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**Abstract:**

**Aim:** To explore the experiences and needs of partners who are supporting adolescents and young adults with cancer.

The diagnosis of cancer at any age is significant. Uniquely, in adolescents and young adults this is set against the backdrop of early adult development. This is at a time when young people may be embarking on new experiences and the development of romantic relationships is no exception. There is limited evidence of how partners cope during this time and what their role is alongside how the relationship may change over time.

**Design:** An exploratory qualitative study utilising narrative enquiry.

**Methods:** The protocol was approved in February 2018 and data will be collected between May and December 2018. The theoretical approach will incorporate positioning theory by considering the contextual situation of the partner with reference to their stories, including their rights and duties. Two interviews will be undertaken which will be approximately two months apart, where participants will be asked to share their stories. They will also be given a diary at the end of the first interview to record their thoughts about their role and relationship. The diary and interview data will be thematically analysed.

**Discussion:** It is envisaged that the study will culminate in the identification of key themes which will illuminate the experiences, needs and roles of partners of adolescents and young adults with cancer.

**Impact:** These findings will inform the development of guidance which will help partners in the future in this area of practice,

**Key words:** Adolescent, young adult, cancer, partner, relationship, support, role, nursing, support needs.

## 1. Introduction

Experiencing cancer as an adolescent or young adult is not common. Each year between 2013 and 2015, there was an average of 2,630 new cases of cancer in AYA, which equates to around 7 new cases diagnosed every day (Cancer Research UK, 2018). However, data from the Information Services Division Scotland, the Office for National Statistics, the Welsh Cancer Intelligence and Surveillance Unit and the Northern Ireland Cancer Registry, provided for Cancer Research UK, indicates that since the early 1990s, cancer incidence rates in teenagers and young adults have increased by 28% in the UK. The increase in females is higher rising by 38%, compared to males where there has been an increase of 19% (ISD Scotland, 2017; Office for National Statistics, 2017; the Welsh Cancer Intelligence and Surveillance Unit, 2017; Northern Ireland Cancer Registry, 2017). Cancer in this age group occurs against the backdrop of significant transitions in a young person's life and as such this can result in a number of challenges for them both in terms of their treatment and their everyday lives. This group of young people are in the process of building their early adult life platforms and therefore are often moving towards becoming fully independent. Also at this time they may enter into their first close and serious relationship. These experiences have relevance not just in the UK but throughout a number of international jurisdictions.

Evidence and discussion is available which highlights the differences in this age group which reflects the need to provide appropriate care and treatment (Fern et al., 2013; Gibson et al., 2012; Taylor et al., 2012; Taylor et al., 2013; Taylor et al., 2015a; Taylor et al., 2015b). Recent policy and guidance also outlines the requirement to understand the needs of this particular age group in relation to cancer treatment and care (Patel and Sundell 2018). The emphasis here has been primarily on recognising that this is a unique age group who therefore require care, which is tailored to their specific needs. One of the most consistently cited documents in the literature was published by The National Institute for Health and Clinical Excellence (NICE), who recognised that the needs of children and young people with cancer were different from those of older adults with the disease (NICE, 2005). The guidance covers all types of cancer from birth to the age of 24 years. NICE comment for example, that during childhood and adolescence there are a number of physical changes, which occur that will have an impact on the type of cancer present, how it needs to be treated and how well the treatment works. Children and young people's emotional response to cancer might also be affected due to the psychological changes they experience (NICE, 2005). Policy reflects very clearly some of the differences in cancer experience due to age. Equally there are a number of other relevant guidance documents and reports which advocate similar strategies in providing care for this group throughout their cancer journey and beyond treatment (Department of

Health, 2007; Department of Health, 2008; Gibson and Levitt, 2010; Rajani et al., 2011; National Cancer Intelligence Network, 2012; Department of Health, 2014). Evaluation of regional services have also been completed to ascertain both performance and the future needs of young people (Wright, 2012). Moreover, a publication which outlines the priorities for future research in this field has been disseminated in an attempt to target projects based on unmet needs (Aldiss et al., 2018).

Following the NICE guidelines and in response to the argument for a tailored approach, a number of documents have been developed including most notably: the NHS Cancer Services Guidance for Teenagers and Young Adults in England and in Wales, and the National Standards for Teenagers and Young Adults with Cancer (Welsh Government, 2015). These documents cover a wide range of aspects of care from diagnosis, referral, treatment options and the environment in which care takes place. The Welsh publication attempts to strengthen the argument for working in a way that is focussed on the unique needs of this age group. There are also a number of specialist organisations and charities in the UK, who have acted on policy recommendations by publishing guidance aimed at providing targeted information for anyone involved in the field of adolescent and young adult cancer. One such organisation is Teenage Cancer Trust (TCT).

TCT, in consultation with a number of experts in the field of TYA cancer, including Teenagers and Young Adults with Cancer (TYAC) the organisation for professionals, published a guidance document, A Blueprint of Care for Teenagers and Young Adults with Cancer outlining the care required for those aged between 16 and 24 years with the disease. This document provides extensive advice for those who work with this age group. The development of this guidance drew directly on recommendations from teenagers and young adults who were either receiving or had completed cancer treatment (Smith et al., 2016). Policy and guidance can act as a catalyst and has the potential to drive forward focussed change. This can be the case in a number of contexts and the development of service provision in the area of adolescent and young adult cancer is one such example.

## **1.1 Background**

A range of evidence exists which is relevant to the relationships engaged in by young people with cancer. For example there is research which explores the importance of peer relationships during the cancer experience (D'Agostino et al., 2011; Zebrack and Isaacson, 2012). Additionally, a limited amount of literature illuminates the difficulties in disclosing a cancer diagnosis to a new partner (Lewis et al., 2013). Furthermore commentary and studies have focused on a number of issues relating to sexual matters during treatment (Morgan et al., 2010; Quinn et al., 2011; Peddie et al., 2012). In another study which considered young adults perceptions of social support, loved ones

including partners where important to them during their cancer treatment (Breuer et al., 2017). Additionally, the researcher's PhD illuminated the importance of partners in contributing to decision making when AYA had cancer (name removed 2015). However, very little is known about the specific experience of the partners of young people, when they are in a relationship with someone who is experiencing cancer. A search of the literature yielded no research which focused specifically on the voices of partners. A number of databases were searched using key words including; teenagers, adolescents, young adults, cancer, partners, relationships girlfriends and boyfriends. Although research was retrieved which made reference to partners as identified above, there were no studies which collected data exclusively from partners during cancer treatment in the age group between 16 and 24 years.

The experience of the partners of adults has been examined, particularly in the field of psychology. Girgis et al., (2011) for example investigated the supportive care needs of partners and care givers using a survey method with 547 cancer caregivers. The findings identified caregiver needs in four domains which included, health care service needs, psychological and emotional needs, work and social needs and information needs. It is therefore important, helpful and relevant that we begin to learn and understand more about the experience of partners in the identified age group which in future could contribute to enhancing the care of young people with cancer. Whilst there is potential for fragility in relationships concerning adolescents and young adults, it is important that we learn more about how we can help. Interestingly however, it was apparent in the findings from the researchers last study that, these relationships also had strength, intensity and significant commitment from both the partners and the young people with cancer (name removed 2015).

The theoretical intention of this study is focused on some of the facets of positioning theory. Although this theory originates in the field of social psychology, it has application to a number of fields including education and health care. Whilst the theory can attend to positioning between subjects in the workplace and wider society, detailed attention can also be given to interpersonal encounters most explicitly to the role of rights and duties and how actions are managed as storylines evolve ( Harre' et al ., 2009). It is envisaged that these concepts will be applied to partners as they share their stories of supporting the young person with cancer in attempting to understand their experiences more fully.

## **2. The study**

### **2.1 Aims**

The aim of this study is to examine and understand the experience and role of partners in meeting the support needs of AYA with cancer

2.2 The objectives are as follows:

- To explore the nature of the experience relating to the partners of adolescents and young adults between 16 and 24 with cancer
- To understand what helps and what hinders in the context of partners giving support to adolescents and young adults with cancer
- To provide an in-depth account of the types of support that partners provide
- To develop a substantive evidenced based toolkit for partners of adolescents and young adults with cancer in this age group, thus enabling them to provide the most effective support.

### **3. Design/Methodology**

An exploratory qualitative design will be utilised in attempting to illuminate the views of those who are the partners of AYA with cancer. A narrative approach will provide an opportunity for the lives of participants to be better understood as a result of hearing their stories (Hall and Powell, 2011). The population of those being treated for cancer in this age group is small. It will also inevitably be the case that not all those receiving treatment will be in a relationship.

Therefore a purposive sample of 10 partners both male and female will be invited to take part in the study. They will be recruited from two specialist cancer treatment centres where their partners are receiving treatment.

#### **3.1 Participants**

Recruitment to the study will involve the lead cancer nurse at each site acting as a gatekeeper, making the first approach to potential participants. Prior to making the first approach to potential participants, the final study protocol was discussed with each lead nurse to ensure that all steps were taken paying attention to carefulness, openness and inclusivity. The chief investigator was also available to answer any questions that the two lead nurses had about the first approach and information giving.

The gatekeepers will make contact with potential participants to assess their interest in taking part. Those who are interested will then receive an introductory letter and information sheet from the

chief investigator via the lead cancer nurse. Potential participants will be made aware that they can ask for as much information as they require and an independent person who knows about the study and can answer further questions will be identified on the patient information sheet, should they wish to contact them. Potential participants are given two weeks to think about their involvement. If they agree to take part, the lead nurse will contact the chief investigator who will then meet with them and go through the information again before gaining their consent to participate. In line with the principles of informed consent there will not be any coercion at any time.

### **3.2 Eligibility criteria**

#### 3.2.1 Inclusion:

- The relationship between the AYA with cancer and their partner will have been established for a minimum of three months
- The AYA with cancer will be receiving curative treatment
- Treatment will have been in place for a minimum of one month
- Partners will be aged between 16 and 30 years
- Potential participants must have the capacity to provide informed consent

#### 3.2.2 Exclusion:

- A relationship which is less than three months old
- The AYA with cancer is receiving palliative care
- Treatment has been in place for less than a month
- Partners who are younger than 16 and older than 30 years
- Potential participants who do not have the capacity to provide informed consent

It is important to note that when the lead nurse makes the first approach, this will be in the cancer unit and in the presence of the young person with cancer along with their partner. Subsequently they will be fully aware of the study, although not a participant.

### **3.3 Data Collection**

Semi-structured interviews will be undertaken with partners on two occasions during the study providing a temporal perspective of experience and allowing for a variety of support needs which could potentially change over time. As much as possible the researcher will encourage the participants to tell their story at the outset, only confirming information and then seeking

clarification towards the end of the interview using a narrative approach (Jovchelovitch and Bauer 2000). The first interview will be in the earlier phase of treatment but not less than one month following diagnosis. The second interview will take place approximately two months later as young people in some cases are moving towards the completion of treatment. This will provide the opportunity to highlight the potentially different experiences as treatment progresses. The interviews will be audio recorded and transcribed verbatim, thus providing a narrative for analysis. Each participant will also be asked to keep an unstructured electronic/handwritten diary for the duration of the study, which will form the basis of a document analysis (Bowen, 2009). The participants will be able to keep their diaries if they wish, they will be advised to use pseudonyms in their records and to exclude place names to protect confidentiality. A copy of this diary data will need to be kept by the chief investigator in line with the requirements of the Research Integrity and Governance Code of Practice (Cardiff University, 2017).

### **3.4 Data Analysis**

Narrative approaches can employ a number of analytical techniques. In this study a thematic analysis will be undertaken utilising Braun and Clarke's six steps to iteratively examine the data, develop codes and identify themes (Braun and Clarke, 2006). This will be achieved both manually and using NVIVO software to categorise data before identifying themes for subsequent interpretation and discussion. The researcher will familiarise themselves with the data as soon as is practicable, this will involve listening to the audio recorded interviews and forming some initial impressions. Once the typed transcripts are available they will be read and re read for the same purpose. Once the entire data set is available, codes will be generated across all data types. There will initially be a wide number of codes and these will need to be categorised in relation to the aims of the research, resulting in a manageable number of relevant codes. Data relevant to each chosen code will then be systematically imported into NVIVO, the data analysis tool. Searching for themes through the collation of codes will take place and the researcher will check whether themes work in relation to individual extracts as well the entire data set. A process of on-going analysis will be in place in order to refine the themes. Clear definitions of themes which depict the overall story through an analytic lens will be finalised. A selection of extracts which best illuminate the analysis from the findings and which relate to the research aims will be presented in a findings paper for publication.

### **4. Ethical Considerations**

The study was approved through the NHS UK research ethics committee process as a result of proportionate review (18/WS/0025). Subsequent approval through local Research and Development sites was obtained and the study was adopted onto both the NIHR and the Health and Care Research Wales portfolios.

Ethical considerations are essential to ensure that the public are safe when participating in research. The Research Integrity and Governance Code of Practice will be utilised (Cardiff University, 2017). The Royal College of Nursing ethics for researcher guidance (2015) will also be applied. The participants in this study will all be over 16 years old. However one could argue that because they are still in transition from childhood to early adulthood they will demonstrate some vulnerability. The National Children's Bureau (NCB) published guidance on involving children and young people in research, which refers to monitoring impact when undertaking research (Shaw et al., 2011). This is supported by practical guides such as that published by Alderson and Morrow (2011). The NCB note issues and potential problems that may cause risk. These could include distress when discussing sensitive issues, which may provoke a negative emotional response and there is a possibility that this could be linked to maturity. Nevertheless there is a body of evidence not just in this topic area but across the field of child health which argues that it is critically important that we hear the 'voices of young people' if we are to learn more about their experience. The researcher will however pay close attention to each participant throughout the study, with the intention to consider withdrawal even if there is the slightest concern relating to their welfare. Guidelines for conducting research with children and young people make clear the important considerations required in gaining consent amongst vulnerable groups (Shaw et al., 2011). They identify a number of issues, which apply in the same way in all aspects of consent for research. For example: the requirement for informed consent and the need to ensure that the participant fully understands what is involved in the study before agreeing to take part.

Prior to providing consent, potential participants will be contacted by the chief investigator and provided with detailed but easy to understand information about the aims, objectives and purpose of the study. The information sheets have been developed with the help of a small group of young people. It is essential that participants have all the information that they will need to understand the study so that they can make an informed decision about participation. The chief investigator will make clear the way in which the interviews will be conducted and make clear her role as a professional in the context of the research ensuring that there are clear boundaries in place. Understanding the need for professional boundaries is important in this field of practice and steps should be taken to ensure that the participants best interests are protected (Davies and Wilsher

2012). Participants will be informed of the potential risks and benefits of participating in the research. They will also be made aware that their participation is voluntary and that they can withdraw from the study at any time for any reason, which they do not need to disclose. In such instances, data that has been generated whilst the participant was involved will be retained and utilised with their consent. I will be alert to any distress that the participant may have and take the appropriate action in protecting their interests if there is the slightest concern.

## **5. Validity, Reliability and Rigour**

As is recognised in qualitative approaches, credibility, transferability, confirmability and dependability as originally outlined by Lincoln and Guba (1985) will be utilised to ensure that the trustworthiness of the data is prioritised, ensuring that the research process has a rigorous and robust audit trail. The involvement of a young person's advisory group will enhance the credibility and dependability of the study. Reflexive practice will be employed throughout the study and reflective accounts recorded following each data collection activity as soon as is possible following each event.

## **6. Discussion**

The study was designed from the outset with the involvement of an advisory group which included two couples one of whom in each whom had been treated for cancer in the past. The group were able to advise on the ideas for study design and for data collection methods. Additionally, the group will be involved in helping to develop guidance based on the findings from the study. In terms of the implementation of the study, there could be challenges related to completing data collection. If the AYA with cancer is unwell this might mean that interviews have to be postponed, equally partners may also have to work/study and a degree of flexibility will be required when arranging interviews. The study also requires that partners are interviewed alone so that they are able to tell their story. It is important to navigate a way to make this happen without causing any distress to the patient and this will require a sensitive approach.

## **7. Limitations**

This study will provide a relatively short snapshot in time of the experience of having a partner with cancer. This data will not capture their experience in real time relating to the point at which they were diagnosed rather it will be a retrospective account. Neither will the study explore what experiences there are following the completion of treatment.

## **8. Conclusion**

The findings resulting from this research will provide information relating to the experience of a partner caring for an adolescent and young adult with cancer. This will culminate in the development of a usable toolkit which will assist the partners of young people in providing support which is evidenced directly from those who have had experience of caring for a partner with cancer. All relationships have unique elements and therefore there will certainly be differences between the experiences of couples in this study. In analysing the data the key will be to identify themes which are common to partners in a relationship with someone undergoing treatment for cancer. It is difficult to give examples of what these might be as the gap in the evidence in this area means that we have a very limited sense of what will help partners. Therefore, as is commonly the case with information, guides and toolkits, the materials will be broad, rather than specific to individuals. However the common themes identified from the findings will be central to the toolkit in this study.

The toolkit could possibly have the potential to be delivered online thus providing an easily accessible and appropriate format for the age group in this particular study. Research with this age group is beginning to develop but there are still many opportunities for the exploration of experience relating to AYA receiving cancer treatment. The outcomes of this study will add to this emerging area of research, particularly in Wales where there is no evidence of a qualitative work stream which explores the adolescent and young adult cancer journey.

Research dissemination will take place locally in the research sites through the presentation of the findings. Outputs in the form of peer reviewed papers will be formulated and targeted to specialist cancer audiences. The project will also be submitted as an abstract at a national Teenagers and Young Adults with Cancer conference and internationally at a European Oncology Nursing Society conference. The research will also be submitted for presentation to the Adolescent and Young Adult Global Teenage Cancer Trust conference. Additionally, links with the independent cancer charities in England will mean that events to potentially further disseminate the toolkit could also take place.

AYA with cancer form a small part of the population being cared for in the NHS. Nevertheless, their cancer experience has a significant impact on their lives during what is commonly regarded as an optimistic and exciting time. Care for these patients is complex and multi-layered with the involvement of a significant number of people. However it is often those who are closest to the young people who provide vital support in what is recognised as a difficult and challenging

## Partner protocol paper

experience. Partners are very much at the centre of this support and yet the lack of any evidence based advice or help is absent. The development of a toolkit which can go some way to rectifying this situation has the potential to provide a powerful impact in terms of assisting the partners of AYA in meeting the support needs of AYA with cancer. The toolkit would have the capacity to be used widely therefore potentially providing impact, locally, nationally and internationally.

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