and developer of the only accredited AYACC course in the UK and I held a privileged position of having access to information on AYACC in general. I was also conscious of my power balance as a holder of knowledge. I became aware of the insider researcher challenges which accompany the fluctuating role (Drake, 2010).

To manage those I had taught, my supervisors and I agreed that these three nurses had stories to tell and that they wanted to be heard by the fact they had volunteered to participate. I respected their offer, so they were included. I would be speaking with them about things we had not spoken of before in past teaching. I did not want to take for granted anything they would tell me because I had met them online for a short time previously. Afterall, as Kim (2015) espouses, I was keen to develop an ethical relationship with the participants, ascribed as relational ethics (Clandinin and Murphy, 2009), an important stance in NI.

3.9 Narrative analysis

Given the relational and interactive approach of NI, I moved between the stories gathered from the conversations, the research question, the literature and the methodological approach of Clandinin and Connelly (2000) that is founded on Dewey's theory (1938). This was an equally exciting and daunting part of the process of developing narrative analysis. Clandinin and Connelly (2000) and Riessman (2008) warn of the struggle researchers have in letting narrative field texts speak for themselves (Clandinin and Connelly, 2000, p. 130) in order to preserve the uniqueness of the narration in analysis. Therefore, I sought to

explore within what was told, not told and how it was told by the nurses to gain a deeper meaning (Holloway and Freshwater, 2007).

3.9.1 NVivo 11

I used the computer package NVivo 11 to help me manage the data. NVivo can be used to assist with qualitative data management and give the user tools to discover tendencies, recognise themes and derive conclusions from large data sets (Mortelmans, 2019). It has several functionalities such as transcription, document storage, coding and categorising, making connections and comparisons between themes and general project organisation. For the most part, I used this package to manage the data and to look for broad themes and code the transcripts. I was mindful that I did not wish to reduce the files wholly to themes and worked hard to not lose sight of the research question. As a researcher with dyslexia, I felt I needed to physically handle the data so I also used manual processes such as highlighter pens and post-it notes to help me arrive at the themes.

3.9.2 Early flirtations

The nine nurses were given pseudonyms and any potential identifying information has not been used in this thesis. They provided me with basic demographic data. At this point, I introduce the reader to the participants to give some contextual information based on this demographic data. As well as transcribing the stories, I re-created a short biography of each participant which included a title of their story. These are discussed later in this chapter. By way of introduction to the nurses, Table 3.3 outlines demographic information on each nurse in this research.

Table 3.3 Demographic information

Name	Age	Gender	FT/PT	AYA Unit	Adult, Children's or dual qualified	Years Qualified	Years working with AYAC
Brian	25	M	F	1	A	2	1
Jade	23	F	F	2	C	2	>0.5
Anna	28	F	F	3	A	7	6
Claire	23	F	F	4	A&C	1	1
Jessica	24	F	F	2	C	2	1.5
Jemma	25	F	F	5	A	2.5	1.5
Lauren	48	F	F	6	A	1.5	1.5
Rachel	28	F	F	6	C	6	1.2
Amy	25	F	F	6	A	4	0.8

Polkinghorne (1995) considers two main analytical approaches in NI: paradigmatic mode and narrative mode. The former tends to recognise categories and patterns. Kim (2015) postulates that this is an acceptable means to find patterns in stories and fit them into existing constructs or theories. This also connected me with the stories in my early flirtations. The narrative mode of analysis (Polkinghorne, 1995) advocates that the researcher relates to the stories in a more congruent way which is in keeping with NI methodology.

I needed to consider how I was going to approach this aspect of my study very carefully given that no one procedure is deemed acceptable without taking into account the context (Holloway and Galvin, 2016; Riessman, 2008). Riessman (2008) describes various approaches to this such as thematic, structural and dialogic/performance analysis. In this instance I decided to adopt a thematic analytical approach (Braun and Clarke, 2013). I recognise that this can be interpreted as a reductionist approach, but I wanted to take a holistic view of the data and look to what is said within the whole story rather than 'fracture the data'. By coding and categorising data I sought to identify patterns across the data, thereby taking a holistic perspective (Holloway and Freshwater, 2007; Holloway and Galvin, 2016).

The narrative mode of analysis (Polkinghorne, 1995) advocates that the researcher relates to the stories in a more congruent way, which is in keeping with NI methodology. By adopting this approach, I focused on the whole story,

considering aspects of the experiences that were relayed to me taking account of context, feelings and interactions whilst I remained present in the retelling (Chase, 2003).

3.9.3 My analytical framework

Clandinin claims that “moving from field texts [transcript, field notes] to interim and final research text is a complicated and iterative process, full of twists and turns. There is no linear unfolding of data gathering to data analysis to publishing research findings” (Clandinin and Caine, 2013, p. 49) and this was also my experience. Based on Dewey’s (1938) understanding of experience, Clandinin and Connelly (2000) suggest working in a relational way with the data and speak of a three-dimensional space in which all stories occur.

The three-dimensional spaces are known as the ‘three commonplaces’ and include temporality, sociality and place. This was used as an analytical framework to find meanings and interpretations from the stories. The ‘temporality commonplace’ refers to continuity, the past, present and future of an experience. The ‘sociality commonplace’ refers to personal and social aspects of the experience; and the ‘place commonplace’ addresses a place or places where an experience occurred (Clandinin and Connelly, 2000, pp. 50-51). This conceptualisation of research data is central to NI based on Dewey’s theory, is referred to by Clandinin and Rosiek (2007) as “Attending to experience through attending to all 3 commonplaces simultaneously is, in part, what distinguishes Narrative Inquiry from other methodologies” (p. 39).

Clandinin and others emphasise the importance of thinking ‘with’ stories, to relate to the stories and to avoid imposing my presuppositions (Clandinin et al., 2011). Clandinin and Caine (2013) also consider the contexts of stories and in this case, I constantly referred to the research question.

Using NVivo 11, I read each story, gave it a title, and, during my flirtation with the data, began to highlight and code sections of the transcript, keeping an open mind as to where these early codes might take me. I arrived at 56 codes (Table 3.4).

Table 3.4 Initial codes

1. Initial codes	
1. Adult vs paediatric care perspectives	29. Negotiating the cancer journey
2. Becoming clinically competent	30. Parental and family involvement
3. Being a junior nurse	31. Patient friendship or attachment
4. Being a similar age	32. Patient stories
5. Being an older nurse	33. Poor outcome patients
6. Boundaries and being professional	34. Pre-registration experience
7. Communication strategies	35. Relating to patients and families
8. Coping in the moment	36. Rewards of TYA cancer work
9. Coping with losing patients	37. Self-care strategies
10. CPD	38. Staffing challenges
11. Dealing with death	39. Support outside work
12. Dealing with sad news	40. Switching off from work
13. Different to adult or paediatrics	41. The ward team
14. Difficult conversations	42. Things I have learned along the way.
15. Doing something positive for the family or patient	43. Things that might be supportive for nurses
16. Early career decisions	44. Time
17. Emotion work	45. TYA care differences
18. Enjoy working with TYA	46. TYA specialist care
19. Feeling special; that you make a difference.	47. Uniqueness of TYA
20. Getting on with it when patients are ill or dying.	48. Using humour
21. Getting to know patients	49. Using the physical environment
22. If it was me	50. Ward support mechanisms
23. Impact of COVID-19	51. What keeps me going on
24. Impressions of physical environment	52. When it's difficult or sad
25. Interpersonal interaction with TYA	53. When the news is bad
26. Learning to do the job	54. When the news is good
27. Managing complex clinical care	55. Wondering about patients when they're not there
28. Moving beyond Band 5	56. Youthful vibes on the ward

I revisited the data several more times and began to collapse codes (Table 3.5).

Table 3.5 Collapsed codes

2. Collapsed codes
AGE OF NURSE
COMMUNICATION AND ENGAGEMENT
COVID*
EMOTIVE WORK
FAMILY & FRIENDS
MOTIVATION
PT STORIES*
SUPPORT MECHANISMS FOR THE NURSE
TYAC nursing

‘PT STORIES*’ was removed as it gauged how often nurses talked of patients when telling their story rather than interpreting what they meant by said stories.’. Similarly, COVID* was also removed as this was inevitably spoken about because the study was conducted amidst the pandemic, and I felt this was an outlying factor. It was also not an aim of the study to examine this, though as said previously I had to acknowledge its presence.

As I did this, I revisited the transcripts and audio conversations and looked for what the ECNs were saying within the three commonplaces. I was working in a relational way, backwards and forwards (Clandinin and Connelly 2000; Kim 2015) from the ECNs’ stories to my thinking within the three-dimensional spaces. Using NVivo I was able to create framework matrices and as I ‘flirted’ with this some more, I decided that elements from the stories would fit within the broader remit of all three commonplaces: temporality (which I shortened to time), sociality and place. An example of the data as it appeared on the NVivo framework matrix for time is given in Table 3.6, sociality in Table 3.7 and place in Table 3.8

Table 3.6 An example of framework matrix time

Framework...	A: Becoming	B: Becoming clinically competent	C: Early career decisions	D: Pre registration experience	E: Learning to do the job	F: Being a junior
<p>Clipboard</p> <p>Search...</p> <p>8: Rachel Age = 25-29 yrs Gender = Female</p> <p>9: Lauren Age = 45-49 yrs Gender = Female</p>		<p>I think i think i'm quite glad that I was (qualified for 4 years) before i'd gone there as is it's quite specialized and there's lots to sort of wrap your head around. So I was glad I got sort of my basic nursing skills together first and emm learn how to sort of engage patients and their families and their parents and things because cos obviously it's like seems to be like next level there the conversations and the information that's obviously, because they got either cancer or some something quite serious, so it's nice to sort of get your basic communication skills together first and then. Well, I felt it helped anyway.</p> <p>there was some things that they just did, slightly different, and what I feel like a fish out of water in the actual job because you've got so much health stuff to learn, you know, and emmm in particular skills bit I think, you know, being older and trying to learn new skills is a little bit like ooh (takes a big intake of breath and smiles)</p> <p>I am definitely trying to learn all</p>	<p>I think i think i'm quite glad that I was (qualified for 4 years) before i'd gone there as is it's quite specialized and there's lots to sort of wrap your head around. So I was glad I got sort of my basic nursing skills together first and emm learn how to sort of engage patients and their families and their parents and things because cos obviously it's like seems to be like next level there the conversations and the information that's obviously, because they got either cancer or some something quite serious, so it's nice to sort of get your basic communication skills together first and then. Well, I felt it helped anyway.</p> <p>first ones that were introduced to a new streamlining method of getting a job after you've qualified emm so that meant that we weren't going for an actual interview,</p> <p>first ones that were introduced to a new streamlining method of getting a job after you've</p>	<p>I had a few different placements and I was lucky enough to have a placement on teenage cancer unit. And it was like it was a six week place when I think, it was them the just the one before Christmas. So there was like a really nice atmosphere on there and even though I found it really intimidating to start with emm because it's so specialized and I didn't really know lots of why's and what's and what was going on really, but I just straight away saw the relationships between like the nurses and the patients was like the focus on the wards and and I really, I really like that.</p> <p>I had a few different placements and there's not a lot of that young people I've made assumptions; probably, from working within it myself. But no, not a lot in the training.</p> <p>There's not a lot of that young people I've made assumptions; probably, from working within it myself. But no, not a lot in the</p>	<p>we were encouraged when we started to look at the blueprint of care and the cancer plan for in COUNTRY. And so that was sort of our managers have encouraged us all to read that. And the COUNTRY protocol for caring for young people with cancer and those were emm I think she sent those to us when we started and told us to read through those and I mean, there's the age range, I don't think... I haven't ever been any sort of study days or any opportunities so far on like specifically to TYA and sometimes you know some of the nurses, we would like a bit more teaching maybe on how to deal with that age range because I think sometimes you just have to learn on the job and you just you feel a bit in the deep and sometimes emm, I still do.</p> <p>I qualified as a nurse 18 months ago</p> <p>I feel like a fish out the actual job because you got so much health learn, you know, and particular skills bit I miss being capable, I suppose, because you know you go in and you're not capable are you ooh (takes a big int</p>	

Table 3.7 An example of framework matrix sociality

G : Support outside	F : Self care strategies	E : Feeling special- that you make a difference	D : Boundaries and being professional	C : Being an older nurse	B : Being a similar age	A : Being a different age
<p>just speaking to colleagues and stuff has been the most helpful thing for me.</p> <p>usually I used to walk and my walk from work to home, used to be my like transition period like work to home and now I drive so guess it's quite a similar thing</p> <p>I always think of myself, I sort of identify as a nurse. I'm dressed and I'm a nurse and I just feel like, I don't know, I feel like when I'm at work. I'm probably more sort of emotionally okay with everything because I've got my uniform on and I'm a nurse, and emm sometimes I feel like after that. I'm like, oh yeah, I'm actually human again and now I'm sad</p> <p>get in a bath or spending a bit of me time listening like to podcasts or and watching telly and just trying to focus and and you know sit and think what was even if theres things can discuss without : you know, and still r of time to chill and get things off your mind, rather than just, you know, and I walk home from work, for example, as well. I think friends don't always sometimes walking home and not the situation if you've</p>	<p>Or when a patient remembers something specifically about you or they say, I'm really glad that you're looking after me today</p> <p>And I was there for them for a lot of that journey and the parents are there as well. And it was You know your mind, rather than just, you know, hearing from other people feedback that you'd really help them erm or that they really liked</p>	<p>I do have that professional boundary and I don't know whether his dad said it to make him feel better because he was really agitated at the time but that really, that was one of the most challenging times of this whole year for me.</p> <p>And I think that at the moment that's something that I'm trying to figure out (protect yourself.... to keep yourself contained), and I think everybody tells you when you're training you need to keep that boundary, need to keep that line, you need to protect yourself. But no one actually tells you how to do that specifically emm so I feel like I'm definitely trying to work that out</p>	<p>some of the adult nurses will find it harder to look after the teenagers, because they think 'oh I don't like them' or they maybe don't know how to relate to them or they find the more difficult to look after cos they maybe find it more emotional or they just.... it's just not what they used to.</p>	<p>I think over the course of the year, you do have, like, a lot of laughs with them a lot of like jokes emm whilst also doing all the like the nurse stuff. So I think that's where it's really different with and teenagers as well as especially when you're like when you're I mean I'm 23 so I come in that age bracket of TYA's ... when you're that age yourself looking after these people. I think that's a really unique and different situation.</p> <p>I think it can help in a lot of ways and emm then I think that it's also maybe not so good in a lot of ways, and that I personally really really like looking after that age group emm yeah</p> <p>I also think that the age can make a difference as well because I think I'm looking after patients that similar age to me and this is the same to some of the other nurse who are maybe some in the similar age range as me that it can be easier to relate to someone if you are if you can see similarities in them, you know, where as some of the old</p>	<p>1 : Claire Age = 20-24 yrs Gender = Female Yrs working with TYAC = ...</p>	<p>2 : Jade Age = 20-24 yrs</p>

Table 3.8 An example of framework matrix place

Experiences of TYA Nurses.nvp - NVivo 12 Pro

File Home Import Create Explore Share Framework Matrix Tools Framework Matrix

Clipboard Format Find & Select Annotations Editing

Undo Cut Copy Paste New Annotation Annotations

Delete Summary Link Auto Summarize See Also Link Summary

Zoom Quick Coding Annotate Annotatic View Also I View

Associated View Layout

Rows & Columns

SEARCH PLACE

Framework Matrices

Name	Framework Matrix
TIME Cancer journey	
TIME Beyond	
TIME Becoming	
TIME 24 hour care	
SOCIALITY Social	
SOCIALITY Personal	
SOCIALITY Culture	
PLACE	

4 : Brian
Age = 25-29 yrs
Yrs qualified = 2yrs
Yrs working with TYAC =...

5 : Jemma
Age = 25-29 yrs
Yrs qualified = 2.5 yrs
Yrs working with TYAC =...

Code At	Code At	Code At	Code At
A : Impressions of physical environment yeah, I'd never do it on any other wards. You know if I mentioned it to my other friends that are like, what?, Yeah.	B : Using the physical environment If I'm not too busy then we'll kind of try and watch a bit of TV with them or just have a chat. Ummm, we've got a pool table in our day rooms so some of the lads like to do that and see that it really depends on the workload.	C : Youthful vibes on the ward because of the patients and then the team. It's kind of quite a youthful vibe. Everyone like ... it's a nice, it's really nice as everyone gets along well. Hmm, and also because it's quite you know, when you go to other groups, you can get a bit of a kind of cliquy groups forming between staff members, which we don't have at all.	
I'd worked on as a health care assistant from being a student on the bank, it was, it was just so bright and airy and have a lovely games room as you walk in and I just thought, wow this would be such a nice place to work.	I said 'we're going to have a movie night at six o'clock. I'm going to have all of our work done and we're going to watch a movie until eight o'clock' and the girls were like but you won't have time. So we made hot chocolates and they got to pick the movie and actually two of the parents emmm mothers sat in with us as well.	yeah, I'd never do it on any other wards. You know if I mentioned it to my other friends that are like, what?, Yeah.	because of the patients and then the team. It's kind of quite a youthful vibe. Everyone like ... it's a nice, it's really nice as everyone gets along well. Hmm, and also because it's quite you know, when you go to other groups, you can get a bit of a kind of cliquy groups forming between staff members, which we don't have at all.
I think the environments quite that big thing. I think it's different when you have a bay comparing to a side room. I think it's quite nice that you go into their space			

In Nodes Enter node name (CTRL+Q)

This in turn was helping me shape my representations of the stories. Each nurse's experience was unique and within the dimensions of my framework, I found many interesting elements to the stories that often related to my own experience and knowledge base.

3.10 Chapter summary

Gradually it became apparent that there were also many interconnections between the various stories which I called 'common strands' and these eventually formed the basis of the findings and discussion in Chapter 5. I made choices about which elements of the nurse's story to present to the reader. These choices were based on what I felt were relevant to the research question and influential to data analysis either because they made me think of something I had not previously considered; something they said provoked an unanticipated consideration; or they talked of something I eventually recognised as a common strand.

The next section presents three of the nurses' stories. Due to the word limitations of the thesis, six of the stories appear in Appendix 12, in part because I did not want to reduce some of the quotes for fear of diminishing the participant's voice. For clarity, all narratives contributed to the analysis and the reader is reminded to attend to the additional narratives in Appendix 12.

3.11 Nurses' stories

Brian's story: *Stepping up to the job*

Brian was a 25-year-old registered nurse (adult), qualified for two years. Straight after qualifying he did a full-time master's degree and returned to clinical practice in an AYAC unit to consolidate his clinical skills. He went to an NHS open day where there were a variety of jobs on offer. He was intrigued by the AYAC unit and enjoyed adult oncology experiences whilst a student nurse but never worked in a youth setting.

Brian was keen to consolidate his clinical skills set, become clinically competent and confident in managing complex care, recognising the accountability that accompanied that. He became skilled at managing IV lines/bloods,

chemotherapy administration etc., which he seemed to enjoy. He saw this as an asset for progressing his career.

His view of meeting AYACs' holistic or specialist needs depended on if clinical care was completed. *"If I'm not too busy then we'll kind of try and watch a bit of TV with them or just have a chat."* He countered this by recognising the value of developing long-term relationships with patients *"but it's nice that you can kind of talk to the patients and build that relationship more than a lot of ones where it's kind of just in and out, don't really get to talk to them much."*

He enjoyed building relationships with AYAC patients and felt rewarded when patients who he had got to know over time during treatment, were discharged and returned when in remission. Equally, he found it upsetting when he incidentally heard that patients he cared for had died. It was as if his job is the 'treater' only, yet he was not afforded the chance to learn about the outcome of his efforts, good or bad.

He recognised that when patients die it was sad but was not sure how he dealt with it; he seemed to be able to compartmentalise it: *"I think you just have to remember that you can only try your best...I think you shouldn't be in the profession if you don't [find it challenging when a patient dies], to be honest with you. I think I deal with it. I'm not sure. My mom always asked me about it."*

He found it easy to communicate with TYAs, particularly because they were the same age and have shared common interests; he referred to seeing them as friends: *"sometimes you have to treat them as friends to kind of get along with them"* and seemed to feel comfortable with this.

He valued his co-workers who were supportive, particularly when there were any difficult issues to deal with: *"they [co-workers] are like whenever you have issues there, they are kind of dealt with very nicely."* There did not appear to be any structured support system for staff. He recognised that even if staff were troubled by poor patient outcomes which might affect their mood, the work still carried on: *"everyone just kind of had to...get on with the day, to*

be honest with you, I think you just can't dwell on it for too long or else it will kind of bring you down."

Brian appeared to have a plan that this job would help him consolidate his clinical experience and learn his craft of being a registered nurse: ***"And I think one of the positive things is that you get very skilled on this particular ward and so it gives you the opportunities to move on...."***

He had ambitions to further his learning in the field of TYA cancer care, despite not being offered any specific continuing professional development (CPD) in this field, and ultimately wants to work in research. In addition, he mooted that he did not want to be doing shift work long term. I was struck by his ambition to move beyond this which is synonymous with being an ECN where the expectation is to predominantly work shifts: ***"if you're working a lot of weekends, a lot of nights, it wears down at you after a while."***

Jemma's Story: Being responsible

Jemma was a 25-year-old registered nurse (adult), qualified for two and half years. A post-qualifying rotational post in oncology meant she had a six-month AYAC placement which secured her passion for this specialism. She thought the environment was appealing: ***"it was just so bright and airy and they have a lovely games room as you walk in and I just thought, wow this would be such a nice place to work."***

In the first year of qualifying, she had a lot to learn including many clinical competencies. In AYAC she was struck by the intensity of work with parents/families who were constantly on the ward: ***"I wasn't really prepared to kind of nurse the patient and the family all together."*** She recounted where a parent became acutely unwell on her shift and she had to manage the parental emergency alongside the patients. She spoke of being the only RN on shift who could undertake specialist clinical skills such as administer chemotherapy and recognised the pressure/responsibility that this brings: ***"if anything happened to them [parents/family], I still have to nurse them as well. You know, so there's a lot to it. I know it's easy for the matron, cos sometimes it's all about numbers, but you have to realistically, think of safety, safety in***

numbers.” She described where once she did not feel it was safe to give chemotherapy one evening as there were reduced nurses on shift and refused to do this. The next day the young person became acutely unwell during treatment when a full complement of staff were on duty. The patient was transferred to intensive care. She was relieved she made the right decision.

She enjoyed seeing patients return when treatment ended: *“It’s so nice for that relationship, both for nurses and for the patients... It’s just so nice to see people at the other end.”* The opposite of this is if patients relapse or die. This could be carried beyond the shift: *“when a death happens in the ward... and you’re not on shift we’ll always get a message.... Because you’ll always be wondering I wonder how they are today.”* She described how this can be further compounded if a patient is more accepting of their fate than their parents. Where this happened, it appeared to have been difficult for all involved and structured support was put in place for the parents and the staff by way of a facilitated meeting with psychologists/counsellors. She said she had very supportive colleagues.

She enjoyed getting to know patients and building a rapport, in the knowledge AYA go through significant developmental changes. As a young person herself, she understood the nuances of life as a young adult. She recounted when she worked hard to finish all clinical jobs to create a movie night for three girls, one of whom was younger and shy. This was a purposeful action to encourage the younger one to engage with the older ones, so she was less socially isolated. A friendship between those patients blossomed afterwards.

She used her youth to gain middle ground and gain trust with patients but made it clear to them that she had their well-being at the fore, as a professional. She described some feedback from a patient: *“I trust you Jemma, I know you’re like seeing that other side that’s not just a friend.... you have to think of the well-being of the patient at the end of the day.”* She acknowledged the need to have fun and humour at work with patients too: *“I know there’s always bad days but when the good days are good they are, you know, we always have good fun.”* I was struck by the extremes of emotion she experiences, all of which could happen in very short spaces of time.

Outside of work she revealed she had support from nursing friends and her family, particularly her parents. Her parents appeared to play an important role in strengthening her resolve to do her work. She valued this very much and was conscious of maintaining professional boundaries here: ***“so my parents are very good at listening and kind of then, just kind of forget about it.”*** She recognised the difficulty for her friends of comprehending the work she does. She had a sporty active lifestyle which was key to her maintaining her own well-being. Jemma was reflective, keen to learn and develop and had undertaken AYAC specific education. She was keen to educate colleagues too. Her ultimate ambition was to become a clinical nurse specialist.

Lauren’s Story: Balance of hope and sadness

Lauren was a 46-year-old RN (adult) qualified 18 months. This was her first nursing post on an AYAC ward. She had been a social worker for 20 years and studied family therapy. She had an AYAC placement experience in her training and was drawn to that field. From her previous work, she felt she brought transferable skills into this field of care, especially focusing on the family unit. Lauren focused on developing clinical competence as well as attending to the holistic needs of TYAs and recognised there were times when these aspects of care compete. She recounted a difficult situation involving communicating bad news to a 15-year-old patient whose treatment had failed. She spoke about what a lovely boy and family this was to deal with and of the disappointment on a personal level for her as well as for the patient and the family: ***“you know those moments are critical for people aren’t they, and the emotions are going to be high.”*** She had to concentrate on delivering complex clinical care and balance her high emotions with those of the patient and family: ***“it’s just really emotional and yet... as the nurse. I need to be going in there dead on three o’clock... give him treatment... when he and mum are both full of tears and it’s just sad.”***

She was very aware of AYAs’ emerging adulthood experiences. She used her intuitive knowledge to gauge the mood as to how and when to interact in emotive situations. Lauren told stories of several patients who resonated with her for different reasons, one because he had relapsed disease and another girl she cared for who was actively dying. She affirmed that she was not taught any

adolescent care in her nurse training. She appeared to know when and how to intervene, possibly strengthened by her previous experience as a social worker. However, as an ECN she recognised the tensions of managing expectations of being an autonomous practitioner and now having to work in a team when decision-making is shared.

Working alongside a close team was important to her and she valued their experience and diversity. Bonds were made with colleagues on a shift when something significant happened: the value of a shared experience. Staff support was an informal process in her work but there were support systems available if she wanted to seek them out. She was not used to this as a social worker where supervision was mandatory. She was perplexed that it was not in nursing. She was a reflective person and read and wrote reflectively, finding this therapeutic. Her mother, an ex-nurse understood some of the complexity of her work which was helpful. Her husband was supportive of her work in a nonverbal sense and knew when she needed to self-care. She was motivated by this type of work with young people and spoke of the importance of maintaining their hope. She wanted to work clinically for the next five years and may pursue a research career. She has found fulfilment in working with TYAs with cancer: ***“I think there you get a nice balance of hope and sadness in cancer care.”*** It may have given her more fulfilment than she might have expected, and she recognised that it had longevity as a career: ***“I think the scope of learning is really big in cancer care. So, it's kind of grabbed me, I think.”***

As I revisited and retold each narrative the common strands developed. In undertaking narrative smoothing and retelling (Kim, 2015), perceptions progressed to enable the elaboration of common categories embedded within the three commonplaces. Through this analytical process, three overarching strands were formed: emotion of it all, age matters and AYAC nursing. The next chapter, Chapter 4, elaborates on the inquiry findings which are then discussed in the context of common strands in Chapter 5.

Chapter 4 Inquiry Findings

4.1 Introduction

This chapter sets out the findings in relation to Clandinin and Connelly's three-dimensional context (Clandinin and Connelly, 2000, p. 50), illustrating the connections made between temporal, social and place elements as I interacted within and across the conversations to make sense of them. I used this as the analytical framework by which to explore and analyse findings. Some individual narratives and descriptive analysis of the conversations with the ECNs are presented. Following this, common strands are discussed in Chapter 5.

4.2 Temporality

In Clandinin and Connelly's (2000) framework, temporality considers past, present and potential future aspects of stories. When analysed in this way, it may reveal how change occurs over time and serves to remind us how past experiences influence how future events are perceived (Clandinin and Connelly, 2000; Clandinin and Rosiek, 2007; Connelly and Clandinin, 1990). Often when stories are reminisced, subtle changes are retold which allow for new experiences that can add depth to a person's narrative. Therefore, there is a notion of 'process', 'journey' or 'continuity' in narrative analysis as we listen to stories that are told and retold, (Carr, 1991; Clandinin et al., 2016). As I listened to these stories being retold, I recognised similarities that gave rise to several temporal themes to illuminate their experiences.

4.2.1 *Becoming an AYA cancer nurse*

Each conversation opened by inviting the nurse to tell me how they came to be working in AYAC care, signalling a temporal aspect to their story from the outset. Hence, the theme 'becoming' became apparent as it signalled the start of their AYA cancer nursing experience.

Six of the nine nurses (Anna, Brian, Claire, Jess, Jemma and Rachel) gained insight into haematology/oncology and or AYA cancer from having had a student nurse placement in an AYA cancer or haematology/oncology unit which fuelled their interest in working in the specialism. Claire gave a good example of this:

“As a part of that placement, I got to spend two weeks in the teenage young adult cancer unit... and I just really, really enjoyed working there and enjoyed the fact that I could use paediatric skills and adult skills.”

Anna recognised that she learned more about caring for AYAs in general from working in the unit than she was taught during her university course, suggesting she was unprepared to meet the specific needs of teenagers/adolescents as a newly qualified nurse:

“I had also been a student, a management student on that ward and the patient was there at the same time and kind of the trajectory of her diagnosis and treatment really kind of impacted me and made me kind of see things from different perspectives to how we were being shown at university.”

Jess had a second-year student nursing placement on the unit and was offered a job at that time. The manager capitalised on recruiting student nurses to grow them as potential employees in the future. This practice exists in part because of the challenge in recruiting nurses in the NHS:

“I had a placement upon the ward that I’m working at the minute. I got offered an interview for the job in my second-year training and so went for it.” (Jess)

Katie, Brian and Jemma were recruited to the AYA cancer setting as new graduates through a hospital-wide recruitment scheme, some of which offered a rotation between wards, to secure their first post-qualifying job.

“I did acute oncology for six months, then I did the oncology day ward for six months and then my final placement within the TYA ward and so it’s a nice specialist unit and that’s where I’ve stayed.” (Jemma)

Whilst Lauren did not have a student placement on the unit, she, like Anna, acknowledged that little was taught in her pre-registration nursing programme on caring for teenagers. Lauren had experience of this type of work from her previous career as a social worker, which gave her a unique perspective:

“There’s not a lot of that...I’ve made assumptions, probably, from working within it myself. But no, not a lot in the pre-reg training.”

This suggests that Lauren's previous exposure to working with AYAs was a motivator for working in this field as a registered nurse, and perhaps that she was comfortably familiar working with this age group.

The nurses felt that it took about a year before they became clinically competent in AYACC. Jade, Amy and Rachel all had worked in other environments (18 months to four years) before securing employment on the AYAC unit and all were pleased to have gained in confidence and clinical competence prior to starting work on the ward as reflected in Rachels comment:

"I'm quite glad that I was [qualified for four years] before I'd gone there as is it's quite specialised and there's lots to sort of wrap your head around. So, I was glad I got sort of my basic nursing skills together first and learned how to sort of engage patients and their families and their parents and things."

It was apparent that all these nurses needed to learn to deliver very complex clinical care within weeks of starting on the unit. Once they were assessed as clinically competent, they would often be assigned as the senior nurse on the ward, mostly out of hours, delivering complex clinical care and making clinical and management decisions despite their junior position. For some this very challenging. Lauren summed this up when she said:

"I feel like a fish out of water in the actual job because you've got so much health stuff to learn, you know, and in particular the skills bit I think... being older and trying to learn new skills is a little bit like ooh [took a big intake of breath and smiled]."

Whilst all see this as something that must be accomplished, Brian saw this as an opportunity for developing clinical competence that may benefit him in the future; perhaps he saw this as clinical or professional currency:

"It gives you the opportunities to move on with stuff like getting your chemo competence, you know your lines, you're taking bloods, calculations. You know, you become quite a skilled nurse with, you know, lots of chances to move on to other places."

It appeared that learning to be an AYAC nurse came after they had developed their clinical competence as approved by the ward management. The priority for the service was that they became competent and safe at delivering clinical care such as administration of chemotherapy, IV-line management and dressings over what the specific AYAC needs might be. Claire gave a good example of this when she told me that:

“I think I’m getting better at more sort of holistic care and because there’s obviously less to focus on because you know how to get your drugs, how to do your PICC dressing for example, but then I think...one of the biggest things for me was at the start everything was so overwhelming and how busy it was.”

This appeared to be all-consuming for these ECNs and as their competence and confidence grew, Claire, Jemma and Anna recognised this in terms of taking a year:

“I got signed off from my chemo within, I suppose, like a less, just less than a year of qualifying so then when I went up to the TYA ward I had this extra responsibility because I was able to give chemo, I was able to do quite a lot of things.” (Jemma)

Despite Laura being an older entrant to nursing, she acknowledged the challenges that learning these clinical skills brought and that they took priority over considering the unique needs of AYAC. She also wrestled with no longer being as competent as an ECN as she was as an experienced social worker:

“I just focus on the nursing skills bit and learn those things... And sometimes I miss being capable, I suppose, because you know you go in and you’re not capable are you when you start?”

When she developed these technical skills and gained experience, she began to enjoy the specialism and communicate with patients more confidently.

The ECNs recognised the ongoing importance of developing their technical/clinical competence in the specialist environment all of which was delivered by them over the 24-hour period, seven days per week. This care delivery was task-orientated and had to be signed off by managers indicating

they were competent so quite quickly they could be given responsibility for a group of patients as newly registered nurses. Those with a year or more previous experience prior to starting on the AYA unit, valued this preceptorship period as a new registrant but still acknowledged they were entering a specialism that required a very distinct technical and holistic care skill set for looking after this patient population. Arguably though, they could not quite define what holistic AYA cancer care was until they had accomplished specific technical skills.

4.2.2 Time - shift work

A recurrent factor for all these ECN was that they worked over the 24-hour time period, seven days a week, on the frontline, and I recognised this as another temporal feature in this study. They were often left in charge in the evenings and night-times from about one year after qualifying. Many of them referred to activities that happened out of hours, when there were no senior nursing or medical staff on duty, and how they dealt with them. These activities could be clinical or psychosocial in nature. I was struck by the amount of activity that went on outside of normal working hours and the responsibility that they felt encumbered with. It was almost as if once they were signed off as clinically competent, they were left with hugely complex clinical responsibility as well as feeling responsible for lodging parents. Jemma explained:

“One night a couple of months ago I heard them saying that all you know you’ll be the only nurse here, and there’ll be a senior nurse across the corridor. I was like ‘you can’t leave me’...it’s not like it’s just the patients I have here, it’s like I have family members in those rooms too.”

She acknowledged the stress this brought and appeared to have been self-aware that on one occasion she was working at the edge of her professional capacity/competence. She asserted herself and was supported in her clinical decision-making by the consultant. Her story highlighted the pressure of staffing challenges that she experienced:

“The division was so short staffed. I had seven in-patients and six people to start their next cycle of chemotherapy and one patient was a day 1, cycle 1 of IV methotrexate and I just rang the consultant. And I was like, ‘I can’t

start today... I physically it's not safe... I haven't had a break... it's just so unsafe'. If anything happens like I have no, I have no backup."

She recognised the pressure associated with lack of staff support as she became an autonomous practitioner. She proceeded to make a sound judgement call as the next day the patient reacted badly to chemotherapy, requiring an intensive care admission.

During out-of-hours shifts there were strong clinical demands on the nurses' time but on balance the nurses recognised that during these periods, they often had more time to engage in meaningful conversations with patients, which they appeared to find favourable and enjoyable.

Brian saw the opportunity on using the environment to engage with patients at night, though he may have identified this as a personal treat than a purposeful opportunity to engage with AYA:

"We've got a pool table in our day rooms so some of the lads like to do that and see that it really depends on the workload. I think on the night shifts you can do it a bit more you know, until it's too late, but it is nice to do that when you can."

Amy and Jade spoke of the value of quieter times at nights when they could get to know patients better:

"I'll go in, especially in a nightshift when you've got time.... go in and have a chat with people and some patients I could sit with for an hour and just talk to them and then you go to the next patient." (Amy)

Perhaps this quieter time at night created time and space for patients and ECNs to reflect on the enormity of cancer that has disrupted their lives, and the ECN happened to be the one to illicit this expression. Without shift work they may not get these opportunities to bond with patients and develop their autonomy as registered nurses. It felt like shift work was a 'rite of passage' and an important part of their career trajectory.

4.2.3 Being part of the cancer journey over time

Given they worked with patients over the 24-hour time period, they also spoke about getting to know patients and families over a long period of time as they

witnessed their cancer experience. Jade recognised this quite clearly once she had experienced it:

“I feel that you get to follow a lot of the patient's journey... and you're sort of there all the time... Yeah, definitely I think that it's such a long process that maybe you didn't realise until, until you're faced with it.”

Jemma relished watching young people grow into young adults such as the amount of time they spent with them during protracted treatments:

“I think it's nice to sometimes watch if we have young girls or boys who come in and they're kind of 13 and, you know, sometimes they're with us for quite a long time. And I know I haven't been on the service like five years or anything, but you get to see them develop as a teenager.”

This observation of young people's transition into adulthood was another temporal feature. Anna enjoyed seeing patients improve at end of treatment having cared for them over a period of time:

“Over the course of a couple of weeks being reduced to being in bed.... not being able to do anything for yourself, struggling with eating and drinking and actually that really stuck with me.... so probably 10 months after me starting as a registered nurse she walked onto the ward and with crutches and it was really quite impactful to see that.”

Rachel and Lauren noted that the relationships with patients and families developed over months to years through having various conversations, but that the counter to this was that these conversations posed a risk of patients wanting to know more about the personal lives of nurses too:

“Because you are spending so much time with them and they do want to know more about you.” (Rachel)

I wondered if this might be the start of them blurring their professional boundaries as their relationships with young patients and families were developing over time.

4.2.4 Beyond

Towards the end of our conversation to draw it to a close, I asked the nurses what kept them motivated and where they saw their future. I identified three sub-themes relating to this: job fulfilment, continuous professional development and career aspirations.

4.2.4.1 Job fulfilment

In general, they all enjoyed their work and seemed happy to be working in that environment, despite its busyness and sadness. I was struck by their energy to keep doing it and to advocate for young people knowing they were making a big difference to their lives.

Claire tried to compare it to working in an older adult environment:

“It can be one of the saddest environments, but it's not actually one of the saddest environments that you can work in, because I think a lot of the time people like ‘Oh that’s awful, like why would you want to work with teenagers have cancer, that is awful’ and you’re like, ‘yeah, it is really, really like it’s awful’ obviously but actually it’s, I find it one of the better environments to work in, one of the happier environments, in a way, because for example like I’ve worked with elderly people and I find that personally really, really sad, sort of not surrounded by their families and things sometimes.”

This comment also showed the intrigue that some outsiders might have in these ECNs’ work.

Jess, Brian, Rachel and Anna all stated passionately that they enjoyed their work despite the early morning starts and unsocial hours. Jess said:

“For knowing that you go in and for 12 hours, you can make a difference to somebody’s life and I, you know, I love the TYAs, I love that patient group, and yeah, I just, I just love being able to make a difference... I love my job.”

These nurses were proud of, and aware that their direct care genuinely influenced the patients’ experiences. Brian and Jess, expressed dislike for shift work and early morning starts in the long term and Brian recognised his own youth in this context:

“As a Band 5 you just do a lot of... you're just on and off nights all the time. So, I think that just takes its toll on you. And some people just, you know, just like to move on to somewhere where they're not doing as many or not doing any at all. You know, particularly when you're young, you still want a social life.”

I recognised that they too were as young as some of the patients they cared for which is discussed further in this chapter, 4.3.1.1.

4.2.4.2 CPD aspirations

Eight nurses stated that they wanted to undertake academic study in AYACC, some so that they could be better at doing their jobs and for others it seemed to be linked to career progression. Amy, Claire, Rachel and Jemma were keen to study a specialist course in AYACC with Amy adding:

“I'd love to do more training and maybe a master's, things like that and like things like the Coventry course really interest me but I don't know, I don't think management is where I want to go.”

Anna and Jemma had completed a specialist module in AYACC and recognised the value of learning for them. Jemma was pursuing more education in this field, thinking how this might help her future career:

“It's nice to say in five years' time, I'd love to have done a couple of courses in specific areas and maybe be a Band 6 or be a specialist nurse that everyone can't just stay as a Band 5.”

4.2.4.3 Career Aspirations

Alongside CPD aspirations, these nurses spoke of how they envisioned their careers and what would help them get there. Six nurses (Claire, Anna, Jade, Jess, Jemma and Amy) aspired to become CNSs in some form of AYACC, possibly as an outreach nurse, in clinical trials, palliative care or AYAC in general.

Jess considered experiences that could broaden her scope of practice that may situate her well to gain a position as a CNS:

“One day I would love to be a CNS. So... I think I want to go and get all my acute skills first and then go and get all my experience.... and get lots more

knowledge first. That's my goals. I will. I feel like I'm always going to want to stay into a TYA and oncology haematology unless something drastically changes, don't think I'm going to want to do anything else."

Anna, who was qualified the longest, began to question other oncology related work:

"I'm kind of torn at the moment... seven years down the line. And I really love TYA nursing but I don't know if I should dip my toe into something else a little bit just to see if I do really love TYA nursing and I'm quite at the start of my career really."

She spoke of considering experience in palliative care as did Lauren, who was unsure of her long-term commitment to working with AYAC. Lauren, with a previous profession behind her, seemed to enjoy her work with young people but was conscious of other experiences that she may like to pursue:

"I love young people and, but I'm not opposed to working with all age ranges of the adulthood. Yeah I want, I want to stay in oncology....When I came into nursing as at the beginning and I was thinking, I would work in palliative care, but now I'm in it. I quite like the live treatments.... if you're thinking about sustainability for yourself throughout to a career... I think you get a nice balance of hope and sadness in cancer care."

Brian and Lauren also offered that they may like to pursue a research career in this field. Brian seemed to be surprised at how much he was enjoying his experience in AYACC when he said:

"At some point, I'd like to go down that kind of clinical academic pathway. I like research myself..., I like to do a PhD.... But now working in this, I think I'd quite like to stay in it, and possibly do some research."

In this section, I learned how nurses arrived at working in this specialism and heard about their career aspirations, all strong temporal features in their narratives. Another striking feature was the fact that they, more than their more senior colleagues, all worked over the 24-hour, seven day a week, period. This highlighted some of the experiences they had of working with these patients during times when there was little senior support available to them. However, it

also shone a light on the fact that these nurses were getting to engage with patients during quieter times, perhaps when there were opportunities to explore personal insights that would not be expressed during busier times. It was clear that these patients were in hospital for long periods, so their relationships were being built longitudinally with the nurses.

4.3 Sociality

Connelly and Clandinin (2006) assert that narrative inquirers must attend to the 'social' dimension of their participants which draws attention to how personal (feelings about their experiences), social and cultural experiences or conditions influence their narrative. By personal conditions they mean "the feelings, hopes, desires, aesthetic reactions and moral dispositions" (Connelly and Clandinin, 2006, pg. 480) of the inquirer and participants. Social conditions refer to the situation itself, the conditions within which the nurse's experiences and events are evolving. They further add that a second dimension of the sociality commonplace usually focuses on the relationship between researchers' and participants' lives which has already been discussed in Chapter 3, as narrative inquirers cannot subtract themselves from the inquiry. Sociality also refers to the inward and outward focus on a person's desires, and aesthetic and moral reactions, as well as existential conditions, that is, environment and contextual forces (Connelly and Clandinin, 2006).

In considering the transcripts from this perspective, I found that some early codes often overlapped and during the analysis stage I made decisions about where each dimension should appear. For example, CPD featured in 'temporality' as I felt it was time bound but could also have featured in sociality or place as it could arguably form part of the learning culture of the specialist unit itself. For the purpose of the analysis, they appear where they do in order to provide structure to the thesis but it is recognised they will overlap and unfold as the analysis and discussion takes place, which is common in narrative analysis (Caine et al., 2013; Clandinin et al., 2017).

4.3.1 Personal

4.3.1.1 The nurses age and personal experiences

A striking personal feature of the participants was their age, which ranged from 23-48 years. The mean age was 28 years and the median was 25 years. All but one was 28 years or less, not much older than some AYAs they cared for as they are treated on the unit up until their 25th birthday. After this time, they are cared for in adult services. All nurses alluded to their own age or the ages of other nurses in the conversations.

Mostly, they felt that being a similar age had its benefits, particularly in helping them relate to patients. Jade articulated this in relation to her youthfulness (23yrs) and how older nurses might feel:

“I also think that the age can make a difference as well because I think I’m looking after patients that are similar age to me.... that it can be easier to relate to someone if you are, if you can see similarities in them, you know, whereas some of the old, older nurses might say that they prefer looking after the older patients because that’s what they can relate to.”

Jess, 24 years old, also saw her age as an advantage yet recognised the transience for her as she ages:

“Just sometimes it does cross my mind that sometimes they will know whoever’s in the, in the charts and whatever and no one else will know what they’re talking about.”

A remarkable feature of this appeared to be their perception of relatability because of age. Being a similar age was also reported as having risks associated with it. Anna, 29, Jess, 24 and Brian, 25, felt it potentially brought risks of being over-friendly by use of their communication styles. Anna recognised this when she spoke of other nurses:

“I think you also risk at times [having] ‘over familiarity’ with looking after the similar age groups because you think you know you’re the same age as me and I can do this, or this is how I would want to talk to you and almost it can, it can blur the language that you use at times where perhaps you’re using over friendly language or sometimes it’s actually a fine line.”

She also said that she altered her language according to the way she might like to be treated but equally, could see that this may be problematic. This risky strategy was noted when Brian stated that:

“Sometimes you have to treat them as friends to kind of get along with them, particularly as they’re your age, rather than treat them as patients and I think maybe helps.”

He saw this as a way to become an ally, as a means to enhance the relationship and did not articulate any risks associated this. Brian, Anna and Amy recognised personal similarities with patients that made them think they too could be in a similar position, which enhanced their relatedness.

Amy said that if it was she who had cancer, she would have a strong parental need:

“If it was me, I’d want my family there, you know because I’m 25.”

Despite this, Anna also recognised that as she has aged and become more experienced in AYACC, that the young age of patients still resonated with her:

“I’ve probably matured slightly, things can always touch a nerve and I think I can deal with that a bit better in myself, so I don’t always put all of that on to myself but... I still think it kind of resonates.”

Lauren, 48 years, the oldest of the nurses worried about her age when she started to work in AYACC, wondering if she would fit in:

“When I first went there I came away and I thought, I don’t know that I’m young enough, or trendy enough to sort of hang around with them....but then I thought to myself, but you know sometimes you just need the maturity to care and to sort of I think, be able to hang there and sort of say, ‘do you want to talk about anything? How are you?’”

In the end she recognised the juxtaposition of this and that age or being trendy were not important, it was having an ability to connect with young people. She had lots of experience of this in her former career but somehow forgot this might also be important in her new role. Perhaps this is because the surroundings were so overtly youth oriented, which is discussed further in the place analytical theme.

The nurses could see both advantages and disadvantages of being a similar age to the patients they cared for. Whilst the younger nurses felt it could be an advantage, only some of them could recognise this would be a transient advantage in terms of developing relatedness with patients. Perhaps there was a nervousness about caring for patients of a similar age and, in a way, used their youth as leverage in conversations to assist in developing a therapeutic relationship. They were comfortable in discussing youth culture because they too were also living it. I also saw that being of a similar age caused an existential crisis for some of these nurses who put themselves in the shoes of their patients. This exposed them to the hardship of having cancer as a youth and recognised the implications for the patient and their families, which resonated quite deeply with them. Another risk associated with being a similar age was a potential to use more youth-friendly language which the nurses recognised as being less professional and bounded, but they seemed to know consciously or subconsciously that there was a line to be drawn. Anna recognised this in herself and told of when her colleagues struggled to manage this which caused her moral distress. As an older nurse, Lauren recognised that age was irrelevant and what was important was connecting with the patient on a human level.

4.3.1.2 Nurses' emotions

Irrespective of age and/or experience another particularly strong theme that recurred across all nurse stories was the emotional impact of their work with AYAC and their families that developed. They spoke of the challenges of when the outcome for patients was poor, especially in and around the time when the news is broken that cure is no longer possible. They also spoke of managing this emotional load whilst still negotiating clinical care delivery.

Amy spoke of the strength of her relatedness with one relapsed patient's family by expressing:

“With certain patients it's really hard to take yourself away from that. It's important to go through the motions with the patients, of course, and to be able to simply be empathetic towards them. But like this example I'm saying

at the moment we're all absolutely... we all basically feel like we're all part of the family for this one patient."

Lauren, despite her added life experience, also spoke about a similar patient and acknowledged the strength of emotional turmoil experienced when cure is no longer likely:

"There are moments where you're in that space and it's emotional, isn't it, and you know that you really care about those people and you want some miracle."

She did not want this young person to be experiencing the reality of incurable cancer; it was an uncomfortable feeling for her. Lauren added that having this, emotional connection was important for patients and their family, despite her having to navigate her own way through it.

"In my talking, you know, you sort of have an eye contact with that mum and you can see her eyes are full and I could feel my eyes were filling and I think that's okay, I think it's okay. I don't think it's appropriate for you to sort of break down and have a good cry or anything, you know, and you don't want any transference of your emotions to go to them. But I think the transference that you've got with some of their emotions is connecting with them.... it is important."

She seemed to accept this is part of AYACC work. She recognised the concept of transference/countertransference (Evans, 2007) where she put the patient and family needs before her own. This signalled the emotional intensity of the work. In parallel with this, Lauren also spoke of being in a heightened emotional state alongside having to deliver highly complex clinical care.

"It's just really emotional and yet you know, as the nurse and I need to be going in there dead on three o'clock, to give him [drug name] and get it ready."

This signified that even when the work was highly emotional, intense clinical care could not stop and she continued to deliver complex clinical care. Jemma tried to balance the emotional cost with the benefits that this type of work gave her:

“I always say it’s really hard sometimes but the rewards are worth it... I think the relationships and the stories are something that I think I’ll never forget.”

It appeared that the emotional toughness of the work got carried over to when the nurses were not working, indicating that switching off was difficult. Rachel recognised the enormity of cancer for AYAs when away from work when she said:

“You start, you start thinking about it outside of work and ... you start putting all your hopes towards them as well and yeah, you know, it’s completely devastating for them when they hear it but it’s just, it’s so oppressing... you just, you just do it for them.”

Like Lauren, she clearly wished for her patients to get better and acknowledged the difficulty for her when this was not possible. Her sadness was palpable.

Brian reflected on the significance of not knowing about patients when they left the ward and noted how sad it was to learn, incidentally, that they had died:

“Sometimes we wouldn’t hear when patients had passed away. So this kind of sister started emailing us to let us know if any patients have passed away, who weren’t on the ward at the time. Just so that we’re aware, because, because we’ve built up the relationships with them and thought it was nice for us to do.”

What resonated here was that these nurses gave enormous amounts of practical, clinical and emotional care to patients and families without considering the enormity of this work on themselves, or on other colleagues. They did not see the long-term impact of their collective labour which went unrecognised by the clinical system. They did not know if this effort was worth it for the patient’s outcome. Brian valued the fact that this sister thought of them in this way so that they knew what happened to the patient.

Jemma said she often wondered how patients were doing when she was on her day off and indeed how other past patients were doing in general; they clearly left an impact on her:

“Then you remember we haven’t seen them in ages and you wonder about them.”

She added that when patients returned at relapse, their relationship picked up again signifying the intensity of this prior professional experience. It seemed that both the patient and nurse got solace from the familiarity:

“When they’ve been away for a while and they come back as an inpatient and they start to go through lots of tests again, it kind of brings back that relationship. And I think that’s a, must be quite tough, but then they always ask, ‘is Jemma still here?’.”

Amy appreciated getting special recognition from a female patient when treatment had finished:

“She like sent in a big hamper of things as well for the nurses when she left, bless her and she put things specifically in there for me, which was really nice. It sort of felt like a bit of a recognition.”

Jade was another nurse to remark of valuing having special recognition:

“And it was you know, hearing from other people feedback that you’d really help them or that they really liked having you as a nurse, you know, things like that, that when you’ve been with them for a long time and when they’re leaving and they say we really want you to be here on the day we go home to things like that I like.”

Meaning derived from this is that these nurses provided an enormous amount of clinically complex care and developed intense relationships with patients and families over the duration of their treatment, and for some, right to the end of their lives. They are aware that they are direct caregivers and apart from those who have EOL care needs met on the ward, these ECNs often do not know what happens to these young patients’ long term. They often feel very pleased that they made a difference to their care and potential cure and often wonder about what happens to them as they leave the active treatment phase. For some ECNs, they meet patients by chance after treatment has ended and they are filled with joy that the young people are doing well.

For AYAC who die away from the hospital, the ECNs did not know about this or found out incidentally; therefore, they did not get any closure on their relationship with patients beyond their discharge. This could be the norm for all

patients that ECNs meet in hospitals but given the intensity of the relationships that are built with patients and families, these nurses often seemed bereft when this time was over, whether patients died on the ward or were discharged for follow up and survival. It was as if they are an ancillary passenger on the patient's cancer journey, one who had given a huge amount of themselves to contribute to that young person's cancer experience, like a Sherpa supporting a pilgrim on a mountain.

It appeared that the patients touched ECNs' lives for long periods of time, long after they have been discharged or died. The nurses told of their internal and outward desires as the conversations unfolded; their desire for young patients to be cured and the sadness that they could not articulate outwardly when cure was no longer possible. It was evident that the interactions and experiences of working with AYAC and their families impacted these nurses personally, and in varying ways, not least by touching them emotionally. The social context of their work added further to the building of stories about their nursing, and this is explored next.

4.3.2 Social

This section focuses on the situation or the conditions within which these nurses experienced their work. It is stated that when a person is invited to tell their personal narrative, this conversational act allows them to highlight what is important to them (Haydon et al., 2016). It became apparent that attending to the clinical and unique needs of AYAC was a strong feature of their nursing practice and social fabric within this work environment where they worked. This care was not delivered in isolation by them as individuals but within a multi-disciplinary team (MDT) that focused on the clinical and holistic care of these young patients. As said previously, it was striking how clinically complex the work of these ECNs actually is. Given that more than half of them had been qualified for two years or less, it was clear they were often in charge of the ward out of hours with little or no specialist or senior AYAC staff support.

A key component of the specialist approach to caring for AYAC included the MDT. Another aspect of sociality identified here was the attention the MDT paid

to supportive practices for ECNs for dealing with such complex and emotive care practice.

4.3.2.1 AYA Cancer Specialist Care

All nurses acknowledged that AYAs required different attention to younger children or older adults. Given there were a mix of nurses who were trained to only work with adults (n = 5) or only children and young people up to 18 (n = 3) with one dual trained, they all noticed distinct differences in caring for AYAs. Claire, who was dual trained felt that she was well placed to meet AYAs' distinct needs as she had been exposed to the nursing fundamentals of children and young people as well as adults during her nurse training:

“My adult training has taught me to treat patients to help get them independent and help them strive for independence and sort of self-care, whereas my paediatric training which focused on family-centred care has helped me with family-centred care with teenagers and also sort of understanding that they're not quite adults yet.”

This was despite her having no distinct AYA placements during her training where she could hone her knowledge and skills in caring for AYAs as distinct from children or adults. The only other placements where she came across children, adolescents and adults were in theatres and the emergency department. Claire recognised their needs were unique and could articulate some distinct differences in care approaches to both types of nursing but had limited practical experience of caring for them during her nursing course.

The three other children's nurses articulated the importance of family-centred care to them also. Jess, described favouring her training because,

“I think that it put me in a really, really good position because as a paed nurse a lot of the training is focused on communication and obviously, with TYAs they're not children, but then they're adults and you have to tailor your communication towards that...so I feel like as a paed nurse it did really help to have, you know, the tools to be able to communicate.”

She further added that ***“Then as a paediatric nurse your taught family-centred care as well. So it's not even that much of a problem because you're taught to look at the whole family, not just the patient.”***

Her focus here tended to lean towards caring for children; nonetheless, she placed emphasis on the care needs of all families too, even though the AYAC patients, extend into adult care where there is less emphasis on family-centred care.

Jade described another distinct difference between adult and child practice, that of how things change when they become adults:

“Once you get to 18 and there's like that sudden change of everything, it is then down to the teenagers, like they consent to everything themselves and it's a lot more their choice.”

She seemed uneasy with this as she was not used to the amount of agency that is held by those 18 years and over. In particular, she recognised that maturity did not always come with age but in law things change. Claire also recognised that as young adults, many are striving for independence from their parents yet when cancer appeared they reverted to their parents for support very quickly, even if they were parents themselves.

“They just need very specialist support because they're just at this really, really tricky time in their lives and they're going through lots of different things that they're neither children or adults, even going through all the developmental changes and things.” (Jade)

Rachel offered a similar perspective of recognising parental involvement in AYACC:

“It's different from the paed's where the parents would be there all the times of making lots of decisions and asking you most of the questions and they'd be sort of fronting the care, but on TCT you leave a lot of it up to the patient and they really want to know what's going on.... So it's quite a nice balance of having both of those.”

The adult trained nurses viewed things differently. Brian focused on physical care mostly with no recognition of specialist needs:

“They don't need much kind of care at all in general that from, from that point of view, you're not, you know having to clean them that much - you obviously do at some point. But the kind of basic cares aren't too much.”

He did, however, observe that AYAs were changing developmentally and seemed to see that as *a fait accompli* rather than being something of significance. This may be because of his lack of awareness of developmental or age-appropriate care. It would appear that this was not taught as part of his pre-registration training.

Jemma, RN (adult), contemplated several differences in caring for AYAs from adults. She recognised that they underwent biological changes such as brain development at puberty but did not appear accustomed to the needs of the wider family during cancer treatment. She said:

“I think family is a big thing when you work with teenagers and young adults. I think I wasn't really prepared to kind of nurse the patient and the family all together and their siblings.”

This signified the liminal phase that AYAs go through when major illness strikes and her acceptance that parents and siblings were an inherent part of that family unit who also required care, beyond the AYAC themselves. Jemma adapted her communication style to engage them for a successful outcome, particularly around medication adherence which is well documented in the literature as being problematic in this age group (Kleinke and Classen, 2018):

“Like a lot of the time when you work in an adult setting when you give a patient medications, they take them, you know, whereas the TYAs if you are in the room in the morning and you do the med round, and... you come back and meds are still on the table... two hours later and then they get sick and you're like, ‘well did you take the anti-sickness?... and kind of like that pleading thing when you're a mom... it's just so hard to stand and say no, you have to be like, ‘hey, this is the only option I have on the drug chart’, maybe we have to kind of, you have to put your conversation in there and tell a few fibs sometimes to get, to get your idea across.”

She had to be creative in her communication style to ensure compliance with medicines, more so than she would with adults.

Jemma and Anna were the only two who recognised there were biological changes such as neural development occurring during adolescence which is a distinct difference at this life-stage. Anna questioned whether the team,

“Were appreciating that they are in this difficult age range and being a TYA... they have actually got a lot of other things going on biologically and chemically within them, not just the fact that they have got cancer.”

She said she learned this whilst on a specialist AYAC course and seemed to have a greater understanding as to how she approached AYAC in practice, similarly to Jemma:

“it's kind of an acquired understanding and through different courses that I've been on and most certainly when people are new to the ward and they perhaps haven't looked after teenagers and young adults, they can find it quite difficult.”

This highlighted the value of having learning opportunities specific to caring for the needs of AYAC where nurses recognise unique biopsychosocial issues that are central to the care of these patients.

4.3.2.2 The MDT

It was clear that the nurses did not work in a uni-disciplinary way when delivering biopsychosocial AYA cancer care. Instead, these nurses valued being part of the MDT in their workplaces for a variety of reasons. They spoke positively about their colleagues, as Anna said:

“My team is the most supportive team that you know I've ever met.”

From the stories told I sensed the importance and value they all had of working within the MDT. They spoke of working alongside various types of nurses, staff nurses, nurse managers, clinical nurse specialists, healthcare assistants, doctors, psychologists and YSCs.

The specialist MDT seemed to direct how to meet AYA cancer psychosocial care needs. The YSC role was spoken of several times as one that makes a significant contribution to focusing on the youth element of the lives of the patients. This YSC appeared to pick up on issues that the ECN felt was beyond their scope such as addressing sexual health:

“She was talking about sexual health talks with them.” (Lauren)

Rachel described the YSC as someone who *“Comes and checks them too and then sometimes they just don’t want to talk about it at all and they just want to talk about teenage stuff and they want to talk about you know, what’s on TV or what sport they’re doing, what’s going on in school...to take their mind off everything that’s going on.”*

Amy described the variety of staff who worked on the unit and could clearly see the valuable role they all played to meet the unique needs of patients:

“So we’ve got one nurse practitioner... one registrar who’s based with us... a Band 7 (nurse manager) and then a deputy sister,... I feel like maybe at the moment we have more sixes than fives... it’s a real varied team. Probably a couple more adult nurses than child nurses, but there are some of each which is really good. Especially with things like paediatric charts, which I’ve never had to deal with before... so it’s a nice balance in that sense... we’ve got a really good group of NAs [nursing assistants] as well... one sort of counsellor or activities coordinator which I definitely feel like we need more than that cos she is constantly working but I wish we had more and in that sense.”

Anna explained further why the MDT is of such value for nurses and patients:

“I think it’s really important to be able to communicate and be open and to actually say, what are the barriers in us being able to achieve this goal for the patient?... I think it’s really important to be able to understand each other and also be able to appreciate each other’s role and viewpoints.”

I gained some insight into how well the MDT worked to maximise the impact for patients as well as staff support. The sense of being able to communicate freely was also noted here and in other conversations.

The ECN acknowledged the staffing shortages for direct caregiving nurse like them and their colleagues. I got a sense of the team being stretched to a point where it became stressful to work in the environment because of the clinical challenges that conflicted at times with the holistic care they wanted to give. Jemma alluded to this when she had a high workload of treatments she had to

give, and that in part she was learning to assert herself with managers and doctors as to where her limit of competence was, notwithstanding her need to maintain patient safety. She recalled a time when this was very real issue for her as a newly qualified nurse herself. This highlights the reality of working life for these nurses:

“If I’m the only chemo giver sometimes on days or on nights.... It is quite stressful to share the workload. If you’re working with someone who is quite newly qualified.... in my head I was like, I’m the newly qualified!! Like, how am I looking after someone who’s, ... you know... can’t do that with me, the division was so short staffed.” (Jemma)

Amy also spoke of how difficult it is when staffing levels were challenged:

“at the moment we have three pregnant and three on maternity leave so in such a small team it’s a massive effect.”

Anna alluded to staffing levels feeling unsafe which compromised her and the care she gave:

“I think sometimes staffing can be quite a hindrance to being able to provide really good quality care. And so, if you are unsafely staffed through either vacancies or sickness or lots of different factors, that can be a real impact because perhaps you feel that you can’t give such a high standard of care and you can’t achieve for those patients because of these constraints, because it’s unsafe and that can be a real impact at times.”

Brian felt that the intensity of death on the ward was enough to make nurses feel they could no longer work in the environment:

“It’s been quite a bad six months in terms of the number of people who’ve passed away. And I know that at least a couple of people who are moving on or were thinking about moving on. And that’s one of the reasons for it. That is just not great, you know, hearing about people dying.”

These aspects of our conversations suggested that at times delivering safe clinical care was a challenge. However, amidst these mentions of staffing challenges I did not get a sense that there were chronic staffing issues per se, and that the MDT cohesion was highly valued and strong. Arguably, the ECNs may

have come to accept that, despite working within an MDT, current nursing shortages had impacted their work. It felt as if being short staffed is now the norm and it had become an unquestioned reality. However, these units are normally relatively small, and the complement of nurses will also be smaller, so staff absences of any kind will have a major impact of the type of care that might be delivered. This adds significant pressure for managers to consider.

4.3.2.3 Nurses support systems

Having established the significant emotional impact of this type of work on the ECN, often coupled with staff shortages, I was keen to know how they coped, and asked what coping mechanisms they had both in and outside of the workplace.

They told me they were personally and professionally challenged by certain situations. These included when they were short staffed, when clinical pressures were high, when nurse-patient boundary breaches were felt, when there was bad news for patients and families, and when patients were dying.

Lauren described how she coped in the moment on the ward when she was part of the team that spoke to a 16-year-old boy whose treatment was not successful:

“I went into the treatment room then and I’m a mad cleaner, and I just thought, I’ll just rub everything down and have a good little clean in that room and just sort of have a nice big deep breath and minute to yourself... so was the healthcare assistant who was lovely, we were both kind of doing that.”

It felt as if both colleagues knew without saying anything that in this moment things were bad and they had to keep going. They had the same shared experience and sadness yet knew they had to continue delivering care to the patient, his family as well as the other patients and their families.

Lauren later told of another event where she had another shared experience: ***“I had one patient who arrested on a night shift and, you know, you sort of really bond as a team, when you have those experiences don’t you and... there’s a, there’s a connection created, I think, between colleagues when***

you're sharing that experience together and you sort of support one another."

The situational uniqueness and shared experience with her colleagues were predominant in her thinking and appeared to be a strong and valued coping strategy in that moment.

I got a sense from the ECNs that winding down at the end of the shift and until they got home was a period that carried with it some rituals important in self-preservation, after what could have been a hectic and emotionally charged shift. There seemed to be a sense of immediacy about it too. For several of the nurses, the journey home and physical activity were key features in de-stressing. Claire, Jade, Jemma, Rachel, Anna and Lauren all spoke of their need to exercise or be outdoors to help them debrief:

"I'm trying to do lots of like sports and lots of things to keep me busy."
(Rachel)

Lauren said,

"I do think about, you know, on my journeys or when I exercise. I tend to think about what I've done. And sort of be mindful of it."

Switching off from the intensity of their work was something that many of them spoke of as being a very purposeful and necessary act.

4.3.2.4 Staff support in the workplace

Building on the value of the MDT, the nurses, without exception, valued the support of their colleagues throughout. All nurses felt their teams were overall, very supportive and friendly particularly around coping with emotive patient experiences.

Some of the tensions described, beyond the stress and sadness of caring for patients whose treatment was not going well, centred around staff conduct.

Anna described tensions that arose because colleagues could not see they were potentially breaching boundaries with a patient who had a large social media following.

“so we had a, we had a talk with the ward manager and held a little teaching session a couple of times on the ward where all the staff were able to attend and we looked at communication and professional boundaries and err the use of social media and actually looked at what's right and what's wrong... maybe they need to take a step back and be supported because it's impacting them emotionally and actually things did improve.”

Amy described that as a relatively new member of staff to the ward she was aware there had been psychology sessions for staff which were reported as helpful, but that since she had arrived, beyond working with supportive colleagues, little by way of staff support seem to have existed. This was in part due to COVID-19. This suggests that the managers recognised the importance of this but that creating the opportunity was not always easy.

All nurses, except Brian, were offered the opportunity to attend structured debriefing sessions at some point though this was not mandated.

“At the moment, the culture might be just obviously ‘we let you know’ and ‘we’ll kind of empathetic to each other’. But there’s no specific thing there to talk about it.” (Brian)

Brian was unsure if an opportunity to discuss it might be helpful:

“I’m not, I’m not sure. I think it really depends, person to person. Because I think... it kind of hits you, but I prefer to kind of just think about it and then move on whereas I think there would be some other people who would like to sit down and talk about it, and, you know, kind of a bit like a mini-funerals, as such, to kind of remember the patient, I guess.”

This may indicate that he had never been exposed to this type of opportunity to assess its value for himself or indeed his colleagues. It did not seem to be an active or needed strategy employed by ward managers, though arguably this was just the view of one staff member from one ward.

Elsewhere, the nurses spoke of active offers of staff support of varying types. Claire, Jade, Jemma Jess, Amy and Claire all spoke of support sessions, facilitated by a counsellor/psychologist that they could attend if they felt they needed or wanted to. Often these were held weekly or monthly. However, some

of these nurses spoke of times during the night when the most stressful of situations arose and that during, or after these shifts, no one was available to speak to. It seemed to be hit or miss as to whether managers checked they were coping with what they had experienced. This made me even wonder if managers and ECNs were normalising this type of work, forgetting that many of the nurses were not much older than the patients they were caring for.

Lauren, despite being older, though newly qualified, was very candid when she described this and how it made her feel:

“To say I’ve dealt with this, this was hard.... and actually, the next time I was on a shift [the nurse manager] did grab me.... and sort of ask, how was that, you know, and had a little debrief as well. And I think that was important for that one. But that’s hit and miss you know, you get that sometimes, you don’t generally get it, I think you take your own initiative, as a nurse.”

Jemma’s experience of attending a support session was optional and said that:

“We can have a debrief as a one to one or we have a debrief as a group.... the councillor can come in and they kind of can take a couple of us off and go into the quiet room and sometimes do some relaxation and then chat about it.”

The ECNs valued senior nurses checking in on them, not only to see if they were coping but they valued learning from their greater experience and knowledge too. Jess valued having an opportunity to speak to a counsellor as well as the CNS:

“So if especially after any death, we can have a debrief or anything like that. We can talk to this lady that comes in to support as well, obviously the CNS is a really good, they help, will help us if we need it.”

The CNS appeared to be able to add a dimension to the experience that perhaps the counsellor may not because the CNS is more likely to have had a similar shared experience of knowing the patient and possibly having had a similar experience as an ECN themselves. Jess referred to a story of a patient who died a traumatic death at night on her shift that was particularly disturbing:

“That one was really hard, and it happened on the night shift... then I just go in and have a chat to a nurse or one of the CNSs and just go over things ... they've said like, there's nothing else you could have done. And hearing that sometimes helps I think because you do go home and you think, what did I miss what if I had done this.”

It was important to the nurses that they did all they could for patients, even if in the end it was not what they would have hoped. A psychologist or counsellor may not be able to respond to clinical details despite their expertise in providing psychological support. It appeared this clinical dimension to some debrief sessions could be important.

4.3.2.5 Support outside of work

I asked them about any support systems they might have away from their workplace. Eight nurses spoke of feeling supported by people close to them away from work such as partners, family members or friends. At least half emphasised where these people also had a nursing/medical background as being particularly helpful in understanding their work and associated feelings.

Anna encapsulated the value this emotional and practice support gave her:

“My mum's a nurse so actually I can talk to her really confidentially, so while I won't say any names if I've had a really bad day or bad situation, or I need some advice on it, I'll sometimes go to her and kind of give her a little bit of an insight into it and it's quite helpful at times to be able to have someone to be able to say 'Have you thought about this' or 'actually, that's a really valid feeling and how can I help you either offload' or 'is there anything that I need to be doing to help you at home?'”

Conversely, Jade spoke of the difficulty of discussing work with non-clinical acquaintances away from work. It can be fraught with difficulty, even if acquaintances are well-meaning. Equally she perhaps did not expect to, so therefore carried this emotional load with her to home where it could be burdensome:

“I've got a good support network and friends and family....it's difficult to discuss things and even if there's things that you can discuss.... and still

maintain confidentiality, it can be hard because they [family and friends] don't always understand the situation if you've not been in it... it can be hard to relay that for people to sort of empathise."

Jess acknowledged this tension too with her partner, who clearly respected her need to contain patient information but he struggled to know how to help:

"He knows when I have had a bad shift because I come in through the door, and I'll just be quiet, I won't want to talk at home because 'you don't understand, you don't, you don't know what, what's happening, what I've just done for 12 hours' and he always knows I've had a bad shift and he always knows to back off."

Without doubt, nurses' families seem to know and respect that this type of work carries an emotional toll, and at times they may have become vicariously emotionally invested in the patients their loved one's care for. One nurse said:

"Even my mum and dad are asking 'how's the boy doing?' ...so it just shows how involved they are you know and over attached I am to some particular patients."

Here I saw how families were affected by the work of their ECN loved ones and was reminded of the rarity of young adult death in our society. I also heard of the unique nature of the work that these ECNs were enacting on a daily basis. However, because they are so immersed in what they do, they do not always fully appreciate this uniqueness.

4.3.3 Culture

In conducting narrative analysis, it is important to also understand the cultural context of the research. This gave me a better idea of what the nurses meant in their narrations particularly, as in this case of working in specialist units, the many hidden layers of meaning that could only be uncovered by an exploration of the culture or environment. There appeared to be several subtexts about culture being storied. I have already alluded to the notion of youth culture and the supportive culture within these units. The youth culture element is further unravelled here. This included the appearance of informality and fun within what is a very clinically complex environment, dominant because of the youth-

friendly approach to this type of care. The ECNs often spoke of having fun or doing playful things with patients; some spoke as if this was almost like a treat for them, yet others spoke of this in a more purposeful way. Brian spoke of the **“youthful vibe”** on the ward because of the patients. He referred to the ability to play pool because there was a pool table on the ward and mentioned that it was something he would do if he **“had time”** and his friends thought it an unusual or cool thing to do in his job:

“I’d never do it on any other wards. You know if I mentioned it to my other friends that are like, what?”

Jemma alluded to the fun element on the ward too, not just that it was fun for her but that she saw it as an important thing for the patients to have too. This was when she spoke about purposefully engaging three AYA girls in a movie night because one of them was shy and had not made any friendships on the unit:

“Three girls on the ward one night and I said ‘we’re going to have a movie night at six o’clock. I’m going to have all of our work done and we’re going to watch a movie until eight o’clock’ and the girls were like.. ‘but you won’t have time’.”

All nurses spoke of the need for humour, not just in relation to having fun, but being important to normalise times for patients and to use it as a means to get to know them. Jade referred to it as a distraction and that establishing humour types was important to gauge:

“Getting to know the patient level of humour, to me I think is a really big one.... All they want is a bit of distraction to talk about normality, or things that they’re interested in and have a bit of a laugh.”

Amy reflected on the use of games on the unit and that she learned after a while that often it was not the act of fun or distraction that was important but that it was used as a tool to build a therapeutic relationship:

“They don’t want to necessarily.... want me to offer to play football with them or play on PlayStation with them. Sometimes they actually just want to have a normal conversation about TV or family, things like that. And especially when I first started, kept trying to think, like, I just don’t know

what to say but letting them settle in with what conversation is I found a bit more beneficial because then I'll say, 'I don't know about that, tell me about it', or whatever they're interested in."

Lauren, also recognised that humour had its place and could be used purposefully:

"I like humour, I think it's quite good to lighten things and to sort of try to find sense with it... because you've got patients sometimes not well enough to cope with it."

Anna was mindful of the potential mixed signals this gave young people, that the nurses may become their friends which she recognised as risky practice:

"It kind of gives you that challenge of communicating with them and getting that balance right of not being too overfamiliar and that you're not their best friend... But actually being there as a, as a friendly healthcare professional and being able to talk through it with them and you know have a bit of a laugh and a joke at times."

Claire recognised that relationships with AYAs and families could be tinged with sadness and awkwardness by patients and families. She recalled how it felt when she was referred to as being a friend of a patient by a father:

"You also have to be really careful about having that sort of nurse/patient relationship whilst also talking to them and chatting to them like you would... for example, like a friend and obviously you're not their... I remember at one point he was really, really confused and really agitated... so that was really difficult. And then his dad said to him 'no this is Claire, she's your friend'. Rather than say 'no this is Claire, she is your nurse' and that was the first time when I was like, all like that really shocked me that, that really upset me and made me really think about it..."

She questioned herself further:

"It made me kind of wonder whether I had been almost... not too friendly but like had been less professional, but I think looking back on it, I feel that he said that to help his son in that situation."

Clearly, she was trying to make sense of the situation herself by reflecting on practice. She also recognised the intensity of the relationship with AYAs and families, having fun or otherwise, and the perceptions of her from parents.

Jemma reflected on a patient she had enjoyed spending time with and that maybe she was getting too close to her for her own good too:

“It’s all nice for us, we were able to have all those kinds of conversations then I think it did become... It was hard when she became unwell because we’re becoming nearly such good pals.”

It could be said that the culture of youth and fun on the ward is a primary feature experienced by the ECNs amidst the chaos and enormity of treating very sick AYAs. It would suggest there are risks for ECNs in inadvertently portraying themselves, or being portrayed by patients and families, as being friends of patients and families rather than being friendly professionals.

4.4 Place

None of what has been discussed in this chapter could have been experienced if it were not occurring in a particular place. In this case these locations are charity-funded built environments based within NHS hospitals. All the ECNs worked in a specialist AYAC unit. These specialist-built environments look remarkably different to children and adult wards as the décor has been funded largely by one charitable organisation. They are designed to feel like a home from home where young people will feel comfortable, whilst being cared for by experienced staff who specialise in teenage and young adult cancer care (TCT, 2021). The charity describes the physical space as:

The walls are bright, the furniture is funky, and there’s often a social space, Wifi access, flat screen TVs, Xboxes and jukeboxes. You might walk into a unit and find a game of pool going on, someone chatting to friends online, or a photography workshop going on (Teenage Cancer Trust, N.D.).

The nurses all referred to the built environment in some form or another. For some like Claire they believed that it promoted a sense of normality where young people could continue being young and do things young people liked to do:

“I really do think that the environment helps, having the big chatroom with the pool table and the jukebox. And then the teenagers go in there and they’ve got the music on or they’re sat in there they’re watching the football with a couple of other young people on the ward.... We had one boy and we had all his brothers down, all his brothers and him were like in the chatroom playing pool, had the music on, so it’s so nice that they could still do that sort of thing. And I think that makes it more of a positive environment as well because I think there’s more stuff in place for them to still do the things that they enjoy and have fun and be happy.”

Jemma appreciated this environmental perspective that invited young people to share something more of themselves, it acted as a bridge helping them get to know the AYA’s life before and during cancer:

“I think the environments quite that big thing.... I think it’s quite nice that you go into their space and.... sometimes patients make it really homely and they have loads of pictures of all their friends on the wall and when you’re chatting and you’re doing some of their stuff like changing PICC line dressings so you’re like ‘Oh my gosh like that’s you with hair and you look so different and like who are these friends?’ and they kind of tell us a bit of like life outside which is quite nice.”

This builds on the comments earlier that getting to know patients was really important and that the physical space was being used as a means to promote that. Anna recognised that other attributes of the physical space were important for young people too, such as having access to the internet so they could keep connected with the outside world:

“We have free internet access so that’s a really big factor for teenagers and young adults to be able to listen to music or watch films or connect with their friends from their gaming. And that’s a really big, important thing for them... and having the option to have a social space... so not being trapped in four walls and having that space for them to either be alone, or to be able to meet with other people, or just have a bit of fresh air can be very important.”

The physical space was a big reminder that the care for these younger patients is very different from a physical and philosophical approach to care in paediatric or adult services.

I wondered if the social aspect of the physical space was in any way linked to how professional relationships could be blurred. Would young people be influenced to see the nurses as friends because they were doing things together socially, albeit in an NHS clinical environment? Whilst the environments may look different and have a different ambience, they remain clinical environments where patients receive complex clinical care by junior nurses in uniforms, so that retains its significance.

These physical spaces were where AYAC and nurses convened. It is unlikely that these storied lives would be the same if care was delivered in a paediatric or adult setting where the built environment looks very different.

4.5 Chapter summary

For many of these nurses, they happened upon AYACC only because of their pre-registration nurse training placement experiences. The positive learning experience they had, as well as interest in the patient type, appears to have appealed to them when securing their roles as ECNs. Which in itself was not problematic. This reflected the national issue of nursing recruitment challenges within the NHS where vacancies exist in many places. For those like Amy and Rachel who were more experienced RNs, their lack of experience of looking after AYAs in other clinical settings did not hinder their recruitment. Perhaps their age and personalities were seen as a good fit to work in the specialism?

It appeared that it takes about a year to become a confident, competent RN and sometime after that to really begin to understand the nuances of AYACC. Experience of working in the area helped develop knowledge and skills, and where nurses undertook specialist courses, they gained greater insight into meeting the unique needs of AYAC. As newly qualified ECNs in AYACC, they were expected to quickly become competent in a range of clinical skills such as the administration of cytotoxic chemotherapy, management of intravenous lines, managing acutely ill patients and suchlike. It appeared that only when they had gained these clinical competencies as required by the hospital management,

could they begin to consider care beyond complex treatments to become more holistic in their approach to AYAC. Many of the nurses reflected on how surprisingly complex the clinical care of AYAC actually was.

Another element of temporality spoken of was in relation to the time of day. These nurses, the most junior of the qualified nurses, worked over the 24-hour period and this often came up during our conversation. It appeared that for large parts of the day these nurses bore great responsibility in terms of delivering highly complex clinical care, which required a fair degree of clinical decision-making as their main priority. At times, it appeared that some of the clinical matters they had to manage could be very burdensome as described by Jess, Amy Lauren and Jemma in particular.

In contrast to this, they saw when their time had less clinical demands on it, they spent it getting to know patients. Sometimes this appeared to be opportunistic where perhaps they were finding certain patients more engaging than others. On the other hand, as in Jemma's case she recognised this as a potential time to engage young people with each other, so her actions to host a movie night were really purposeful.

All nurses spoke of the amount of time they spent with patients from diagnosis, through their treatment to whatever the outcome may be them. This could be for weeks, months or indeed years. They spoke often of the relationships that were built with the AYAs as well as their families. Jemma noted that she even noticed these young people were growing into young adults. The similar age of the ECNs was seen as an advantage by many of them, yet they could also see how challenging this might be for them because of it.

The emotional labour associated with this work was unsurprising and it was interesting to begin to understand what in particular created this type of emotion work for ECNs. Relapsing and dying patients and their families were reported as very distressing to work with, despite the rewards that were also reported.

These burdens appear to be accentuated by staffing shortages and clinical demands. In turn these clinical demands add to the distress that nurses spoke of as they enacted their work and, indeed, when they carried it beyond the unit as

the finished their shifts. The emotional burden that they carried, as a consequence of developing relationships with acutely ill and dying young patients, cannot be ignored. It seemed to be an accepted hazard or 'fact of the matter' of the job that the intensity of the relationships that were built would be severely affected when a young patient was dying, and as the nurse became personally and professionally invested in them and their families lives and care. In turn, the nurses own families became invested, vicariously, too.

When drawing conversations to a close, the nurses reflected on what kept them motivated and where they saw their future. They all appeared to enjoy their work despite the complexity of care they were responsible for, and the sadness they experienced. This was despite working unsocial hours. Most of the ECNs saw long-term employment in working with AYAC. All the ECNs had ambitions to undertake more academic study in AYACC. Six of the eight nurses were inspired to become CNSs. For Anna, who had been qualified for seven years and working with AYAC, still saw herself as relatively junior and was clearly at a pivotal point in her career regarding what she might do next. Lauren on the other hand had changed careers and was able to draw on her previous experience as a social worker. She saw the advantages of bringing her past life experiences into her current work. Moving forward she was keeping an open mind but thoroughly enjoyed working in oncology which had surprised her. It was becoming apparent that these nurses were beginning to notice distinct nuances in caring for AYAC.

During the early analysis of these stories, I established that nurses were often talking about similar topics within the dimensions of my analytical framework. Whilst they all differed in what they said, they offered perspectives on a theme which helped me to understand their experiences of caring for AYAC. In the next chapter, I refer to these themes as 'common strands', such as those found in a tapestry, as they were important in aiding my interpretation of the stories. The cross-stitch picture below (Figure 4.1) represents how I visualised the common strands. The common strands helped me to 'retell' the stories so I could use them to inform my findings, and recommendations, and guide the readers of this thesis and future audiences. The common strands will be presented and discussed in Chapter 6.



Figure 4.1 My visual representation of common strands

Chapter 5 Discussion

5.1 Introduction

I started this study seeking an answer to the research question, *What are the experiences of early career nurses (ECNs) who care for adolescents/young adults (AYAs) with cancer in specialist age-appropriate settings?*

The aims were:

- a) To generate meaning of the experiences of ECN who care for AYA with cancer in specialist settings by exploring their narratives.
- b) To identify aspects of uniqueness attributed to the nursing care of AYAC.
- c) To examine the personal and professional impact on ECNs associated with caring for AYAC.
- d) To identify training/education and support needs for ECNs to support them in their care of AYAC.

I adopted a NI approach to arrive at common strands that I constructed from the analysis of the ECNs' stories of their experiences; this process is referred to as 'retelling' by (Clandinin and Caine, 2013, p.34). Whilst this thesis outlines a systematic approach to this study, the integration of several theoretical perspectives has been weaved throughout as opposed to applying a single theory from the outset. Therefore, as this discussion unfolds, contributions to the development or extension of existing theoretical frameworks have evolved. Another outcome was that applied theory to the experiences that have been retold.

In this study, the intention was to create a sense of meaning and significance to the topic of the role of nursing in AYAC, thereby adding to existing knowledge in this field. These meanings will not prescribe general applications but will offer insights into those who read this work. I recognise the formalistic tensions that this brings with other forms of research, such as in randomised controlled trials, and appreciate that I was at the formalistic boundary as I engaged in narrative

thinking throughout this study, a concept well described by Clandinin and Connelly (2000).

The ‘retold’ story is based on common strands I found meaningful during data analysis. The common strands are matters that were elaborated in participants’ stories from their own experience and these are represented in Figure 5.1.

Discussion on these strands is presented forthwith along with recommendations, strengths and limitations of the study which appear at the end of the chapter.

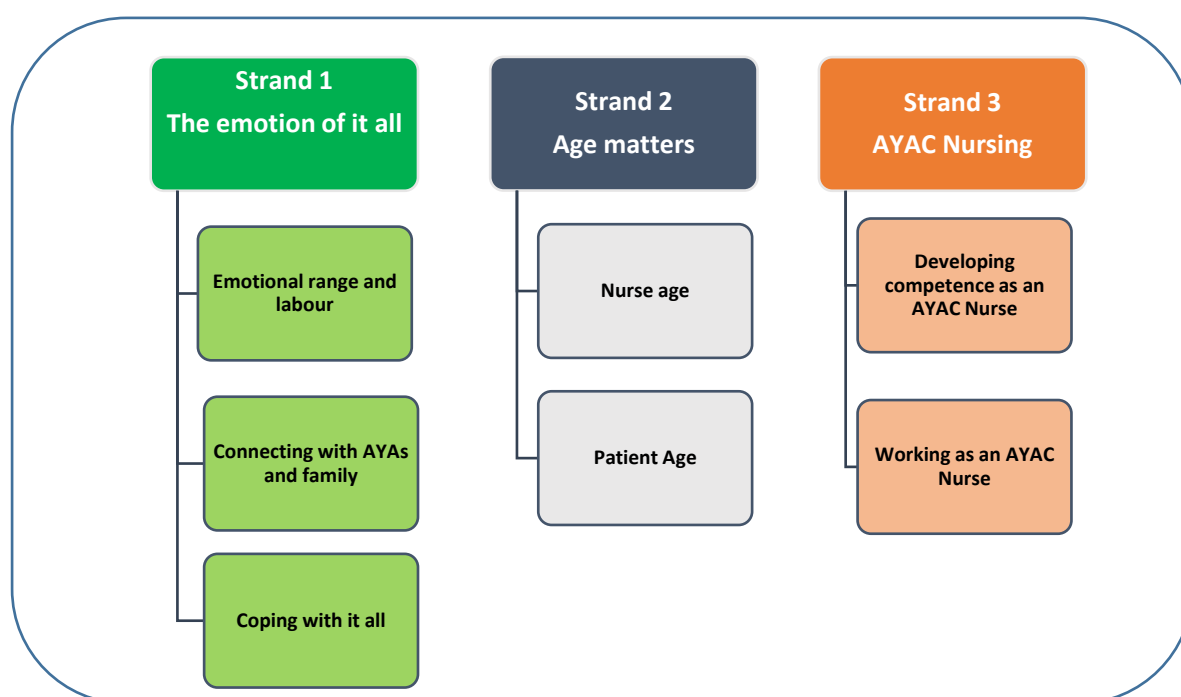


Figure 5.1 Common Strands

To return to the discussion of the place of theory in this study, as this chapter evolves several theoretical perspectives are explored within the common strands.

5.2 Strand 1 The emotion of it all

The major strand ‘the emotion of it all’ represented the prolonged and intense nature of the ECNs’ work with AYAC and their families. As was outlined in the introductory chapter and referred to in the literature review by others in the literature review, this was not an unanticipated finding, however factors that impact this because of the patient and care type are novel and I draw on some additional literature here, building on the literature review, to expand on these

concepts to contextualise this in relation to the work of nurses in AYACC. The ENC depictions of working in the specialist units were that it was busy and stressful, with acutely ill or dying young patients which required the integration of highly specialised technical and human skills. I interpreted three distinct elements to this strand: emotional range and labour, connecting with AYAs and families and coping with emotion. These elements acted as contributors to how all the nurses contended with managing the emotional aspect of their work in this field. Their stories helped me to gain insight into the intensity of the emotion work involved and what motivated them to do this work.

5.2.1 Emotional range and labour

5.2.1.1 Emotional range

The nurses described a range of basic emotions brought about by working with young people with cancer and their families. We are reminded that everyone knows what an emotion is, until asked to give a definition (Fehr and Russell, 1984, p. 464.). Whilst several theories exist to categorise and explain the emotions people feel (Ekman and Cordaro, 2011; Izard, 2007; Tracy and Randles, 2011), early thinking established that there are six universal categories: happiness, sadness, anger, surprise, fear and disgust, all of which appeared in these nurses' stories to varying degrees, see Table 5.1.

Emotion	Examples within Nurses story
Happiness	Brian, Amy, Jemma were happy when patients returned to see them in remission. Anna helping a patient go to a rock concert. Jess and Rachels recognition that humour was important. Claire when she implemented beads of courage. Brian, Jade and Lauren at gaining clinical competence.
Sadness	<u>All</u> nurses reported this when patients were dying, or treatment had failed.
Anger	Brian spoke of the unfairness of a young patient who was dying. Jemma when she felt she was just a number to the Matron.
Surprise	Claire when a father referred to her as his son's 'friend'. Rachel when a patient disclosed their sexuality to her.
Fear	Jemma when she felt the strain of being in charge of the ward with so many acutely ill patients.
Disgust	To a degree for Anna when her colleagues breached a boundary. For Jess when a patient's rectal bleed would not stop.

Table 5.1 Examples of emotions in nurses' stories

It is difficult to separate emotion from experience. Central to the science of emotion is the principle that emotions are rooted in subjective experiences that people represent with language (Cowen and Keltner, 2017; Kövecses, 2003). Further, people represent a variety of emotions during temporal experiences using a rich diversity of semantic terms that go beyond these six basic emotions which have been conceptualised to 27 different categories of emotion (Cowen and Keltner, 2017). Rather than being entirely distinct, Cowen and Keltner (2017) found people experience these emotions along a gradient, recognising that the boundaries between categories of emotion are fuzzy rather than discrete. To define these emotions would be limiting as when emotions are expressed, they are often entangled with thoughts, actions and feelings; therefore, the nature of the emotions expressed is discussed as it is represented through theoretical lenses of others.

Emotions, as with experiences are relational and arise through interaction and communication. Both are multi-faceted and represented across various

biopsychosocial discourses (Theodosius, 2008). 'Story telling' within NI often involves the recollection of emotions during an experience (Holloway and Freshwater, 2007; Riessman, 2008); therefore, it was not unexpected that this became apparent in the data analysis and notable in the findings. I was struck by the intensity of the emotions described by the ECNs; when it was sad it was very sad and when it was happy it was delightful.

Lauren spoke about the emotional turmoil of when cure was no longer possible for a patient and that she was seeking a miracle for them. She sounded sad and desperate for that patient and family. She was managing this emotion whilst continuing to deliver acute clinical care which could not be hindered because of the demands of the service and patient acuity.

Jess spoke of when a patient died at night and the challenge this brought for her in relation to not having senior nursing support to guide her. Jemma also spoke about the tensions of being in charge out of hours. These nurses were left managing these highly charged emotional and complex clinical care episodes with no support around them. The ECNs, of similar age to the patients, were working hard to manage their emotions in the moment whilst acutely aware of the clinical responsibility they had.

The contrast to extreme sadness was reflected in comments from happier times such as having fun (in the social hubs or helping a patient go to a rock concert); using humour; or when patients went into remission. I interpreted that, as much as Amy used humour as a communication tool she also seemed to enjoy the rapport this brought, recognising there was a place to use it appropriately. I sensed that she and the patients benefited from having a humorous encounter, even during harrowing chemotherapy, and it may even have been a coping strategy for them both.

Bolton (2000) speaks of a positive side to using humour when it is considered as a way of managing emotions in an environment that could experience a range of complex and challenging emotions, such as grief, frustration or anger; this may be in part what was occurring here. Jemma tried to balance her emotional cost with the benefits of this type of work by telling me that the memories of relationships she built with patients would be positively indelible and extremely rewarding part of her work.

My explication was that the ECNs go through a range of emotions with the AYAs, brought about by the disease trajectory itself and length of time they got to know them. They were conscious of trying to manage their outward emotional expression in front of patients and families whilst they were also responsible for sustaining high levels of cognitive engagement by delivering complex care and treatment. This fits with Jackson et al.'s conceptualisation of nursing work that encompasses physical, emotional, cognitive and organisational labour (Jackson et al., 2021) all of which can be taken for granted. Physical, emotional and organisational labour have been well established in the literature and Jackson et al. (2021) purport that cognitive labour referring to the mental workload of nursing is as complex and skilled as other aspects of nursing work. In their meta-narrative review, they identified that cognitive labour included learning, thinking, stacking and cognitive load, all of which form a considerable part of nurses' work. This is evident for these nurses who are managing all four aspects of nursing work from very early in their careers.

The ECNs seemed to display very caring attributes and emotions towards patients and families, which nursing scholars identify as at the heart of nursing: caring for others (Jackson et al., 2021; Theodosius, 2003; Watson, 1999; Watson, 1979). Watson's *Philosophy and Science of Caring* (1979) is concerned with how nurses express care to their patients. Her belief is that the act of caring is central to nursing practice and that a holistic approach to healthcare is central to the practice of caring in nursing. She recognises that nursing care promotes better health than a cure. Moreover, Watson (1979) is mindful of the human caring process in nursing, connected to human struggles and human tasks, all of which have been described by the nurses in this study. Building caring and compassionate relationships with patients has far reaching benefits for both patients and nurses. Not only can it improve patient outcomes, but it can also improve the well-being of practitioners themselves (Kinman and Leggetter, 2016). As the role of nurses has developed and evolved within the last half century, concepts such as emotional management and intelligence have been emphasised and discussed in policy and evidence linked to patient safety, working cultures, stress, resilience and emotional labour (Department of Health, 2013; Francis, 2013; Health and Safety Executive, 2020; Nursing and Midwifery Council, 2018).

In these stories I heard that working in AYA cancer specialist units can be hugely rewarding and satisfying, yet it can also be emotionally demanding and stressful. Given that the literature (Duarte and Pinto-Gouveia, 2017; Grant and Kinman, 2014; Kinman and Leggetter, 2016; Kutluturkan et al., 2016) reports that the emotional demands of caring work make strong contributions to the high levels of stress observed in the nursing, as well as to compassion fatigue and burnout, it seems fitting to consider the concept of emotional labour in the context of AYA cancer nursing as told in these stories. I saw evidence of this being played out for these nurses during the study.

5.2.1.2 Emotional labour

Emotional labour (EL) is a sociological concept first described by Hochschild (1983) as the commodification of managed emotions, where employees induce or suppress their feelings to create a desired display to generate a feeling in a customer. Her work examines this in airline staff, a discipline quite removed from nursing. However, she suggests that jobs that experience EL require three criteria: it involves face-to-face or voice-to-voice interaction; it requires the worker to produce an emotional state in another person; and lastly, it allows the employer, through training and supervision to exercise a degree of control over the emotional activities of the employee (Hochschild, 1983 p., 147). These criteria have been considered, debated and expanded in their application to nursing (James, 1989; McClure and Murphy, 2007; Smith, 1992; Theodosius, 2008) but not reported on in the context of AYA cancer nursing.

These expressions of emotions, which differ when portrayed in public and private spheres are guided by feeling rules (Hochschild, 1983) and these rules are managed by two key strategies: 'deep' and 'surface' acting. Surface acting is likened to the purposeful act of 'faking' emotions that workers know they are not feeling. In deep acting, employees attempt to feel a genuine emotion to connect with those they serve. Theodosius (2008) further develops and applies EL in the context of nursing by identifying three types of EL in nursing: therapeutic, collegial and instrumental. Therapeutic EL concerns the interpersonal relationships and interactions between nurses and patients and/or their families. Instrumental EL relates to nurses' communication and interpersonal skills and confidence in performing clinical tasks to reduce

patients' pain or distress or patients/families' worries concerning clinical procedures and processes. Lastly, collegial EL refers to the interpersonal relations and interactions between nurses and their colleagues where information exchange is important for effective nursing care. In all three types, interpersonal processes and communication are required between nurses, patient/families and colleagues. In this study all three types of EL have been expressed by nurses.

Recounting stories revealed that during interactive interpersonal activities, the ECNs in this study were managing their emotions and emotional expressions through strategies of deep and surface acting, which in themselves can be very emotionally demanding (Debesay et al., 2014; Delgado et al., 2017; Theodosius, 2008). The effects of deep and surface acting in employees and nurses have been debated in the literature. Surface acting is recognised as having negative consequences for employees' personal well-being and is associated with emotional dissonance (Grandey, 2015; Humphrey et al., 2015). This results in additional strain for nurses such as experiencing emotional exhaustion, burnout, stress, and psychological and physical ill health (Schmidt and Diestel, 2014). Deep acting is associated with positive elements of emotional labour such as job satisfaction, increased sense of connection with patients and patient satisfaction (Delgado et al., 2017; Humphrey et al., 2015) and arguably, less harmful to the employee.

Some nurses in this study struggled to manage their emotions in front of patients and families, and indeed with colleagues. Anna found herself having a moral panic about colleagues becoming 'friends' with a patient on social media, thus potentially breaching professional boundaries and brought this to the attention of her manager as it was distressing her. She recalled that it was negatively impacting collegial relationships on the ward. It felt as if she had allowed herself to surface act to a point until she recognised the emotional demand it was causing her and the potential poor outcomes for patients and the nurses involved. What I saw here were indications of emotional labour having an adverse effect on the ECNs in AYACC, though they may not have realised the potential impact this was having on them long term. I questioned the cumulative effect this will have on these nurses and saw it as a personal and professional

risk if it is not pointed out as such. I also wondered about the age and maturity of the nursing colleagues Anna spoke about who engaged with a patient's social media followership. She implied that her young colleagues (who seemed to be as young as her or younger) did not recognise the risks associated with developing social media friendships with patients, given that social media is such a defining part of current youth culture (Christensen et al., 2018).

Caring for young dying patients clearly employs EL for these nurses, which is in keeping with findings from the literature review and the literature more broadly of dying adult and child cancer patients (Kelly et al., 2000; Lovatt et al., 2015). Other authors acknowledge that managing distress, suffering, trauma, death, bereavement, anxiety and anger were a common source of EL for nurses (Bolton, 2000; Gray, 2009; Kelly et al., 2000). The evocative narrative of these stories highlights that EL is an active and demanding process, and this study explores the nature of that, as described in the next section.

Whilst I interpreted that EL has potential negative connotations for these nurses, I am also mindful that the nurses expressed they got job satisfaction from working in this field. All nurses reflected on this when prompted to think about what motivated them to work in this area. Anna and Jemma captured this clearly when they told me they really enjoyed their profession and were motivated by it. Jade and Brian acknowledged their AYAC nursing learning journey and how they had begun to recognise the complexities of this type of care, as it involved more than they, and others thought it might.

It could be argued that these nurses may not have seen EL as a burden, but rather as a gift, another concept that appears in nursing and EL literature. Hochschild (1983) suggests there is a 'degree of control' required by employees and employers in how emotions are managed between public sector workers (such as nurses and social workers) and face-to-face workers in the for-profit sector. Nurses, who are expected to display feeling rules at their own discretion, can surpass these rules and offer more of themselves to patient-carer relationships (Bolton, 2000). Hochschild and Bolton refer to this capacity to offer extra emotion work as a 'gift'. Accounts from the ECNs in this study show how they may have enacted this so they may offer their emotion work as a gift to AYAs in their care. Jemma seemed happy to offer this in terms of her time with

AYA patients when they specifically asked for her to care for them. This included her staying late to specifically meet this request.

Amy seemed to 'gift' herself in a variety of roles, all of which demanded EL, such as counsellor, nurse, friend or family member. Remarkably, in nursing there is little expectation this 'special gift' will be returned. This, unlike the concept of a 'gift exchange', carries with it no explicit or implicit demand for a return gift (Bolton, 2000; Titmuss, 2018). Mauss argued that gifts are part of reciprocal exchange because they are imbued with a 'spiritual mechanism' (Mauss, 1990). He refers to this as "the spirit of the gift", whereby the gift carries with it the 'spirit' of the giver. The giver, in this case the ECNs, do not just give an object or service, but also donate part of themselves, and something that is greater than themselves. It maybe that these ECNs provide gifts of care as part of creating a social bond with an unspoken obligation for reciprocation with AYAC and their families. This concept of 'gifting' was an unanticipated revelation that I established on the work of ECN with AYA with cancer, and one which has not been explored in the AYAC literature before.

5.2.2 Connecting with AYAs and family

Connecting with patients and families is well documented in the literature, and it appears to be the essence of nursing work. A striking temporal narrative retold in these stories related to the connections or attachments the nurses had with patients and their families that developed over long periods of time, often years; a similar finding identified in the early research of Kelly et al. (2004) on a specialist teenage cancer unit. Some of the nurses recounted how they knew patients for as long as it took the patients to progress from adolescence into adulthood.

Jade made the connection with the sadness of when treatment was no longer curative with the fact that she had got to know patients and the families over a long period of time. Amy extended this by noting the negative impact on herself and the wider team when the news is bad and that it becomes difficult to contain at times, again echoing Kelly et al.'s (2004) findings from their early study that relapsed disease is particularly hard-hitting.

There was a clear sense that the ECNs felt they got to know the families very well, stating that they knew these patients and families ‘properly’ and intensely, which is less likely to happen if they were working in a clinical area with a high turnover of patients. This resonates with the principle of therapeutic presence which is defined as a healthcare worker’s ability to make others feel safe, valued and understood through genuinely demonstrated empathy, compassion and respect (Chochinov et al., 2013). Delgado et al. (2017) derived from their literature review, that therapeutic presence was embodied within nurses’ interpersonal communication skills, that they were physically and emotionally present and available to patients/families and maintained an emotionally supportive environment amid competing demands and time constraints, much like these nurses. By demonstrating empathy and/or compassion in emotionally difficult situations the ECNs were continuing to support patients and families. The ECNs recognised the heartache that families were going through and often felt these family scenarios also resonated with them and their own families. Brian recognised a particular young patient’s age and family situation which resonated with him and his own family, thus enhancing his connectedness with the patient. This may be similar to the core concept of ‘bridging’ that was explored in Olsen and Harder’s (2011) study which emphasises the commitment that AYAC nurses have to patients and families.

The ECNs’ stories reflected findings from an Australian study where healthcare providers working in paediatric oncology rated the relationship with the parents as an important reward, as well as being appreciated by the family, having a long-term or close relationship with parents, helping families through their entire cancer journey, and doing important things for families (Klassen et al., 2012). The ECNs clearly also experience value in these relationships.

I also interpreted that the nurses were experiencing different levels of connections with patients and families. I sought to explore if this had been explored in the AYAC literature previously and was introduced to the concept of ‘connectedness’ which was defined as the extent to which a person perceives significant, shared, and meaningful personal relationship with another person, a spiritual being, nature or an aspect of one’s inner self (Haase et al., 1992). Phillips-Salami et al. (2012) proffer that the concept of connectedness in

patient-provider relationships have been hampered by a lack of conceptual clarity and propose a preliminary theoretical framework that identified antecedents, attributes and consequences of connectedness. Phillips et al. (2012) further developed this definition of connectedness:

in social relationships, connectedness is the degree to which a person perceives that he/she has a close, intimate, meaningful and significant relationship with another person or group of people. This perception is characterised by positive expressions (i.e. empathy, belonging, caring, respect and trust) that are both received and reciprocated, either by the person or between people, through affective and consistent social interactions. (2012, p. 235)

Phillips et al. (2017) applied this to AYA cancer care and noted that fostering connectedness was particularly important at the diagnostic phase as AYAs were acclimatising to their diagnosis and this had not been explored in the literature previously. Several strategies can be used by HCPs to deepen the connection with AYAs and these include identifying common bonds and humour (Phillips et al., 2017). I recognised this several times with the ECNs. Brian, Jess, Amy and Rachel all echoed this when they noted that they may have similar age-related interests that enhance their relationship by drawing on youth specific issues such as choosing career or education paths, music tastes and other related cultural issues. Humour initiated by the HCP is appreciated by AYAs (Phillips et al., 2017). This is similar to Essig et al. (2016) and Gibson et al.'s (2012) research, discussed previously in the literature review chapter, where there was an expectation that nurses would spread good humour and cheer, balance professionalism and close relationships with parents and check to make sure AYAC patients had all they needed.

What should be avoided is AYAs feeling disconnected with HCPs as this can lead to AYAC feeling dehumanised, powerless and having a lack of self-determination (Phillips and Haase, 2018). I did not get a sense from the ECNs that they had conceptualised the importance of humour in regard of fostering connectedness. This seemed like a 'nice to have' approach to care as opposed to it being considered a powerful one for patient engagement. Equally, it seemed that the nurses were enacting these strategies quite unwittingly, which may have been

part of the culture of care in these specialist units. Additionally, the use of humour as employed by the ECNs in this study appears to give joy to the nurses as well as being of benefit to the patients.

Connection with patients and families is an integral component of all health and social care work. Some see it as a central truth of human life such as Brown when she says that 'connection is why we're here. We are hardwired to connect with others, it's what gives purpose and meaning to our lives, and without it there is suffering,' (Brown, 2015, p. 8). In nursing, we do this in many ways such as in physical care as well as in all our communication, be that for information exchange or any other therapeutic purpose. Much communication and connection happen simultaneously for these nurses, AYAs and their families, which is reflected as a theme and being a challenge in the literature review chapter. One reason for this relates to the AYAs' age (15-25yrs), they cross the legal threshold of having autonomy in legal terms whilst grappling with the start of developing an independent relationship from their parents (Chisholm et al., 2018; Day et al., 2018; Essig et al., 2016; Flynn et al., 2017). Whilst there are arguments for and against the presence of parents and time alone for AYAs, there is no doubt that separating them for all communication is unhelpful. In the stories told here, parents featured heavily. The intensity of parental input may have come as a surprise to some of the nurses, particularly those who were trained as RNs (adult) compared to those trained as RN (child) nurses when they first worked in the specialist setting. Jemma, as an adult trained nurse found the intensity of parental involvement a shock when she started working in the field whereas Claire and Jess, RN (child) saw this as an integral part of their work. I saw this as adult trained nurses having a focus on patient-centred care whereas RN (child) have a family-centred approach to care. Neither branch of nursing appears to consider the unique needs of AYAs within person-centred or family-centred care, suggesting this needs to be enhanced in both curricula.

Facilitating communication within triads such as HCPs, AYAC and parents/supporters is beginning to receive traction in the literature in terms of how to navigate this around key phases in the cancer trajectory, such as in shared decision-making, adherence and end of treatment (Robertson et al., 2015; Smith et al., 2020). Smith et al. (2020) refer to supporters as those within

the family, act as if they are family or significant others so I will use that terminology to depict the same herein. Arguably, some of the ECNs in this study may not have appreciated the significance of this in terms of fostering connectedness or indeed information exchange. Smith et al. (2020) state that HCPs can have a profound impact on an AYA's view of, and engagement with, healthcare. It is the responsibility of those working with AYAs, regardless of the setting, to ensure they have the appropriate skill set. They need this to understand the importance of appreciating an AYA's individual perspective to be able to fully engage the AYA in their healthcare. The nurses in this study seemed to be learning this vicariously without considering the risk to themselves of potentially over-sharing or investing, or indeed of managing triadic communication as a concept during their day-to-day clinical activity.

5.2.3 Coping with emotion

Cancer nursing is a specialism that poses higher risk for burnout due to the persistent and sometimes overwhelming emotional stress from witnessing patient death and dying (Davis et al., 2013). Although as discussed earlier, the nurses all reflected on the range of emotions experienced in caring for AYAs, they also told me about how they coped with the sadness and stress of this, both in and away from work. Whilst this doctoral research is not exploring the concept of burnout per se, to ignore this as a potential risk for these nurses would be an oversight. Maslach (1998) describes the concept of burnout as a persistent response to interpersonal job-related stressors characterised by “overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and failure” (Maslach, 1998, p. 68). This syndrome is characterised by three dimensions: emotional exhaustion, depersonalisation and reduced personal accomplishment (Maslach and Jackson, 1984). Emotional exhaustion resulting from high stress levels is described as job-related exhaustion and depletion of one's emotional resources. Depersonalisation is defined as cynical, negative attitudes that may result in callous and noncaring conduct (Maslach, 1998). Reduced personal accomplishment reflects one's perception of a lack of competence and productivity in the work setting (Maslach, 1998). According to Maslach (1998), these three dimensions are interrelated. Although all areas of oncology nursing are stressful, studies tend to

focus on inpatient paediatric or adult oncology settings more than any other when discussing levels of stress and burnout, so it is interesting to hear of the types of emotion work and challenge these nurses describe in an AYAC specialist setting, which are not dissimilar.

My interpretation was that the nurses were at that point, not showing signs of burnout, possibly because I was not exploring this as an element of their story, but given the theoretical framework presented by Maslach, I could see the intensity of the emotions the nurses experienced might lead to this. A major stress for oncology nurses is when a patient, with whom they have developed a close relationship, dies (Barnard et al., 2006). This is significant for nurses working in paediatric oncology (Spinetta et al., 2000; Zander et al., 2010) and is reflected here in AYA cancer care too.

The nurses in these narratives described three main ways of managing their stress levels. These centred on personal coping mechanisms, organisational support mechanisms and social support mechanisms and these will be discussed next.

5.2.3.1 Personal coping mechanisms

Five nurses (Claire, Jade, Jemma, Rachel, Anna and Lauren) described the importance of exercise to help them deal with the demands of work. Claire compared her nursing job to an office type job whereby she could switch off from work - once she removed her uniform, she was no longer a nurse. She added that as she took no objects such as a laptop home with her, she would not be reminded of work that had to be done. She spoke of her journey home as a transitional phase. Here, these nurses describe healthy, adaptive coping mechanisms (Happell et al., 2013). Claire could be described as using emotion-focused coping by removing her uniform, which has been hypothesised as dealing with the unpleasant emotional effects of stress rather than finding a way to ameliorate its cause (Folkman and Lazarus, 1988). Some would say this is a lesser coping strategy (Lambert and Lambert, 2008) yet others argue this use of distancing and self-control may predict better emotional health in nurses (Lim et al., 2010). For now, the nurses appear to be actively recognising and attempting

to manage their emotional well-being by using a range of personal techniques such as exercise, distancing and writing a reflection, as Lauren described.

These ECNs displayed resilience which has been described as having the capacity to respond to stress in a healthy way such that goals are achieved at minimal psychological and physical cost. Resilience has also been identified as a key to enhancing quality of care and sustainability of the healthcare workforce (Hlubocky et al., 2017). From the stories told, the nurses have developed adaptive mechanisms, or resilient characteristics similar to those described by critical care nurses that allow them to continue to deliver high quality care and stay intact in spite of adverse situations that AYA cancer patients and families find themselves in (Mealer et al., 2017). However, having strong adaptive personal coping mechanisms alone may not be sufficient as protective factors against stress and burnout.

5.2.3.2 Organisational support mechanisms

All the nurses reported positively on the general support of their colleagues, particularly when emotions were high on the units. Rachel referred to the normalcy of distress that can be felt by staff and that they automatically recognised this in each other and then gave support. I interpreted this to mean she felt confident and safe to express how she was feeling, a phenomenon that Maytum et al. (2004) suggested was useful as a short-term work-related coping strategy in a descriptive qualitative study with 20 experienced nurses who work with children with chronic conditions, interviewed about their experiences with compassion fatigue and burnout. This is further echoed by researchers who found that colleagues' support could enhance nurses' resilience (Cameron and Brownie, 2010).

Anna expressed concern about the coping strategies of her colleagues as well as helping them maintain their own professional boundaries with a particular patient which was an added stress for her. She was pleased that an episode where she perceived her peers were potentially breaching their professional boundary with a young patient was handled sensitively and proactively by managers, leaving the team able to function in a constructive supportive way. She further encapsulated the value of working within a supportive team saying

how important it was to work where openness is fostered. She recognised the importance of the offer of support from the wider HCP team which was proactive and verbalised regularly. This appears to normalise the notion that support is needed in what is considered an extraordinary environment. This offer comes in the form of individual or group support, and confidentiality and respect seem to be at the heart of it which promotes a sense of comradeship. She described it as being “*in the same boat*” and placed great value in this.

The notion of structured organisational support was recounted in several of the nurses’ stories. Six of the nurses (Claire, Jade, Jemma Jess, Amy and Claire) mentioned there were structured support sessions, facilitated by a counsellor/psychologist that they could attend if they felt they needed this. Few of these occurred on the units specifically, with the majority of these being offered as a self-selecting activity for the nurse to undertake. Claire spoke positively of that staff support and mentioned having access to structured and unstructured sessions with psychologists, support from nursing colleagues of all levels including the lead nurse and access to a “wobble room” described as a relaxation space, where she could go if the work became too demanding. This demonstrates that in this region, staff support was held in high regard and was actively supported and delivered.

In the NHS England (2017) *Next Steps on the NHS Five Year Forward View* it is posited that NHS staff health and well-being is a priority for the NHS as it struggles to cope with rapidly ageing populations, burgeoning chronic disease burdens and events such as the recent COVID-19 pandemic. They state that interest in improving both the mental and physical health and well-being of HCPs is paramount. Interventions to improve healthcare staff health and well-being have tended to focus on supporting or improving individual coping skills rather than affecting the workplace environment such that it promotes healthier behaviours (Brand et al., 2017). To some degree that is what these nurses also report; there are support mechanisms, but the nurse must be self-motivated to access them. They also reported that these organisational support mechanisms (e.g., group support sessions) were reduced during COVID-19, when they were never more needed. It is argued that NHS environments, whether funded by the NHS itself or part-funded by charities as in the case of AYAC, have a

responsibility to place staff well-being needs as a priority. This should be acknowledged by strong visible leadership at senior management and board level on improving the health and well-being of staff working in such emotive environs.

A systematic review by Brand et al. (2017) into whole-system approaches to improving the health and well-being of healthcare workers, revealed that interventions incorporating these whole-system approaches can improve healthcare staff health and well-being and increase health behaviours. The reality for these ECNs is they were not experiencing a whole-systems approach to improving their well-being. Few studies report favourably on a whole-systems approach suggesting that in AYA cancer care it is poorly understood, resourced and enacted so staff continue to run the risk of having their health and well-being impinged. There is still work to be done by AYACC organisations in supporting staff as indicated by Beresford et al., (2018)

5.2.3.3 Social support mechanisms

All the nurses in the study spoke of the support they got from family and friends outside of work. Some, like Jemma, spoke of the intrigue their families and friends have about their work. Some like Anna, Lauren and Rachel had family members who were nurses or HCPs, so they spoke of the value of these supporters having a common professional insight into their work. Lauren reflected on the value of this for her when she spoke of her mother, an ex-nurse. I understood this to mean that having the opportunity to debrief with someone she respected, who knew the 'display rules' of nursing, would understand what she was going through so that she could process things when they were difficult for her. I felt this was something she needed that was over and above what was offered in a structured way by her organisation.

The impact of the emotional work of AYAC nurses on their own loved ones has not been reported in the literature to date and thus is an unanticipated and novel finding in terms of AYAC nursing. This deserves further research. Jess' partner, for example, seemed to be at a loss as to how to support her if she had a bad day and she did not want to burden him with what she was experiencing, mostly because he could not understand it. She was also mindful of protecting

patient confidentiality, so I felt she was almost 'imprisoned' by this, which led her to carry this emotional burden home with her. Jemma and Amy spoke of sharing some information on patients, without breaching confidentiality with their parents. Both indicated their parents became vicariously involved with these situations, especially when the news was not good. One of these nurses told me her parents were now asking after 'the boy'. I felt that she was beginning to show signs of reaching the limit of her coping capacity and perhaps needed to start managing her feelings about getting close with patients through a route other than her parents, as much for her parents' sake as for her professional standing. I began to see the risks of over-connecting with patients and families that may have inadvertently caught up with these nurses without them realising it.

Although family can be considered as a strategy for nurse coping surrounding the death of a child, nurses' professional confidentiality remains an issue with this type of social support as has been established elsewhere (Forster and Hafiz, 2015). This was echoed in a literature review which recognised the tensions between closeness and professionalism existing between nurses and parents of children in palliative care settings (Brimble et al., 2019), although not especially in AYACC. This made me question the further need for educating AYAC nurses on the risks that leaning too much on friends and family for this type of support may have for them as professionals, and on those with whom they share their emotional burden, however confidential they maintain patient information. This is in keeping with suggestions from Brimble et al. (2019) and needs to be applied in AYAC training and education programmes.

5.3 Strand 2 Age matters

The concept of age in the narratives features strongly. Primarily this begins with the demographic of the patients these nurses care for. The fact that they are AYAs cared for in clinical settings suggests from the outset that they have particular age-related needs which will be discussed. In addition, the age and experience of the nurses is striking, unanticipated and novel; this will also be discussed.

5.3.1 Nurse age and experience

None of the nurses had actively sought to work in AYA oncology and they framed their arrival there as ‘something that just happened’ because of their student nursing placement experience or local employment practices once they qualified. Therefore, working in the environment had been opportunistic rather than planned. When I planned this study, I had an open mind about the age of participants. I was interested in the most junior staff nurses and as a nurse teacher/academic, expected to see a broad age range given the expanding range of routes into nurse education in the past five years. All bar one (Lauren, 46 years) were aged less than 29 years.

This led me to explore and apply the concept of generational diversity (not previously been reported in the AYAC) which has emerged as an international challenge for workforce design to ensure it attracts both the earlier generation and retains existing generations of nurses (Cole, 2020; Hart, 2006; Shacklock and Brunetto, 2012; Wolff et al., 2010). In generational theory it is acknowledged that workforce diversity is far more heterogeneous than in the past (Howe and Nadler, 2010). However, in nursing workforce literature much is aligned with the challenges that managers have regarding working with generational groups of nurses who have differences in attitudes and values in and to the workforce (Hendricks and Cope, 2013). The ECN participants in this study fall into the categories of Generation Y (born between 1977-1993) or Z (born after 1993), making them a similar age to the patients and their parents, so they have much to relate to in terms of generational experiences (Stevanin et al., 2018).

Stevanin et al. (2018) found differences among generations in work-related attitudes, emotional aspects of nursing work, leadership preferences and practice in their mixed methods systematic review of international nursing studies. It is suggested that generational differences and their impact on perspective with which they interpret and experience the world and workplace, should be taken into account when creating study and work environments (Weston, 2006). A study in 2016 of Generation Z in general, revealed they sought constant development, mentoring and security. Generation Z are prepared to work hard yet at the same time there is an expectation that they will have quick career progression (Iorgulescu, 2016). Additionally, Generation Z value when

honesty and integrity is shown by managers but they do not have fully developed specific skills and competence essential for the workplace (Deloitte, 2017) . Thus, Generations Z appear to have different needs and motivating factors that impact the work when they commence employment. I interpreted from the nine nurses that they aspired to be clinical nurse specialists from early on in their careers without spending a protracted period at the bedside providing direct care. I wondered if this could be seen as a protective factor from the emotion of the work they were involved in. The nursing shortage may also be a conduit to an expedient promotion to this role given that managers will not want to lose nurses to other areas or even the profession.

Similarly, the age of nurse was perceived as significant by the participants in terms of appreciating youth culture and youth issues, a factor they felt may not be understood by older nurses. The ECNs felt this assisted with their relatedness, yet I was struck by the fact that they had not quite factored in that they would age beyond the age bracket of those they cared for. I also saw that being of a similar age caused an existential crisis for some of these nurses who put themselves in the shoes of the patients they were caring for. This exposed them to the hardship of having cancer as a youth and recognised the implications of this for patients and their families, who resonated deeply with them. Another risk associated with being a similar age was a potential to use more youth friendly language which the nurses recognised as being less professional, but they seem to know consciously or subconsciously there was a line to be drawn when using this. Anna could recognise this in herself and told of when her colleagues struggled to manage this which caused her moral distress. As an older nurse Lauren, recognised that age was irrelevant and what was important was connecting with the patient on a human level.

I wondered if the ECNs were recruited with their youth in mind, but felt that on balance, with the nursing shortage being so prevalent this was unlikely as the needs of the managers was to have nurses on the ground over quality of care or age of nurses. Jemma alluded to this when she was fretful of being the most senior nurse on the night shift when she commented that the matron was just interested in numbers of nurses to cover the floor, as opposed to considering the support needs of nurses doing the work with little consideration of their age or

experience. Given the lack of proactive structured support to help nurses deal with the four types of labour, as described by Jackson et al. (2021), I derived meaning from the stories that the work of these AYA cancer nurses entailed all aspects of that conceptualisation of nursing work. This included the emotional labour of it which links to the age similarity of the patients they were caring for, which appeared to add another dimension to the AYAC nurse-patient relationship.

I was reminded of the extraordinariness and vulnerability of young nurses caring for young dying patients especially as these nurses told me how much their age enhanced their relatedness with patients and parents. Again, this appears to be an original finding and not previously discussed in the AYAC literature. Exposure to prolonged death, to the death of patients to whom the nurses feel close to, to the death of young patients and to the death of patients with an incurable disease, is associated with increased stress and emotional exhaustion in health professionals (Redinbaugh et al., 2001). In a study of 360 nurse working with patients at EOL in five hospitals in Lisbon, researchers concluded that nurses' attitudes to death only differ in their sociodemographic and professional characteristics in a depersonalisation subscale, which obtained statistically significant higher scores in single, younger male nurses (Gama et al., 2014). This is not something that was established in this doctoral study but it does highlight that age and experience may influence how nurses respond to death and dying, as indicated in findings from the literature review, where dealing with EOL conversations was deemed difficult for many HCPs (Avery et al., 2019; Sansom-Daly et al., 2020; Wiener et al., 2015). As already mentioned in the introductory chapter, Banerjee et al. (2017) study of professional burnout in 600 European young oncologists (40 years or younger), identified that four fifths reported that burnout was significant. This would place the oncologists from Banerjee et al.'s study as Generation Y or Z and denotes the importance of recognising the potential serious personal sequelae of burnout such as anxiety, depression and suicide which have been reviewed elsewhere (Bowden et al., 2015; Shanafelt and Dyrbye, 2012).

Zander et al. (2010) argued that although an experienced paediatric oncology nurse may feel the intensity of grief on the death of a patient as acutely as when

they were newly qualified, with experience they developed more coping strategies to manage their grief. Hinds et al. (1994) identified that nurses attempted to develop their own coping ability in their first year after graduating, using various strategies such as crying, venting or problem solving. Conversely, the same study established those who were more experienced in were able to “let go” over time (Hinds et al., 1994). This meant that they permitted themselves to accept the loss of patients they had grieved for or by leaving their emotional burdens at work. What also emerged in that review was that the use of reflective practice and learning from experience also influenced how nurses cope (Zander et al., 2010). The needs of health care professionals coping with the loss of an AYA with cancer in a specialist setting has not been written about in the AYAC literature to date. What is interesting here is that all the ECN were fairly recently qualified, and they told me how they coped in and out of the workplace. I felt Claire and Brian to be the only two who were able to compartmentalise their emotional burdens and leave them at work; in fact, Claire spoke of the process of donning and doffing her uniform as part of the process, actively leaving work behind when she removed her uniform. Otherwise, the other nurses all spoke of carrying this emotional burden away from work. Whilst Lauren is in her second career and a late entrant to nursing, she is still an ECN. Her life experience may have helped her cope with the loss or impending loss of young patients, as well as her story of writing reflections to aid her learning and coping. Nonetheless, despite both being seemingly protective factors, she still expressed intense emotion. This perhaps highlights that irrespective of age, these nurses can be troubled by the work they do because of the age of the patients but what may be different, is how they cope with this as they become older and more experienced.

No study has examined stress and coping in nurses in AYA cancer care specifically, and this study now illuminates aspects of these issues and thus offers an original contribution to knowledge. What has been identified is that nurses who manage their emotions emanating from stressful oncology work settings and can understand emotions in their adult patients, could effectively make more emphatic clinical decisions that positively influence patient-focused care. What may be more difficult for nursing AYAC patients is recognising that during their developmental phase, AYAC may struggle to label their own

emotions which leaves the nurses having to guess what they might be feeling. This may be against the backdrop of the nurses themselves, who are at the lower age range, not having completely developed brains or adolescence until the age of 25 (Foulkes and Blakemore, 2018).

What this ECN study emphasises, and the meaning I have derived from the stories here, is the importance of managers to consider how ECNs manage their emotions and cope with the stress from this work setting. They can then implement supportive measures such as clinical supervision for these nurses through their initial employment period, keeping them at the bedside to ensure high-quality patient care, as well as caring for the welfare of the nurses themselves (Mazzella Ebstein et al., 2019). Taking account of the age and experience of the nursing team in these units is something managers may want to consider, as the various needs and expectations that each generation has of its job and their employers can vary. Some of the ECNs in this study reported the CNS or senior nurse checking in on them and the positive impact and value of this should not be underestimated. Therefore, being aware of generational differences in relation to nursing recruitment, retention, communication, continuous professional development and succession planning should not be ignored. What has not been examined in this study is if nurses or their managers have considered that there may be generational differences, and the differences between staff are attributed merely to age rather than generational differences.

On these specialist units, as in all workplaces, all generations of nurses interact regularly. Each has varying insights and opinions, and there are likely to be differences within the teams as described by the nurses within the study, some of whom were of similar age to patients or of similar age to parents of patients. If Generation Z nurses feel they can relate particularly well to AYA with cancer, as they have reported in these stories, they will inevitably grow out of this relatability because of their own ageing.

5.3.2 Patient age

The age of these patients transcends this whole thesis and research process as it underpins the specialism of AYACC and the specialist environments within which these nurses work. It features heavily in the stories that have been told, attending to it forms the essence of care that these nurses provide. It is not the

purpose of this study to describe what AYACC is, as that has already been explored in the work of others (Bibby et al., 2017; Cable and Kelly, 2019; Kelly et al., 2004; Kirchhoff et al., 2017; Smith, 2004; Smith et al., 2016; Warner et al., 2016; Wright et al., 2014). However, it is important to reflect on the literature review as well as findings from the analysis. Key themes from the literature review (Chapter 3) are echoed by the nine nurses. Given that no previous study has explored the experiences of junior nurses such as these ECNs, this study highlights some but not all of the patient age-specific issues that were identified in the literature review. In the main, this concerns the acknowledgement that these young patients were proceeding through their adolescence into young adulthood and that developmentally and socially they were different. Secondly, communication about key issues such as at EOL or sexuality can be a challenge. None of the stories revealed any particular challenges as regards clinical decision-making, FP and managing an altered appearance that were identified as key issues in the literature review. The stories did not take us there, or rather these were not themes identified in the analysis.

However, what is apparent from the stories told is that the nurses are part of a unique approach to AYA cancer care, by the nature and culture and physical environment of the specialist unit, that aims to provide adolescent responsive care. Several concepts that have been used to support this include developmentally appropriate healthcare (DAH) (Dovey-Pearce et al., 2020; Farre et al., 2016; Farre et al., 2015; Rapley et al., 2019) and age appropriate (AA) healthcare. DAH comprises five dimensions as outlined in Table 5.2.

Table 5.2 Conceptual dimensions of developmentally appropriate healthcare for young people (Farre, 2015, 2016)

1	Biopsychosocial development and holistic care
2	Acknowledgement of young people as a distinct group
3	Adjustment of care as the young person develops
4	Empowerment of the young person by embedding health education and health promotion
5	Interdisciplinary and interorganisational work

This differs from attempts to provide AA care, which tends to focus on a more AA physical environment, and describes features of provision such as appropriate communication, confidentiality and a general holistic focus (Rapley et al. 2019). The context of AA cancer care is known to be multi-faceted and complex, thus limits any attempts at generating a straightforward definition. A mixed-methods study by Lea et al. (2018) sought to develop an evidence-based, contextually relevant and operational model defining AA care for teenagers and young adults (TYA) with cancer in England. Seven core components of AA care were identified and were presented as a conceptual model.

This is in keeping with what was defined as unique in TYA cancer specialist units in England in an earlier study (Taylor et al., 2011) where the care approach in these units is underpinned by expertise and a distinct philosophy of care. The nine ECNs in this study all alluded to this concept of AA care and were cognisant that the environment lent itself to promoting that, with access to social spaces, later waking times and the opportunity to have family and friends visit more freely (outside COVID-19 restrictions). Key in the studies of Lea et al. (2021); Lea et al. (2018); Taylor et al. (2011) is recognising individuality for AYAC which seems to be a developing concept for the ECNs. Lea et al. (2018, 2021) and Taylor et al. (2011), argue, however, that with more recent discourse referring to DAH, understanding of young people's developmental needs is a part of understanding young people's holistic needs, which also features in Lea's (2018) conceptual model. This has been recognised as a major challenge for health services because young people have a range of needs based on their personal circumstances (World Health Organization, 2003).

What is not so well understood from these ECN stories is the level to which the nurses understood these key conceptual frameworks and their role within them. Their entry to this specialism was mostly opportunistic so they may have initially been captivated by the physical space and general vibe of the specialist unit. As they develop into their posts, they become enculturated to an environment that is about more than its physical space. The reality of this is that despite having an AA or DAH approach to the care of these young patients, these nurses are still required to be technically competent in the delivery of clinical care, irrespective of patient age.

Despite the development of DAH, AA care or any other conceptualisation to make youth healthcare more mainstream, serious illness or death of a child or young person is difficult and often inconceivable for HCPs who care for them. This was recognised in Tutelman et al. (2019) and Avery's (2019) studies where HCPs expressed feelings of helplessness at not being able to fix or cure the cancer in AYAs. This sense of failure was linked to a feeling of frustration that cure was not possible for young patients. Both of those studies suggested training and education of those involved in the care of AYAC, but if these nurses have not had any insight into this possibility in the context of delivering complex clinical care, then post-registration training and development on their own may be seen as a luxury waiting to happen. What is to be avoided is the normalising of death in young people and acceptance by nurses and managers that this will happen and that preparedness and support, through formal and informal measures, be considered. This study strengthens this need. What appears difficult in the context of DAH or AA care is the application of this to AYAC who are dying, thus I recognise there is a gap in the literature on how well-prepared nurses and other healthcare workers are for this occurrence. This narrative study highlights this as a challenge for ECNs, their colleagues and indeed their own families, because the death of someone so young is not a regular occurrence.

5.4 Strand 3 AYAC nursing

The final strand relates to AYAC nursing and the continual learning journey that the ECN are on. Others have written about elements of AYA care and aspects of the specialism, but few have determined what is distinct about AYACC nursing practice and this section offers new insights into what this might look like. I determined that not only were the ECNs striving to learn about nursing in this specialism, but also how to survive and thrive within it. The ECNs in this study had been qualified for a minimum of six months up to seven years with the average length of qualification being just over three years. They were also starting their career when sustainability of healthcare workers is an international imperative (World Health Organization, 2016), with nursing shortages posing particular challenges for many governments including the UK, the USA, across Europe and Australia (Health Workforce Australia, 2014; NHS England, 2017; NSI Nursing Solutions Inc, 2019; Zander et al., 2016). The impact

of COVID-19 on nurses has also been problematic owing to shortages of personal protective equipment, insufficient staffing and inadequate safety precautions (Gómez-Ochoa et al., 2021; Jackson et al., 2020), placing all nurses at risk of adverse mental health (Pappa et al., 2020; Shaukat et al., 2020).

At the time of writing this thesis, the second report of session 2021-11 by the Health and Social Care committee (HSCC) appointed by the House of Commons on Workforce burnout and resilience in the NHS and social care was published, (Health and Social Care Committee, 2021). It highlighted that the COVID-19 pandemic increased NHS workforce pressures exponentially and workforce burnout was described by many as the highest in the history of the NHS and care systems and as such, it is an extraordinarily dangerous risk to the future functioning of both the NHS and social care services. In that report, The Kings Fund scathingly informed the HSCC that before the pandemic resilience was a picture of significant fragility in both the NHS and social care workforces which had not been managed effectively at a national level. They add they do not feel the current workforce could be described as resilient because of several key issues. These include significant shortages of particular staff groups, including nurses, widespread vacancies and tolerance of excessive workloads; difficulty in retaining existing staff (especially nurses), with inability to achieve a work-life balance increasing rapidly as the reason given for resignations; an incoherent approach to workforce planning; and inadequate funding for education and training.

It is remarkable that these ECNs are working to survive, thrive and strive in their care for AYAC despite and during the COVID-19 pandemic. In their efforts to do this, I felt that they sought two main foci in their learning and development: (1.) developing competence as an AYA Cancer nurse and (2.) Working as an AYA cancer nurse.

5.4.1 Developing competence as an AYA cancer nurse

What struck me when hearing the stories of these most junior nurses on these units was that after a period of clinical upskilling to meet the demands of their employers, they were often left in charge of caring for AYAC with very complex needs and treatment regimes. Several of them told me they had been or were in the processes of being taught or assessed as competent in technical clinical skills

such as administration of chemotherapy, management of peripherally inserted central catheters and percutaneous endoscopic gastrostomy feeds. Clearly there were opportunities for them to access this extra training and they were keen to develop further clinical competence. Brian vocalised that he had become quite a skilled nurse and saw this as a positive acquisition that could prepare him for working in other clinical environments. This echoes the notion of portability as a priority for early to mid-career nurses as identified in a Canadian study (Price and Reichert, 2017). In addition, Price and Reichert (2017) determined that ongoing professional development is an expressed need and expectation for nurses across the various career stages. Healthy work environments were identified by nurses as those that invested in CPD opportunities to ensure continuous growth in their practice and provide optimal quality patient care. What can be seen in this study of ECNs in AYACC is that training and development is being offered to ensure the oncology service can be delivered, though some of the nurses referred to an additional desire to become more knowledgeable and competent in meeting the unique needs of AYAC, which may not be seen as a priority for managers of those services. With the gap in any mandate or direction at policy level on this (relating to AYA cancer in general or AYA cancer care), it is difficult to argue for additional training to meet this need.

It is indisputable that the clinical competence of registered nurses is an essential component in the delivery of nursing care. Despite competence being widely debated in the literature, ambiguity as regards its definition still exists, as illustrated by several concept analyses where much complexity exists around this notion (Garside and Nhemachena, 2013; Smith, 2012).

I derived meaning from the stories that in essence the nurses had achieved basic clinical competence and they were on a journey to prepare to develop their competence in becoming an AYAC nurse, with aspirations to become a CNS. This is in keeping with the seminal work of Benner who described competence development as a process that begins as a novice, advancing through several phases to the level of an expert nurse (Benner, 1984). She highlighted the significance of experience, alluding to capacity for theoretical thinking and judgment, rather than the length of service. However, nursing practice is not

only shaped by individual nurse's experiences but also by the work environment (Pennbrant et al., 2013). Therefore, multiple factors that enhance the development of nurse competence early in their career is important.

Given the relative novice emergence of AYA cancer as a specialism, little has been written about nursing competence in the field. The TCT (2014) undertook a 3-stage Delphi process (engaging expert nurses, nurses from across generic clinical areas and a consensus group of nurses) to build on the work of (Gibson et al., 2012; Gibson et al., 2003) to develop a competence and career framework for nurses. Gibson et al. (2012) reported on 13 core competencies derived from across various health professions working in teenage and young adult cancer care (including nursing) and offered an early description of the knowledge and core skills required by these professionals. It was the first systematic attempt to outline the contribution that AYAC nurses make to AYAC.

More recently Lea et al., (2021) determined that four key factors facilitated holistic competence in AYA cancer care for HCPs, by conducting a multiple case study in four regions across England, in 24 different care settings. HCPs described how their knowledge, skills and abilities, and overall competence were central to their caring role. AYAC wished to receive care which considered them as a whole person, including their social, emotional and psychological needs, in comparison to care which focused on their clinical and physical care needs only. The four key interlinking factors were identified as the environment alone, the experience continuum, enthusiasm and education.

Lea et al. (2021) noted that aside from the physical environment looking different, there was also access to the specialist multi-disciplinary team. This reflects the environment issue for the ECNs in this study where they reflected on the facilities such as 'hubs' or hangout spaces that were created especially for young people to convene in. In addition, the ECNs referred in their stories to having access to specialist professionals such as YSC and CNS in TYAC where dedicated emotional support for patients formed the backbone of care delivered there. Accordingly, I questioned whether these ECNs realised they were on the path of developing competence in AYA cancer care because of the environment, which cannot be expected to afford them this in isolation.

Narratives from the ECNs in this study suggest that once they have achieved their basic clinical skills and competence to be able to deliver clinical care, the ECNs aspire to learn more through inhouse and formal education. They recognise that AYAC have different needs but did not articulate them very clearly at this stage in their career. What is not contested in the literature from both UK (Gibson et al., 2012; Taylor et al., 2016) and Australian (Bradford et al., 2018) studies is the need for HCPs in AYAC to have specialist education. These studies propose content that might be included within courses. Caring for this group of patients requires some generic and specialist understanding of cancer care as well as AYAC needs (Cable and Pettitt, 2018). Arguing for specialist education in this niche field, however, competes with other greater service demands and is difficult to implement.

5.4.2 Working as an AYA cancer nurse

In this study I heard about many aspects of the ECNs' work in specialist AYAC settings. Much of what they described includes delivery of complex cancer treatments and management of IV lines, and I propose a model AYAC nursing work which has not been described before. This builds on the meta-narrative of Jackson et al. (2021) that recognises four key types of nursing labour that are of equal importance: physical, emotional, cognitive and organisational.

Through the stories told here, this study has demonstrated that AYAC nursing work is complex and included the four types of nursing work described by Jackson et al. (2021). This is demanding and difficult work, for which these ECNs are accountable for from the minute they register. These nurses are operating in and across many occupational, departmental, organisational and age-related boundaries. Through this narrative study, I have strengthened the view of the specific AYA cancer related knowledge and skills that underpin this type of nursing and offer an original insight into this unique type of nursing practice.

From reviewing the literature (Chapter 3), gathering and analysing stories from nine ECNs (Chapter 4) and discussing themes identified in the common strands (Chapter 5), whilst drawing on my own philosophical assumptions, I propose a new conceptual framework for AYAC nursing.

This proposed framework builds on the work of Lea et al. (2021) (holistic competence in AYACC) and Jackson (2021) (four types of nursing labour) and my representation of it is outlined in Figure 5.2.

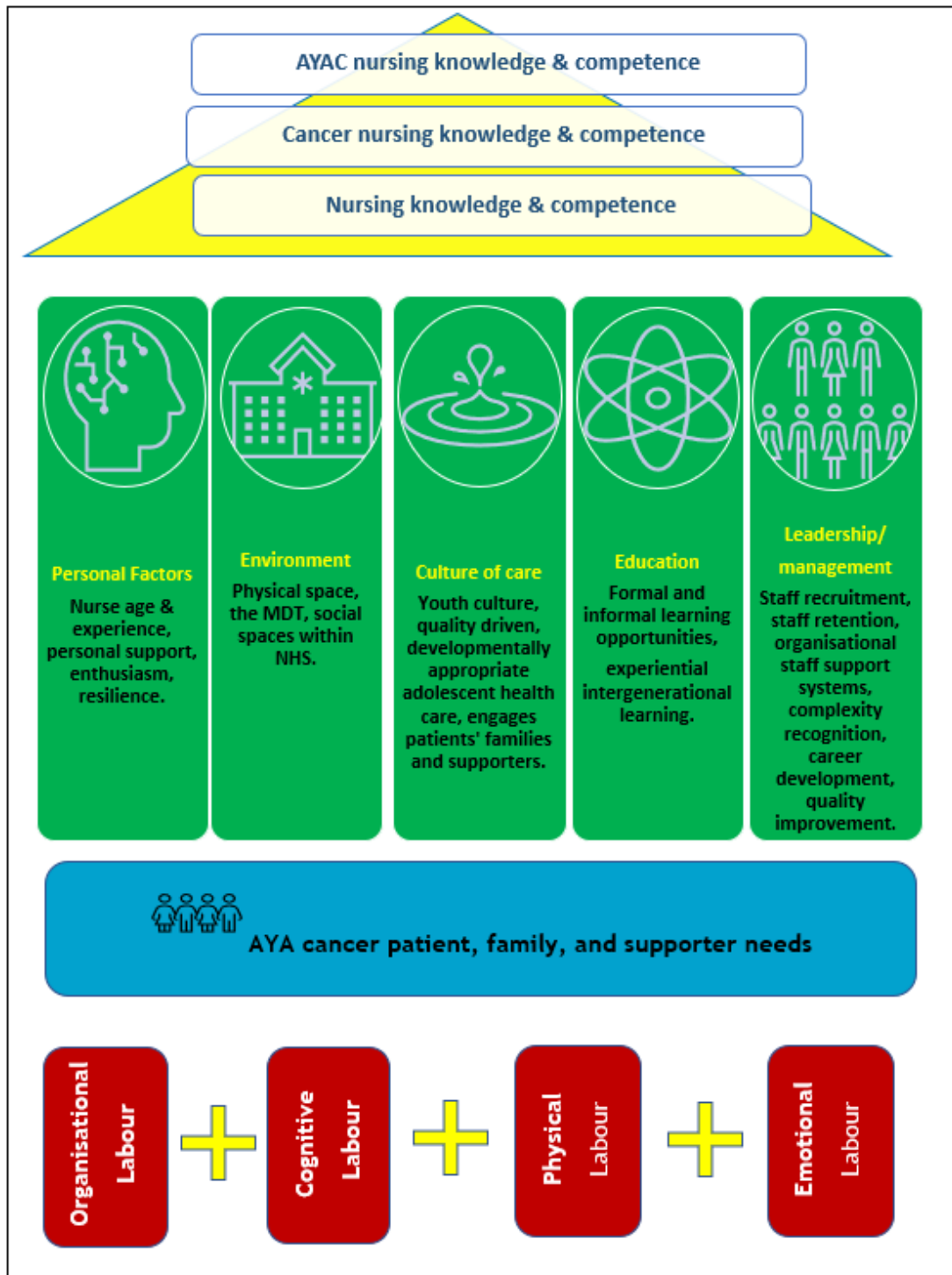


Figure 5.2 Conceptual framework of adolescent/young adult cancer nursing

Underpinning this framework is:

1. A supportive cancer care environment where the holistic, social and developmental needs of AYAs with cancer, their families, peers and supporters are considered.
2. Recognition that a range of specific AYAC nursing knowledge and skills that include clinical, technical, psychosocial, critical appraisal, leadership/management, collaboration, reflection and self-caring ability are required.
3. Recognition of the need for emotional support, continuous professional development and career development opportunities is necessary in AYAC nursing.
4. An ability to plan and measure quality and safety outcomes that consider AYA nursing practice, patient care and service improvement.
5. Recognition that physical, organisational, emotional and cognitive work of nurses are of equal importance throughout the career development of all AYAC nurses.

The construct of this original conceptual framework serves as a starting point for the discussion of the work of AYAC nurses particularly for those early in their careers. Whilst the framework may be perceived as linear, it is important to acknowledge that AYAC nursing work is dynamic and complex. For now, it is based on the work of ECN and has the potential to be extended for other levels of nurses as they progress their careers in AYA cancer care. The framework highlights the complexity of the type of work that these nurses do and how they work in complex adaptive systems.

5.5 Recommendations

In this section I link recommendations to the common strands of meaning and offer recommendations for practice, education, research and policy.

5.5.1 Practice recommendations

It is important to acknowledge and discuss the impact of caring for this patient population has on nursing staff. The following are suggested:

1. That a whole-systems approach in AYACC be considered in regard to staff well-being.

2. That regular purposeful staff check-ins from experienced members of the MDT be implemented on AYAC Units.
3. After significant events such as a particularly stressful/busy shift or when a patient relapses or dies, nurses should have the opportunity for a 1:1 conversation to reflect upon their experience, to articulate and 'make sense' of their feelings and learning and consider how it may impact upon their future nursing practice. This conversation should be with a designated member of senior staff.
4. Further support e.g., counselling should be offered if nurses require ongoing support.
5. That managers consider the intergenerational needs of nurses and teams working on units.
6. That managers are aware of some of the risks and benefits of Generation Z nurses caring for Generation Z patients.
7. That staff inductions to these units include preparedness for difficult conversations as well as the death of young people.
8. That all staff, including nurses have opportunity to engage in AYAC specific education in addition to developing mandatory clinical skills.

5.5.2 Education recommendations

Whilst few formal courses exist in the UK, many aspects of AYAC need to be conveyed, formally and/or informally, with nurses working in this field in order that knowledge, skill and competence is developed, for example:

1. That formal and informal learning on the unique holistic needs of AYAC are integrated into workforce plans.
2. That formal and informal post-registration curricula/courses consider the types of labour involved in AYACC including emotional labour involved in AYACC, AYAC developmental needs, teaching on holding difficult conversations and supporting AYAC, their supporters and staff during EOL.
3. That attention is paid to the protection and management of professional boundaries when working with AYAC and their supporters.
4. That the health and psychosocial needs of AYAs in general are taught in undergraduate nursing curricula, in both CYP and adult nursing.

5. A purposeful programme of experiential learning for newly appointed staff should be developed whereby more experienced AYAC nurses should mentor and share learning with junior nurses

5.5.3 Research recommendations

Whilst aspects of AYACC have been established from empirical study to support its specialism development, nursing contribution to this is less well understood. Therefore, it is recommended that:

1. The proposed model of AYA cancer nursing is tested for use across the span of nursing roles and in various settings, nationally and internationally.
2. Formal evaluation of any education initiatives is undertaken, particularly those that support holding difficult conversations with AYAC and their supporters.
3. Longitudinal evaluation of the emotional impact on ECNs and those who are more established in their careers in AYACC should be undertaken to assess its impact and consider strategies to support it.

5.5.4 Policy recommendations

At the time of writing, NHS England awaits an update on the Service Specification for Teenagers/Young adults with Cancer which define the standards of care expected from organisations funded by NHS England to provide specialised care. Patients were advised that the cancer service should have enough staff to give good safe care and that professionals should have the right qualifications and experience.

1. It is advised that a workforce analysis is undertaken in each specialist unit to review what skills and qualifications staff, including ECNs have.
2. Funding should be made available by the NHS to support nurses to undertake CPD in the field of AYACC.

5.6 Original contribution to knowledge

As a narrative inquirer, I am concerned with a deeper understanding of the research puzzle and thus by examining the stories relaying experiences of ECNs in AYAC specialist units, it may encourage readers to rethink and reimagine the

working life for early career nurses in these specialist environments and beyond, thus contributing to nursing knowledge in this specialist area. Having reviewed the literature and evidence within this area, it is evident that some of the issues explored in this thesis have been explored previously as per the literature review, whilst others have not. These studies may have included different types of nurses and indeed HCPs, settings and geographical locations, and through different methodologies. My study offers new perspectives on the work of early career nurses in AYACC in the UK, insights into the uniqueness of this work and acts as a springboard for further discussion for nurses in this specialism in the UK and beyond.

What is also an original contribution to knowledge, is an acknowledgement that age matters for patients and nurses themselves, especially as both progress through their adolescence into young adulthood.

5.7 Limitations

Narrative inquiry methodology acknowledges there is no final, end or single story we can tell. Therefore, this may not satisfy those who want to “see a single truth, or accuracy and verifiability of data” (Clandinin, 2013, p. 205). The stories told by participants were not narratively smoothed and their inherent tensions and contradictions were made apparent.

The limitations of narrative inquiry methodology, as used in this study, are those inherent to immersion in the three-dimensional narrative inquiry space.

Therefore, this inquiry was limited to the stories of experience told by nine participants across six different hospitals and may not be representative of nurses’ experiences in AYAC units across the rest of the UK or internationally, or indeed for nurses who care for AYAC outside of these specialist units.

It is acceptable to have smaller sample sizes in narrative inquiry, though some would argue that nine is an adequate sample size in qualitative research.

Recruitment was hampered by COVID-19 which could not have been anticipated. This resulted in a gendered sample, with, all bar one, identifying as female and I accept that this may limit the data from a gender perspective. I am mindful that the nurses told their stories during COVID-19 and their experiences and own well-being may have been hampered by the timing; therefore, timing may have

been an issue. This is something that I could not have avoided within the timescales of the doctoral course.

My own experience as a novice researcher must be acknowledged. Kim (2015, p. 20) alerts novice researchers to the risks of narrative inquiry given the fact that the dominant view in a positivist world dominates the discourse on research. I accept this is my interpretation of rich, complex data presented in story form. I felt obliged to retell every aspect of the nurses' stories here, but with time and word limitations, this could not be done. Whilst I tried to present each story uniquely, I accept there may have been some omissions which could have added to the richness and analysis.

5.8 Dissemination plan

Table 5.3 outlines the dissemination plan I intend to use with the study.

Table 5.3 Dissemination plan

Product	Target Audience/Event	Target date	Lead	Status
Presentations				
1. A Foucauldian analysis of the development of AYA cancer care in the United Kingdom	AYA Cancer Global Congress Sydney, Australia	Dec 2018	MC	Done
2. Emotional labour in AYA cancer care	TYAC Conference (Online) AYA Cancer HCP	Sept 2021	MC	Done
3. A conceptual framework of AYA cancer care nursing	In progress congress UKONS & EONS Conference AYA Global	2022 2023	MC	Progressing
4. Surviving and thriving as an ECN in AYA cancer care	In progress congress UKONS & EONS Conference AYA Global	2022 2023	MC	Progressing

Social Media To share findings, publication and develop networks via my Twitter feed @Mariacable2	Cancer nurse @UKONS @CancernurseEu @RCNResearchSoc @RCNCancerforum @Cancerlead		MC	Ongoing
	Nursing general @RCNNRN @CypRCN @RCNstudents @Wenurses @WeStudentNurse		MC	Ongoing
	Charity funders @TeenageCancer @TeenCancerUSA @CanteenAUS @Canteen_Ireland @YLvsCancer		MC	Ongoing
	AYAC social movement stakeholders #AYACSM		MC	Ongoing
	Policy makers/Influencers @APPGyoungcancer @TYACpro @CCLG_UK		MC	Ongoing
Publications 1. An analysis of the development of adolescent and young adult cancer care in the United Kingdom: A Foucauldian perspective 2. The experiences of ward nurses who care for adolescents/ young adults with cancer (AYAC) in specialist settings - a scoping review	Nursing Inquiry Planning stage	Jan 2019 Circa Jan 2022	MC and DK MC/DK/ TW/CR	Done To start

3. Emotional labour in AYA cancer care for ECNs	Planning stage	Circa Jan 2022	MC/DK/TW/CR	To start
4. A conceptual framework of AYA cancer care nursing	Planning stage	Circa Jan 2022	MC/DK/TW/CR	To start
5. Surviving and thriving as an ECN in AYACC	Planning stage	Circa Jan 2022	MC/DK/TW/CR	To start
Posters				
1. The experiences of ward nurses who care for adolescents/ young adults with cancer (AYAC) in specialist settings - a scoping review	AYA Global congress (Online)	Dec 2021	MC/DK/TW/CR	Accepted

5.9 Chapter summary

This chapter presented my interpretation of the common strands which helped me interpret nurse stories. Figure 5.3 represents how I visualised these strands which on the outside appear ordered and well presented to create a picture, yet when the underside is revealed, it can be very messy, fuzzy, complex, and interwoven.

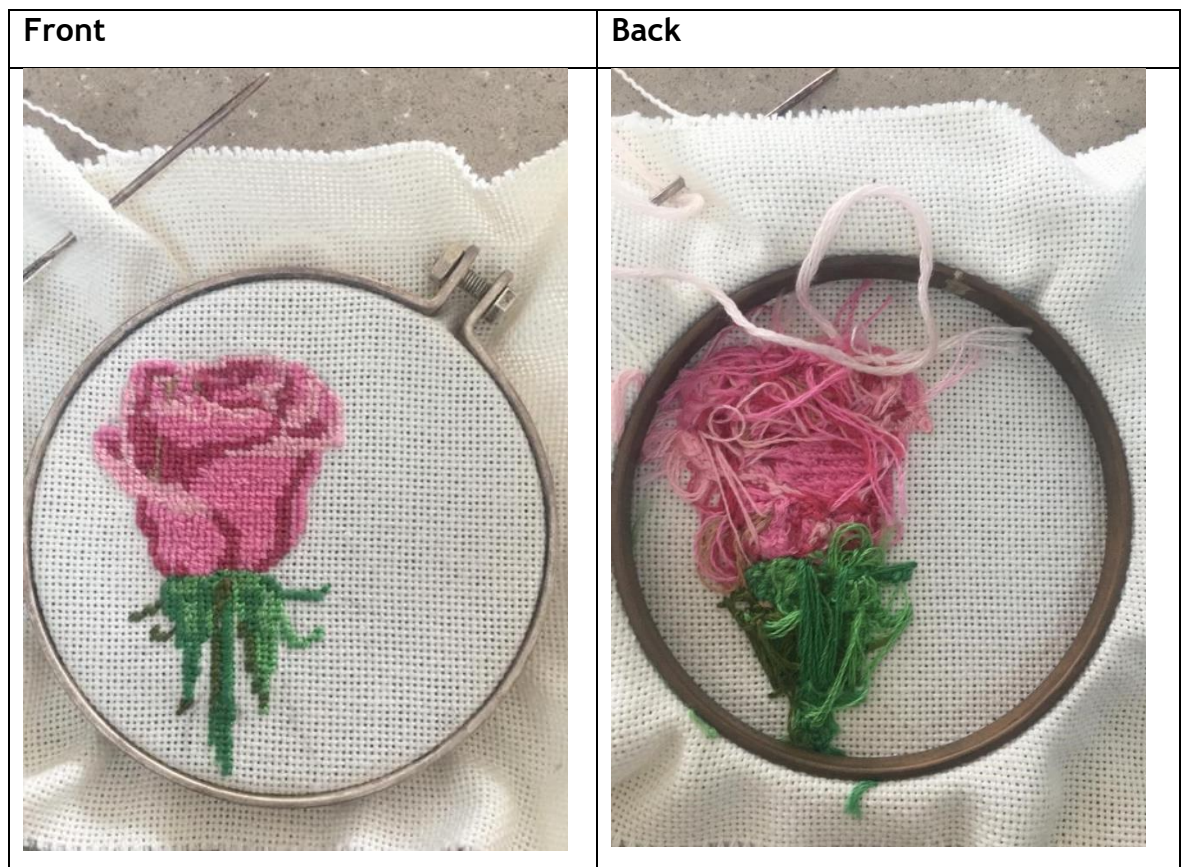


Figure 5.3 Revised visual representation of common strands

The experiences of ECNs who work in specialist AYAC settings are manifold; these nurses are impacted by this work in their professional and personal lives as are their personal supporters because of the unique nature of their work. For many, they are engaged in, or recently completed, the preceptorship period of their newly registered nursing career and are establishing their role as a registered nurse in a specialist oncology setting within the NHS. Only when they have achieved the perceived competence required to safely deliver care to cancer patients, do they feel ready or have the capacity to learn more about the holistic care for AYAC. Clinical skill development and ward management are both considered to be important aspects of their role, yet all the nurses acknowledged there was a greater need to understand the developmental aspects of AYAC patients' lives which included managing and working with their parents/supporters. The emotional labour of this work has been highlighted in this narrative research which concurs with other existing empirical evidence and theoretical perspectives. The tensions and complexity of this work have been revealed and a critical construction of AYA cancer nursing knowledge developed. Study limitations and a dissemination plan have been articulated.

Chapter 6 Conclusion

Complete understanding of these stories from ECNs is not possible. These stories may have been told and heard in incomplete or inconsistent ways. The relationships the ECNs have with patients and families are powerful, yet transient and often never reaching closure. Therefore, nurses often live with ambiguity and transience and may struggle to spare time, energy and emotion to move towards a subjective stance/position with AYAC and their families. If the ECN's goal is to strive to completely understand the practice of AYAC nursing, they have to accept that coping with ambiguity and transience is part of that understanding. They must also recognise the risks and tensions between positions of empathy, neutrality and distance as part of the nature of this work.

I am mindful that I do not hear the subjective experiences of the patient, families/supporters or managers. I only heard the subjective experiences of nurses so cannot lay claim to certainty. These stories are not the actual experiences, merely rendering or ordering of them. My postmodern view also looked at what was not said as the stories are not linear (Clandinin and Caine, 2013). Narrative inquiry is not simply a recount of stories nor is it an assumption that what was experienced is what was described. By attending to this contention as is often part of the postmodern position, I may not have arrived at any emergent truth or certainty but revealed events compounded by complexity that may challenge assumptions about the nature of AYAC nursing and the practice of young nurses being with young patients and their families.

The stories told in this thesis, whilst localised and personal, have yielded a novel and insightful narrative about the nature of AYAC nursing. What is important is that we look after our young - patients and nurses - for they are all deserving of a bright future. How we do this bears great consequence for their long-term potential, for if we do not look after our ECNs, young cancer patients will struggle to receive the unique nursing care that they need.

References

- Albers, L. F., Bergsma, F. B., Mekelenkamp, H., Pelger, R. C., Manten-Horst, E. & Elzevier, H. W. 2020a. Discussing sexual health with adolescent and young adults with cancer: a qualitative study among healthcare providers. *Journal of Cancer Education*, pp. 1-8.
- Albers, L. F., Haj Mohammad, S. F., Husson, O., Putter, H., Pelger, R. C. M., Elzevier, H. W. & Manten-Horst, E. 2020b. Exploring communication about intimacy and sexuality: what are the preferences of adolescents and young adults with cancer and their health care professionals? *Journal of Adolescent & Young Adult Oncology*, 9, pp. 222-238.
- Arigo, D., Pagoto, S., Carter-Harris, L., Lillie, S. E. & Nebeker, C. 2018. Using social media for health research: methodological and ethical considerations for recruitment and intervention delivery. *Digital Health*, 4, pp. 1-15.
- Arimon-Pagès, E., Torres-Puig-Gros, J., Fernández-Ortega, P. & Canela-Soler, J. 2019. Emotional impact and compassion fatigue in oncology nurses: results of a multicentre study. *European Journal of Oncology Nursing*, 43, pp. 101666-101666.
- Arksey, H. & O'Malley, L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8, pp. 19-32.
- Armstrong, R., Hall, B. J., Doyle, J. & Waters, E. 2011. 'Scoping the scope' of a cochrane review. *Journal of Public Health*, 33, pp. 147-150.
- Avery, J., Geist, A., D'Agostino, N. M., Kawaguchi, S. K., Mahtani, R., Mazzotta, P., Mosher, P. J., Al-Awamer, A., Kassam, A., Zimmermann, C., Samadi, M., Tam, S., Srikanthan, A. & Gupta, A. 2019. "It's More Difficult...": clinicians' experience providing palliative care to adolescents and young adults diagnosed with advanced cancer. *Journal of Oncology Practice*, 16, 1, pp. e100-e108.
- Aveyard, H., Payne, S. A. & Preston, N. J. 2016. *A post-graduate's guide to doing a literature review in health and social care*, London: Open University Press.
- Aveyard, H. & Sharp, P. 2017. *A beginner's guide to evidence-based practice in health and social care*, London, McGraw-Hill Education (UK).
- 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. *Supportive Care in Cancer*, 25, pp. 1587-1596.
- Bailey, P. H. & Tilley, S. 2002. Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing*, 38, pp. 574-583.
- Bal, M. & Van Boheemen, C. 2009. *Narratology: introduction to the theory of narrative*, Toronto: University of Toronto Press.

- Banerjee, S., Califano, R., Corral, J., De Azambuja, E., De Mattos-Arruda, L., Guarneri, V., Hutka, M., Jordan, K., Martinelli, E. & Mountzios, G. 2017. Professional burnout in European young oncologists: results of the European society for Medical Oncology (ESMO) young oncologists committee burnout survey. *Annals of Oncology*, 28, pp. 1590-1596.
- Barlevy, D., Wangmo, T., Elger, B. S. & Ravitsky, V. 2016. Attitudes, beliefs, and trends regarding adolescent oncofertility discussions: a systematic literature review. *Journal of Adolescent and Young Adult Oncology*, 5, pp. 119-134.
- Barnard, D., Street, A. & Love, A. W. 2006. Relationships between stressors, work supports, and burnout among cancer nurses. *Cancer Nursing*, 29, pp. 338-345.
- Bartel, K. A., Gradisar, M. & Williamson, P. 2015. Protective and risk factors for adolescent sleep: a meta-analytic review. *Sleep Medicine Reviews*, 21, pp. 72-85.
- Beech, J., Bottery, S., Charlesworth, A., Evans, H., Gershlick, B., Hemmings, N., Imison, C., Kahtan, P., McKenna, H., R, M. & Palmer, B. 2019. *Closing the gap: key areas for action on the health and care workforce*. London: The Health Foundation.
- Benner, P. 1984. *From novice to expert*, Menlo Park, Addison: Wesley Publishers.
- Benner, P. E. & Wrubel, J. 1989. *The primacy of caring: stress and coping in health and illness*, Wokingham: Addison-Wesley/Addison Wesley Longman.
- Beresford, B., Gibson, F., Bayliss, J. & Mukherjee, S. 2018. Preventing work-related stress among staff working in children's cancer Principal Treatment Centres in the UK: a brief survey of staff support systems and practices. *European Journal of Cancer Care*, 27, p. e12535.
- Berger, I., Thompson, K. & Joubert, L. 2019a. An exploratory study into the experience of health care professionals caring for adolescents and young adults with incurable cancer. *Journal of Adolescent and Young Adult Oncology*, 8, pp. 458-462.
- Berger, I., Thompson, K. & Joubert, L. 2019b. An Exploratory Study into the Experience of Health Care Professionals Caring for Adolescents and Young Adults with Incurable Cancer. *Journal of Adolescent & Young Adult Oncology*, 8, pp. 458-462.
- Bibby, H., White, V., Thompson, K. & Anazodo, A. 2017. What are the unmet needs and care experiences of adolescents and young adults with cancer? A systematic review. *Journal of Adolescent and Young Adult Oncology*, 6, pp. 6-30.
- Blanchard, P., Truchot, D., Albiges-Sauvin, L., Dewas, S., Pointreau, Y., Rodrigues, M., Xhaard, A., Loriot, Y., Giraud, P. & Soria, J. 2010. Prevalence and causes of burnout amongst oncology residents: a comprehensive nationwide cross-sectional study. *European journal of cancer*, 46, pp. 2708-2715.

- Bolton, S. C. 2000. Who cares? Offering emotion work as a 'gift' in the nursing labour process. *Journal of Advanced Nursing*, 32, 3, pp. 580-586.
- Booth, A. 2004. Formulating answerable questions. In: Booth A. and Brice, A. (eds.) *Evidence based practice: an information professional's handbook*. London: Facet, 2004, pp. 61-70.
- Booth, A., Sutton, A. & Papaioannou, D. 2016. *Systematic approaches to a successful literature review*, Los Angeles, Sage.
- Bowden, M. J., Mukherjee, S., Williams, L. K., DeGraves, S., Jackson, M. & McCarthy, M. C. 2015. Work-related stress and reward: an Australian study of multidisciplinary pediatric oncology healthcare providers. *Psycho-Oncology*, 24, pp. 1432-1438.
- Boyle, D. A. & Bush, N. J. 2018. Reflections on the emotional hazards of pediatric oncology nursing: four decades of perspectives and potential. *Journal of Pediatric Nursing*, 40, pp. 63-73.
- Bradford, N. K., Greenslade, R., Edwards, R. M., Orford, R., Roach, J. & Henney, R. 2018. Educational needs of health professionals caring for adolescents and young adults with cancer. *Journal of Adolescent & Young Adult Oncology*, 7, pp. 298-305.
- Brand, S. L., Thompson Coon, J., Fleming, L. E., Carroll, L., Bethel, A. & Wyatt, K. 2017. Whole-system approaches to improving the health and wellbeing of healthcare workers: a systematic review. *PloS one*, 12, p. e0188418.
- Braun, V. & Clarke, V. 2013. *Successful qualitative research: a practical guide for beginners*, Los Angeles: Sage.
- Braun, V. & Clarke, V. 2021. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13, pp. 201-216.
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A. & Jemal, A. 2018. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, 68, pp. 394-424.
- Brimble, M. J., Anstey, S. & Davies, J. 2019. Long-term nurse-parent relationships in paediatric palliative care: a narrative literature review. *International Journal of Palliative Nursing*, 25, pp. 542-550.
- Brogden, L. M. 2010. Double hermeneutic. *Encyclopedia of case study research*. pp. 322-324, California, USA: SAage Publications.
- Brown, B. 2015. *Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead*, UK: Penguin.
- Buchan, J., Ball, J., Shembavnekar, N. & Charlesworth, A. 2020. *Building the NHS nursing workforce in England*. London: The Health Foundation.

- Burns, K. C., Hoefgen, H., Strine, A. & Dasgupta, R. 2018. Fertility preservation options in pediatric and adolescent patients with cancer. *Cancer*, 124, pp. 1867-1876.
- Buzan, T. & Buzan, B. 2006. *The mind map book*, London: Pearson Education.
- Cable, M. & Kelly, D. 2019. An analysis of the development of adolescent and young adult cancer care in the United Kingdom: A Foucauldian perspective. *Nursing Inquiry*, 26, p. e12272.
- Cable, M. & Pettitt, N. 2018. Educating and developing AYA cancer nurses. *Nursing adolescents and young adults with cancer: developing knowledge, competence and best practice*. pp. 41-62, Cham: Springer.
- Caine, V., Estefan, A. & Clandinin, D. J. 2013. A return to methodological commitment: reflections on narrative inquiry. *Scandinavian Journal of Educational Research*, 57, pp. 574-586.
- Cameron, F. & Brownie, S. 2010. Enhancing resilience in registered aged care nurses. *Australasian Journal on Ageing*, 29, pp. 66-71.
- Cañadas-De la Fuente, G. A., Gómez-Urquiza, J. L., Ortega-Campos, E. M., Cañadas, G. R., Albendín-García, L. & De la Fuente-Solana, E. I. 2018. Prevalence of burnout syndrome in oncology nursing: a meta-analytic study. *Psycho-Oncology*, 27, pp. 1426-1433.
- Cañadas-De la Fuente, G. A., Gómez-Urquiza, J. L., Ortega-Campos, E. M., Cañadas, G. R., Albendín-García, L. & De la Fuente-Solana, E. I. 2018. Prevalence of burnout syndrome in oncology nursing: a meta-analytic study. *Psycho-oncology*, 27, pp. 1426-1433.
- Cancer Research UK. 2021. *Young people's cancers incidence statistics* [Online]. Available: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/young-people-cancers/incidence#heading-One> [Accessed 20/07/2021].
- Carr, D. 1991. *Time, narrative, and history*, USA, Indiana University Press.
- Challinor, J. M., Alqudimat, M. R., Teixeira, T. O. & Oldenmenger, W. H. 2020. Oncology nursing workforce: challenges, solutions, and future strategies. *The Lancet Oncology*, 21, p. e564-e574.
- Charalambous, A., Raftopoulos, V. & Talias, M. A. 2013. The confirmatory factor analysis of the Job Diagnostic Survey: the oncology nursing setting. *Journal of Nursing Management*, 21, pp. 273-282.
- Charmaz, K., 2014. *Constructing grounded theory*. Los Angeles, Sage.
- Chase, S. E. 2003. Learning to listen: Narrative principles in a qualitative research methods course. In: Josselson, R., Lieblich, A. & Mcadams, D. (eds.) *Up close and personal: the teaching and learning of narrative research*. pp. 77-79, Washington: American Psychological Association.

- Chisholm, J., Hough, R. & Soanes, L. 2018. *A practical approach to the care of adolescents and young adults with cancer*, Cham: Springer.
- Chochinov, H. M., McClement, S. E., Hack, T. F., McKeen, N. A., Rach, A. M., Gagnon, P., Sinclair, S. & Taylor-Brown, J. 2013. Health care provider communication: an empirical model of therapeutic effectiveness. *Cancer*, 119, pp. 1706-1713.
- Christensen, S. S., Wilson, B. L. & Edelman, L. S. 2018. Can I relate? A review and guide for nurse managers in leading generations. *Journal of Nursing Management*, 26, pp. 689-695.
- Clandinin, D. J. 2006. Narrative inquiry: a methodology for studying lived experience. *Research Studies in Music Education*, 27, pp. 44-54.
- Clandinin, D. J. & Caine, V. 2013. Narrative inquiry. *Reviewing qualitative research in the social sciences*. pp. 178-191, New York: Routledge.
- Clandinin, D. J., Cave, M. T. & Berendonk, C. 2016. Narrative inquiry: a relational research methodology for medical education. *Medical Education*, 51, pp. 89-96.
- Clandinin, D. J., Cave, M. T. & Berendonk, C. 2017. Narrative inquiry: a relational research methodology for medical education. *Medical Education*, 51, pp. 89-96.
- Clandinin, D. J. & Connelly, F. M. 2000. *Narrative inquiry*. San Francisco: Jossey-Bass.
- Clandinin, D. J. & Murphy, M. S. 2009. Comments on Coulter and Smith: relational ontological commitments in narrative research. *Educational researcher*, 38, pp. 598-602.
- Clandinin, D. J. & Rosiek, J. 2007. Mapping a landscape of narrative inquiry. In Clandinin, J., *Handbook of narrative inquiry: mapping a methodology* Thousand Oaks CA: Sage, , pp. 35-75.
- Close, A. G., Dreyzin, A., Miller, K. D., Seynaeve, B. K. & Rapkin, L. B. 2019. Adolescent and young adult oncology—past, present, and future. *CA: A Cancer Journal for Clinicians*, 69, pp. 485-496.
- Clough, P. 2002. *Narratives and fictions in educational research*, Buckingham: Open University Press.
- Cole, E. 2020. Supporting Gen Y and Z: what it takes to retain newly qualified nurses. *Nursing Standard*, 35, pp. 14-17.
- Collins, C. S. & Stockton, C. M. 2018. The central role of theory in qualitative research. *International Journal of Qualitative Methods*, 17, pp. 1-10.
- Connelly, F. M. & Clandinin, D. J. 1990. Stories of experience and narrative inquiry. *Educational Researcher*, 19, pp. 2-14.

- Connelly, F. M. & Clandinin, D. J. 2006. Narrative inquiry. In: Green, E., Camilli, G. & Elmore, P. (eds.) *Handbook of complementary methods in education Research*. pp. 477-487, Washington: Routledge.
- Coolican, H. 2018. *Research methods and statistics in psychology*, London: Routledge.
- Cordeiro, L., Soares, C. B. & Rittenmeyer, L. 2017. Unscrambling method and methodology in action research traditions: theoretical conceptualization of praxis and emancipation. *Qualitative Research*, 17, pp. 395-407.
- Cowen, A. S. & Keltner, D. 2017. Self-report captures 27 distinct categories of emotion bridged by continuous gradients. *Proceedings of the National Academy of Sciences*, 114, pp. E7900-E7909.
- Currie, E. J. & Hill, R. A. C. 2012. What are the reasons for high turnover in nursing? A discussion of presumed causal factors and remedies. *International Journal of Nursing Studies*, 49, pp. 1180-1189.
- D'Agostino, N. M., Penney, A. & Zebrack, B. 2011. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*, 117, pp. 2329-2334.
- Darlington, Y. & Scott, D. 2020. *Qualitative research in practice: stories from the field: Stories from the field*, London: Routledge.
- Daudt, H. M., van Mossel, C. & Scott, S. J. 2013. Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*, 13, p. 48.
- Davis, S., Lind, B. K. & Sorensen, C. 2013. A Comparison of Burnout Among Oncology Nurses Working in Adult and Pediatric Inpatient and Outpatient Settings. *Oncology Nursing Forum*, 40, pp. E303-E311.
- Day, E., Jones, L., Langner, R., Stirling, L. C., Hough, R., Bluebond-Langner, M. & Bluebond-Langner, M. 2018. "We just follow the patients' lead": healthcare professional perspectives on the involvement of teenagers with cancer in decision making. *Pediatric Blood & Cancer*, 65, 3, p. e26898
- Debesay, J., Harsløf, I., Rechel, B. & Vike, H. 2014. Dispensing emotions: Norwegian community nurses' handling of diversity in a changing organizational context. *Social Science & Medicine*, 119, pp. 74-80.
- Delgado, C., Upton, D., Ranse, K., Furness, T. & Foster, K. 2017. Nurses' resilience and the emotional labour of nursing work: an integrative review of empirical literature. *International Journal of Nursing Studies*, 70, pp. 71-88.
- Deloitte Touche Tohmatsu 2017. The 2017 Deloitte Millennial Survey: apprehensive millennials: seeking stability and opportunities in an uncertain world, Deloitte Touche Tohmatsu, [Place of publication not identified], Available: <https://www2.deloitte.com/global/en/pages/about-deloitte/articles/millennialsurvey.html>. [Accessed 10/10/2021]

Denzin, N. K. & Lincoln, Y. S. 2011. *The Sage handbook of qualitative research*, Los Angeles: Sage.

Department of Health 2013. *Patients first and foremost: the initial government response to the report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, London: The Stationery Office.

Dewey, J. 1938. *Experience and education*, New York, USA.: Collier books.

DiCicco-Bloom, B. & Crabtree, B. F. 2006. The qualitative research interview. *Medical Education*, 40, pp. 314-321.

Diesch, T., Rovó, A., Von Der Weid, N., Faraci, M., Pillon, M., Dalissier, A., Dalle, J. & Bader, P. 2017. Fertility preservation practices in pediatric and adolescent cancer patients undergoing HSCT in Europe: a population-based survey. *Bone Marrow Transplantation*, 52, pp. 1022-1028.

Dovey-Pearce, G., Rapley, T. & McDonagh, J. E. 2020. Delivering developmentally appropriate health care: roles for psychologists as members of the multi-disciplinary health care team. *Clinical Child Psychology and Psychiatry*, 25, pp. 579-593.

Duarte, J. & Pinto-Gouveia, J. 2017. The role of psychological factors in oncology nurses' burnout and compassion fatigue symptoms. *European Journal of Oncology Nursing*, 28, pp. 114-121.

Dyrbye, L. N., Shanafelt, T. D., Sinsky, C. A., Cipriano, P. F., Bhatt, J., Ommaya, A., West, C. P. & Meyers, D. 2017. Burnout among health care professionals: a call to explore and address this underrecognized threat to safe, high-quality care. *National Academy of Medicine;perspectives*. Washington DC. Available: 1501524077-Burnout-Among-Health-Care-Professionals-A-Call-to-Explore-and-Address-This-Underrecognized-Threat.pdf (iuhcpe.org). [Accessed 10/10/2021]

Ekman, P. & Cordaro, D. 2011. What is meant by calling emotions basic. *Emotion Review*, 3, pp. 364-370.

Essig, S., Steiner, C., Kuehni, C. E., Weber, H. & Kiss, A. 2016. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. *Pediatric Blood & Cancer*, 63, pp. 1423-1430.

Essig, S., Steiner, C., Kühne, T., Kremens, B., Langewitz, W. & Kiss, A. 2019. Communication skills training for professionals working with adolescent patients with cancer based on participants' needs: a pilot. *Journal of Adolescent and Young Adult Oncology*, 8, pp. 354-362.

Evans, A. M. 2007. Transference in the nurse-patient relationship. *Journal of Psychiatric Mental Health Nursing*, 14, pp. 189-95.

Farre, A., Wood, V., McDonagh, J. E., Parr, J. R., Reape, D. & Rapley, T. 2016. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Archives of Disease in Childhood*, 101, pp. 628-633.

- Farre, A., Wood, V., Rapley, T., Parr, J. R., Reape, D. & McDonagh, J. E. 2015. Developmentally appropriate healthcare for young people: a scoping study. *Archives of Disease in Childhood*, 100, pp. 144-151.
- Fehr, B. & Russell, J. A. 1984. Concept of emotion viewed from a prototype perspective. *Journal of Experimental Psychology: General*, 113, pp. 464-486.
- Figley, C. R. 1995. *Compassion fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized*, New York: Psychology Press.
- Flynn, H. K., Felmlee, D. H. & Conger, R. D. 2017. The social context of adolescent friendships: parents, peers, and romantic partners. *Youth & Society*, 49, pp. 679-705.
- Folkman, S. & Lazarus, R. S. 1988. Coping as a mediator of emotion. *Journal of Personality and Social Psychology*, 54, p. 466.
- Forster, E. & Hafiz, A. 2015. Paediatric death and dying: exploring coping strategies of health professionals and perceptions of support provision. *International Journal of Palliative Nursing*, 21, pp. 294-301.
- Foucault, M. 1977. *Discipline and punish: the birth of the prison* (A. Sheridan, Trans.). New York: Vintage Books.
- Foulkes, L. & Blakemore, S.-J. 2018. Studying individual differences in human adolescent brain development. *Nature Neuroscience*, 21, pp. 315-323.
- Francis, R. 2013. Report of the Mid Staffordshire NHS Foundation Trust public inquiry: executive summary, London: The Stationery Office.
- Gama, G., Barbosa, F. & Vieira, M. 2014. Personal determinants of nurses' burnout in end of life care. *European Journal of Oncology Nursing*, 18, pp. 527-533.
- Geiger, A. M. & Castellino, S. M. 2011. Delineating the age ranges used to define adolescents and young adults. *Journal of Clinical Oncology*, 29, pp. e492-e493.
- Garside, J. R. & Nhemachena, J. Z. 2013. A concept analysis of competence and its transition in nursing. *Nurse Education Today*, 33, pp. 541-545.
- Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S. & Richardson, A. 2010. Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *International Journal of Nursing Studies*, 47, pp. 1397-1407.
- Gibson, F., Fern, L., Whelan, J., Pearce, S., Lewis, I., Hobin, D. & Taylor, R. 2012. A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'. *European Journal of Cancer Care*, 21, pp. 330-339.
- Gibson, F., Fletcher, M. & Casey, A. 2003. Classifying general and specialist children's nursing competencies. *Journal of Advanced Nursing*, 44, pp. 591-602.

- Gilbert, N. 2008. *Researching social life*, Los Angeles: Sage.
- Gómez-Ochoa, S. A., Franco, O. H., Rojas, L. Z., Raguindin, P. F., Roa-Díaz, Z. M., Wyssmann, B. M., Guevara, S. L. R., Echeverría, L. E., Glisic, M. & Muka, T. 2021. COVID-19 in health-care workers: a living systematic review and meta-analysis of prevalence, risk factors, clinical characteristics, and outcomes. *American Journal of Epidemiology*, 190, pp. 161-175.
- Gough, D., Oliver, S. & Thomas, J. 2017. *An introduction to systematic reviews*, Los Angeles: Sage.
- Grandey, A. A. 2015. Smiling for a Wage: What emotional labor teaches us about emotion regulation. *Psychological Inquiry*, 26, pp. 54-60.
- Grant, L. & Kinman, G. 2014. Emotional resilience in the helping professions and how it can be enhanced. *Health and Social Care Education*, 3, pp. 23-34.
- Gray, B. 2009. The emotional labour of nursing - defining and managing emotions in nursing work. *Nurse Education Today*, 29, pp. 168-175.
- Guba, E. G. & Lincoln, Y. S. 1994. Competing paradigms in qualitative research. In Denzin N., Lincoln, Y., eds., *Handbook of Qualitative Research*, pp. 163-194.
- Haase, J. E., Britt, T., Coward, D. D., Leidy, N. K. & Penn, P. E. 1992. Simultaneous concept analysis of spiritual perspective, hope, acceptance and self-transcendence. *Image: The Journal of Nursing Scholarship*, 24, pp. 141-147.
- Happell, B., Reid-Searl, K., Dwyer, T., Caperchione, C. M., Gaskin, C. J. & Burke, K. J. 2013. How nurses cope with occupational stress outside their workplaces. *Collegian*, 20, pp. 195-199.
- Hart, S. M. 2006. Generational diversity: impact on recruitment and retention of registered nurses. *The Journal of Nursing Administration*, 36, pp. 10-12.
- Haydon, G., Van der Riet, P. & Maguire, J. 2016. The suitability of narrative inquiry in health research. In Abstracts, Oral for Qualitative Methods Conference, 2016, *International Journal of Qualitative Methods*, 15, 1, p 19.
- Health and Safety Executive. 2020. *Work-related stress, anxiety or depression statistics in Great Britain, 2020* [Online]. HSE. Available: <https://www.hse.gov.uk/statistics/causdis/stress.pdf> [Accessed 16 /05/2021].
- Health and Social Care Committee 2021. Workforce burnout and resilience in the NHS and social care: Second Report of Session 2021-22. In: COMMITTEES, Health and Social Care Committee. (ed.). House of Commons.
- Health Workforce Australia 2014. *Nursing workforce sustainability, improving nurse retention and productivity*. Canberra: Australian Government.
- Hendricks, J. M. & Cope, V. C. 2013. Generational diversity: what nurse managers need to know. *Journal of Advanced Nursing*, 69, pp. 717-725.

- Hesselgrave, J. 2014. Coping with compassion fatigue in pediatric oncology nursing. *Oncology Times*, 36, pp. 2-3.
- Hinds, P. S., Quargnenti, A. G., Hickey, S. S. & Mangum, G. H. 1994. A comparison of the stress--response sequence in new and experienced pediatric oncology nurses. *Cancer Nursing*, 17, pp. 61-71.
- Hinds, P. S., Sanders, C. B., Srivastava, D. K., Hickey, S., Jayawardene, D., Milligan, M., Olson, M. S., Puckett, P., Quargnenti, A. & Randall, E. A. 1998. Testing the stress-response sequence model in paediatric oncology nursing. *Journal of Advanced Nursing*, 28, pp. 1146-1157.
- Hinds, P. S., Srivastava, D. K., Randall, E. A., Green, A., Stanford, D., Pinlac, R., Tong, X., Tyc, V., Davis, J. & Taylor, K. 2003. Testing the revised stress-response sequence model in pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, 20, pp. 213-232.
- Hlubocky, F. J., Rose, M. & Epstein, R. M. 2017. Mastering resilience in oncology: learn to thrive in the face of burnout. *American Society of Clinical Oncology Educational Book*, 37, pp. 771-781.
- Hochschild, A. R. 1983. *The managed heart: commercialization of human feelings*, Berkley, CA: University of California Press.
- Hollingsworth, S. & Dybdahl, M. 2007. Talking to learn. In: Clandinin, J. (ed) *Handbook of narrative inquiry: mapping a methodology*, pp. 146-176.
- Holloway, I. & Freshwater, D. 2007. Vulnerable story telling: narrative research in nursing. *Journal of Research in Nursing*, 12, pp. 703-711.
- Holloway, I. & Freshwater, D. 2009. *Narrative research in nursing*, Oxford: John Wiley & Sons.
- Holloway, I. & Galvin, K. 2016. *Qualitative research in nursing and healthcare*, Chichester: John Wiley & Sons.
- Holmes, C. A. & Warelow, P. J. 2000. Some implications of postmodernism for nursing theory, research, and practice. *Canadian Journal of Nursing Research Archive*, 32, pp. 89-101.
- Howe, N. & Nadler, R. 2010. *Millennials in the workplace: Human resource strategies for a new generation*, Great Falls, Lifecourse Associates.
- Humphrey, R. H., Ashforth, B. E. & Diefendorff, J. M. 2015. The bright side of emotional labor. *Journal of Organizational Behavior*, 36, pp. 749-769.
- Iorgulescu, M.-C. 2016. Generation Z and its perception of work. *Cross-Cultural Management Journal*, 18, pp. 47-54.
- Isikhan, V., Comez, T. & Danis, M. Z. 2004. Job stress and coping strategies in health care professionals working with cancer patients. *European Journal of Oncology Nursing*, 8, pp. 234-244.

- Izard, C. E. 2007. Basic emotions, natural kinds, emotion schemas, and a new paradigm. *Perspectives on Psychological Science*, 2, p. 261.
- Jackson, D., Anders, R., Padula, W. V., Daly, J. & Davidson, P. M. 2020. Vulnerability of nurse and physicians with COVID-19: Monitoring and surveillance needed. *Journal of Clinical Nursing*, 29, pp. 3584-3587.
- Jackson, J., Anderson, J. E. & Maben, J. 2021. What is nursing work? A meta-narrative review and integrated framework. *International Journal of Nursing Studies*, 122, p. e103944.
- James, N. 1989. Emotional labour: skill and work in the social regulation of feelings. *The Sociological Review*, 37, pp. 15-42.
- Kelly, D., Pearce, S. & Mulhall, A. 2004. 'Being in the same boat': ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies*, 41, pp. 847-857.
- Kelly, D., Ross, S., Gray, B. & Smith, P. 2000. Death, dying and emotional labour: problematic dimensions of the bone marrow transplant nursing role? *Journal of Advanced Nursing*, 32, pp. 952-960.
- Kendall, S. 2007. Witnessing tragedy: nurses' perceptions of caring for patients with cancer. *International Journal of Nursing Practice*, 13, pp. 111-120.
- Kim, J.-H. 2015. *Understanding narrative inquiry: The crafting and analysis of stories as research*, Los Angeles: Sage Publications.
- Kinman, G. & Leggetter, S. 2016. Emotional labour and wellbeing: what protects nurses? *Healthcare*, 4, p. 89.
- Kirchhoff, A. C., Fowler, B., Warner, E. L., Pannier, S. T., Fair, D., Spraker-Perlman, H., Yancey, J., Bott, B., Reynolds, C. & Randall, R. L. 2017. Supporting adolescents and young adults with cancer: oncology provider perceptions of adolescent and young adult unmet needs. *Journal of Adolescent and Young Adult Oncology*, 6, pp. 519-523.
- Klassen, A., Gulati, S. & Dix, D. 2012. Health care providers' perspectives about working with parents of children with cancer: a qualitative study. *Journal of Pediatric Oncology Nursing*, 29, pp. 92-97.
- Kleinke, A. M. & Classen, C. F. 2018. Adolescents and young adults with cancer: aspects of adherence-a questionnaire study. *Adolescent health, medicine and therapeutics*, 9, p. 77.
- Knapp, M. & Lemmi, V. 2014. *Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence*. London: Department of Health.
- Kövecses, Z. 2003. *Metaphor and emotion: Language, culture, and body in human feeling*, Cambridge: Cambridge University Press.

- Kroeze, J. 2012. Postmodernism, interpretivism, and formal ontologies. In: MORA, M. (ed.) *Research Methodologies, Innovations and Philosophies in Software Systems Engineering and Information Systems*. pp. 43-62.
- Kutlururkan, S., Sozeri, E., Uysal, N. & Bay, F. 2016. Resilience and burnout status among nurses working in oncology. *Annals of General Psychiatry*, 15, p. 33.
- Kvale, S. 2008. *Doing interviews*, Los Angeles: Sage.
- Lambert, V. A. & Lambert, C. E. 2008. Nurses' workplace stressors and coping strategies. *Indian Journal of Palliative Care*, 14, p. 38.
- Laryionava, K., Heußner, P., Hiddemann, W. & Winkler, E. C. 2018. "Rather one more chemo than one less...": oncologists and oncology nurses' reasons for aggressive treatment of young adults with advanced cancer. *Oncologist*, 23, pp. 256-262.
- Lavender, V., Gibson, F., Brownsdon, A., Fern, L., Whelan, J. & Pearce, S. 2019. Health professional perceptions of communicating with adolescents and young adults about bone cancer clinical trial participation. *Supportive Care in Cancer*, 27, pp. 467-475.
- Lazard, L. & McAvoy, J. 2020. Doing reflexivity in psychological research: what's the point? What's the practice? *Qualitative Research in Psychology*, 17, pp. 159-177.
- Lazarus, R. S. & Folkman, S. 1984. *Stress, appraisal, and coping*, New York: Springer publishing company.
- Lea, S., Gibson, F. & Taylor, R. M. 2021. "Holistic competence": how is it developed, shared, and shaped by health care professionals caring for adolescents and young adults with cancer? *Journal of Adolescent and Young Adult Oncology*, Ahead of Print, pp. 1-9.
- Lea, S., Taylor, R. M., Martins, A., Fern, L. A., Whelan, J. S. & Gibson, F. 2018. Conceptualizing age-appropriate care for teenagers and young adults with cancer: a qualitative mixed-methods study. *Adolescent Health, Medicine and Therapeutics*, 9, p. 149.
- Levac, D., Colquhoun, H. & O'Brien, K. K. 2010. Scoping studies: advancing the methodology. *Implementation Science*, 5, p. 69.
- Lim, J., Bogossian, F. & Ahern, K. 2010. Stress and coping in Australian nurses: a systematic review. *International Nursing Review*, 57, pp. 22-31.
- Lincoln, Y. S. & Guba, E. G. 1986. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*, 30, pp. 73-84.
- Lindsay, G. M. & Schwind, J. K. 2016. Narrative inquiry: experience matters. *Canadian Journal of Nursing Research*, 48, pp. 14-20.

Lovatt, M., Nanton, V., Roberts, J., Ingleton, C., Noble, B., Pitt, E., Seers, K. & Munday, D. 2015. The provision of emotional labour by health care assistants caring for dying cancer patients in the community: a qualitative study into the experiences of health care assistants and bereaved family carers. *International Journal of Nursing Studies*, 52, pp. 271-279.

Low, J. 2019. A pragmatic definition of the concept of theoretical saturation. *Sociological Focus*, 52, pp. 131-139.

Lyon, D. 1999. *Postmodernity*, Buckingham: Open University Press.

Maben, J., Peccei, R., Adams, M., Robert, G., Richardson, A., Murrells, T. & Morrow, E. 2012. Patients' experiences of care and the influence of staff motivation, affect and wellbeing. *Final report. NIHR Service Delivery and Organisation programme*, London: NIHR.

Macnee, C. L. & McCabe, S. 2008. *Understanding nursing research: using research in evidence-based practice*, Philadelphia, Lippincott Williams & Wilkins.

Maslach, C. 1998. A multidimensional theory of burnout. In: Cooper, C. (ed.) *Theories of Organizational Stress*. p. 85, Oxford: Oxford University Press.

Maslach, C. & Jackson, S. E. 1984. Burnout in organizational settings. *Applied Social Psychology Annual*, 5, pp. 133-153.

Mauss, M. 1990. *The gift: the form and reason for exchange in archaic societies*, London: Routledge.

Maytum, J. C., Heiman, M. B. & Garwick, A. W. 2004. Compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. *Journal of Pediatric Health Care*, 18, pp. 171-179.

Mazzella Ebstein, A. M., Sanzero Eller, L., Tan, K. S., Cherniss, C., Ruggiero, J. S. & Cimiotti, J. P. 2019. The relationships between coping, occupational stress, and emotional intelligence in newly hired oncology nurses. *Psycho-oncology*, 28, pp. 278-283.

McCabe, M. G. 2018. Overview of adolescent and young adult cancer. In: Chisholm, J. et al., (eds.) *A Practical Approach to the Care of Adolescents and Young Adults with Cancer*. pp. 1-18, London: Springer.

McClure, R. & Murphy, C. 2007. Contesting the dominance of emotional labour in professional nursing. *Journal of Health Organization and Management*, 21, pp. 101-120.

McGrath, C., Palmgren, P. J. & Liljedahl, M. 2019. Twelve tips for conducting qualitative research interviews. *Medical Teacher*, 41, pp. 1002-1006.

Mealer, M., Jones, J. & Meek, P. 2017. Factors affecting resilience and development of posttraumatic stress disorder in critical care nurses. *American Journal of Critical Care*, 26, pp. 184-192.

- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P. & Stewart, L. A. 2015. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic reviews*, 4, pp. 1-9.
- Morgan, S. & Soanes, L. 2016. Nursing young people with cancer: What is “different” about it? *Bulletin du Cancer*, 103, pp. 999-1010.
- Mortelmans, D. 2019. Analyzing qualitative data using NVivo. In Van den Bulck H., Puppis M., Donders K., Van Audenhove L. (Eds) *The Palgrave Handbook of Methods for Media Policy Research*. pp. 435-450, Cham: Springer.
- Moule, P. 2020. *Making sense of research in nursing, health and social care*, Los Angeles: Sage.
- Mukherjee, S., Beresford, B., Glaser, A. & Sloper, P. 2009. Burnout, psychiatric morbidity, and work-related sources of stress in paediatric oncology staff: a review of the literature. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 18, pp. 1019-1028.
- National Institute for Health and Clinical Excellence 2005. *Improving outcomes in children and young people with cancer*. London: Department of Health.
- National Institute of Health Research. 2020. *Good Clinical Practice (GCP)* [Online]. Available: <https://www.nihr.ac.uk/health-and-care-professionals/learning-and-support/good-clinical-practice.htm> [Accessed 8/10/2021].
- Newell, R. & Burnard, P. 2010. *Research for evidence-based practice in healthcare*, Chichester: John Wiley & Sons.
- NHS Employers. 2021. *NHS terms and conditions of service (Agenda for Change)* [Online]. NHS Employers. Available: <https://www.nhsemployers.org/pay-pensions-and-reward/nhs-terms-and-conditions-of-service---agenda-for-change> [Accessed 10/03/2021 2021].
- NHS England 2017. *Next Steps on the NHS Five Year Forward View*. Available: <https://www.england.nhs.uk/publication/next-steps-on-the-nhs-five-year-forward-view/> [accessed 08/07/2021].
- Norton, W. & Wright, E. 2020. Barriers and facilitators to fertility-related discussions with teenagers and young adults with cancer: nurses' experiences. *Journal of Adolescent and Young Adult Oncology*, 9, pp. 481-489.
- NSI Nursing Solutions Inc. 2019. *2019 National health care retention & RN staffing report*. NSI Nursing Solutions Inc. Available: [NSI_National_Health_Care_Retention_Report.pdf](https://www.nsinursingsolutions.com/NSI_National_Health_Care_Retention_Report.pdf) (nsinursingsolutions.com) [Accessed 09/10/2021].
- Nursing and Midwifery Council 2018. *Future nurse: standards of proficiency for registered nurses*. Nursing Midwifery Council, [Online]. Available; <https://www.nmc.org.uk/globalassets/sitedocuments/education-standards/print-friendly-future-nurse-proficiencies.pdf> [accessed 07/07/2021].

- Nursing Midwifery Council. 2018. *The Code: professional standards of practice and behaviour for nurses, midwives and nursing associates* [Online]. Nursing Midwifery Council, Available: <https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf> [Accessed 05/03/2021].
- O'Hara, C., Moran, A., Whelan, J., Hough, R., Stiller, C., Stevens, M., Stark, D., Feltbower, R. & McCabe, M. 2015. Trends in survival for teenagers and young adults with cancer in the UK 1992-2006. *European Journal of Cancer*, 51, pp. 2039-2048.
- Olsen, P. R. & Harder, I. 2011. Caring for teenagers and young adults with cancer: a grounded theory study of network-focused nursing. *European Journal of Oncology Nursing*, 15, pp. 152-159.
- Olsen, P. R. & Smith, S. 2018. *Nursing adolescents and young adults with cancer*, Cham: Springer.
- Ortega-Campos, E., Vargas-Román, K., Velando-Soriano, A., Suleiman-Martos, N., Cañadas-de la Fuente, G. A., Albendín-García, L. & Gómez-Urquiza, J. L. 2020. Compassion fatigue, compassion satisfaction, and burnout in oncology nurses: A systematic review and meta-analysis. *Sustainability*, 12, p. 72.
- Palmer, S., Mitchell, A., Thompson, K. & Sexton, M. 2007. Unmet needs among adolescent cancer patients: a pilot study. *Palliative & Supportive care*, 5, pp. 127-134.
- Pappa, S., Ntella, V., Giannakas, T., Giannakoulis, V. G., Papoutsis, E. & Katsaounou, P. 2020. Prevalence of depression, anxiety, and insomnia among healthcare workers during the COVID-19 pandemic: a systematic review and meta-analysis. *Brain, Behavior, and Immunity*, 88, pp. 901-907.
- Parahoo, K. 2014. *Nursing research: principles, process and issues*, Hampshire: Palgrave Macmillan.
- Pearce, S., Brownsdon, A., Fern, L., Gibson, F., Whelan, J. & Lavender, V. 2018. The perceptions of teenagers, young adults and professionals in the participation of bone cancer clinical trials. *European Journal of Cancer Care*, 27, pp. 1-15.
- Pennbrant, S., Nilsson, M. S., Öhlén, J. & Rudman, A. 2013. Mastering the professional role as a newly graduated registered nurse. *Nurse Education Today*, 33, pp. 739-745.
- Peters, M. A. 1998. *Naming the multiple: poststructuralism and education*, Westport, Connecticut: Praeger.
- Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D. & Soares, C. B. 2015. Guidance for conducting systematic scoping reviews. *International Journal of Evidence-based Healthcare*, 13, pp. 141-146.
- Pfaff, K. A., Freeman-Gibb, L., Patrick, L. J., DiBiase, R. & Moretti, O. 2017. Reducing the “cost of caring” in cancer care: evaluation of a pilot

interprofessional compassion fatigue resiliency programme. *Journal of Interprofessional Care*, 31, pp. 512-519.

Phillips-Salimi, C. R., Haase, J. E. & Kooken, W. C. 2012. Connectedness in the context of patient-provider relationships: A concept analysis. *Journal of Advanced Nursing*, 68, pp. 230-245.

Phillips, C. R. & Haase, J. E. 2018. A connectedness primer for healthcare providers: adolescents/young adult cancer survivors' perspectives on behaviors that foster connectedness during cancer treatment and the resulting positive outcomes. *Journal of Adolescent & Young Adult Oncology*, 7, pp. 174-180.

Phillips, C. R., Haase, J. E., Broome, M. E., Carpenter, J. S. & Frankel, R. M. 2017. Connecting with healthcare providers at diagnosis: adolescent/young adult cancer survivors' perspectives. *International Journal of Qualitative Studies on Health and Well-being*, 12, p. 1325699.

Polit, D. F. & Beck, C. T. 2017. *Nursing research: generating and assessing evidence for nursing practice*, Philadelphia: Wolters Kluwer Health.

Polkinghorne, D. E. 1995. Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, 8, pp. 5-23.

Popper, K. 2005. *The logic of scientific discovery*, London: Routledge.

Potter, P., Allen Berger, J., Olsen, S. & Chen, L. 2013. Evaluation of a compassion fatigue resiliency program for oncology nurses. *Oncology Nursing Forum*, 40, 2, p. 180-187.

Potter, P., Deshields, T., Divanbeigi, J., Berger, J., Cipriano, D., Norris, L. & Olsen, S. 2010. Compassion fatigue and burnout: Prevalence among oncology nurses *Clinical Journal of Oncology Nursing*, 14, 5, p. e 56-62.

Price, S. & Reichert, C. 2017. The importance of continuing professional development to career satisfaction and patient care: meeting the needs of novice to mid-to late-career nurses throughout their career span. *Administrative Sciences*, 7, p. 17.

Rapley, T., Farre, A., Parr, J. R., Wood, V. J., Reape, D., Dovey-Pearce, G. & McDonagh, J. 2019. Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. *BMJ open*, 9, p. e029107.

Redinbaugh, E. M., Schuerger, J. M., Weiss, L. L., Brufsky, A. & Arnold, R. 2001. Health care professionals' grief: a model based on occupational style and coping. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 10, pp. 187-198.

Riessman, C. K. 2008. *Narrative methods for the human sciences*, Los Angeles: Sage.

Robertson, E. G., Wakefield, C. E., Marshall, K. H. & Sansom-Daly, U. M. 2015. Strategies to improve adherence to treatment in adolescents and young adults

- with cancer: a systematic review. *Clinical Oncology in Adolescents and Young Adults*, 5, pp. 35-49.
- Robinson, J. A. & Hawpe, L. 1986. Narrative thinking as a heuristic process. In Sarbin T., *Narrative psychology: The storied nature of human conduct*. pp. 111-125, Westport: Praeger Publishers/Greenwood Publishing Group.
- Sansom-Daly, U. M., Wakefield, C. E., Patterson, P., Cohn, R. J., Rosenberg, A. R., Wiener, L. & Fardell, J. E. 2020. End-of-life communication needs for adolescents and young adults with cancer: recommendations for research and practice. *Journal of Adolescent & Young Adult Oncology*, 9, pp. 157-165.
- Savin-Baden, M. & Major, C.H. 2013. *Qualitative research: the essential guide to theory and practice*, Oxford: Routledge.
- Savin-Baden, M. & Niekerk, L. V. 2007. Narrative inquiry: Theory and practice. *Journal of Geography in Higher Education*, 31, pp. 459-472.
- Sawyer, S.M., Azzopardi, P.S., Wickremarathne, D. & Patton, G.C., 2018. The age of adolescence. *The Lancet Child & Adolescent Health*, 2(3), pp.223-228.
- Schmidt, K.-H. & Diestel, S. 2014. Are emotional labour strategies by nurses associated with psychological costs? A cross-sectional survey. *International Journal of Nursing Studies*, 51, pp. 1450-1461.
- Schneider, Z., Whitehead, D., LoBiondo-Wood, G., Faan, P. R., Haber, J. & Faan, P. R. 2016. *Nursing and midwifery research: methods and appraisal for evidence based practice*, Sydney: Elsevier.
- Shacklock, K. & Brunetto, Y. 2012. The intention to continue nursing: work variables affecting three nurse generations in Australia. *Journal of Advanced Nursing*, 68, pp. 36-46.
- Shanafelt, T. & Dyrbye, L. 2012. Oncologist burnout: causes, consequences, and responses. *Journal of Clinical Oncology*, 30, pp. 1235-1241.
- Shanafelt, T. D., Raymond, M., Horn, L., Moynihan, T., Collichio, F., Chew, H., Kosty, M. P., Satele, D., Sloan, J. & Gradishar, W. J. 2014. Oncology fellows' career plans, expectations, and well-being: do fellows know what they are getting into? *Journal of Clinical Oncology*, 32, pp. 2991.
- Shaukat, N., Ali, D. M. & Razzak, J. 2020. Physical and mental health impacts of COVID-19 on healthcare workers: a scoping review. *International Journal of Emergency Medicine*, 13, pp. 1-8.
- Shea, C. 2000. Don't talk to the humans. *Lingua Franca: The Review of Academic Life*, 10, pp. 26-34.
- Sim, J. & Wright, C. 2000. *Research in health care: concepts, designs and methods*, Cheltenham: Nelson Thornes.
- Smith, L. A., Critoph, D. J. & Hatcher, H. M. 2020. How can health care professionals communicate effectively with adolescent and young adults who

have completed cancer treatment? A systematic review. *Journal of Adolescent and Young Adult Oncology*, 9, 3, pp. 328-340.

Smith, P. 1992. *The emotional labour of nursing: its impact on interpersonal relations, management and educational environment*, Hampshire: Macmillan International Higher Education.

Smith, S. 2004. Adolescent units—an evidence-based approach to quality nursing in adolescent care. *European Journal of Oncology Nursing*, 8, pp. 20-29.

Smith, S., Mooney, S., Cable, M. & Taylor, R. M. 2016. *The blueprint of care for teenagers and young adults with cancer*, London: Teenage Cancer Trust.

Smith, S. A. 2012. Nurse competence: a concept analysis. *International Journal of Nursing Knowledge*, 23, pp. 172-182.

Smith, S. L. 2017. Advance care planning communication for young adults: a role for simulated learning. *Journal of Hospice and Palliative Nursing*, 19, p. 460.

Spinetta, J. J., Jankovic, M., Ben Arush, M. W., Eden, T., Epelman, C., Greenberg, M. L., Martins, A. G., Mulhern, R. K., Oppenheim, D. & Masera, G. 2000. Guidelines for the recognition, prevention, and remediation of burnout in health care professionals participating in the care of children with cancer: report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology. *Medical and Pediatric Oncology: The Official Journal of SIOP—International Society of Pediatric Oncology (Société Internationale d'Oncologie Pédiatrique)*, 35, pp. 122-125.

Stevanin, S., Palese, A., Bressan, V., Vehviläinen-Julkunen, K. & Kvist, T. 2018. Workplace-related generational characteristics of nurses: A mixed-method systematic review. *Journal of Advanced Nursing*, 74, pp. 1245-1263.

Stiller, C., Trama, A., Serraino, D., Rossi, S., Navarro, C., Chirilaque, M., Casali, P. & Group, R. W. 2013. Descriptive epidemiology of sarcomas in Europe: report from the RARECARE project. *European Journal of Cancer*, 49, pp. 684-695.

Sullivan, C., King, A., Holdiness, J., Durrell, Spencer, C., Roberts, J., Ogg, S. & Cartwright, C. 2019. Reducing compassion fatigue in inpatient pediatric oncology nurses. *Oncology Nursing Forum*, 46, pp. 338-347.

Taylor, R. M., Feltbower, R. G., Aslam, N., Raine, R., Whelan, J. S. & 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, p. e011361.

Taylor, R. M., Fern, L., Whelan, J., Pearce, S., Grew, T., Millington, H., Ashton, J., Brooman, K., Starkey, C. & Gibson, F. 2011. “Your place or mine?” Priorities for a specialist teenage and young adult (TYA) cancer unit: disparity between TYA and professional perceptions. *Journal of Adolescent and Young Adult Oncology*, 1, pp. 145-151.

Teenage Cancer Trust 2014. *Competencies: Caring for Teenagers and Young Adults with Cancer: A Competence and Career Framework for Nursing*. London: Teenage Cancer Trust.

Teenage Cancer Trust. N.D. *How we design our units* [Online]. Teenage Cancer Trust. Available: <https://www.teenagecancertrust.org/about-us/what-we-do/cancer-units/how-we-design-our-units> [Accessed 20 /03/2021 2021].

Tennyson, R. E. & Griffiths, H. C. 2019. A systematic review of professionals' experiences of discussing fertility issues with adolescents and young adults with cancer. *Journal of Adolescent & Young Adult Oncology*, 8, pp. 387-397.

Teusner, A. 2020. *Qualitative insider research*, Los Angeles: Sage.

The Kings Fund, Nuffield Trust & Foundation, T. H. 2018. *The health care workforce in England: Make or break?* London: The Kings Fund.

Theodosius, C. 2003. *Developing the sociology of emotion and emotional labour: a case study of nurses*. University of Essex.

Theodosius, C. 2008. *Emotional labour in health care: the unmanaged heart of nursing*, London: Routledge.

Thompson, K., Dyson, G., Holland, L. & Joubert, L. 2013. An exploratory study of oncology specialists' understanding of the preferences of young people living with cancer. *Social Work in Health Care*, 52, pp. 166-190.

Timonen, V., Foley, G. & Conlon, C., 2018. Challenges when using grounded theory: A pragmatic introduction to doing Grounded Theory research. *International Journal of Qualitative Methods*, 17(1), p.1609406918758086.

Titmuss, R. 2018. *The gift relationship: From human blood to social policy*, London: Policy Press.

Toh, S. G., Ang, E. & Devi, M. K. 2012. Systematic review on the relationship between the nursing shortage and job satisfaction, stress and burnout levels among nurses in oncology/haematology settings. *International Journal of Evidence-Based Healthcare*, 10, pp. 126-141.

Tracy, J. L. & Randles, D. 2011. Four models of basic emotions: a review of Ekman and Cordaro, Izard, Levenson, and Panksepp and Watt. *Emotion Review*, 3, pp. 397-405.

Trafford, V. & Leshem, S. 2008. *Stepping stones to achieving your doctorate: by focusing on your viva from the start: Focusing on your viva from the start*, Maidenhead: McGraw-Hill Education

Tricco, A., Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Levac, D., Moher, D., Peters, M., Horsley, T., Weeks, L., Hempel, S., Akl, E., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M., Garritty, C. & Straus, S. 2018. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Annals of Internal Medicine*, 169, 7 p.467-473

Tutelman, P. R., Drake, E. K. & Urquhart, R. 2019. "It could have been me": an interpretive phenomenological analysis of health care providers' experiences caring for adolescents and young adults with terminal cancer. *Journal of Adolescent & Young Adult Oncology*, 8, pp. 587-592.

Vindrola-Padros, C., Dyer, K. E., Cyrus, J. & Lubker, I. M. 2017. Healthcare professionals' views on discussing fertility preservation with young cancer patients: a mixed method systematic review of the literature. *Psycho-Oncology*, 26, pp. 4-14.

Wang, C. C. & Geale, S. K. 2015. The power of story: narrative inquiry as a methodology in nursing research. *International Journal of Nursing Sciences*, 2, pp. 195-198.

Warner, E. L., Kent, E. E., Trevino, K. M., Parsons, H. M., Zebrack, B. J. & Kirchhoff, A. C. 2016. Social well-being among adolescents and young adults with cancer: a systematic review. *Cancer*, 122, pp. 1029-1037.

Watson, J. 1979. *Nursing: the philosophy and science of caring*, Norwalk, Connecticut: Appleton & Lange.

Watson, J. 1995. Postmodernism and knowledge development in nursing. *Nursing Science Quarterly*, 8, pp. 60-64.

Watson, J. 1999. *Nursing: human science and human care: A theory of nursing*, Boston, Jones & Bartlett Learning.

Westman, M. & Bakker, A. B. 2008. Crossover of burnout among health care professionals. In: Halbesleben, J. (ed.) *Handbook of stress and burnout in health care*. pp. 111-125, New York: Nova Science Publishers, Inc.

Weston, M. J. 2006. Integrating generational perspectives in nursing. *The Online Journal of Issues in Nursing*, 11, pp. 1-9.

Whiteson, M. 2003. The Teenage Cancer Trust—advocating a model for teenage cancer services. *European Journal of Cancer*, 39, pp. 2688-2693.

Wiener, L., Weaver, M. S., Bell, C. J. & Sansom-Daly, U. M. 2015. Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clinical Oncology in Adolescents and Young Adults*, 5, p. 1.

Wilkinson, S. M. 1994. Stress in cancer nursing: does it really exist? *Journal of Advanced Nursing*, 20, pp. 1079-1084.

Williamson, H. & Rumsey, N. 2017. Perspectives of health professionals on the psychosocial impact of an altered appearance among adolescents treated for cancer and how to improve appearance-related care. *Journal of Psychosocial Oncology*, 35, pp. 47-60.

Willig, C. 2013. *Introducing qualitative research in psychology*, Maidenhead: McGraw-hill education (UK).

- Wise, J. 2018. Hospital suspends chemotherapy because of nurse shortage. *BMJ*, p. 363: k4687.
- Wolff, A. C., Ratner, P. A., Robinson, S. L., Oliffe, J. L. & Hall, L. M. 2010. Beyond generational differences: a literature review of the impact of relational diversity on nurses' attitudes and work. *Journal of Nursing management*, 18, pp. 948-969.
- World Health Organization 2003. *Adolescent friendly health services: an agenda for change*. Geneva. World Health Organization.
- World Health Organization 2016. *Global strategy on human resources for health: workforce 2030*. Geneva. World Health Organization.
- Wright, C., Coad, J., Morgan, S., Stark, D. & Cable, M. 2014. 'Just in case': the fertility information needs of teenagers and young adults with cancer. *European Journal of Cancer Care*, 23, pp. 189-198.
- Young, A. M., Charalambous, A., Owen, R. I., Njodzeka, B., Oldenmenger, W. H., Alqudimat, M. R. & So, W. K. W. 2020. Essential oncology nursing care along the cancer continuum. *The Lancet Oncology*, 21, pp. e555-e563.
- Yu, H., Jiang, A. & Shen, J. 2016. Prevalence and predictors of compassion fatigue, burnout and compassion satisfaction among oncology nurses: a cross-sectional survey. *International Journal of Nursing Studies*, 57, pp. 28-38.
- Zander, B., Aiken, L. H., Busse, R., Rafferty, A. M., Sermeus, W. & Bruyneel, L. 2016. The state of nursing in the European Union. *EuroHealth*, 22, pp. 3-6.
- Zander, M., Hutton, A. & King, L. 2010. Coping and resilience factors in pediatric oncology nurses CE. *Journal of Pediatric Oncology Nursing*, 27, pp. 94-108.

Appendices

Appendix 1 Cable and Kelly (2019) Publication

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FEATURE

WILEY *Nursing Inquiry*

An analysis of the development of adolescent and young adult cancer care in the United Kingdom: A Foucauldian perspective

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Abstract

This paper analyses the development of the specialism of adolescent and young adult (AYA) cancer care via a Foucauldian lens to consider how knowledge and awareness have grown since questions were first raised about unmet needs of AYAs with cancer. The AYA specialism has gathered momentum over the last 30 years in the United Kingdom (UK) and is fast gathering pace internationally. Fundamental to this process has been the combined contribution from nursing and other health professionals, researchers, policy-makers and philanthropists. From an initial process of problematisation, through a gradual growth in empirical knowledge and resultant shifts in health policy, a new nexus of expertise has emerged that enabled AYA cancer care to become recognised as distinct from either child or adult oncology. Different stakeholders contributed to the discourses that have underpinned this development—a process likely to continue as it expands further. This paper draws on examples from the growth of the AYA specialism, the emergence of new professional roles and a growth in research. It illustrates how the coalescing of multiple perspectives allowed new discourses and, ultimately, new practices to be established that now have global impact.

KEYWORDS

adolescents, cancer, Foucault, governmentality, nursing, philanthropy, power, young adults

1 | INTRODUCTION

The focus of this analysis is the development of the specialism of adolescent and young adult (AYA) cancer care, and it adopts a genealogical approach based on Foucault's thinking. The growth of this specialism provides a contemporary example of how ideas and practices once considered radical can move towards acceptability based on a process of shifting power dynamics and emergent discourses that both shape, and are shaped by, these new ways of thinking. One example of this from the iconic work of Foucault focussed on the emergence of mental illness and stemmed from recognition of the importance of the process of labelling (of madness as abnormal behaviour), leading to the rise in the acceptability of psychiatric diagnoses and the eventual disciplinary power that revolved around psychiatry itself (Armstrong, 1997).

In this paper, we examine how AYA cancer care has progressed from a situation that stemmed from a process of problematisation, to one that increasingly became the focus of philanthropic support and a similar growth in empirical research, up until today where it attracts the attention of policy-makers and those involved in such work on a global scale.

The paper recounts this process of development and draws on Foucault's (1977) concept of the gaze. This, we argue, has shifted attention away from cancer purely as a biological malfunction, towards one where 'the person' is recognised with, in this context, the requirement to cope with a cancer diagnosis in a social sense (as a member of kinship or friendship groups) during a specific phase of the human life course (as an adolescent or young adult).

Foucault termed genealogy a form of reflection on the nature and development of modern institutions, such as medicine, and their associated sources of power, and is quoted as saying:

'One 'fictions' history starting from a political reality that renders it true, one 'fictions' a politics that does not yet exist starting from a historical truth' (cited in Dreyfus & Rabinow, 1982, p. 204). While Foucault's work may be considered complex in its interpretation of social movements, it is very often adopted and shaped by other author's application of its core elements. Being mindful of this, it is anticipated that this genealogical interpretation seeks to uncover relationships from a range of perspectives and to suggest the links between power, knowledge and the emergence of specialist AYA cancer care in the present context. Furthermore, it will portray how this specialism is shaped by historical forces—the most relevant being the underpinning shifts in power away from paediatric or adult oncology models of care, within which the loci of power were located previously. The shift was towards something radical and new. An attempt to investigate the 'history of the present of AYA care' will be made by avoiding grand historical and social formations, but rather looking more towards the 'numberless beginnings', 'accidents', 'errors', 'false appraisals' and 'faulty calculations' (Foucault, 1977, pp. 145–6), that more often characterise the evolution of ideas. By adopting this genealogical approach, it is intended that this paper will highlight difference, abrogation and rupture (Anais, 2013), rather than seeking simplistic answers as to why this occurred. However, we do not seek to trace AYA cancer care from its beginnings to the present in a nuanced way but rather to suggest explanations primarily through accounts of the way that power, and in turn practice, has changed. Purposefully, this work also suggests that, although the specialism has developed considerably over the last 30 years, it may still be considered fragile and at risk of disruption based on resistance to further change from those who still hold positions of power and influence within adult or paediatric cancer fields, and who can prevent innovation if they feel this is against their own interests. The first step in the process of AYA cancer specialism was the process of problematisation that took place and the role of early champions and their role in numberless beginners (Foucault, 1977, p. 145).

2 | PROBLEMATISATION OF CANCER CARE FOR THE YOUNG ADULT

Foucault (1986) asserts that *problematizations* emerge in tangible practices; they are not simply mental images or ideas. He describes 'the problematisation of madness and illness arising out of social and medical practices' and 'a problematisation of crime and criminal behaviour emerging from punitive practices' (Foucault, 1986, p. 12). In the context of examining AYA cancer care, a useful starting point is to explore polemical texts, meanings and problems associated with adolescent and young adulthood (and associated terms) so as to determine what the 'problem' actually is for those in these age groups

when cancer is diagnosed, or indeed the extent to which age itself is problematic and meriting special attention. Furthermore, if it is a problem, who is it a problem for and what manner of problems need to be addressed?

3 | THE CONCEPTUALISATION OF CHILDHOOD, YOUTH AND ADOLESCENCE

Fass (2013) suggests that modern childhood was idealised long before it was a serious reflection of child life (p. 12). Childhood as a concept began to emerge in the 1700s (Ariès, 1962), further evolved in the late postmodern era (Docherty, 2014), and has since been accepted as a social reality (Pupavac, 2001; Valentine, Butler, & Skelton, 2001). From Valentine et al.'s (2001) and Bell's (2011) insights into this process of development, it is claimed that that it was not until the late eighteenth/nineteenth centuries that the modern construction of human childhood as a time of innocence started to gain prominence in Europe and North America. Before then, children, although living within the family unit, were usually depicted as 'savages', in need of strict control and corporal punishment and/or equated with adult norms (such as expectations that they should work). Such changes in attitudes towards human childhood heralded new social action, and what had previously been deemed true was changed irrevocably.

In the last century, child development theorists such as Bronfenbrenner (1977), Erikson (1963), Freud (1952) and Piaget (1970) posited patterns in human development, which focus largely on the following areas: physical, psychological and cognitive, social and emotional, and sexuality and gender identity. They have stood the test of time and remain widely influential. These models which shape our understanding of how humans change over time have become increasingly complex and are now seated within multilevel dynamic systems.

Foucault suggested that, as a result, the family became a densely saturated, permanent, continuous physical environment that served to envelop, maintain and assist the child's growing body (Foucault & Rabinow, 1991, p. 280). In addition, much of his work asserts that hospitals became institutions devoted to knowledge production, as much as caring for the sick, and that the health of children became a target for great enterprise (and social standing) for medical professionals who were gaining independence and esteem in the specialism of child health. Literary sources, driven by medical science, further educated the wider population on the issues of childhood and youth in an attempt to promote the value of health promotion for future generations (Bell, 2011). What was missing in these early discourses was a clear differentiation between childhood and adolescence in chronological, legal or biopsychosocial terms.

Youth as a concept has been the subject of much research and debate since. Then The common endpoint usually being that 'youth' or 'young people' represent a distinct body of the populace, with the common agreement that they are neither adults nor children but are in a state of becoming. Foucault (in Foucault & Rabinow, 1991, p.

279) spoke of childhood and adulthood as distinct entities; beyond childhood came adulthood, despite this employing the term 'youth' in regard to pre-adulthood. This stems from his views of the privileges of the child and the medicalisation of the family.

What is often not posited in such a theory is the apparent love/hate relationship between youth and adulthood with negative connotations attributed to both. Diametrically opposed values and life experiences may be felt by both groups, with adults seeming to forget what it was like to be young and not having the experience of being this age in the present moment, while youth forge ahead with fervour and tempestuousness. An often-attributed quote to Socrates is that 'children now love luxury. They have bad manners, contempt for authority; they show disrespect for elders and love chatter in place of exercise', so it appears that this divergence of understanding among adults and adolescents is age old (Birchwood & Singh, 2013).

Adolescence itself was given little credence prior to the end of the last century. Demos and Demos' (1969) literature review from the period 1800 to 1875 uncovered little or no usage of the word and postulated that there was a limited degree of concern with the life stage and its characteristic behaviours. They add that it was around 1900 that G. Stanley Hall made adolescence the focus of a psychological study. What was questioned was not the concept of adolescence itself, but ideas related to their roles within the structure of the family.

In the context of modernity, and regarding cancer in adolescence, questions of independence or dependence are commonly associated with this age group, irrespective of the presence of a cancer diagnosis. The relationship within the family of the adolescent when cancer is present is therefore subject to disruption for multiple reasons, not least because of the uncertain nature of cancer itself (Long, Ginsberg, & Kolon, 2016; Loren et al., 2013). This includes demanding treatments and the impact that symptoms have on the transition towards independence. The power of cancer itself lies in altering the status quo for the young person who is expected to continue transitioning into adulthood regardless of a life-threatening diagnosis.

Given the differentiation between childhood and adulthood, there is also an assumption that a social infrastructure exists for children and young people to achieve a successful transition, including those with cancer. Similarly, while the development of the United Kingdom's (UK) National Health Service (NHS) in 1948 promised free healthcare from the cradle to the grave (Platt, 1959), it was not until the late 1990s that individuals began to suggest that adolescents with cancer had unmet needs (Whiteson, 2005, p. 1). Indeed, the World Health Organization echoed this sentiment by stating that, in addition to child and women's health, adolescents were being marginalised and suffered from various forms of inequities and discrimination, including those based on gender, income, age, place of residence, and education level—all resulting in poorer health outcomes (Temmerman, Khosla, Bhutta, & Bustreo, 2015).

Furthermore, modern positivist bioscience scholars (Bolte-Taylor, 2013; Casey & Jones, 2010; Foulkes & Blakemore, 2018) also were suggesting that neuro-biological changes occurring in the human brain may account for at least some of the behavioural responses of

young people. Thus, in parallel with Foucault's (1978a, 1978b) work on sexuality and madness, society seemed to be experiencing an attitudinal shift in the connection between the negative discourse of the past in relation to young people, and the realisation that there may be novel biological and psychosocial explanations for (at least some) of their behaviour.

In the UK, the momentum for the initial focus on the needs of AYA with cancer stemmed primarily from the actions of key individuals with philanthropic intent. It is important to draw attention to the ways in which language was used to highlight their level of need, with common terms such as 'unmet needs' (Palmer, Mitchell, Thompson, & Sexton, 2007, p. 280), 'lost tribe' (Stevens, 2006, p. 280), 'no-man's land' (Hollis & Morgan, 2001, p. 43) being used. This highlighted further the isolation of the AYA cancer experience which, in turn, influenced others in the field to challenge current health policy and societal attitudes towards young people living with cancer (Hollis & Morgan, 2001). Over time, these events evoked a shift in perceptions about professional/social/political identities within this newly emerging specialism. The challenge was for this process of problematising to be met with sufficient financial and professional support to develop specialist AYA cancer care on the ground.

4 | POWER AND PHILANTHROPY IN AYA CANCER CARE

Bacchi (2012) advises that Foucault's process of problematising of social issues emerges primarily via discourses and practices; they are more than imaginings, mental images or ideas. Underpinning much of process is the combination of power, accepted truths and impact on the self, and the relationships between each (Bacchi, 2012; Rabinow, 1991; Willig, 1999; Willing & Stainton-Rogers, 2008). By focussing on power as the overarching concept, for example, a range of discourses can be identified by government, academics, clinicians or charities who either support or deny unmet needs or bring AYA cancer to the fore to gain support from the wider public.

Within this process of growing support can be seen the work of Hollis and Morgan (2001)—two nurses who were among the earliest to write about the adolescent with cancer and suggested their location 'at the edge of no-man's land' (p. 43). Concerns were also being articulated at this time by prominent champions such as Whiteson (2003), a founding member (lay, non-clinician) of the UK charity Teenage Cancer Trust (TCT). In addition, Eden, Barr, Bleyer, and Whiteson (2005) were also calling for attention to be paid to the AYA cancer patient population (Eden, Barr & Bleyer as specialist oncologists); thus, the issue was reaching a stronger state of being problematised. Importantly, the problem was being constructed primarily through polemical texts and professional argument with the goal of gaining credibility and support, with the ultimate end-result being a new discourse around AYA cancer care and the support needs of this age group.

From a philanthropic perspective, this emerging, and still novel, discourse around AYA cancer care was also having an effect. The

Oxford English dictionary (2018) defines philanthropy as 'the desire to promote the welfare of others, expressed especially by the generous donation of money to good causes, ('philanthropy, 2017')'. Without financial support, the needs of the group in question would probably never have changed.

Because of the process of problematisation, various philanthropic solutions emerged first in the UK that highlighted unmet AYA cancer needs and charities, such as TCT, sought to provoke health service providers and governments to act (Bacchi, 2012). However, Bacchi (2012) adds a note of caution about philanthropy as it can simultaneously support the very system it seeks to address:

...it disguises its own discourse in its portrayal of the mediums of consumption, profit, and media celebration as the basis for benevolent human relations. In its subordination of benevolence to money, the current texts of philanthropy stabilize the very system that results in suffering. (p. 2)

Charity is a word often used interchangeably with philanthropy. The Oxford English dictionary (2018) defines charity as the 'voluntary giving of help, typically in the form of money, to those in need' ('charity, 2018'). Sulek (2010) suggests that philanthropy is less well defined but that it is generally recognised as the private giving of time or valuables (money, security, property) for public purposes. Furthermore, it is characterised as one of the forms of income of private non-profit organisations (Salamon, 1992).

Clearly little separates the intentions of charity and philanthropy but it would appear that philanthropy is more long-term, strategic and 'big picture' in its scope than charity, being based on longer-term vision, whereas charity is more allied to immediacy. In the case of AYA cancer care, a relationship between philanthropists/charities and health service managers, clinical staff, and policy-makers gradually developed, which was often purported to be based on the voice of young people themselves who were being presented as 'unheard' or 'unable to be heard' while also having unique unmet needs (Hollis & Morgan, 2001; Kelly, Pearce, & Mullhall, 2004; Morgan & Soanes, 2016; NICE, 2005; Smith, Mooney, Cable, & Taylor, 2016; Smith et al., 2012). Words such as 'neglected group', 'special needs' and 'disadvantaged position' (Whiteson, 2005, pp. 1–10) were used in emerging research, policy and marketing literature with powerful effect.

In the early 1990s, these needs were commonly focussed on seemingly inadequate clinical environments (mostly by the UK charity Teenage Cancer Trust), who went on to fund up to 28 specialist units across the UK. This building programme was supported by emerging evidence of improved levels of satisfaction with age-appropriate facilities; however, evidence of improved clinical outcomes has taken longer to emerge (Kelly & Hooker, 2007; Kelly et al., 2004; Marris, Morgan, & Stark, 2011; Teenage Cancer Trust 2018a, 2018b; University College London Hospitals, 2017). Another significant feature of the charity's early work was the funding of specialist

nurses to support these young people through the cancer experience (Morgan & Soanes, 2016; Smith et al., 2016).

Teenage Cancer Trust is only one of many charities in the UK focussing on supporting adolescents with cancer (Teenage Cancer Trust, 2018c) but claim they are the only one to provide specialist support. As each has developed, they had to create an identity and convey their own market-based discourse of philanthropy which has included marketing of products such as clothing (i.e., cause-related marketing) as well as endorsement by various media and celebrities (or 'charitainment') for benevolent outcomes (Mooney Nickel & Eikenberry, 2009).

Social theorists, such as Mooney Nickel and Eikenberry (2009), have posited binary tensions between such 'marketised philanthropy' that gives an impression of 'giving back', when in fact it is disguising action that it is based on 'taking away' (primarily money). Furthermore, the discourse underpinning contemporary philanthropy may, in fact, be creating a claim of unmet need without necessarily inducing transformative change for wider society, or ever truly seeking to eliminate the cause of such problems. This exemplifies the accidents or errors that may occur the shifting of power and the emergence of new discourses as proposed by Foucault (1977).

The dominant AYA discourse of unmet need could be reinforcing the demand for more philanthropy, or philanthropy as alternative social policy, within the current system (Eikenberry, 2006). High-profile UK charity/media events (such as in the case of Teenage Cancer Trust, Royal Albert Hall rock and comedy concerts, with the involvement of major UK celebrities (Teenage Cancer Trust, 2018d), may be applauded for heightening public awareness (through a process of popular problematisation) and fundraising to provide financial support. Tester (2001) echoes this stance by arguing that such activity stirs individuals into moral action. However, there is also the less obvious conclusion that out of such problematising and philanthropic effort come publicity and rewards for those who take part.

In 2013, a rather unique situation arose in the UK where, through social media, 19-year-old Stephen Sutton, who was dying from cancer, became famous by seeking to raise large sums of money for the Teenage Cancer Trust. Rather than resulting in compassion fatigue as seen with audiences over-exposed to celebrity figures, the public became engaged in his personal narrative and the nature of his dying (Grant, 2015; Lumb, 2014). While celebrities may not always enable structural change or access scarce financial resources, it can be argued that Stephen Sutton did indeed achieve this goal, to some degree. His public campaign, being executed in parallel with his own demise, was supported by the charity to encourage engagement with the public and he has generated more than £5 million to date (Grant, 2015; Teenage Cancer Trust, 2017).

By so doing so, this individual rendered immediate the discourse of suffering in adolescents with incurable cancer to the wider population which, in turn, further highlighted the plight of cancer in these age groups as still inherently 'problematic'. While Stephen Sutton also became a celebrity to some degree in the process, the public saw him an adolescent facing his death from cancer with courage, and in a uniquely positive spirit. This event challenged the binary

tensions within celebrity endorsement as he became an important agent in the dominant problematising discourse around adolescent cancer.

In keeping with Foucault's (1977, pp. 145–6) thinking, it seems that Stephen's Story, although unique, is another series of 'numberless beginnings', 'accidents' or 'errors', and as such has played a significant part in reinforcing the discourse for social change around adolescent cancer care. His dying now forms part of the Teenage Cancer Trust charity's own narrative and is used to leverage public engagement and donations to support education for professionals about young people with cancer.

5 | POWER, PROFESSIONALS AND POLICY IN AYA CANCER CARE

Ferlie, Mcgovern, and FitzGerald (2011) argue that, for Foucault, power resides in mundane day-to-day practices, dominant languages and taken for granted rationalities. Foucault's view is that government, as a concept, is something existing beyond the institutions of political power. Foucault (1977) coined the term *governmentality* which refers to the way in which the state exercises control over, or governs, its populace. This infers that the balance of power shifted from a central authority, for example, the state or an institution (controlled by laws and punishment), to be dispersed among the population so that it eventually becomes self-governing and concerned about the 'status of things'. What we commonly understand by the term government in its political sense is that the populace is governed by bureaucratic offices, and doing the work of the elected government, instead of sovereigns.

In AYA cancer specifically, few if any rules had been set out until adolescents with cancer were acknowledged in UK policy in 1995 (Department of Health, 1995) and again via the National Institute for Health and Care Excellence (NICE) in 2005 and 2014 when further practice guidance and quality standards were launched (NICE, 2005, 2014). These later documents were set to further alter the landscape for this group of patients in England (and to some extent the rest of the UK) with the aim of ensuring that the development and standardisation of high-quality specialist and equitable care (Pearce, 2009). This placed emphasis on centrality of quality/standardised care for all AYAs with cancer and highlighted the need for their choice in a place of care. As a result, the concept of 'age-appropriate' facilities became part of the NHS lexicon. However, apart from one clinical unit, the NHS has not actually commissioned one AYA cancer unit in the UK—all have continued to be funded by the Teenage Cancer Trust and staffed by a combination of NHS and other UK charity posts (e.g., Macmillan Cancer Support and Clic Sargent). So, while government have stipulated the ideal standard of care, the funding for AYA cancer services remained the responsibility of the charity sector. Arguably though, had the same charities not lobbied for these changes in policy, there would be a lower profile for them and their future ambitions for further philanthropic endeavours.

While emphasis may have been placed on the creation of the built environment and specialist staff by charities in the UK, there has also been development of multiprofessional AYA cancer teams driven by the additional discourses and values underpinning multidisciplinary. Integral to this has been the influential role of nurses with leadership positions in AYA services, practice and research (Kelly & Gibson, 2008; Morgan & Soanes, 2016; Olsen & Smith, 2018; Smith et al., 2016; Taylor, Solanki, Aslam, Whelan, & Fern, 2016; Taylor, Feltbower et al., 2016). July 2014 marked the launch of the first nursing-specific publication on practice competencies entitled *Caring for Teenagers and Young Adults (TYAs) with Cancer: A Competence and Career Framework for Nursing* (Teenage Cancer Trust, 2014). This set out ways that the AYA cancer nursing workforce should be developed and specified key competencies that should apply to nurses caring for AYAs with cancer, acknowledging clinical practice, leadership, academic and research roles. This Framework is currently being introduced across regional AYA cancer services in the UK. Positioning itself as a distinct professional group, nursing has been successful in promoting its own professional status via such discourses that promoted its contribution to AYA cancer practice and service innovation.

In Foucauldian terms, self-governance also arises from acts of surveillance and so, in effect, from a 'them and us' stance. One key principle of Foucault's notion of power is that it cannot always be located; it can also be universal and therefore located within each individual agent (Foucault, 1982, p. 779). In this sense, it is worth examining the agents of power within the context of AYA cancer care in the UK. They now include:

1. The National Health Service, who fund and deliver cancer care to AYAs with cancer and their families. Responsibility for standards of care for all healthcare lies with the government.
2. Charities who pay for 'age-appropriate' environments, fund specialist staff to meet the unique needs (non-medical) of young people with cancer, lobby government for improved care and education.
3. Academics who seek to generate knowledge through research and teaching about AYA cancer care.
4. AYA cancer professionals who deliver care and undertake research with Universities and the NHS who provide access to patients for research.
5. Policy-makers who respond to lobbying and perceived needs of AYA groups.
6. Patients—perhaps the most important of agents without whom there would not be a problem to be examined. Stephen Sutton is an example of this form of agency played out in the public arena.

This list suggests a range of interests and centres of power for all stakeholders as AYA cancer care has developed in the UK in the past thirty years. Currently, all AYAs cared for in the UK are managed by multiprofessional teams though some would argue that such teams may not always be fully aware of the background to current AYA cancer issues. When explored in greater detail, such as the competencies,

knowledge skills and attributes required of professionals as postulated by clinicians and researchers, what is most often recognised are the needs of AYAs in general, as well as the specific needs of AYAs with cancer (Morgan & Soanes, 2016; Smith et al., 2016; Taylor et al., 2011; Taylor, Feltbower et al., 2016; Taylor, Solanki et al., 2016; Teenage Cancer Trust, 2014).

The emergence of additional discourses around evidence-based AYA practice as a means of employing the best available research-based assessments and treatments in day-to-day patient care has led to a more standardised approach to professional practice and service delivery. This knowledge is produced by academics/clinicians and shared in specialist peer-reviewed journals, following pre-agreed academic discourses, and now underpins the development of clinical guidelines and policy. The National Institute of Clinical Excellence and the National Cancer Research Institute, two influential UK government-funded organisations are examples of the key agents who now draw on such empirical sources. In addition, some charities also fund and publish research findings on AYA cancer matters in peer-reviewed journals and thereby remain in a position of power and credibility by claiming adherence to quality control, authority and evidence. Research produced in the AYA cancer community currently spans the cancer experience of young people in clinical trials (e.g., Schafer & Hunger, 2011), through to applied psychosocial research (e.g., Zebrack et al., 2014) and research priority setting in this age group (Aldiss, Fern, Phillips, & Gibson, 2018). Over the last 25 years, we have seen more explicit evidence emerge to inform AYA cancer policy and standards in UK (NICE, 2005), and small but important advances in AYA cancer care such as highlighting issues with routes to diagnosis (Fern et al., 2011; Gibson et al., 2013), and raising awareness of challenges for AYAs with cancer in accessing clinical trials (Fern, Lewandowski, Coxon, & Whelan, 2014; Fern & Whelan, 2010, 2013).

In Foucauldian terms, power lies with such elite knowledge producers, in this case clinical academics, who produce such formal research-based knowledge. Patients are viewed as important but are often peripheral, though Taylor et al. (2011); Taylor et al. (2015); Taylor, Feltbower et al. (2016); Taylor, Solanki et al. (2016) have purposefully engaged AYAs with cancer in their recent national study evaluating specialist care models. One critique is that objectivity may be at risk in such approaches. On the other hand, the notion of patient engagement is often criticised as tokenistic, patchy and slow (Ocloo & Matthews, 2016) so it is encouraging to see that, within the growing research in this field, empowerment of AYAs is now being encouraged to help shape research and service delivery. While it is academic nurses, clinician researchers and health economists whose evidence is being used to shape practice and who may be perceived as key power brokers, it is those at the bedside such as nurses, junior oncologists or social workers, who are expected to implement care, while also holding less power than senior oncologists or service commissioners. In parallel, the power of charities is also noted, as their branding and marketing activities provide a strong social voice and help them leverage gains in other ways (often using patient narratives), and to fund innovations in practice, without necessarily

always waiting for research evidence. Through such action, AYA charities often remain the go-between, crossing the gap between state/academia and practice.

Foucault posits that 'Power is everywhere' and 'comes from everywhere' (Foucault, 1978a, 1978b, p. 93). In AYA cancer, a duality of structure and agency exists between those who subscribe to the immediate development of the specialism via action (charities), and the knowledge creators operating within the slower confines of NHS and academic structures. AYAs with cancer continue to be treated in the NHS; however, everyday care is shaped by nurses and other professionals, but it is not without the voluntary acts of those whose financial contributions create additional sources of support (and power/agency to individual AYAs) that would otherwise be lacking.

6 | EXAMPLES OF AN ARCHIVE OF THE DEVELOPMENT OF AYA AS A SPECIALISM

In assembling an archive of thought, Foucault (2002) argued that archives are not a totality, not 'the sum of all texts' or 'evidence of a continuing identity' (p. 145). Instead, they offer a set of discourses that are grouped together in distinct figures, composed together in accordance with multiple relations. Anais (2013) adds that the genealogist of thought or praxis does not look to a unified data set which can tell the whole story of a set of practices. Rather, they study the relational elements of discourse or events, and how these are articulated alongside other discursive formations. Therefore, in terms of a genealogical data set, any archive is relatively amorphous but at the same time it is a collection of discursive materials for examination. Table S1 outlines examples of supplementary materials that are relevant to this analysis of the development of specialist AYA care. The examples included here are not intended to be exhaustive but offer a range of materials on which the discussion here is built.

The selection of materials listed in table 1 are in keeping with the sentiments of Hollway (1989), who asserts that, in such an analysis, the notions of statistical sampling and generalisation are abandoned as this 'does not address the complex conditions of people and their conduct, either in their uniqueness or their commonality' (p. 15). The choice of text is guided rather by theoretical principles, purpose and relevance. The boundaries placed around the choice of texts are based purely on pragmatic considerations, as it is recognised that meaning is never achieved within a single work, sentence or even an extract, but rather in an infinite network of relevant texts (Hollway, 1989). Therefore, in keeping with a Foucauldian approach, 'a corpus of statements' has been gathered and organised over time and by type, this is intended to be relatively regular and systematic (Willing & Stainton-Rogers, 2008).

The rationale for this paper was premised both on personal insights and on professional experiences and can be supported further by a historical overview of the emerging empirical literature, policy and theory base (discourses of a more traditional

nature are included within the Supplementary Materials). The process of problematisation that first began the development of AYA cancer care reveals the shifting nature of power and its relationship with philanthropy, professionalism and policy in keeping with Foucauldian thinking. This also reveals the assumptions that first underpinned, and eventually prompted the growth of, this relatively new specialism to be seen as having clinical and social validity, and eventually to become established on a national, and now international level.

Supporting Information Table S1 lists key milestones in the emerging discourse of AYA cancer care since the early 1990s. Statements by Eden et al. (2005) were contained within early polemical textbooks that collected and shared the opinions of experts in the field and argued for attention to be paid to these patient's needs. Empirical work started to emerge slowly, and early examples include the work of Hollis and Morgan (2001), Lewis, Fallon, van Dongen-Melman, and Barr (2002) and Kelly et al. (2004).

What Supporting Information Table S1 also shows is that with this new and emerging discourse of challenge of the status quo, policy developments soon followed in the UK with the *Improving Outcomes Guidance Document for Children and Young people with Cancer* in 2005 (NICE, 2005) and updated quality standards in 2014 (NICE, 2014). The charity sector also responded alongside the growth of empirical research and reports (included in the Supplementary Materials) with recommendations for competency required of professionals and care standards outside of specialist AYA centres. Alongside these were accounts of young people dying from cancer (Daily Mail, 2013)—one the best-known being Stephen Sutton, mentioned previously, whose death trajectory was relayed on social media, and captured the public's imagination and raised several million pounds for the UK-based Teenage Cancer Trust (2017).

The scale of empirical research has grown in scope and ambition with the current *Brightlight* study exploring the benefits of specialist care for AYAs with cancer (Taylor et al., 2015). More recently, the *James Lind Alliance* (Aldiss et al., 2018) reported after a *Priority Setting exercise* on the top ten AYA cancer research priorities that identified gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples' cancer.

As the empirical, policy, public and charitable discourses grew, so did the public awareness of AYA cancer care and, in 2018, documentaries on AYA cancer narratives are on primetime television (Harrison, 2018). Special units for AYAs expanded in number, and international influence has also grown with congresses now taking place every two years in the UK or Europe, the United States or Australia (Cavallo, 2018; Lewis et al., 2002). Philanthropic organisations have been established in each of these countries and work collaboratively with the UK Teenage Cancer Trust to raise the global profile of AYA cancer care. At the heart of their work is strengthening the case for ongoing support and establishing an international nexus of expertise to counteract the external threats that face any charitable endeavour from losing public support at the national or local level.

The 30 years over which this archive has been drawn have witnessed change and development in AYA care, but challenges do remain. In a Foucauldian sense, the growth of specialist AYA care began with an emerging process of 'anatomy-politics' driven often by individual champions who drew attention to the unmet needs of this group. A process of problematisation preceded a subsequent period of rapid growth in research, policy, philanthropic effort and changes to service provision and practice itself (Foucault, 2002). Importantly, the voices of young people themselves were heard in each of these different forms of discourse, adding further strength to the challenges that were put to long-standing focus of professional power located within adult or paediatric oncology.

7 | CONCLUSION

We suggest here that, viewed through a Foucauldian lens, the AYA cancer movement now operates as an established (although not universally) power/knowledge nexus that is realised through innovative care practices, service developments, philanthropic endeavours and heightened public/health awareness. The expanding empirical literature on AYA cancer care, which now must be seen within its own sociopolitical framework, has grown in tandem with the emergence of the specialism across diverse health systems in the UK, United States and Australia. Entire careers are now built on this new specialism.

Through a Foucauldian lens, therefore, the power base of AYA cancer care is not static but is open to further challenge as age-appropriate services for this group become more established. However, the growth of AYA cancer as a specialism has also had many forces to contend with and as it looks to its future and, we suggest, it may benefit from understanding the ways that power and associated discourses were challenged successfully to allow it to arrive at its present situation, as well as help shape its future.

For the disproportionately small percentage of AYA patients who are diagnosed with cancer, the specialism now enjoys a powerful global voice, fuelled by committed philanthropic support with a growing empirical base and an emerging health policy discourse. While it may struggle to maintain as much momentum as over the past 30 years, it may find that its experience can assist in the empowerment of other groups who also require age-appropriate models of care. Importantly, the possibilities associated from a coalescing of historic, social, philanthropic and academic discourses may offer solutions, at least in part, to those who seek to advocate for the care of young people. Establishing AYA cancer care as a distinct specialism has shown that existing power structures can be contested and, with the coalescing of empirical research, policy developments and assistance from public philanthropy, changes can be achieved that echo at the global level.

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REFERENCES

- Aldiss, S., Fern, L. A., Phillips, B., & Gibson, F., on behalf of the Teenage and Young Adult Cancer Priority Setting Partnership Steering Group (2018). Teenage and young adult cancer: Research priorities. Final report of the James Lind alliance priority setting partnership. Retrieved from <http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/downloads/teenage-and-young-adult-cancer-PSP-final-report.pdf>
- Analís, S. (2013). Genealogy and critical discourse analysis in conversation: Texts, discourse, critique. *Critical Discourse Studies*, 10(2), 123–135. <https://doi.org/10.1080/17405904.2012.744321>
- Aries, P. (1962). *Centuries of childhood*. New York, NY: Vintage Books.
- Armstrong, D. (1997). Foucault and the sociology of health and illness: A prismatic reading'. In A. Peterson, & R. Bunton (Eds.), *Foucault, health and medicine* (pp. 15–30). London, UK: Routledge.
- Bacchi, A. (2012). Why study problematisations? Making politics visible. *Open Journal of Political Science*, 2(1), 1–8. <https://doi.org/10.4236/ojps.2012.21001>
- Barr, R. G., Bleyer, W. A., Ries, L., Whelan, J., & Ferrari, A. (Eds.) (2017). *Cancer in adolescents and young adults*. Cham, Switzerland: Springer.
- Bell, S. (2011). Through a Foucauldian lens: A genealogy of child abuse. *Journal of Family Violence*, 26(2), 101–108. <https://doi.org/10.1007/s10896-010-9347-z>
- Birchwood, M., & Singh, S. P. (2013). Mental health services for young people: Matching the service to the need. *The British Journal of Psychiatry*, 202(s54), s1–s2. <https://doi.org/10.1192/bjp.bp.112.119149>
- Bolte-Taylor, J. (2013). *The neuroanatomical transformation of the teenage brain* [Video file]. Retrieved from https://www.youtube.com/watch?v=PzT_5BQ1-s
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513–531. <https://doi.org/10.1037/0003-066X.32.7.513>
- Casey, B., & Jones, R. M. (2010). Neurobiology of the adolescent brain and behaviour. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(12), 1189–1285. <https://doi.org/10.1016/j.jaac.2010.08.017>
- Cavallo, J. (2018). *Second global AYA cancer congress highlights research advances and the global burden of cancer among young adults*. The ASCO Post. Retrieved from <http://www.ascopost.com/issues/January-25-2018/second-global-aya-cancer-congress-highlights-research-advances-and-the-global-burden-of-cancer-among-young-adults/>
- Daily Mail Online. (2013). Bereaved family calls for change in the law after teenage daughter died when she was denied cancer drugs. Retrieved from <http://www.dailymail.co.uk/news/article-2315818/Debbie-Binner-Bereaved-family-calls-change-law-teenage-daughter-Chloe-Drury-died-denied-cancer-drugs.html>
- Demos, J., & Demos, V. (1969). Adolescence in historical perspective. *Journal of Marriage and the Family*, 31(4), 632–638. <https://doi.org/10.2307/349302>
- Department of Health. (1995). *A report by the expert advisory group on cancer to the chief medical officers of England and Wales. A policy framework for commissioning cancer services – the Calman-Hine report*. London, UK: Department of Health.
- Docherty, T. (2014). *Postmodernism: A reader*. New York, NY: Routledge.
- Dreyfus, R., & Rabinow, P. (1982). *Michel Foucault: Beyond structuralism and hermeneutics*. Chicago, IL: Chicago University Press.
- Eden, T. O. B., Barr, R. D., Bleyer, A., & Whiteson, M. (Eds.) (2005). *Cancer and the adolescent*, 5th ed. Malden, MA: Blackwell. <https://doi.org/10.1002/9780470994733>
- Eikenberry, A. M. (2006). Philanthropy and governance. *Administrative Theory & Praxis*, 28(4), 586–592. <https://doi.org/10.1080/10841806.2006.11029557>
- Erikson, E. H. (1963). *Childhood and society*. New York, NY: W. W. Norton & Company.
- Fass, P. S. (Ed.) (2013). *The Routledge history of childhood in the western world*. London, UK: Routledge. <https://doi.org/10.4324/9780203075715>
- Ferlie, E., Mcgovern, G., & FitzGerald, L. (2011). A new mode of organizing in health care? Governmentality and managed networks in cancer services in England. *Social Science & Medicine*, 74(3), 340–347. <https://doi.org/10.1016/j.socscimed.2011.03.021>
- Fern, L. A., Campbell, C., Eden, T., Grant, R., Lewis, I., Macleod, U., ... Whelan, J. (2011). How frequently do young people with potential cancer symptoms present in primary care? *British Journal General Practice*, 61(586), e223–e230. <https://doi.org/10.3399/bjgp11X572418>
- Fern, L. A., Lewandowski, J. A., Coxon, K. M., & Whelan, J. (2014). Available, accessible, aware, appropriate, and acceptable: A strategy to improve participation of teenagers and young adults in cancer trials. *The Lancet Oncology*, 15(8), e341–e350. [https://doi.org/10.1016/S1470-2045\(14\)70113-5](https://doi.org/10.1016/S1470-2045(14)70113-5)
- Fern, L. A., & Whelan, J. S. (2010). Recruitment of adolescents and young adults to cancer clinical trials: International comparisons, barriers, and implications. *Seminars in Oncology*, 37(2), e1–e8. <https://doi.org/10.1053/j.seminoncol.2010.04.002>
- Fern, L., & Whelan, J. (2013). National Cancer Research Institute teenage and young adult clinical studies group: The United Kingdom approach to research. International perspectives on AYA0, part 4. *Journal of Adolescent and Young Adult Oncology*, 2(4), 161–166. <https://doi.org/10.1089/jayao.2012.0030>
- Foucault, M. (1977). *Discipline and punish: The birth of the prison*. London, NY: Allen Lane.
- Foucault, M. (1978a). Nietzsche, genealogy, history. In D. F. Bouchard (Ed.), *Language, counter-memory, practice: Selected essays and interviews* (pp. 76–100). Ithaca, NY: Cornell University Press.
- Foucault, M. (1978b). *The history of sexuality*, Vol. I. New York, NY: Vintage.
- Foucault, M. (1982). The subject and power. *Critical Inquiry*, 8(4), 777–795. <https://doi.org/10.1086/448181>
- Foucault, M. (1986). *The use of pleasure: The history of sexuality*, Vol. 2. New York, NY: Vintage.
- Foucault, M. (2002). *The archaeology of knowledge*. Abingdon, UK: Routledge.
- Foucault, M., & Rabinow, P. (1991). *The Foucault reader*. London, UK: Penguin Books.
- Foulkes, L., & Blakemore, S. J. (2018). Studying individual differences in human adolescent brain development. *Nature Neuroscience*, 21(3), 315–323. <https://doi.org/10.1038/s41593-018-0078-4>
- Freud, A. (1952). The mutual influences in the development of ego and id. *The Psychoanalytic Study of the Child*, 7(1), 42–50. <https://doi.org/10.1080/00797308.1952.11823151>
- Gibson, F., Pearce, S., Eden, T., Glaser, A., Hooker, L., Whelan, J., & Kelly, D. (2013). Young people describe their prediagnosis cancer experience. *Psycho-Oncology*, 22(11), 2585–2592. <https://doi.org/10.1002/pon.3325>
- Grant, K. (2015). *Postscript: Jane Sutton on how 'Stephen Sutton effect' gives mum reason to stay positive*. The Independent Newspaper. Retrieved from <http://www.independent.co.uk/news/people/profiles/postscript-jane-sutton-on-how-stephen-sutton-effect-gives-mum-reason-to-stay-positive-10432415.html>
- Harrison, G. (Director), Crabtree, S. (Editor) (2018). *Teenagers v's cancer: A user's guide*. In Liddel, R. (Producer). BBC Horizon, London, UK.
- Hollis, R., & Morgan, S. (2001). The adolescent with cancer: At the edge of no-man's land. *The Lancet Oncology*, 2(1), 43–48. [https://doi.org/10.1016/S1470-2045\(00\)00195-9](https://doi.org/10.1016/S1470-2045(00)00195-9)
- Hollway, W. (1989). *Subjectivity and method in psychology: Gender, meaning and science*. London, UK: Sage.
- ITV News. (2014). *Life lessons from 'true hero' Stephen Sutton*. ITV News. Retrieved from <http://www.itv.com/news/2014-05-14/stephen-suttons-most-inspirational-quotes/>

- Kelly, D. M., & Gibson, F. (2008). *Cancer care for adolescents and young adults*. Oxford, UK: Blackwell. <https://doi.org/10.1002/9780470697740>
- Kelly, D. M., & Hooker, L. (2007). Evidence based cancer policy: The needs of teenagers and young adults. *European Journal of Oncology Nursing*, 11(1), 4–5. <https://doi.org/10.1016/j.ejon.2006.12.004>
- Kelly, D. M., Mullhall, A., & Pearce, S. (2002). Adolescent cancer: The need to evaluate current service provision in the UK. *European Journal of Oncology Nursing*, 7(1), 53–58. <https://doi.org/10.1054/ejon.2002.0204>
- Kelly, D. M., Pearce, S., & Mullhall, A. (2004). 'Being in the same boat': Ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies*, 41(8), 847–857. <https://doi.org/10.1016/j.ijnurstu.2004.03.011>
- Lewis, I. J., Fallon, S., van Dongen-Melman, J., & Barr, R. (2002). Cancer and the adolescent: The second Teenage Cancer Trust international conference. Royal College of Physicians, London, England, March 2001. *Medical and Pediatric Oncology*, 39(3), 198–201. <https://doi.org/10.1002/mpo.10144>
- Long, C. J., Ginsberg, J. P., & Kolon, T. F. (2016). Fertility preservation in children and adolescents with cancer. *Urology*, 91, 190–196. <https://doi.org/10.1016/j.urol.2015.10.047>
- Loren, A. W., Mangu, P. B., Beck, L. N., Brennan, L., Magdalinski, A. J., Partridge, A. H., ... American Society of Clinical Oncology. (2013). Fertility preservation for patients with cancer: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology*, 31(19), 2500–2510. <https://doi.org/10.1200/jco.2013.49.2678>
- Lumb, D. (2014). Stephen's story: What's the secret to teen's fundraising success? BBC News. Retrieved from <http://www.bbc.co.uk/news/uk-england-27192089>
- Marris, S., Morgan, S., & Stark, D. (2011). 'Listening to Patients': What is the value of age-appropriate care to teenagers and young adults with cancer? *European Journal of Cancer Care*, 20(2), 145–151. <https://doi.org/10.1111/j.1365-2354.2010.01186.x>
- Mooney Nickel, P., & Eikenberry, A. M. (2009). A critique of the discourse of marketized philanthropy. *American Behavioral Scientist*, 52(7), 974–989. <https://doi.org/10.1177/0002764208327670>
- Morgan, S., & Soanes, L. (2016). Nursing young people with cancer: What is 'different' about it? *Bulletin du cancer*, 103(12), 999–1010. <https://doi.org/10.1016/j.bulcan.2016.10.007>
- National Institute for Health and Care Excellence (2005). *Guidance on cancer services: Improving outcomes in children and young people with cancer*. London, UK: NICE.
- National Institute for Health and Care Excellence (2014). *Children and young people with cancer, NICE quality standard 55*. London, UK: NICE.
- Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement. *BMJ Quality & Safety*, 25(8), 626–632. <https://doi.org/10.1136/bmjqs-2015-004839>
- Olsen, P., & Smith, S. (Eds.) (2018). *Nursing adolescents and young adults with cancer*. Cham, Switzerland: Springer. <https://doi.org/10.1007/978-3-319-73555-9>
- Oxford University Press. (2018). *English Oxford living dictionaries*. Retrieved from <https://en.oxforddictionaries.com/definition/charity> & <https://en.oxforddictionaries.com/definition/philanthropy>
- Palmer, S., Mitchell, A., Thompson, K., & Sexton, M. (2007). Unmet needs among adolescent cancer patients: A pilot study. *Palliative & Supportive Care*, 5(2), 127–134. <https://doi.org/10.1017/S1478951507070198>
- Pearce, S. (2009). Policy and practice in teenage and young adult cancer care in England: Looking to the future. *European Journal of Oncology Nursing*, 13(3), 149–153. <https://doi.org/10.1016/j.ejon.2009.05.003>
- Piaget, J. (1970). *Science of education and the psychology of the child*. New York, NY: Viking.
- Platt, R. (1959). *The welfare of children in hospitals*. London, UK: H.M.S.O.
- Pupavac, V. (2001). Misanthropy without border: The international children's rights regime. *Disasters*, 25(2), 95–112. <https://doi.org/10.1111/1467-7717.00164>
- Rabinow, P. (1991). *The Foucault reader: An introduction to Foucault's thought*. London, UK: Penguin.
- Salamon, L. M. (1992). *America's nonprofit sector: A primer*. New York, NY: Foundation Center.
- Schafer, E. S., & Hunger, S. P. (2011). Optimal therapy for acute lymphoblastic leukemia in adolescents and young adults. *Nature Reviews Clinical Oncology*, 8(7), 417–424. <https://doi.org/10.1038/nrclinonc.2011.77>
- Smith, S., Case, L., Waterhouse, K., Pettitt, N., Beddard, L., Oldham, J., & Siddall, J. (2012). *A blueprint of care for teenagers and young adults with cancer*. London, UK: Teenage Cancer Trust.
- Smith, S., Mooney, S., Cable, M., & Taylor, R. M. (2016). *A blueprint of care for teenagers and young adults with cancer*, 2nd ed. London, UK: Teenage Cancer Trust.
- Soanes, L., & Gibson, F. (2018). Protecting an adult identity: A grounded theory of supportive care for young adults recently diagnosed with cancer. *International Journal of Nursing Studies*, 81, 40–48. <https://doi.org/10.1016/j.ijnurstu.2018.01.010>
- Stevens, M. C. (2006). The 'Lost Tribe' and the need for a promised land: The challenge of cancer in teenagers and young adults. *European Journal of Cancer*, 42(3), 280–281. <https://doi.org/10.1016/j.ejca.2005.11.007>
- Sulek, M. (2010). On the modern meaning of philanthropy. *Nonprofit and Voluntary Sector Quarterly*, 39(2), 193–212. <https://doi.org/10.1177/0899764009333052>
- Taylor, R. M., Feltbower, R. G., Aslam, N., Raine, R., Whelan, J. S., & Gibson, F. (2016). Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer. *British Medical Journal Open*, 6(5), e011361. <https://doi.org/10.1136/bmjopen-2016-011361>
- Taylor, R. M., Fern, L. A., Solanki, A., Hooker, L., Carluccio, A., Pye, J., ... Whelan, J. S. (2015). Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer. *Health and Quality of Life Outcomes*, 13(1), 107. <https://doi.org/10.1186/s12955-015-0312-7>
- Taylor, R. M., Fern, L., Whelan, J., Pearce, S., Grew, T., Millington, H., ... Gibson, F. (2011). "Your place or mine?" Priorities for a specialist teenage and young adult (AYA) cancer unit: Disparity between AYA and professional perceptions. *Journal of Adolescent and Young Adult Oncology*, 1(3), 145–151. <https://doi.org/10.1089/jayao.2011.0037>
- Taylor, R. M., Solanki, A., Aslam, N., Whelan, J. S., & Fern, L. A. (2016). A participatory study of teenagers and young adults views on access and participation in cancer research. *European Journal of Oncology Nursing*, 20, 156–164. <https://doi.org/10.1016/j.ejon.2015.07.007>
- Teenage Cancer Trust (2014). *Competencies: Caring for teenagers and young adults with cancer: A competence and career framework for nursing*. London, UK: Teenage Cancer Trust.
- Teenage Cancer Trust. (2017). Stephen Sutton. Retrieved from <https://www.teenagecancertrust.org/get-help/young-peoples-stories/stephen-sutton>
- Teenage Cancer Trust. (2018a). Support outside our units. Retrieved from <https://www.teenagecancertrust.org/about-us/what-we-do/support-outside-our-units>
- Teenage Cancer Trust. (2018b). Our policy work. Retrieved from <https://www.teenagecancertrust.org/about-us/what-we-do/policy/our-policy-work>
- Teenage Cancer Trust. (2018c). Young people with cancer need specialised nursing care and support. Retrieved from <https://www.teenagecancertrust.org/>
- Teenage Cancer Trust. (2018d). Royal Albert Hall. Retrieved from <https://www.teenagecancertrust.org/about-us/our-story/music/royal-albert-hall>

- Temmerman, M., Khosla, R., Bhutta, Z. A., & Bustreo, F. (2015). Towards a new global strategy for women's, children's and adolescents' health. *British Medical Journal*, 351, h4414. <https://doi.org/10.1136/bmj.h4414>
- Tester, K. (2001). *Compassion, morality, and the media*. Buckingham, UK: Open University Press.
- University College London Hospitals. (2017). *Brightlight: Do specialist services for teenagers and young adults add value?* Retrieved from <http://www.brightlightstudy.com/>
- Valentine, G., Butler, R., & Skelton, T. (2001). The ethical and methodological complexities of doing research with 'vulnerable' young people. *Ethics, Place & Environment: A Journal of Philosophy & Geography*, 4(2), 119–125. <https://doi.org/10.1080/13668790123540>
- Whiteson, M. (2003). The Teenage Cancer Trust—advocating a model for teenage cancer services. *European Journal of Cancer*, 39(18), 2688–2693. <https://doi.org/10.1016/j.ejca.2003.08.023>
- Whiteson, M. (2005). A right, not a privilege. In T. O. B. Eden, R. D. Barr, A. Bleyer, & M. Whiteson (Eds.), *Cancer and the adolescent*, 2nd ed. (pp. 1–10). Oxford, UK: Blackwell. <https://doi.org/10.1002/9780470994733>
- Willig, C. (Ed.) (1999). *Applied discourse analysis: Social and psychological interventions*. London, UK: Open University Press.
- Willing, C., & Stainton-Rogers, W. (2008). *The SAGE handbook of qualitative research in psychology*. London, UK: SAGE. <https://doi.org/10.4135/9781848607927>
- Zebrack, B. J., Corbett, V., Embry, L., Aguilar, C., Meeske, K. A., Hayes-Lattin, B., ... Cole, S. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psycho-Oncology*, 23(11), 1267–1275. <https://doi.org/10.1002/pon.3533>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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Appendix 2 Section of data charting summary

Database	Author	Year	Title	Publication	Type of ar Source	Target Population	Geograph Intervention/Articles	Research Methods	Sample size	Conceptual/Major Themes/Findings	Recommendations
Cinahl	Albers, Haj Mc	2020a	Exploring AYAO	Journal	Empirical	AYAC & HCP	Netherlands	Qual	N=52, Nurses=40	NA	Communication about sexuality AYAs do report unmet needs regarding adequate communication
Scopus	Albers, Bergs	2020B	Discussing	Journal	Empirical	Dr & Nurses	Netherlands	Qual	Semi structure Drs=6, Nurse s=8	NA	Interviews with the healthcare To facilitate discussing sexual health, clear defined re
Cinahl	Avery-Geist, L	2020	It's More CO Oncology	Journal	Empirical	Dis & Nurses	Canada	Qual	Semi structure Drs =10, Nurse =4	NA	Four themes emerged that spea Providers articulated powerful and meaningful them
Proquest	Bahrani, Nari	2020	Informati Supportive	Journal	Empirical	AYA, Parents and HCP ind nurses	Iran	Qualitative	descriptive exp: 33- 6 of which were nurses	NA	1. Disaffiliation of adolescents in HCP's need more training taking into account familial a
Cinahl	Barlevy, Wang	2016	Attitudes, AYAO	Journal	Lit Review	AYA, Parents and HCP ind nurses	Canada	NA	96 articles	NA	HCP and parents underestimate Educating profess on having these conversations
Cinahl	Berger, Thom	2019	An Explor, AYAO	Journal	Empirical	HCP INCL NURSES	Australia	Qual	Interviews 12 MDT-6 NURSES	NA	1. Healthcare challenges- variati Oncology experience alone is inadequate, lack of train
Cinahl	Bradford, Gre	2018	Educational Needs of	Journal	Empirical	HCP ind nurses	Australia	Qual	survey 2 N=195	NA	The most prominent educational health professionals require ongoing opportunities fo
Cinahl	Day, Jones, La	2017	We just Paed Blood	Journal	Empirical	HCP ind nurses	UK	Qual	Observation ann=58, nurses- 19	NA	HCP revealed principles relating Specialist haematology teams are aware of the indivi
Cinahl	Essig, Steiner,	2016	Improving AYAO	Journal	Empirical	Dis and Nurses	Switzerland	Quant	Focus Groups N=54, NURSE =18	NA	themes within the following se The framework within which professionals communic
Cinahl	Essig, Steiner,	2019	Communi, AYAO	Journal	Empirical	Dis and Nurses	Switzerland Communication Skills training	Survey	Drs =26, nurses= 24	NA	The proportion of participants w The results of CST tailored to the specific needs of HC
Psychinfo	Gibson, Shipw	2012	A scoping EION	Journal	Empirical	Nurses	UK	Qual	Diamond Ranki N=102, WS1 N=32, nurses=4, WS2 8 NA	NA	The workshops generated three These results will form the basis of future discussion
Cinahl	Kelly, Pearce,	2004	Being in UNS	Journal	Empirical	AYA, Parents, HCP ind nurses	UK	Qual	Ethnography 10 TYA, 10 parents and 14 HCP	NA	Two data themes cancer and th The need to discover whether adolescents with ca
Cinahl	Lanyonava, H	2018	Rather on The Oncology	Journal	Empirical	Dis and Nurses	Germany	Qual	Interviews n=29, Nurses=7	NA	Oncologists and nurses reported "Struggling" together with the patient against the
Proquest	Laverder, Gib	2019	Health pri Supportive	Journal	Empirical	HCP INCL NURSES	UK	Qual	Narrative inquir 18 ind nurse but not clear how mar NA	NA	professional expertise, the de Developing expertise, effective communication skills
Cinahl	Norton and W	2020	Barriers a AYAO	Journal	Empirical	Nurses	UK	Qual	Interviews and N=11	NA	Parents/family were experience Nurses should manage parental involvement sensitiv
Cinahl	Olsen and Har	2010	Caring for EION	Journal	Empirical	NURSES on aya ward	Denmark	Qual	grounded theo 7 nurses	Bridging	'Bridging' was defined as the co Network-focused nursing is a complex and demandi
Cinahl	Pearce, Brown	2016	The perso EICC	Journal	Empirical	AYA & HCP ind Nurses	uk	Qual	Narrative inquir HCP=18	NA	New understandings emerged a We conclude that addressing these factors may increa
Cinahl	Smith	2004	Adolescer EION	Journal	Lit review	Nursing	UK	NA	27 articles	NA	Analysis of the research included in this study indicates that there are a number of psy
Cinahl	Smith	2017	Advanced Journal of H	Journal	Empirical	Nurses	USA	Quant	Questionnaire Nurses=18	Kings Fran	There was an overwhelmingly p Offering a simulated learning environment enables th
Pubmed	Taylor, Felbic	2016	Modified BMI Open	Journal	Empirical	HCP ind Nurses	Intl	Quant	Survey N= 294, Nurses =105	NA	The areas of competence rated Given the high degree of consensus, this list of compo
Cinahl	Temson and	2019	A Systematic Review cul	Journal	Empirical	HCP	UK	NA	15 articles	NA	Participants reported patient, parent, professional, and institutional factors that influe
Cinahl	Thompson, Dy	2013	An Explor Social Work	Journal	Empirical	Healthcare professionals	Australia	explorato	Questionnaire 60 various HCP ind nursing n=32	NA	top 5 issues for aya c, perception unique needs need to be known by HCP. Support to m
Cinahl	Tutelman, Dre	2019	It Could Have Been M	Journal	Empirical	MDT ind nurses	Canada	Qual	IPA SEMI STRUCTURED NURSES=4, DRIS=5	NA	1. The unknowns and uncertain HCPs recognise need for training to support clinicians
Cinahl	Vindrola-Padr	2017	Healthcare Psycho-oncol	Journal	Empirical	HCP	UK	NA	16 articles	NA	Common themes reported across Future work should ensure that HCP's possess knowle
Cinahl	Williamson &	2017	Perspecti of Psychos	Journal	Empirical	HCP's	UK	Mixed me phase 1 semi st N=62, Nurses =18		NA	Two main themes- 1. HCP persp Education needed. Validating AVA concerns. Educating

Appendix 3 Summary of included papers

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
1	<p><i>Albers, Bergsma et al. 2020</i> Netherlands</p> <p>The aim of this study was to determine preferences of AYAs regarding communication about intimacy and sexuality and examine discrepancies between AYA and HCP.</p> <p><i>Source of Data</i> JAYAO</p>	A cross-sectional survey	AYAC & HCP N = 52, Nurses = 40	Communication about sexuality was considered important by >90% of AYAs and HCPs. Of the AYAs, 41% did receive information from a HCP, 21% of them was satisfied with it. HCPs held physicians and nurse practitioners responsible to discuss sexuality; AYAs preferred nurse practitioners and sexologists. Main barriers to initiate a discussion on sexuality are “feeling of shame” for AYAs and “presence of a third party” for HCPs. Most AYAs would like to receive information about sexuality through a website (66%) or conversation with a HCP (64%) before start of treatment (64%). HCPs would be helped by written material (75%) and additional training (71%) to give to AYAs.
2	<p><i>Albers, Haj Mohammad et al. 2020</i> Netherlands</p> <p>This study aimed to gain insight into perspectives of healthcare providers in facilitating AYAs’ needs regarding sexual health</p> <p><i>Source of Data</i> - Journal of Cancer Education</p>	Semi-structured interviews	Drs = 6, Nurses = 8	Interviews with the healthcare providers revealed five themes concerning the discussion of sexual health: (1) being responsible for bringing up the topic of sexual health, (2) finding optimal timing to discuss sexual health, (3) acquiring knowledge to enable discussion of sexual health, (4) facilitating communication about sexual health, and (5) providing informative material for AYAs.

	Author, Year, Country, Aim of Study, Source of data,	Design & Methods	Target Population	Findings
3	<p><i>Avery et al. 2019</i> Canada</p> <p>This study aimed to explore the experiences of HCPs involved in introducing and providing palliative care caring for AYAs with advanced cancer and their families to understand the unique challenges HCPs experience.</p> <p><i>Source of Data</i> JCO Oncology</p>	Semi-structured interviews	Drs = 10, Nurse = 4	Four themes emerged that speak to HCP difficulty: (1) challenges helping AYAs/families to engage in and accept palliative care; (2) uncertainty regarding how to involve the family; (3) HCP sense of tragedy; and (4) HCP sense of emotional proximity. Participants described an increased emotional connection with the AYA population and more turmoil when treating younger people with advanced cancer. This type of emotional proximity contributed to their reluctance to engage in discussions about palliative care with AYAs and their families. In addition, HCPs were unsure how to approach/include the family in palliative care discussion when there is the common perception that palliative care is synonymous with EOL.
4	<p><i>Bahrami et al. 2017</i> Iran and Australia</p> <p>This study aimed to assess the viewpoints, experiences and preferences within the clinical communication triangle (parent, adolescent, healthcare team) concerning the information sharing process for adolescents with cancer.</p> <p><i>Source of data</i> - Journal-Supportive Care Cancer</p>	Descriptive exploratory study. In-depth semi-structured interviews were conducted, and data were analysed using constant comparative analysis.	N = 33 participants were recruited (to include adolescents diagnosed with cancer aged 15-20 years, their parents, oncologists and nurses).	Data analysis yielded three main themes. 1. Disaffiliation of adolescents in information-sharing process with three sub-themes: confusion and unanswered questions and seeking information from inferior sources. 2. Barriers to information-sharing with three sub-themes: parents as gatekeepers in the information-sharing process, cultural background creating strong barriers for information-sharing and the negative attitude of the medical team towards information-sharing. 3. The last theme is cornerstones in information-sharing process with three sub-themes: trust and honesty to enhance communication between adolescents and the medical team, the necessity of paving the way for information-sharing, and the value of gradual information-sharing based on the adolescents need and mental readiness. Information-sharing process needs to be gradual and based on the adolescent's need and mental capacity

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
5	<p><i>Barlevy, et al. 2016</i> Switzerland and Canada</p> <p>This systematic literature review aims to aggregate and summarise the attitudes, beliefs, and patterns of behaviour of all stakeholders (i.e., patients, parents, and healthcare providers) in oncofertility discussions when the patient is an adolescent (12-17 years old).</p> <p><i>Source of data</i> Journal - Journal of Adolescent and Young Adult Oncology</p>	<p>Systematic Review</p> <p>96 articles are included in this review</p>	<p>AYA patients, Parents and HCPs</p>	<p>The findings are grouped into four main thematic categories: the adolescent patient's perspective, the parent's perspective, the healthcare professional's perspective and recommendations.</p> <p>HCP and parents underestimate the need for oncofertility counselling. YP believe HCPs misperceive it is as big a problem as it is for them. Some HCPs are uncomfortable to discuss often due to language and cultural barriers</p>
6	<p><i>Berger, et al. 2019</i> Australia</p> <p>The aims of this study were to (1) understand the experience of HCPs caring for AYA with incurable cancer; (2) explore whether experiences vary across professional disciplines; and (3) identify challenges in the management of AYA and the factors enabling HCPs to deliver care with greater confidence.</p> <p><i>Source of data</i> - Journal of Adolescent and Young Adult Oncology</p>	<p>Descriptive.</p> <p>Using semi-structured in-depth interviews, underpinned by grounded theory.</p>	<p>MDT n = 12 (which included nurses n = 6)</p>	<p>Healthcare challenges: variation in knowledge and experience impacting care delivery; absence of guidelines or CPD; communication, lack of care-planning forums, barriers to age apt info delivery, lack of formalised structures, lack of skill building opportunities.</p> <p>Enablers include MDT care, shared decision-making, interdisciplinary support and collegiality, understanding life stage in context of incurable disease, role of AYA cancer specialist service, maintaining professional boundaries, role of senior staff.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
7	<p><i>Bradford, et al. 2018</i> <i>Australia</i> The aim of this study was to identify the learning needs of HCPs providing cancer care to adolescents and young adults before and following the introduction of a state-wide AYA cancer education programme. <i>Source of data</i> - Journal of Adolescent and Young Adult Oncology</p>	<p>Descriptive. Survey x 2</p>	<p>Survey1 n = 122 (Nurses n = 52, Dr n = 13, HCP n = 47, Other n = 10) Survey 2 n = 73 (Nurses n = 36, Dr n = 4, HCP n = 30, Other n = 4)</p>	<p>To provide high-quality healthcare to AYAC, HCPs require ongoing opportunities for education and training.</p>
8	<p><i>Day et al. 2018</i> To investigate healthcare professionals' (HCP) views of teenagers' involvement in decisions about their care and treatment for leukaemia <i>Source of data</i> - Paed Blood and Cancer</p>	<p>Participant observation at 98 MDT meetings and 95 open ended, semi-structured interviews and informal conversations with clinical teenage cancer teams at one UK tertiary referral centre.</p>	<p>Observations of MDT meetings (N = 98; 58 HCP), semi-structured interviews with HCP (N = 12 of them 5 nurses;</p>	<p>HCP revealed principles relating to the involvement of teenagers with leukaemia in decision-making: (1) do the 'right thing'; (2) act on the care and treatment preferences of the teenager; and (3) openly disclose information about the teenager's condition. These principles were prioritised and utilised uniquely in each situation, reliant on three mediating factors: (1) family communication styles; (2) stage of illness; and (3) nature of the disease. Specialist haematology teams are aware of the individual and shifting and situational preferences of teenagers. They follow the lead which teenagers give them regarding these preferences. If actual practice with regard to the involvement of teenagers is found to be wanting, this study refutes that this should be ascribed to insensitivity on the part of HCPs about teenagers' informational and decisional role preferences.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
9	<i>Essig et al. 2016</i> A multi-perspective approach, drawing on perspectives of former adolescents with cancer, patients' parents, physicians and nurses with the aim to provide suggestions for improvement in communication in adolescent cancer Care <i>Source of data</i> - Paediatric Blood Cancer	Focus groups	Adolescent cancer survivors (n = 16), parents (n = 8), paediatric oncologists (n = 12), and paediatric oncology nurses (n = 18)	The following themes were identified (1) The framework in which professionals communicate with adolescents with cancer (regression in a time of detachment, adolescents' perception and knowledge of illness, cognitive versus legal maturity, "lost in transition" between paediatric and adult oncology); (2) communication difficulties between professionals and patients and parents (professionals and patients/parents identified the other party as the source of difficulties); and (3) effective professional communication (there was some overlap on how doctors and nurses should communicate, along with substantially different expectations for the two professions).
10	<i>Essig et al. 2019</i> To pilot and evaluate communication skills training (CST) for HCPs interacting with adolescent patients with cancer and their parents based on participants' needs <i>Source of data</i> - JAYAO	Pre and post-test Questionnaires	Drs = 26, nurses = 24	The proportion of participants who felt confident increased significantly in 6 of 19 communication items ($p < 0.05$). Positive feedback outweighed negative in quantity and quality. Predominant themes immediately after training were the training's practical orientation and intensity, and 6 months later, increased self-confidence and applied communication techniques. Participants noted that the effect diminishes with time and expressed their need for booster trainings.
11	<i>Gibson, et al. 2012</i> <i>Source of data</i> Journal - European Journal of Cancer Care	Descriptive. Diamond ranking of 2 workshops	N = 102, WS1 N = 22, nurses = 4; WS2 80 HCP	The workshops generated three diamonds, which exhibited agreement of 13 principal skills, knowledge and attitudes. The top two being: 'expertise in treating paediatric and adult cancers' and 'understanding cancer'. The data from the education day suggested communication, technical knowledge and teamwork as being core role features for professionals who care for young people with cancer. Integration of both datasets; one derived inductively, the other deductively provides a comprehensive outline of core skills health professionals require to be proficient in young peoples' cancer care

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
12	<p><i>Kelly, et al. 2004</i> United Kingdom The aim was to conduct an empirical investigation into the adolescent cancer care experience by focusing on the first specialist unit to be established in the United Kingdom in the early 1990s. The primary aim was to describe how this care setting itself was perceived from the perspective of those involved. <i>Source of data</i> Journal - International Journal of Nursing Studies</p>	<p>Descriptive. An in-depth ethnographic approach - Observation and interviews</p>	<p>Teenage/Young Adults n = 10, Parents n = 10, and HCP n = 14 (incl nurses)</p>	<p>Two data themes ‘cancer and the cancer unit’ and ‘changes over time’ are discussed in this paper. Benefits of the unit included shared understandings and the way the privations of adolescent cancer was contained and managed by those involved.</p>
13	<p><i>Laryionava et al. 2018</i> Germany To understand oncologists’ treatment decisions and oncology nurses’ perception of these decisions in young adult patients and to investigate the extent to which young age was a factor in cancer treatment decisions <i>Source of data</i> - The Oncologist</p>	<p>Interviews</p>	<p>HCP n = 29, incl Nurses = 7</p>	<p>Oncologists and nurses reported that decisions about limiting cancer treatment with young adult patients are the most challenging and stressful in clinical practice. Apart from using young age as a proxy for patient’s medical fitness, oncologists’ decisions in favour of more aggressive treatment of younger patients were mainly guided by ethical reasons such as patient preferences and the perceptions of injustice associated with dying at a young age, as well as by psychological reasons, such as identification and emotional entanglement</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
14	<p><i>Lavender, et al. 2019</i> United Kingdom</p> <p>The aim of the study was to explore health professional perceptions of communicating with adolescents and young adults with bone sarcoma about clinical trial participation. <i>Source of data</i> Journal - Supportive Care in Cancer</p>	Narrative Inquiry using in-depth interviews	18 multidisciplinary HCPs working in a supra-regional bone and soft tissue sarcoma centre.	<p>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. Identified 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.</p>
15	<p><i>Norton and Wright 2020</i> This study explored nurses' experiences of undertaking fertility-related discussions with AYAC aged 13-24 years <i>Source of data</i> JAYAO</p>	Semi-structured interviews/IPA	N = 11 Nurses	<p>Parents/family were experienced as self-appointed informal gatekeepers who were perceived to hold the power to control nurses' access to communicate with young people about fertility issues. Nurses adopted a supportive role, which was enhanced by the positive nature of their relationship with the TYA. Uncertainty was expressed over whether the TYA had been fully informed of their infertility risk and potential FP options. Nurses should manage parental involvement sensitively if TYAs are to make informed decision regarding their future reproductive health.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
16	<p><i>Olsen and Harder 2011</i></p> <p>Denmark</p> <p>The aim of the study was to generate a substantive theory by exploring processes and strategies of oncology nurses engaged in a nursing programme, which aims at supporting these young patients and their significant others to maintain, establish and strengthen support from their social network during the treatment period.</p> <p><i>Source of data</i> Journal - European Journal of Oncology Nursing</p>	<p>A grounded theory approach was used and data were generated through interviews, observations, informal conversations and documents.</p>	<p>Nurses n = 7</p>	<p>'Bridging' was defined as the core concept in nurses' strategies aimed at creating a space for the TYAs' normal growth and development. By strategies of 'Tuning in', 'Framing the situation', 'Navigating towards the goal' and 'Connecting people' the nurses attempted to provide a foundation for the seriously ill TYAs to connect to their normal everyday life.</p>
17	<p><i>Pearce et al. 2018</i></p>	<p>Semi-structured interviews using narrative inquiry.</p>	<p>HCP = 18 incl nurses</p>	<p>New understandings emerged about perceptions of, and factors that influence participation in, clinical trials. These include perceptions about the importance and design of the clinical trial, communicating with young people in an age-specific manner, using language young people are comfortable with, support from family, peers and specialists in teenage and young adult cancer care.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
18	<p><i>Smith, 2004</i> <i>United Kingdom</i></p> <p>The aim of this literature review was to identify the evidence available to support the need for adolescents to be nursed on specific Adolescent Units.</p> <p><i>Source of data</i> Journal - European Journal of Oncology Nursing</p>	<p>Systematic literature review.</p> <p>27 studies included.</p> <p>Of these, 13 quantitative, 8 qualitative and 6 mixed methods.</p>	<p>AYA Cancer units/ HCPs</p>	<p>Analysis of the research included in this study indicates that there are a number of psychosocial factors that affect the quality of the hospital experience for the adolescent with cancer. Key factors include ward environment, attitudes of HCP, adolescent development, nurse's knowledge and spending time with them, place of care important. Staff have education & development needs to care for AYAC and support for them is also required.</p>
19	<p><i>Smith et al. 2017</i></p> <p>The purpose of this evidence-based project was to use an advance directive document as a guide to initiate communication about ACP for young adults with high-risk cancer in a simulated clinical setting</p> <p><i>Source</i> - Journal of Hospice and Palliative Nursing</p>	<p>A pre-test/post-test nonexperimental design</p>	<p>N = 18 nurses</p>	<p>There was an overwhelmingly positive response to this simulation activity. The participants felt that the simulation should be held routinely and that ACP should be a regular part of conversations with patients. Advance care planning is important and, too frequently, a missing step in the care of young adults with life-limiting conditions.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
20	<i>Taylor et al. 2016</i> International	E-Delphi study	HCPs N = 294, Nurses = 105	The areas of competence rated most important were agreed to be: 'Identify the impact of disease on young people's life' (skill); 'Know about side effects of treatment and how this might be different to those experienced by children or older adults' (knowledge); 'Honesty' (attitude); and 'Listen to young people's concerns' (aspect of communication). Given the high degree of consensus, this list of competencies should influence education curriculum, professional development and inform workforce planning. Variation in strength of agreement for some competencies between professional groups should be explored further in pursuit of effective multidisciplinary team working.
21	<i>Tennyson and Griffiths 2019</i> United Kingdom This review aimed to synthesise and critically evaluate studies investigating professionals' experiences of discussing fertility issues with AYAC patients and to understand the barriers and facilitating factors to having these conversations with this specific age group. <i>Source of data</i> Journal - Journal of Adolescent and Young Adult Oncology	Systematic review. 15 articles reporting 14 studies were included in this review.	HCPs	Participants reported patient, parent, professional and institutional factors that influenced fertility discussions. The most commonly reported barriers were the lack of patient educational materials and staff training. Participants were more likely to discuss fertility with patients who were male; had less severe disease; and raised the issue of fertility themselves. The findings suggest that professionals' own values and opinions influence the likelihood of fertility being discussed, with implications for guidance and training.

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
22	<p><i>Thompson, et al. 2013.</i></p> <p>Australia</p> <p>This study sought to explore oncology professionals' understanding of the healthcare preferences of AYAC receiving treatment at a specialist cancer centre.</p> <p><i>Source of data</i> Journal - Social Work in Health Care</p>	<p>Exploratory study used a survey questionnaire incorporating both qualitative and quantitative questions.</p>	<p>Participants - n = 60 HCP (Incl nursing (n = 32);</p>	<p>Results illustrate that, with a strong focus on survival and physical well-being, professionals significantly underestimate the breadth of AYA psychosocial concerns.</p>
23	<p><i>Tutelman, et al. 2019</i></p> <p>Canada</p> <p>The purpose of the current study was to understand HCPs' experiences of caring for AYAs with terminal cancer.</p> <p><i>Source of data</i> Journal - Journal of Adolescent and Young Adult Oncology</p>	<p>Descriptive. In-depth semi structured Interviews.</p>	<p>Nurses n-4 Drs n = 5</p>	<p>Analyses revealed four superordinate themes: (1) many unknowns and uncertainties associated with providing care for AYAs compounded by minimal or no training specifically concerning this population; (2) an intense emotional experience compared with caring for patients with terminal cancer of other ages; (3) personal identification with patients and their families; and (4) attempts to make sense of the circumstance thwarted by feelings of injustice and unfairness. HCPs experienced unique emotional and logistical challenges when caring for AYAs with terminal cancer, which can influence the care they provide. HCPs' experiences highlight the need for training to support clinicians in caring for AYAs with terminal cancer to optimise their own well-being and delivery of healthcare services to this population.</p>

	Author, Year of Publication Country, Aim of study, Source of data,	Design & Methods	Target Population	Findings
24	<p><i>Vindrola-Padros, et al. 2017</i> United Kingdom and United States of America</p> <p>To explore the factors shaping the discussion of Fertility Preservation with children (0-15 years) and adolescents/young adults (16-24 years) with cancer.</p> <p><i>Source of data</i> Journal-Psych-Oncology</p>	A mixed method systematic review.	HCPs	Common themes reported across studies indicate that five main factors influence HCPs' discussion of FP with young cancer patients: (a) HCPs' knowledge; (b) HCPs' sense of comfort; (c) patient factors (i.e., sexual maturity, prognosis, partnership status and whether or not they initiate the conversation); (d) parent factors (i.e., HCPs' perception of the extent of their involvement); and (e) availability of educational materials.
25	<p><i>Williamson and Rumsey, 2017</i> Australia</p> <p>This study aimed to gain an insight into HCPs' views of the psychosocial impact of an altered appearance and factors influencing AYAC adjustment and, to examine the existing provision of appearance-related care with the intention of identifying ways in which this care might be improved.</p> <p><i>Source of data</i> Journal - Journal of Psychosocial Oncology</p>	<p>Descriptive.</p> <p>Phase 1 semi-structured interviews HCPs (incl 5 nurses).</p> <p>Phase 2 online survey.</p>	<p>Phase 1 n = 14 (5 Drs, 5 nurses, 2 SW, 2 psychologists).</p> <p>Phase 2 n = 48 (Dr n = 7, Nurses n = 13, Youth Workers n = 5, Psychologist n = 5, Social Worker n = 21)</p>	Two main themes: (1.) HCP perspectives on psychosocial impact of appearance and interventions to help; (2.) Barriers inhibiting appearance related care & perspectives on how to improve support. Concern that not addressing appearance matters impacts compliance negatively.

Appendix 4 Thematic matrix

Author	Year	Working in AYA Cancer Care a) Recognising AYA specific issues b) Decision-making c) Emotional impact of the work	Communication/conversations a) Communication skills training b) End of Life Care c) Sexuality/Fertility preservation
Albers, Bergsma et al.,	2020		X
Albers, Haj Mohammed et al.,	2020		X
Avery et al.,	2019	X	
Bahrami et al.,	2017	X	X
Barlevy et al.,	2016		X
Berger et al.,	2019	X	X
Bradford et al.,	2018	X	
Day et al.,	2018	X	
Essig et al.,	2016		X
Essig et al.,	2019		X
Gibson et al.,	2012	X	
Kelly et al.,	2004	X	
Laryionava et al.,	2018	X	
Lavender et al.,	2019	X	
Norton and Wright,	2020		X
Olsen and Harder	2011	X	
Pearce et al.,	2018	X	
Smith	2017		X
Smith	2004	X	
Taylor et al.,	2016	X	
Tennyson and Griffiths	2019		X
Thompson et al.,	2013	X	
Tutelman et al.,	2019	X	X
Vindrola-Padros et al.,	2017		X
Williamson et al.,	2017	X	

Appendix 5 Reflective diary entry examples

Reflections on annual review September 2020

It went well today. The advice I was given was to note the tweet activity and identify how many retweets etc. I got and how many people come forward at certain times. I need to justify why I did not do a systematic review. And it will need to strengthen my methodological stance when it comes to the viva and the thesis itself. I recognised that this aspect was not justified well verbally, but I also had to acknowledge that for the past 18 months I've been stuck in ethics and literature review. Whilst I have drafted that chapter and sent it to supervisors quite a while ago I know that sooner rather than later it will be time to revisit that and put my thinking hat on as regards to all of this when it comes to collecting the data and justifying my methodology. The panel accepted that and recognised my honesty as regards that.

Generally, my review went really well I now recognise that I am 18 months behind because of ethics approval and Covid-19, so I really need to progress this now. All reviewers commented on the length of my literature review and in particular that the fertility section was disproportionately longer than the rest. The reviewers also accepted that I wasn't going to revisit it at the moment because I need to get on with data collection et cetera.

2. Reflection on interview conversation with 007 8/11/2020

The registered nurse (adult trained) has been qualified for 18 months after a 20-year career as a social worker. Her past experience includes being involved in family therapy. She is in her mid to late 40s and this is her second career and she already holds a master's degree.

She came onto the TCT unit as part of the selection process for securing a job when she qualified so it wasn't a particularly planned move. She is clearly very invested in working with young people and families and we spent a lot of time talking about engaging with families. She too speaks of the importance in the early days of developing clinical competence and that the holistic care for Teenagers and Young Adults with Cancer must take a second seat to clinical care until she has established provisional clinical skills such as administration of chemotherapy and managing central lines. She spoke of several patients and of

one very recently, where a 16-year-old boy's treatment is not going according to plan and the likely outcome is that he will have to have palliative treatment. She appeared to be in the medical consultation with the boy and his mother/parents whilst she was in charge of the ward which was her first time having this responsibility. So she is clearly juggling a lot of emotion and practical elements of her job. This is not unlike other junior nurses who are left in charge to manage very complex clinical workloads as well as highly emotional responses that are required when looking after Teenagers and Young Adults with Cancer. She acknowledged the lack of any training in her pre-registration nursing to equip her for this but absolutely drew on her past experience as a social worker who understands young people and families to a greater extent than perhaps some of her peers. She spoke about the emotion of dealing with the sad situations when they are very sad and recognised that the specialism as one where you can experience extreme hope and extreme sadness. I got the impression that her colleagues were supportive generally and that there is a shared experience with perhaps one or two other colleagues when something important happens, such as the death of a young person during their shift. I also felt that there may be some tension within the team here and I don't know if that would make it more difficult for people to ask for help.

We spoke about how she manages patient sadness when she leaves the ward. She exercises and cites that talking with her mum (an ex-nurse) seem to be her self-care strategies as well as generally keeping busy. I did not get a sense that apart from the social aspect of Teenagers and Young adult lessons that she understood much about biological change that they undergo. She was very aware of that transient period that they are in and enjoyed working with them even when it becomes challenging. It was interesting to note that her husband also worked with children and that it was almost an unspoken word when they came home to talk about work but they seem to be able to acknowledge when it's difficult. She is another nurse who spoke of the ability to connect with people and her family who are nurses and sees that as a real tool in her toolkit to cope with the emotional challenges of working with families of Teenagers and Young Adults with Cancer. She very much sees them as a whole unit as opposed to just a teenager themselves. Perhaps because of her past experience as a social worker she is very comfortable with managing her boundaries and remaining

professional and it was interesting to note that she acknowledges that other colleagues will use different, sometimes informal, language to communicate with Teenagers and Young Adults with Cancer. She is very reflective and often takes to written reflections to help her learn from what happened on her day at work so that she can progress. As much as she appreciated the physical environment for where these young people were cared for she did not really seem to acknowledge it as being a particular strength or weakness about her experience of looking after these patients. She did acknowledge having a youth expert on the ward was helpful for young people and her.

I was conscious that towards the end of the interview I felt I wanted to ask her about her own connection with young people given that she wasn't of a similar age demographic to other nurses that I've interviewed, so I carefully selected my words about asking her if there were other young people in her life. She said that there were not in terms of her having her own biological children but that she had many nephews and nieces and that she could relate to some of the youth issues.

Some of the key issues that she addressed here were dealing with dying patients coping with families developing clinical competence alongside holistic TYA cancer competence and working hard to make sure she had self-care strategies for the emotive work that she is doing.

This was one of the longest conversations that I have had with participants and I felt that I was able to sit with her for longer and elicit more information about her story. Perhaps this was because she was a similar age to me and had previous life experience working with teenagers and families. Towards the end when the recording had stopped she asked me if everything she had said was okay. I acknowledged that I was interested in hearing her story and to that end of course everything was okay. She said she was surprised at how much talking she did and how much she had to say because nobody had ever asked for this before. She said that she actually enjoyed the conversation and it really made her think.

This made me contemplate even more, that perhaps she and others don't really get an opportunity to consider the extraordinary work that they are doing in terms of meeting the holistic needs of young people with cancer and their

families against a backdrop of a very stretched NHS where they are delivering extremely complex clinical care. It reminded me that when I was a newly qualified staff nurse, the administration of chemotherapy was an extended role and certainly not one that would be contemplated by a junior nurse. In fact, I had become a CNS and was the first nurse in our hospital to administer chemotherapy yet I had four years of post-qualifying registration under my belt. At that point it was traditionally a role of a doctor which reminded me how nursing has changed, as has the oncology specialism itself.

3. Notes of supervision mtg 27/3/2021.

Thank you all for joining me today and listening to my woes of redundancy before we got onto the thesis. I was pleased to be able to show you that I have transferred all nine stories into NVivo and I have come up with some broad themes, and many more sub-themes. XX suggested that I combine and collapse some of those themes and I will.

We discussed different types of frameworks that I could use to think about analysing this data. We talked about different kinds of stories that might emerge or typologies. We seem to keep arriving at characters, scene and beginning middle and end - future.

I have been using NVivo and it's been quite helpful and I will continue to do that. I'd still like to try and find somebody help me manipulate the data a bit more, so if you can think of anybody that may be more familiar with at Cardiff then please let me know. We decided that my objectives for the next four weeks are to

1. collapse and combine the themes that I have come up with (probably centred around a beginning a middle and an end).
2. Write the biogs of the participants.
3. Give a chapter outline with a structure and some themes.

We will meet again on the 11th of February at 3 pm.

Appendix 6 Conversation schema

Examples of question and prompts that may be used

Candidate number/name/

Date

Mode of interview

- Thank you for agreeing to be interviewed by me today.
- I need to check that you have read the PIS and signed and returned the consent form.
- Have you any questions about anything on the forms?
- I'd like to check the demographic data prior to starting the interview – is this OK?
 - Go through the form
 - Check for pseudonym - try to agree on one mutually
- In the interests of confidentiality I am keen that we do not mention any names in the interview, but should this happen, at the transcription phase I will make that data unidentifiable and ask you to check it.
- I will return the transcription to you for checking generally and this will be sent to the email address you have provided. It may take me some time to transcribe this so please bear with me.
- I would be grateful if you would return this within 2 weeks of that email being sent. Is this ok?
- Is this out of earshot of anyone so we maintain confidentiality? Do you feel comfortable to start?
- I will start the recording. I will use 2 devices for safety.

Let's get started – RECORD

- At end of the interview, check that they feel ok and safe.
- Would they like me to make a check-in call or email in a week or so?
- Would they like to see the transcript of the conversation to verify it?
- You have my contact details so please be in contact if you have any questions or concerns.
- Thank you very much.

- I'm really keen to understand *how and why you came to become an AYA Cancer Nurse? Tell me how you got here.*
- Without giving too much patient information away can you tell me about a patient you looked after - pulling out memorable things about them?
- How does AYA nursing in this setting differ from adult or paediatric nursing from your previous experience? What things stand out for you?
- **Can you recall *what is it about caring for AYAs with cancer that you find particularly rewarding-***
- ***can you think of anything in particular that holds fond memories for you?***
- ***and what was it about it that was so fulfilling?***
- ***What is it like?***
- **Can you tell me about things that make working with AYAs with cancer in any way of a challenge, and what is it about it that made it so, perhaps you can recount an episode of care... ?**
- ***What was it like?***
- ***What helped make things better for you then, if anything?***
- ***What would you have done differently?***
- ***Can you tell me about your coping techniques?***
What if any professional support is in place when these challenges arise?
- ***Can you think of any training or support initiatives that might help?***
- ***Then the researcher will probe to want to stay in caring for AYAs with cancer?***
- ***What do you think your future is in AYA cancer nursing?***
- ***What do you think you have learned from experiences of working with TYA cancer patients in the past few years?***
- ***And for AYA cancer nursing in general?***

Appendix 7 HRA approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Health Research
Authority

Mrs Maria Cable
School of Healthcare Sciences
35 - 43 Newport Road
Cardiff University
CF24 0AB

Email: hra.approval@nhs.net
HCRW_approvals@wales.nhs.uk

03 February 2020

Dear Mrs Cable

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	An exploration of the experiences of nurses who care for adolescents/young adults with cancer in specialist age appropriate settings using narrative inquiry.
IRAS project ID:	265008
Protocol number:	SPON 1761-19
REC reference:	19/HRA/5525
Sponsor	CARDIFF UNIVERSITY

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The "[After HRA Approval – guidance for sponsors and investigators](#)" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **265008**. Please quote this on all correspondence.

Yours sincerely,

~~XXXXXXXXXX~~
Approvals Manager

Email: hra.approval@nhs.net

Copy to: ~~XXXXXXXXXX~~ Sponsor Contact

Are you a Band 5 nurse caring for Adolescents/Young Adults with Cancer in a specialist cancer setting?

**I'd love to
hear from
you!**



My name is Maria Cable and I am a doctoral student at Cardiff University. I am also a nurse educator and researcher at Coventry University. I am interested in knowing more about the experiences of Band 5 nurses who care for these young patients, aged 13-24 yrs.


To do that, I'd like to interview you (and audio-record it) for about one hour. We would do this online using secure video conferencing.

Any information you give me will be managed in the strictest way and be held in a confidential secure database.

If you are interested and want to know more, please contact me below.


Email me at cablem@cardiff.ac.uk or by Direct Message.

Appendix 9 Tweets


Maria Cable RN, RNT @MariaCable2 · Nov 3, 2020
 Would love to hear from more band 5 nurses working with Teenagers/Young Adults with cancer, to learn about the experience of this work for my doctorate. Especially if based in London, Scotland or NI but from across UK is 🙋🏻🙋🏻🙋🏻 please see 📧 & share 📢

Adolescents/Young Adults with Cancer in a specialist cancer setting?

I'd love to hear from you!



My name is Maria Cable and I am a doctoral student at Cardiff University. I am also a nurse educator and researcher at Coventry University. I am also a nurse educator and researcher at Coventry University. I am also a nurse educator and researcher at Coventry University.

Maria Cable RN, RNT @MariaCable2 · Sep 20, 2020

Are you a Band 5 Nurse on a Specialist Adolescent/Young Adult Cancer unit in UK? I'm keen to know about your experience of caring for these patients for my doctoral study. Please share, esp if you know anyone who may be interested. For info email ...

Daniel Kelly and 9 others

10 Retweets 13 Likes


Maria Cable RN, RNT @MariaCable2
 Are you a Band 5 Nurse on a Specialist Adolescent/Young Adult Cancer unit in UK? I'm keen to know about your experience of caring for these patients for my doctoral study. Please share, esp if you know anyone who may be interested. For info email cableM@cardiff.ac.uk or DM 📧

Are you a Band 5 nurse caring for Adolescents/Young Adults with Cancer in a specialist cancer setting?

I'd love to hear from you!



My name is Maria Cable and I am a doctoral student at Cardiff University. I am also a nurse educator and researcher at Coventry University. I am interested in knowing more about the experiences of Band 5 nurses who care for these young patients, aged 13-24yrs. To do that, I'd like to interview you (and audio-record it) for about one hour. We would do this online using secure video conferencing. Any information you give me will be managed in the strictest way and be held in a confidential secure database.

If you are interested and want to know more, please contact me below.

Email me at cablem@cardiff.ac.uk or by Direct Message

DATE: 20/09/2020 VERSION: 0001 Project ID: 243004

Nicky Pettitt and 9 others

6:56 PM · Sep 20, 2020 · Twitter Web App

View Tweet activity

RETWEET NUMBERS BELOW
 54 Retweets 10 Quote Tweets 42 Likes

Appendix 10 Participant information sheet

Project title - Exploring the experiences of early career/Band 5 registered nurses who care for adolescents/young adults with cancer: a narrative inquiry.

I would like to invite you to take part in a research study. Before you decide whether you wish to participate, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Feel free to ask questions by contacting me directly (contact details are below) if anything you read is not clear or if you would like more information.

Information about the researcher and the research project:

I, Maria Cable, am a Principal Lecturer in Adult Nursing and Adolescent and Young Adult Cancer Care at Coventry University, UK. I am also undertaking a Doctorate in Advanced Healthcare Practice at Cardiff University. I am being supervised by three supervisors and all our contact details are at the bottom of this information sheet. This research will form the basis of the thesis which is in fulfilment of this Doctorate. The aim of this research is to further understand the experiences of Band 5 nurses who care for Adolescents/Young Adults with cancer.

The specific aims are:

- a) to generate and explore the meaning narratives of nurses who care for AYAs with cancer
- b) to consider these narratives in relation to improving the care of AYAs with cancer
- c) to establish training/education, support and service development needs that nurses may need to help manage emotional challenges of caring for AYAs with cancer and minimise attrition from the profession.

Why have you been chosen to participate in this research?

As a registered Band 5 nurse who regularly cares for AYAs with cancer in a dedicated unit, you are well placed to give insight into what it is like to care for these young patients.

Do I have to take part?

No, participation is completely voluntary, and you can withdraw from the process at any point.

What do I have to do?

I would like you to participate in an online interview for about an hour. With the information you provide during the interview, we will explore specific aspects of the experience you have had of caring for AYAs with cancer. Should you agree to participate in this research, you will be provided with full details on how we will meet online. You will be emailed specific information on how to participate. You will need to have access to a computer or tablet with camera and microphone.

You will be required to complete a consent form to confirm your agreement to participate in the research which you can return by email, to me, Maria Cable, Doctoral Student/Researcher at cablem@cardiff.ac.uk.

The interview will be audio-recorded and subsequently transcribed. This may be completed by an external transcriber to primarily assist me in remembering what was said. This recording constitutes the data which will then be analysed.

You will be asked some basic demographic data about yourself such as name (which will be given a pseudonym in the transcript to ensure your confidentiality), age, length of time working with AYAs etc. You will then be asked about your experiences of working with AYAs with cancer and you will be reminded to refrain from disclosing any patient/colleague or organisational information that may make anyone or any place identifiable. If this does occur accidentally, this information will be omitted from transcripts.

What are the risks associated with this project?

I do not consider that your participation presents any significant risks to you, but should you have any concerns at any point I would encourage you to raise them with me. Should you become distressed about talking about your experience, you will be given the option to stop or pause data collection. Your participation will have no bearing on future contact with me or my work and your answers will not be shared with your NHS employer.

What are the benefits of taking part?

This research offers the possibility of gaining an improved understanding of the experiences of nurse who care for AYAs with cancer as opposed to nurses who care for adults or children with cancer. We expect that the insights from this research will help to inform a range of areas of practice including improving the care of AYAs with cancer; establishing other perspectives on training/education/supervision needs for nurses caring for AYAs with cancer, as well as service development needs that nurses may need to help manage emotional challenges of caring for AYAs with cancer. This may help with gaining insight as to what aspect of this work makes nurses want to stay in this type of work.

We hope to share the insights from this research more widely, through conference papers, publications and higher education teaching.

What are the withdrawal options?

You will be able to withdraw from the research at any point. You can also ask for your data to be removed but this must be within one month of recording the interview.

Will what I say be confidential?

The information we collect will be treated with strict guidelines in relation to research confidentiality. The interview will be audio-recorded and anonymised. Quotes may be used as part of the research project; however, details of any individuals involved in the research, and those they might be referring to, will be anonymised, so no one will be able to identify your contribution directly. In the event of using an external transcriber, the audio recording of the interview will be sent by secure email to them and returned to me, Maria Cable, by secure

email as well. The transcriber will be asked to sign a confidentiality agreement. The only others who will have sight of the anonymised data will include the supervisors who will act as verifiers.

How will my data be stored and how long for?

Data will be stored initially on a password protected personal computer belonging to the researcher and transferred by the researcher on to a Cardiff University electronic database that will be password protected (known only by the researcher) computer. The data will be destroyed by the researcher after 5 years.

How will my personal data be managed?

Cardiff University is the sponsor for this study based in the United Kingdom. Cardiff University will be using information from you in order to undertake this study and will act as the data controller for this study. This means that the University is responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as Cardiff University needs to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how Cardiff University will use your information at: <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection> or by contacting the University's Data Protection Officer: inforequest@cardiff.ac.uk

If I have a concern about an aspect of the research, how can I raise it?

If you have any concerns about how this research has been conducted you can either raise it directly with me, Maria Cable, Doctoral Student/Researcher at cablem@cardiff.ac.uk. Should you wish to raise a formal complaint, contact Dr

Kate Button, Director of Research Governance, Room 13.17, 13th Floor, Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB. Email address buttonk@cardiff.ac.uk

What will happen with the results of the research?

It will result in the preparation of a 50-60,000-word thesis which will be made available on Cardiff University's digital repository called ORCA. It is anticipated that sections of this research will be presented in a scholarly way such as posters or oral presentations at conferences and journal articles that will contribute to the future education of health professionals in this specialism and beyond, as well as influencing the retention of nurses and improving service delivery.

Who has reviewed this study?

This research project has been rigorously reviewed through Cardiff University's School of Healthcare Science's Research Ethics Committee and the NHS Research and Development approval process.

Research team contact details:

- Maria Cable, Principal Investigator/Doctoral Student/Researcher.
Principal Lecturer, School of Health, Faculty of Health and Life Sciences,
xx
E-mail: hsxxxxxxx Phone: 024 xxxxx
- Professor Daniel Kelly (Doctoral Supervisor)
School of Healthcare Sciences, xxxxxxxxxxxxxxxxxxxxxxx x UK
Email xxxxxx Phone xxxx
- Dr Tessa Watts (Doctoral Supervisor)
School of Healthcare Sciences, xxxxxxxxxxxxxxxxxxxxxxx
Email xxxxxxxxxxxxxxxxxxxxx Phone xxxxxxxxxxxxxxx
- Dr Carly Reagon (Doctoral Supervisor)
School of Healthcare Sciences, xxxxxxxxxxxxxxxxxxxxxxx
Email xxxxxxxxxxxxxxxxxxxxx Phone xxxxxxxxxxxxxxx

Appendix 11 Consent form, blank

Research title:

Exploring the experiences of early career (Bands 5) nurses who care for adolescents/young adults (AYAs) with cancer using narrative inquiry.

Information about this research project:

The aim of this research, in fulfilment of a Doctorate in Advanced Healthcare Practice at Cardiff University, is to further understand the experiences of Band 5 nurses who care for adolescents/young adults in specialist AYA cancer settings. The specific aims are:

- a) to generate and explore the meaning narratives of nurses who care for AYAs with cancer
- b) to consider these narratives in relation to improving the care of AYAs with cancer
- c) to establish training/education, support and service development needs that nurses may need to help manage emotional challenges of caring for AYAs with cancer and minimise attrition from the profession.

Please initial

1. I confirm that I have read and understood the participant information sheet (Version 5) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that all the information I provide will be treated in confidence.

4. I understand that I also have the right to change my mind about participating in the study for a short period after the study has concluded but for data to be removed, this must be within one month of recording the interview.

5. I agree to be audio recorded and for anonymised quotes to be used as part of the research project.

6. I agree to my anonymised data being stored online and for my personal data to be stored online in accordance with the Data Protection Act (2018).

7. I understand that the findings and potentially secondary analysis of the findings and associated data from the study may be presented at conferences and in scientific journals. It may also be used to inform curriculum development of accredited courses. I understand that these will be used anonymously and that no individual respondent will be identified in such report.

8. I understand that one copy of this form will be issued to me, the participant, and a second copy will be stored online in accordance with the Data Protection Act (2018), by the researcher.

9. I agree to take part in the research project

Name of participant:

Signature of participant: Date:

Name of researcher:

Signature of researcher: Date:.....



Appendix 12 Additional nurse' stories

Amy's Story: Risky business

Amy, 25-year-old RN (adult) qualified four years ago and worked in medical assessment unit and intensive care before coming to work on the teenage and young adult cancer unit, nine months before. When she visited the TYA cancer unit she felt immediately that she wanted to work there and really enjoyed how welcoming the nurses were to her. She was really mindful of the physical space of this unit and the positive vibes that it emitted for patients and staff.

She noticed how different the approach to caring for TYA was - she felt that they have more control over their day - their own independence being actively fostered.

She found it difficult in the beginning to engage with male patients as she could not find common ground but after a while, she became more confident in building a relationship with them. She spoke of getting very attached to some patients and their families, such as a 16-year-old boy with incurable cancer who had just been told this news, and how this affected her and the team: *"we all basically feel like we're all part of the family for this one patient and they're transferred to another hospital at the moment, and the family is like, 'oh text us anytime' because they're also just as involved as like with us as we are with them."*

She recognised that sending these texts would be inappropriate, but it suggested that there was a perception that both the team and the patient's family were one. Amy spoke of negotiating professional boundaries that can get blurred when developing trusting relationships with patients and families.

Amy's coping mechanisms vary; she ran when weather permitted her to and also spoke with colleagues. She valued working in a team that has colleagues from various clinical backgrounds and experiences. She wished she had more formal psychological support as it was largely absent. Sometimes she talked to her mother, maintaining confidentiality. She knew that holding on to patients' emotional states was not healthy for her. She even added that her parents get concerned for patients she looks after, particularly when the outcome is not good. Amy is mindful that she did not share positive stories of patients and for the most part tried to not talk about work at home.

When we spoke about support mechanisms in work, she acknowledged the kindness and value of colleagues who are generally very supportive but highlighted that she missed having structured supervision sessions that once did happen. She recounted the benefit of a staff general zoom session with a senior nurse as they grappled with the emotional burden of this work as well as managing complex clinical care.

Receiving special acknowledgement for supporting a young girl who was difficult to engage, meant a lot to her. She recognised that these patients were all different and needed to be treated differently. She was keen to continue to work with TYAs with cancer and undertake some formal education this field and was happy to move up one more 'band' in the hierarchy but beyond that was not sure.

Anna's Story: Settled in

When Anna (28yrs) was a student nurse (19yrs) she had a placement on a ward where she cared for a patient with cancer of the same age, which left an impact on her. She was struck by how her independence could be taken away in every sense from her studies, her parents and even meeting her own personal care needs. Upon qualifying she worked outside of oncology care nearer to her parental home. After a year she secured a job on a TYA cancer ward and has stayed there for seven years. She felt it took about a year to become clinically competent in this field.

On becoming clinically competent she recognised she could only then attend better to the distinct needs of TYAs with cancer and it seemed to trouble her when colleagues did not recognise the same.

"I've heard a number of times that people have said oh that's a difficult patient, well actually it's not that they're a difficult patient it's everything else that's going on, and also the fact that biologically, they are a teenager and young adult and they will have lots of other things going on."

One example she gave was when colleagues were unable to recognise when they had breached a professional boundary by engaging with a patient on social media. She demonstrated courage by bringing this to their attention and the attention of the manager which resulted in some teaching sessions and supervision work for the whole team to recognise and manage professional practice and boundaries. She recognised the significance of being able to switch off from work to protect herself and patient care.

She felt that developing professional relationships with TYA patients required an edginess that is different to working with adults. This included using humour and giving of yourself in a very different way which appeared to carry risk as well as enhance feelings of altruism in terms of supporting these young patients: *"they sometimes have no filter and... they don't always cover up what they're feeling... So it kind of gives you that challenge of communicating with them and getting that balance right of not being too overfamiliar... and that you're not their best friend. But actually being there as a, as a friendly healthcare professional."*

She seemed to be very clear about her own professional boundaries and support systems. One of her biggest support systems was her mother, who was also a nurse, who can empathise with the type of work that she does.

Other support systems that she spoke of included her colleagues and the management structure of the ward, including managers and specialist nurses. She was aware of an employee assistance programme in her organisation. She recognised the value of spending time with her family, friends and pets and to create space for herself away from work. She had opportunity to undertake funded CPD activity in this field which she feels benefited her. She recognised that she can make a unique difference to the care experience of these young people. She wondered if she would like to stay in this field of nursing or consider another aspect of it such as palliative or end-of-life care.

Claire's Story: Keeping myself together

Claire was a 23-year-old dual qualified nurse, adult and paediatric. As a student nurse she had a placement on a teenage and young adult cancer unit and really enjoyed working there and felt she could apply her paediatric and adult nursing skills there. She felt her adult training was useful for supporting TYAs to become independent whereas her paediatric nurse training which focused on family-centred care really helped her when it comes to dealing with their families.

Claire recognised that teenagers are distinct from children and adults predominantly because they are striving for independence, yet they had to rely fully on their families when they got cancer. She was conscious of their developmental changes.

She talked about some of the clinical challenges such as when TYAs do not take their medication on time but equally recognised additional emotional challenges such as when patients died. Claire got to know patients and families over long periods of time. She recognised the need to be careful about overstepping the boundary between friendship and professional relationship and saw her own youthfulness as playing a part in that. She also recognised that there was a risk that patients are unable to differentiate between her as a nurse being their friend and being their nurse. She spoke of one patient who was agitated and confused at the end-of-life and during a period of delirium the patient thought that Claire was a threat to him. When the patient's father said, *"this is Claire, she is your friend"*, Claire was really shocked and upset by this that this is how she was perceived. Yet she knew she was there as his nurse and not his friend and found this quite a conflicting experience: *"you have to really protect yourself as well. And then it made me kind of wonder whether I had been almost... not too friendly but like had been less professional, but I think looking back on it, I feel that he said that to help his son in that situation"*. She recognised the often indistinguishable line that can be crossed with patients and families.

Her coping mechanisms when the emotional aspect of her work becomes challenged included exercise and speaking with colleagues. She spoke about losing patients and how difficult it is to come back into work and keep on going: *"it felt strange because I felt it was obviously a sad situation and then you go back into work and you do the same thing all over again as if... not as if that person hasn't just gone."*

At times in order to cope she used the doffing of her uniform to help disassociate from the emotional pain of losing a patient: *"when you put your uniform on and then when you take your uniform off you're not a nurse anymore."*

She complimented the support systems at work. She noted senior nurses as being particularly supportive as well as having sessions with a psychologist to facilitate group work. Claire has had autonomy to implement a new patient initiative, Beads of Courage and thrived on this.

Despite this environment having particularly sad moments she recognised the positive, fun vibes with patients and colleagues, and this is a motivating factor for her.

Claire would like to undertake some postgraduate education in the field and to continue her career working with teenagers and young adults be that in cancer care or another sector. She believed that, *“it’s really a privilege it, to be a part of their lives at such a massive point in their life”*. She dreams of one day being a TYA cancer clinical nurse specialist in a setting where she can build a new service for this patient group.

Jade's story: *Personal costs*

Jade, 23, is a RN (child) and has two years clinical experience post-qualifying. She spent the first 18 months on a paediatric oncology ward looking after patients from 0 to 16 years. Working with the teenagers appealed to her so she applied for a job on a teenager and young adults with cancer ward that is integrated with adult cancer care.

She has established well rounded clinical competence/experience, yet these demands compete with her desire to see to other TYAs' holistic needs: *“but you're so busy and you know that you've got other things to do and it can be really hard.”*

She felt that paediatric training did not quite equip her for working with TYAs and acknowledges some stark differences such as their ability to consent for treatment. She acknowledged that she may be able to relate to them and develop a humorous relationship because of her similar age: *“I also think that the age can make a difference as well because I think I'm looking after patients that similar age to me... it can be easier to relate to someone if you can see similarities in them.”*

As much as she valued the professional relationship she developed with young patients, she recognised the emotional cost of this especially when they died: *“That can be really hard to deal with when you when you have built a good relationship with someone and even though, even when it's expected you know it's going to happen....and if they've not passed away on the ward then you don't get any more closure or anything with that.”*

She seems to have the maturity to recognise that she needs to self-care when going away from her work and had strategies in place to do this. She appeared to have very good support systems where she worked (monthly supervision sessions, access to a complimentary therapy team and a supportive team of senior nurses). She understood that there were further CPD opportunities she could access in due course. Outside of work she found it difficult to expect friends and family to comprehend the emotional burden she was carrying and found colleagues can empathise more with her.

She acknowledged the pain of hearing about young patients who relapsed or were dying and also noted that finding out that this is almost accidental.

Jade hoped to pursue post graduate studies in TYA cancer nursing and would like to be a clinical nurse specialist but recognised that she needs more experience at the bedside first.

Jess' Story: Learning to be

Jess is a 24-year-old RN (child) in a TYA cancer unit, attached to an adult oncology and haematology ward. She qualified two years previously and had been working on this unit for 18 months. When she was a student nurse she had a placement on that ward and really enjoyed it.

She felt her paediatric training was a good foundation for teaching her how to communicate with TYAs. She felt a bit strange looking after patients of similar age but acknowledged her role as a healthcare professional and was able to put that aside. She appreciated the potential benefits and challenges of being of similar age, as she could relate to a lot of external things such as going to university, music, current youth trends but equally recognised the need to separate her life and the teenager's life so that professional boundaries were not blurred; this seemed to have taken her about a year to establish: *"you just have to separate your life and their life and that's what you would do with any patient, though.... it was challenging at the beginning because.... But then there's a line that you're like, well, okay, That's it. You need to have your professional boundaries but now you know, I don't even bat an eyelid."*

During this time she was also developing her clinical competence which in itself was an intense experience: *"I remember when it first started, it seemed to be a lot, so much to learn. Obviously, you can't just get signed off and give chemo you have to know what the chemo does, where it effects in the cells, what is nephro toxic, then you can't give certain meds, you have to know everything about it."*

Jess spoke of the emotional impact of looking after dying young people and how the sadness and traumatic events of this impacted her. She recounted the traumatic death of a patient with uncontrollable bleeding during a night shift when she and one other colleague were left trying to manage this rather unsuccessfully. She wanted to make the patient comfortable at end of life and was hugely disappointed when this couldn't happen. She was aware of the impact that this has on parents too: *"parents can be very, very intense... And no matter how old they are, they're still their baby. So they're just as stressed, as everyone else going through it."*

Jess had supportive strategies in place. The ward team (clinical nurse specialists, consultants, ward managers and peers) were actively supportive and cohesive. Having a debrief after the death of a young person seemed to be freely offered and accepted as a health protecting behaviour. She viewed it as, *"I don't believe anybody can just leave it at work and come home and be fine, because it's really difficult somebody dying in front of you"*

At home her partner appeared to understand that Jess' coping with the death of a patient is part and parcel of her work. He knew not to ask her too much about it but seemed to be unsure of how to help her. She was mindful of not breaching confidentiality.

Jess has attended CPD activities and was keen to further learn about caring for this group of patients, in TYA cancer care and intensive care where her next post will be. Ultimately, she would like to work on an outreach service and become a clinical nurse specialist.

Rachel's Story: More than just a job

Rachel was a 28-year-old RN (child) working in a TYA cancer ward for just over a year. She had qualified four years previously and spent one year working abroad. As a student nurse she had a six-week placement on a TYA cancer ward and enjoyed it. She acknowledged that her four-year post-registration experience, including intensive care, fostered her clinical competence/confidence so that she could focus on the holistic care element of TYA cancer care.

Aside from developing a trusting relationship with the patients, Rachel also recognised that TYA patients' decision-making and autonomy were developing, and she was keen to nurture this. Since being on the TYA ward, she felt more comfortable in communicating with TYAs. Rachel recognised the challenges that being a similar age to the patients could be for her, even though it also may have had benefits in terms of having similar interests and recognising youth culture.

Conversely, she saw its disadvantages such as when she was trying to ask them to go to bed early or for their visitors to leave. Rachel recounted when a 16-year-old boy was told that his cancer was likely to be incurable. He and his family had clearly resonated with Rachel and she was very sad about this probable outcome for him. She stated, *"that's been really difficult, especially just because... it's just one of those families... I've looked after him most of my shifts.... you just you see them every day you forget just how long you're spending with them."* She went on to consider how life would be like for his parents: *"I think about them and how they'll cope and what they'll do...you start thinking what they will do without him?"* Rachel was clearly impacted by the anticipated loss of this patient and it stayed with her beyond work. She also recognised that whilst this may be a hazard at work she also had to continue to remain composed at work and manage her professional relationship with patients and families: *"you sort of build up some sort of wall because you can't either emotionally invest in every single patient... so you have to take yourself out of it a bit... and realise that it is a professional relationship."*

She recounted a story where a 15-year-old boy who was extremely anxious and reliant on his mother. She enjoyed building a rapport with him to the point where the staff helped him come to terms with his sexuality. Rachel described the ward environment and its purposeful informality. The addition of a jukebox, social space lent itself to having opportunities to get to know patients more whilst doing social activities such as playing pool. She had supportive colleagues though no formal support is set up when the going gets tough. Outside of work family (with medical experience) and friends supported her when work became an emotional challenge. She did not have any opportunities to attend any learning activities on how to care for TYAs with cancer specifically but would have welcomed this. Rachel was keen to stay working in this specialism as she enjoyed building the relationships, learning about doing the job and being an advocate.