

Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <http://orca.cf.ac.uk/124155/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Davies, Jane, Hannigan, Ben and Kelly, Daniel 2019. The experience of partners supporting adolescents and young adults with cancer. *Journal of Advanced Nursing* 75 (11) , pp. 2890-2898. 10.1111/jan.14125 file

Publishers page: <http://dx.doi.org/10.1111/jan.14125> <<http://dx.doi.org/10.1111/jan.14125>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



ABSTRACT

Aims: In a larger study where the aim was to investigate choice and control in decision the role of partners was significant. Reported here are the experiences of those partners of young people with cancer.

Design: A qualitative, exploratory case study approach was utilised.

Methods: In the larger study 22 participants were recruited including five adolescents and young adults with cancer, two sets of parents/carers and three individual parents, five healthcare professionals linked to the adolescent or young adult with cancer and five friends or partners. Data were collected between February 2014 - February 2015 and included interviews, non-participant observation and documentary analysis.

Results: Three themes were identified relating to partner experience derived from partner and patient interview data: 'practical support', 'putting your partner first' and 'acting as a confidante/ally'.

Conclusion: These findings reveal new knowledge of partner experience when adolescents and young adults have cancer. Richer in- depth understandings of partner experience are required in order to improve the care of adolescents and young adults with cancer and those around them.

Impact: These findings will inform the development of guidance and further research which will enhance knowledge of partner experience for those involved in cancer care in the adolescent and young adult age group.

Key words:

Cancer, adolescent, young adult, partner, relationships, support, experience, nursing

The experience of partners supporting adolescents and young adults with cancer

INTRODUCTION

Transitional activities enable young people to build their early adult lives and these can include the development of romantic relationships (Connolly et al., 2014). Emerging adulthood is generally considered an optimistic, exciting time (Arnett 2015). The diagnosis of cancer, however, can interrupt early adult development (Davies et al., 2018). The initiation, maintenance, growth and enhancement of romantic relationships are no exception. This paper will examine the experiences of those involved in romantic relationships with young people being treated for cancer with a view to considering how their needs could be met in the future.

BACKGROUND

Experiencing cancer as an adolescent or young adult (AYA) is not common. In the UK each year between 2013 and 2015, there was an average of 2,630 new cases of cancer in adolescents and young adults (AYAs), which equates to around seven new cases diagnosed every day (Cancer Research UK, 2018). 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%. 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). However, there is an ongoing debate about the age range in terms of young adulthood with some commentary suggesting that the accepted age range is now between 15 and 39 years. In this range there are an estimated 1 million young adults diagnosed with cancer worldwide each year (International agency for research on cancer 2012).

Additional stressors including financial, educational and those related to families, peers and partners are also present. However, evidence relating to understanding the perspective of partners supporting someone with cancer in this age group is limited. A paucity of empirical evidence exists which could inform an understanding of the intimate relationships engaged in by (AYAs) with cancer. Peer relationships during the cancer experience have been shown to be important (D'Agostino et al., 2011; Zebrack and Isaacson 2012). A limited literature presents evidence of difficulties in disclosing a cancer diagnosis to a new partner (Lewis and Mooney-Summers 2013). Furthermore, a small number of

studies and commentary have focused on sexual difficulties experienced during cancer treatment (Morgan et al., 2010; Quinn et al., 2011; Peddie et al., 2012:). Olsen and Harder (2009) focused on significant others, discussing attempts to 'keep the worlds together' (pg493) of AYAs and they discuss the wider social networks of this group. This provides a view on the important role that those other than family play in the experiences of AYAs with cancer. Additionally, Olsson et al., (2015) cite a number of pertinent issues about the cancer experiences of AYAs in Sweden which identify the importance of information on sex and fertility. Information on sex and fertility is important but this may be emphasised without considering the relationship as a whole. Soanes and Gibson (2018) highlight emotional support provided by partners and note that sometimes they also act as carers. Additionally, they state how cancer can disrupt the partner's 'young adult biography' (pg46) whilst highlighting the requirement for further research involving both individuals and couples.

Support from those closest to the AYAs with cancer has focused on the involvement of families and how they can best help and cope during this time (Holm et al., 2003; Grinyer 2009; Kilicarson-Touruner and Akgun-Citak 2013; Barakat et al., 2014). Family is undeniably important in this context, however exploring the needs of partners requires further investigation.

Findings from the larger three year study from which this paper is derived explored choice and control in decision making in young people between 16 and 24 (Davies 2015). The current paper reports on a thematic analysis of data generated through interviews conducted with partners and patients participating in the larger study. The theoretical frameworks of agency and structure were utilised determining the nature of choice, control, freedom and autonomy AYAs had in decision making set against the structures that limited this choice (Davies 2015). Partners of the AYAs with cancer emerged as an important source of data and it became apparent they played a pivotal role in supporting those going through a cancer experience.

AIM

The aim of this paper is to share interview data derived from a larger study investigating choice and control in decision making in young people with cancer to report on the experiences of young people's partners. Sharing this information will stimulate debate relating to partner experience.

DESIGN

An exploratory qualitative case study design was utilised. Multiple sources were included to gather views from individuals close to the AYAs during cancer treatment (Gillham 2000; Flyvberg 2006; Yin

2014). The participants were asked to nominate individuals who would be invited to participate and share their own views of their cancer experience. Patient public involvement prominent in the study development. Experts in the field of AYAs cancer care also contributed to the study design, recruitment and recommendations.

SAMPLE/PARTICIPANTS

Purposeful sampling using maximum variation was utilised recruiting five young people with cancer as participants for the original study. Inclusion criteria for AYAs included being between the ages of 16 and 24, undergoing curative treatment, being a minimum of two months following diagnosis and willing to consent. Using principles of case study design (Yin 2014), young people with cancer were asked to nominate a partner or friend to take part. Invitations were also extended to health or social care professionals involved in the care of the AYAs with cancer, and parents or carers. Three partners were recruited and this paper focuses exclusively on the accounts of this group. The characteristics and context of young people with cancer and their partners can be found in table one.

Table 1 participant characteristics and context

DATA COLLECTION

Data collection took place between February 2014 and February 2015. Each of the five young people in the original study nominated a partner or a friend to be invited for one interview (n=5) revealing the experiences of these individuals and how they sought to help those with cancer. All interviews were audiotaped and transcribed in a timely manner. Interviews with partners lasted between 35 minutes and one hour. The focus of this paper is on the single interviews undertaken with two partners and data detailing partner experience highlighted by one of the young people with cancer. Each partner was interviewed alone.

ETHICAL CONSIDERATIONS

The study was approved by an internal University and NHS ethics review (REC reference number 13/WS/0293). This was a vulnerable population and knowledge, flexibility and skills to detect any concerns on the part of any participants in the study was paramount. Expert gatekeepers who worked in AYAs care made the first approach to potential participants and were available to answer any questions or to pass questions to the researcher throughout the study. The researcher kept a reflective diary throughout the study providing further opportunities to consider any ethical issues as they arose.

DATA ANALYSIS

In case study design it is important to be able to recognise relevant themes both within individual cases and across all relevant cases. Ayres et al., (2003) argue that this process is central to data analysis in case study research. They justify this view by saying although individual experiences may have limited value, there are aspects of individual experience which are unique which can help reveal particular issues. The original study utilised a combined within, and cross case, approach through the application of thematic analysis (Braun and Clarke, 2006). Thematic analysis is amongst the most popular approaches to making sense of qualitative data (Boyatzis 1998) and can provide a consistent pattern of experience across research participants. The primary analysis, as reported in the original study (Davies 2015), identified three overarching themes in the context of decision making. These were titled 'life then', 'life interrupted', and 'life reclaimed'. Data from two interviews with young people's partners, and from one young person who talked about their partner, were subjected to the thematic analysis using their six-step approach (Braun and Clarke, 2006) reported in this paper.

TRUSTWORTHINESS

The larger study in terms of its design, resonates with the notion of trustworthiness within the bounds of credibility, transferability, dependability and confirmability as identified by Lincoln and Guba (1985). Credibility was ensured through the audio recording of all interviews followed by accurate transcribing. Triangulation of data in the larger study offered the potential for experiences to be analysed from a number of perspectives, thus increasing the likelihood of their trustworthiness as similar threads were identified. With reference to transferability the participants involved in the larger study were drawn from a cohort using specialist AYAs cancer services, a number of which exist throughout the UK. Dependability was observed as analysis conducted in the study followed all of the analytical process outlined in the data analysis section above. In attempting to confirm the objectivity of findings, it was important to carefully plan and execute the whole study. An audit trail provided the basis for recognising the formal and planned nature of this process. Respondent validation was felt to be neither helpful nor practical in this context.

FINDINGS

Data from the larger study were reconsidered in relation to how the information provided by partners could be utilised. As with the original study a thematic approach generated several codes which led to

Partner role in AYA cancer

the identification of three key themes: 'practical support', 'putting your partner first' and 'acting as a confidante/ally'.

The three cases considered here summarised in the context of the larger study in Table 1 where all participants have been given pseudonyms can be seen in table 2

Table two Partner background

In theme one, 'practical support', several elements were included such as helping with physical tasks, offering accommodation and giving advice. 'Putting your partner first', the second theme made clear love for the person with cancer. Details were given as to how partners put themselves 'second' by going out of their way to help, changing plans and compromising their own well-being. In theme three, 'acting as a confidante/ally', partners were able to help in keeping matters private and supporting decisions when others sometimes did not.

It was evident in this study that young people placed important emphasis on their personal relationships. Four out of the five were either in, or had been in, what they termed a 'serious relationship'. Of the four who reported their relationships one had ended, thus leaving three young people with partners during the data collection period. They had all been in relationships for a year or more. The participants discussed examples of issues within their personal situation and actions that they had taken independent of others.

Practical support

One partner interviewed Nigel, was in a relationship with Ellen who he met at university. When she complained of pain in her shoulder before a diagnosis of acute lymphoblastic leukaemia, he was keen to offer practical advice:

I think, it's... it's coming back again I do think you should go and see the doctor about it and I think after a few days she did go and finally see the doctor because it was really starting to hurt. (Interview with Ellen's partner Nigel).

He was on the same degree programme and she accepted his help as a way of coping with her symptoms whilst also preparing for examinations. She was beginning to lose some control over events in her life as her symptoms worsened prior to diagnosis. Nigel commented:

I think as the pain grew, she started, it started to get worse she started to ehh, I'm not so sure that she lost control, but like other aspects. It started affecting other aspects of her life really hard. Like she was really, really worried how her exams were going to be because either the

Partner role in AYA cancer

pain was going to affect them or the drowsiness from the strong painkillers were going to affect them, but we got it so we revised together...we revised a lot together, I helped her a lot. (Interview with Ellen's partner Nigel).

Practical support offered by Nigel was crucial here, enabling Ellen to continue with her studies and he was a catalyst for ensuring that she managed to cope, despite her symptoms. He was also extremely worried about his partner's worsening condition although he did what he could to help her to continue with everyday life. At a later stage in treatment, when Ellen was recovering, Nigel offered help which meant he would not even have a bed to sleep in, but he was willing to do this because he was committed to helping Ellen plan her life following the completion of treatment:

When she was first talking about coming back to (city) she was scared that she wouldn't be able to get a flat or she wouldn't be able afford a flat and I said you can come and stay with us... and my family will look after you... you can sleep in my bed I can sleep in a sleeping bag... but Ellen would say a very resounding no to that because she, she would again feel like she was imposing. (Interview with Ellen's partner Nigel).

It is interesting to note just how far Nigel was prepared to go in helping his partner, possibly at the expense of his own wellbeing. Similarly, Will, who was being treated for Osteosarcoma, felt it very important that his partner Meg was there supporting him on a daily basis:

Meg came down as much as she could because she was off for the summer from school even at that time, so it was really nice to have some support (interview three with Will).

...she was pretty much there nearly every day you know there for me. (Interview three with Will).

Practical help was a common feature of partner experience and in Ellen's and Nigel's case he was keen to offer help throughout her cancer experience. This included help both at the onset of the disease, and upon completion of treatment, and included helping with university examination preparation and accommodation on Ellen's return to her academic programme. These elements were very important to her in terms of her continued achievement and being able to live independently. Similarly, although Will was not specific about the practical support that he had from Meg, it was really important for him that she was 'just there' for him.

Putting your partner first

Partners put themselves in 'second position' during the time that the other young person was going through cancer treatment. Partners were keen to let others know what they were willing to do to try and improve the situation. Ellen moved from university to her parental home to have treatment.

Partner role in AYA cancer

However, Nigel wanted to continue the relationship and was determined to ensure that they continued to see each other:

I wanted to keep it going...I love her...and I knew, all this is, is she is going to be away for two years I immediately went, I made the decision I am going to see her every couple of months if I can...so I started taking on work as a maths tutor... so I started taking on tutoring... to get some money. (Interview with Ellen's partner Nigel).

Meg spoke of her intention to stay with Will whatever transpired in terms of his cancer. However, this intention was not welcomed by Will who was upset with what Meg had experienced. Will was determined that she would not put him first if he needed further treatment in the future:

Will: No because I did say to her if it does come back again then I would leave her

Researcher: You would leave her?

Will: Yes, because I wouldn't put her through it again. (Interview two with Will).

Despite these views at a later stage in his treatment Will did appear to really appreciate that, in essence, Meg had put him first and continued with the relationship:

She has also been there for me every step of the way sort of thing it has been really nice to know that she is there and stuck by me sort of thing because I think most people would have walked away you know if they had a partner going through that and losing their leg. (Interview three with Will).

This was further supported by comments made by Nigel about his relationship with Ellen:

Nigel: I think that's probably a result of the sadness from it is she said, like she has told me numerous times like I'm going to have changed from this and I am going to be away for two years like if you decide to move on I won't blame you

Researcher: She doesn't want to hold you back?

Ellen's partner Nigel: She doesn't want to hold me back or anything and I said don't be stupid (interview with Ellen's partner Nigel).

Another partner Harriet, who was in a relationship with Sam, decided that she would change her choice of university so that she could be with him once his treatment was completed:

Well obviously we like discussed it together and he was like, 'Oh don't change your stuff because of me', and I was thinking, 'Well it's half because of you and half because (local city) is better and do I want to move away?' (Interview with Sam's partner Harriet).

Partner role in AYA cancer

Harriet claimed that she wanted to stay in her local city and did not particularly want to move, however she did acknowledge that part of this decision was linked to thinking about Will requiring her support in the future.

In putting partners first, both Ellen and Will stated that they would not mind if their partner decided to end the relationship. This was connected to feelings of being burdensome and a desire not to hold their respective partners back from continuing with their lives. The views of partners, however, did not demonstrate evidence of wanting to end the relationship. Instead they highlighted the need to support their partners throughout the cancer experience.

It is noteworthy that those AYAs who were unwell attempted to exert some control within the relationship but that this had no effect on the way in which their partners behaved. Furthermore, partners did not give any indication that they listened at all to their suggestions, instead they made their own decisions about their continued participation in the relationship. Nigel for example disagreed with Ellen's suggestion, he made arrangements to try and earn extra income so that he could spend time with her. Thus, a key feature of this situation was negotiated support that was shaped by the dynamics of the individual relationship.

Acting as a confidante/ally

Commonly the AYAs who participated, who were in the midst of treatment, confided in their partners. In the extract below this could lead to disagreements with others, namely parents. For example, Harriet was supporting Sam in his decision to move back out of his parental home following completion of his treatment. However, Sam's mother was not particularly happy about this:

He was like 'no I am going to move out' and, umm, I know his mum was like 'I don't think you should'...she understands that he has to grow up and stuff but yeah, he is going to move out. (Interview with Sam's partner Harriet).

Sam did not want to discuss his house move with his parents as he recognised that they were not particularly happy about this. However, Harriet talked at length about how he discussed this with her and saw her as an ally in understanding that he needed to leave his parents' house once he had recovered. This is further substantiated by the on-going support that Harriet gave to Sam to help him achieve his objective of living independently once again:

Partner role in AYA cancer

he actually wanted to move out more than he was letting on and then they (he and a friend) were looking for flats and he kind of like had hygiene, like he had to think about hygiene, because a lot of the flats were like grimy flats, and yeah we're like giving him advice (Interview with Sam's partner Harriet).

Will also confided in Meg, especially in relation to information that he preferred not to share with his parents, and this also happened when his mood was low:

If I have been feeling down or anything like that I will tell Meg about it, sort of thing, like I will tell Meg things that I wouldn't tell my parents, sort of thing, like if I haven't been feeling well or down about something. (Interview three with Will).

In Will's case Meg was his first 'go to' person and whilst he would consult his mother this would not be until he had discussed these issues with his partner:

Will: Umm pretty much tell her everything like

Researcher: So you discuss your decisions with her?

Interviewee: Pretty much yeah and you know if I'm still not sure then I probably talk to my mum (interview three with Will).

An 'extra' person to confide in, to give advice and help and show allegiance was important for these AYAs as it provided another outlet, which was not only supportive, but also different because of the close nature their relationship.

DISCUSSION

This research highlighted the experience of partners who were romantically involved with AYAs with cancer. During data collection partners told their stories relating to aspects of everyday life as well as specific issues related to the cancer experience. Moreover, they discussed different time points during the cancer trajectory demonstrating a range of activities in which they were involved. Soanes and Gibson (2018) discuss the protection of adult identity in young adults recently diagnosed with cancer and recognise the need for further investigation of relationship experience when young people have cancer. Interviews conducted in the larger study from which this paper is derived provided a rich source of data relating to the components of supportive romantic relationships. The analysis presented here reveals how relationships between young people with cancer and their partners can be highly significant and enduring, contrary to the view that relationships in this age group are often trivial and transitory (Collins 2003). Collins argues there are five distinguishing features which

contribute to adolescent relationships being developmentally significant. These include: 'involvement, partner selection, relationship content, quality, and cognitive and emotional processes' (pg1). All of these characteristics, particularly involvement, have resonance for the AYAs and their partners in this study. In earlier work Levesque (1993) asserted that rather than being transitory, romantic relationships involve commitment, companionship and passion, bearing a strong similarity to adult relationships. Helping partners, putting them first and being an ally and confidante reflect key elements of these criteria.

As the data presented here demonstrates partners were able to offer their own subjective insights into the ways in which they helped AYAs to navigate their way through the cancer experience. Evidence of this was at all stages of the disease process, including the time leading up to diagnosis, the treatment phase and planning for life beyond cancer. Sharing this information with others working in the AYAs cancer field could help to improve care to patients and their partners. Ferrari and Barr (2017) report that the needs of AYAs are not effectively met both during and following treatment, arguing that sharing advances relating to cancer care in practice will benefit clinical care education and research, thus benefitting patients and those close to them. Although partners revealed experiences across the cancer trajectory, information relating to partner involvement and experience during treatment was less apparent. This could relate to findings that young people with cancer may be reluctant to mix with peers at this time because they would rather not be viewed as unwell (Larouche and Chin- Peuckert, 2006; Lewis et al., 2013).

Data resulting from the study was framed within three themes: 'practical help', 'putting your partner first' and 'acting as a confidante/ally'. Before diagnosis, as was demonstrated in Ellen's case Nigel was central to providing practical help and advice, rather than her parents as she was living away from home. During this time, it is understandable that this will happen purely as a result of geographical issues. It is therefore important that prior to diagnosis, AYAs need to have an awareness of the signs of cancer and need to seek help in a timely manner. Delayed or complicated routes to diagnosis are not uncommon in AYAs (Gibson et al., 2017).

The notion of putting someone first who you in a relationship with is not surprising, however in this age group, it is likely that AYAs will generally have little, or no, experience of finding themselves in situations such as the ones described here. Nevertheless, Harriet gave an example of changing her university choice so that she could be closer to Sam when he would be living locally following treatment completion. What is crucial therefore is those who are supporting their partners in a relationship are in receipt of help themselves in terms of advice and education. It is also important

they are not isolated and know where to seek help and information, which will protect their well-being as they experience significant challenges. This education and advice would be best provided by those working in clinical practice and those who provide psychosocial support (Zebrack and Isaacson, 2012). Youth workers could also play a useful role in assisting partners in this context. Educational preparation programmes should include information on the experience and needs of partners during this time. There is also a need for a wider strategic approach in determining support for partners throughout the cancer experience and beyond. Policy development and benchmarking standards should seek to include the requirements of partners as part of routine care in cancer treatment centres.

Being a confidante/ally is a role that can be undertaken, however it might also create a serious conflict of interest for the partner, or a feeling that some matters might need to be disclosed particularly if the AYAs with cancer is at risk. In Will and Meg's case, he chose to confide in Meg when he felt down because he preferred not to discuss this with his parents. This could present some difficulty for partners as they might feel pressure to 'hold on' to information when the AYAs with cancer has specifically asked them not to reveal information. In this situation their own well-being might be compromised and relationships with other family members such as parents and siblings may become strained. Cheung and Zebrack (2017) identify the most common resources desired by young people who have been treated for cancer and these resonate with the supportive role offered by partners and include help with loneliness and creating a sense of community and belonging.

For AYAs these relationships were the first long-term ones they had encountered and their partners were a central part of their everyday lives. As with healthy young people of this age, this was also a time of moving away from their immediate family. Partners beginning to take on this role reported that the experience became one that was shared most within the partner dyad, with the family's input being lessened to some extent. In this study it appears that despite the age and inexperience of partners in terms of romantic relationships, they were able to mobilise ability to perform roles which met the needs of the young people with cancer. However, in doing so they had very little guidance, advice or knowledge which would help them with the tasks which they faced on a regular basis.

LIMITATIONS

The study limitations included the collection of data from only one site. A range of sites may have yielded different results linked to the culture of different geographical areas. Whilst the sample was small the detailed data did provide some preliminary insights into the experiences and needs of

partners. Whilst maximum variation was attempted, there are still a number of issues that were not captured including, marginalised groups and other types of cancer than those included. The experience of cancer has the potential to differ widely depending on the treatments involved. Additionally, all those interviewed had opposite sex partners. There is therefore a need to consider same sex partners in future work or other configurations of relationships and partners. In a further study currently being undertaken to examine partner experience in more depth, one pair of participants recruited are in a same sex relationship.

CONCLUSION

The portfolio of research about the experiences of AYAs continues to grow and inevitably more is being learned about a number of psychosocial issues relating to cancer in these age groups (D'Agostino et al., 2011; Zebrack and Isaacson 2012; Olson and Smith 2018). Whilst partners were not the main focus of the original study, a number of interesting and relevant findings resulted that illuminated elements of their experience. Few resources exist within in this area and more education is needed to ensure the needs of partners are met. It is clear that partners play a vital role in supporting AYAs cancer care but it is not clear whether partners have sufficient help or information, which is empirically evidenced, to assist them during this time. These findings add a further dimension to the existing evidence pertaining to close relationships in the AYAs cancer experience.

Further research should explore the partner experience to improve this aspect of the cancer journey for AYAs. In particular the needs of partners should be further examined enabling support for a group which are central to the care of AYAs diagnosed with cancer. Those in a romantic relationship with AYAs who have cancer undertake a significant amount of 'partner work' that can have a positive effect on how individuals cope. It is timely to suggest that future sources of advice and help are now developed. These could assist partners in their relationships and improve experience for AYAs with cancer.

Funding: This article results from a three-year funded PhD studentship at Cardiff University. This research received no specific grant from any funding agency in the public, commercial, or not for profit sectors

References

- Arnett, J.J. (2015). *Emerging adulthood*. (2nd ed). Oxford: Oxford University Press.
- Ayres, L., Kavanaugh, K. & Knafelz, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research* 13, 6, 871-883. DOI:10.1177/1049732303013006008
- Barakat, L.P., Schwartz, L.A., Reilly, A., Deatrick, J.A. & Balis, F. (2014). A qualitative study of phase III cancer clinical trial enrollment decision-making: Perspectives from adolescents, young adults, caregivers, and providers. *Journal of Adolescent and Young Adult Oncology*, 3, 1, 3-11.
- Bjerke, H., (2011). 'It's the way they do it': Expressions of agency in child-adult relations at home and school. *Children and Society*, 25, 93-103. doi/10.1111/j.1099-0860.2009.00266.x/pdf
- Boyatzis, R.E. (1998). *Transforming qualitative analysis: Thematic analysis and code development*. Thousand Oaks CA : Sage Publications.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 77-101.
- Bungay, V., Halpin, M., Atchison, C. & Johnston, C. (2011). Structure and agency: Reflections from an exploratory study of Vancouver indoor sex workers. *Culture, Health and Sexuality*, 13, 15-29. doi/abs/10.1080/13691058.2010.517324
- Cancer research UK. (2018). Young People's cancer statistics. [online]. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/young-peoples-cancers> [Accessed: 23rd October 2018].
- Cheung, C. & Zebrack, B. (2017). What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Support Care Cancer*, 25, 119-126. DOI: 10.1007/s00520-016-3396-7
- Collins, A.W. (2003) More than a Myth: The Developmental Significance of Romantic Relationship During Adolescence. *Journal of Research on Adolescence*, 31, 1, 1-24. doi/abs/10.1111/1532-7795.1301001
- Connolly, J., McIsaac, C., Shulman, S., Wincentak, K., Joly, L., Heifetz, M. & Bravo, V. (2014) Development of Romantic Relationships in Adolescence and Emerging Adulthood: Implications for Community Mental Health. *Canadian Journal of Community Mental Health*, 33,1, 7-19, <https://doi.org/10.7870/cjcmh-2014-002>
- D'Agostino, N. M., Penney, A. & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*, 117, 2329-2334. doi: 10.1002/cncr.26043.
- Davies, J. 2015. The fluctuation of agency in teenagers and young adults with cancer. Unpublished PhD, Cardiff University.

Davies, J., Kelly, D. and Hannigan, B. 2018. 'Life then', 'life interrupted', 'life reclaimed': The fluctuation of agency in teenagers and young adults with cancer. *European Journal of Oncology Nursing*, [e-journal] 36, pp. 48-55. <https://doi.org/10.1016/j.ejon.2018.05.005>

Ferrari, A. & Barr, R.D. (2017). International evolution in AYA oncology: Current status and future expectations. *Pediatric Blood Cancer*, 64, 9. DOI:10.1002/psc.26528

Flyvbjerg, B. (2006). Five misunderstandings about case study research, *Qualitative Inquiry*, 12, 2, 219-245. doi/10.1177/1077800405284363

Gibson, F. et al. (2017). Improving the identification of cancer in young people: a scoping review. *Expert Review of Quality of Life in Cancer Care* 2, 2, pp. 87-101. DOI:10.1080/23809000.2017.1307089

Gillham, B. (2000). *Case study research methods*. London: Continuum.

Grinyer, A. (2009). Contrasting parental perspectives with those of teenagers and young adults with cancer: Comparing the findings from two qualitative studies. *European Journal of Oncology Nursing*, 13, 3, 200-206. DOI: 10.1016/j.ejon.2009.04.002

Holm, KE., Patterson, J.M. & Gurney, J.G. (2003). Parental involvement and family centre care in the diagnostic and treatment phases of childhood cancer: results from a qualitative study. *Journal of Paediatric Oncology Nursing*, 20, 6, 301-313. DOI: 10.1177/1043454203254984.

Information Services Division Scotland. 2017. Publications cancer [Online]. Available at: <http://www.isdscotland.org/Health-Topics/Cancer/Publications/> [Accessed: 23rd October 2018].

International Agency for Research on Cancer, World Health Organization. Estimated cancer incidence, mortality and prevalence worldwide in 2012 [online]. Available at: http://globocan.iarc.fr/Pages/age-specific_table_sel.aspx [Accessed 12th April 2019].

Kilicarslan-Toruner, E. & Akgun-Citak, E. (2013). Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*, 17, 2, 176-183. doi:<https://doi.org/10.1016/j.ejon.2012.03.001>

Larouche, S.S. & Chin-Peuckert, L. (2006). Changes in body image experienced by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23, 4, 200-209.

Lewis, P., Jordens, C., Mooney-Somers, J., Smith, K. and Kerridge, I. (2013). Growing Up with Cancer: Accommodating the effects of cancer into young people's social Lives, *Journal of Paediatric Oncology Nursing*, 30, 6, 311-319.

Levesque R.J, (1993) The romantic experience of adolescents in satisfying love relationships. *Journal of Youth and Adolescence*, 22,219-251

Linclon, Y.S. and Guba, E.G. (1985). *Naturalistic Inquiry*. Beverley Hills CA: Sage.

Morgan, S., Davies, S., Palmer, S. & Plaster, S. (2010). Sex, drugs and rock 'n' roll: Caring for adolescents and young adults with cancer. *Journal of Clinical Oncology*, 28, 32, 4825-4830. doi: 10.1200/JCO.2009.22.5474

Northern Ireland Cancer Registry. (2017). Northern Ireland cancer registry online statistics [online]. Available at: <http://www.qub.ac.uk/research-centres/nicr/> [Accessed: 23rd October 2018].

Office for National Statistics (2017). Cancer registration statistics, England Statistical bulletins [online] available at: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/previousReleases> [Accessed: 23rd October 2018].

Olsen, P.R. & Harder I. (2009). Keeping their world together-meanings and actions created through networked-focused nursing in teenage and young adult cancer care. *Cancer Nursing*, 32, 6, 493-502. doi: 10.1097/NCC.0b013e3181b3857e.

Olsen, P.R. & Smith, S (2018). Beyond no man's land: The development of AYA cancer nursing in Olsen, P.R. & Smith, S (Eds) (2018). *Nursing Adolescents and Young Adults with Cancer*. London: Springer pp 1-6.

Olsson, M., Jarfelt, M., Pergert, P. & Enskär, K. (2015). Experiences of teenagers and young adults treated for cancer in Sweden. *European Journal of Oncology*, 19,5, 575-81. doi.org/10.1016/j.ejon.2015.03.003

Peddie, V.L., Porter, M.A., Barbour, R., Culligan, D., MacDonald, G., King, D., Horn, J. & Bhattacharya, S. (2012). Factors affecting decision making about fertility preservation after cancer diagnosis: a qualitative study. *International Journal of Obstetrics and Gynaecology*, 119, 9, 1049–1057. doi: 10.1111/j.1471-0528.2012.03368.x.

Quinn, G.P., Murphy, D., Knapp, C., Stearsman, D.K., Bradley-Klug, K.L., Sawczyn, K. & Clayman, M.L. (2011). Who decides? Decision making and fertility preservation in teens with cancer: A review of the literature. *Journal of Adolescent Health*, 49, 4, 337-346. doi: <https://doi.org/10.1016/j.jadohealth.2011.01.005>

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 doi: 10.1016/j.ijnurstu.2018.01.010

Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales. 2017. Cancer incidence in wales [online] available at: <http://www.wcis.u.wales.nhs.uk> [accessed 23rd October 2018].

Yin R, K. (2014). *Case study research design and methods*, (5th ed), London: Sage Publications.

Zebrack, B. & Isaacson, S. (2012). "Psychosocial care of adolescent and young adult patients with cancer and survivors." *Journal of Clinical Oncology*, 30, 11 1221-1226. doi: 10.1200/JCO.2011.39.5467