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Support needs of adolescents' post-cancer treatment: a systematic review.

Yousuf Ismail¹ and Julie Hendry²

¹ Student radiographer, Kingston University and St. George's, University of London, United Kingdom. Email: y.ism@hotmail.com. Address: 7 Summerleaze, Bristol, BS16 4HD.

² Course director: BSc (*Hons*) Therapeutic Radiography, Kingston University and St. George's,

University of London, United Kingdom. Email: j.hendry@sgul.kingston.ac.uk

Abstract

Introduction

The study aimed to investigate the support needs for adolescents' post-cancer treatment.

Materials and Methods

A systematic literature review was conducted, articles were obtained from the following databases, Science Direct, PubMed and SCOPUS. Additional studies were identified from the reference lists of articles included in the review.

Results

119 articles were identified as potentially relevant, of these, a total of 16 articles were nominated to be included in the review for analysis.

Conclusion

The role of relationships and key workers were important to enabling survivors to self-manage. Studies have commended the role of friendships during the cancer treatment process but also as a means to coping with issues relating to survivorship. Using a coping mechanism thought to be beneficial by the survivor often improves their overall wellbeing. The eagerness to continue a normal successful life post-cancer treatment seems to be overshadowed by the fear of not being able to conceive offspring. This, in turn, can impact the psychological wellbeing of survivors, thus signifying the need to develop ways in supporting these individuals. With research into quality of life (QoL) and survivorship issues continuing to progress and reach new heights, there is still much to be done.

*Highlights (for review)

Highlights

- No definitive means of combatting survivorship issues
- Many AYA may appear to have managed well following treatment
- Impact of treatment becomes apparent subsequently, 'hiatus in care'.

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Keywords:

Survivorship; Quality of life; Psychosocial issues; Support needs; Support options; Infertility; Body image; Anxiety; Social support.

Introduction

In the United Kingdom, it is estimated that 2,300 adolescents aged between 15-24 years old are diagnosed with cancer each year¹. Due to the advancements in cancer treatment, there have been notable improvements regarding the survival of persons diagnosed with cancer during adolescence². Cancer Research UK reports that the 5-year survival rate amongst adolescents and young adults (AYA) is approximately 80%¹. Therefore, it is crucial to recognise 'survivorship' as a unique stage of the cancer trajectory³.

Transition into life after cancer, side effects from treatment and anxiety of the risk of a recurrence can inflict different emotions and require different levels of support to meet the needs of the individual³. A study uncovered the significance of alopecia on a person's self-perception which in turn promotes body image dissatisfaction, low self-esteem and many other characteristics that are prevalent among AYA currently undergoing cancer treatment⁴.

Although some of the psychosocial pressures begin to ease post-cancer treatment, further problems arise long-term that gravely affect the mental health of AYA cancer survivors⁵. Long-term AYA cancer survivors report a higher incidence of anxiety and depression, which impedes on their ability to gain employment or educational credentials⁵. As the burden of cancer remains, the safeguarding of the survivors' QoL has become increasingly important and plays a fundamental role in the evaluation of cancer therapy⁶.

The aim of the systematic review is to clarify the needs of AYA post-cancer treatment and exploring the support options available.

Research Methodology

The electronic databases Science direct, PubMed and SCOPUS were reviewed, these particular databases were chosen due to their accessibility of numerous peer-reviewed journals. The use of Boolean operators allow the author to narrow the search to retrieve articles most relevant to the research quesiton^{7.}

Search terms

The search terms included combinations of the following phrases or keywords: "adolescents OR young adults OR teenagers" AND "support needs OR quality of life OR support available OR psychosocial support" AND "post-cancer treatment OR after cancer".

Inclusion and Exclusion criteria,

Inclusion criteria included articles: (1) published in English; (2) in a peer-reviewed journal; (3) access to full text; (4) published between January 2004 and August 2016.

Exclusion criteria: (1) participants outside the age constraints (12-26 years old); (2) the studies aim not directly relevant to core concepts of support needs, QoL or support availability for AYA post-cancer treatment; (3) lack of qualitative synthesis.

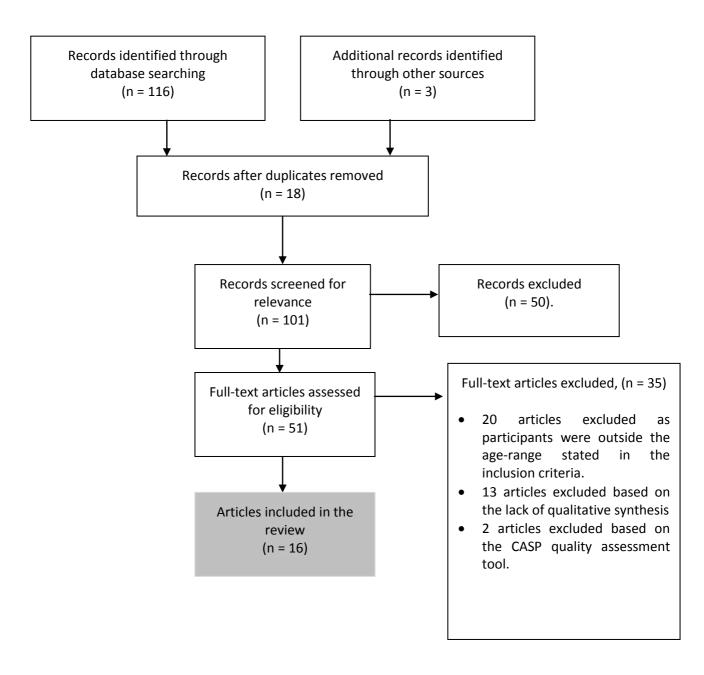


Figure 1: Outcome of the search strategy and the decision-making model

Search strategy and selection process

Reference lists of selected papers were reviewed for additional articles that may be pertinent to the study and seen as a necessary step when conducting a review⁸. Grey literature also provides a sound grounding on the current understanding of issues around support post-cancer treatment⁸. Hence the inclusion of key documents relating to AYA survivorship will be included in the review.

All articles included in the review were subject to attaining ethical approval. Ethics play a vital role in ensuring all researchers are held accountable to upholding the rights and dignity of participants in their research, this is especially important due to the vulnerability of the participants in question⁹.

The quality assessment tool used is the Critical Appraisal Skills Programme (CASP) that will determine the final selection of articles¹⁰. The series of questions used to appraise each article were taken directly from the CASP tool and can be found in Appendix 1.

A total of 16 papers were nominated to be included in the review for analysis.

Results

No	Author	Study type	Methods	Sample Size.	Age range of participants. (years)	Key findings.
1	Barr et al., (2016)	Narrative review	The study reviewed a variety of issues ranging from financial issues, psychological support, sexuality and body image with	-	-	Establishing a discrete AYA oncology discipline with related training programs necessary for health care professionals to attending to challenges facing AYA at any stage of the cancer journey. The introduction to community-led or
			the aim to consider the opportunity for progress.			internet-based initiatives that recognise that access to quality care for AYA is a right, not a privilege.
2	Choquette et al., (2016)	Semi-structured interviews	In-depth interviews were conducted using an interpretive descriptive approach using 11 adolescents' post-cancer treatment. The transcripts of the taped interviews were reviewed by the study team.	11	13-17	Nearly all adolescents were impacted negatively by the cancer experience however the ability to maintain friendships during the transition emerged particularly salient allowing adolescents to rise above the challenges and the residual effects of cancer treatment.

3	Cotton et al., (2005)	Systematic review	18 articles were identified through searching the PsychInfo and Medline databases using a combination of keywords related to spirituality and religion.	- Ultimately, the purpose of religion and spirituality is to evaluate and develop targeted intervention efforts. Through more sophisticated study design can research understand how religion or spirituality impacts adolescents' health and wellbeing.
4	Dudzinski (2004)	Normative ethical analysis.	Different ethical - phenomena were examined to form a basis for the ethical standards if clinical trials were to be conducted.	Initial research into oocyte and ovarian cryopreservation stemmed from semen preservation using non-invasive techniques which resulted in the preservation of male fertility. Though the process of preservation of female fertility would improve the morale of patients. The ability to offer this intervention before the commencement of cancer treatment is difficult as there would be a clear risk to health if any kind of cancer treatment is delayed.
5	Fan and Eiser (2009)	Systematic review	7 studies were - identified from databases CINAHL, MEDLINE and PsychInfo.	- Changes in body image have adverse implications on self-esteem and can be moderated through social support. 7 articles included in the review recognise social support as a means to facilitate in adjusting to changes in physical appearance.

6	Galan et al., (2016)	Delphi Study	A Delphi study was implemented to address the aims of the study, which entailed the participation of AYA cancer survivors and extracting individual opinions with the goal of achieving a	13	14-24	Six themes were highlighted and given high importance among the participants, with each individual theme followed with a number of sub-needs. The themes highlighted were; counselling and psychological support, developing an adaptive social network, financial support, maintaining a healthy lifestyle, needs specific to post-cancer treatment and specialised care and
			consensus among the group.			strategies for returning to 'normal' life and adapting to this new role.
7	Kelly (2013)	Discussion paper	The approach taken consisted in examining the available evidence and combining it with examples of recent service and research developments.	-	-	Results found improved knowledge in sexual issues resulted in improved self-esteem relating to body image and relationships. The study continued to discuss the option of counselling in the hopes of enhancing psychosexual developments in adolescents.
8	Michel and Vetsch (2015)	Systematic review	8 studies were identified from the Cochrane database and PubMed.	-	-	To be able to improve the quality of follow up care, and identify and treat psychological distress among AYA cancer survivors, screening tools should be implemented to better identify psychological distress.

9	Moody et al., (2014)	Mixed methods	A mixed-method approach was implemented including surveys, focus groups and interviews with AYA survivors, parents of survivors and professionals	24	16-24	The study found that survivors need continuous psychological support along with relevant information regarding cancer. Survivors involved in the study had worries of the future, potential relapse, body image and infertility.
10	Pacey (2007)	Literature review	Critically analysing articles pertaining to different methods of fertility preservation.			Understanding the effects of the reproductive system from the cancer treatments has advanced in recent years. With assisted conception improving male fertility, current treatment options do not prove beneficial for women in retaining their fertility post-cancer treatment. Several different treatment modalities were discussed, which include endocrine therapy, in-vitro, use of artificial gametes and freezing and reimplantation of gonadal tissue. All encouraging but require further research and understanding prior to clinical use.

11	Patterson et al., (2015)	Narrative review	To review the medical, psychosocial and behavioural late effects; survivorship care planning and transition; current research priorities; and practice implications.	-	-	Survivors of cancers in adolescence are confronted with dual demands when transitioning into an independent adult, concurrently with their transition from patient to survivor.
12	Stinson et al., (2015)	Semi- structured interviews.	Interviews were conducted to better understand the issues facing AYA cancer survivors	20	12-17	Findings extracted from the interviews had revealed that dating, sexual relationships, fear of infertility and access to care through adolescent friendly and accessible means allow for improvements in support which would ultimately improve psychosocial health of adolescents during and post treatment.
13	Taylor et al., (2013)	Systematic review	MEDLINE, CINAHL and PsychInfo were searched for literature published between 1987 and 2011.	-	-	With 17 articles included in the review, 9 common themes were identified: psychosocial function, the importance of peers, the importance of support, the impact of symptoms, striving for normality, impact of diagnosis, positive experiences, and financial consequences.

14	Teenager cancer trust (TCT).	Document	The aim of the -	- Emotional and social sequelae can
	, ,		document focuses on	impact on AYA QoL, but may be
	(2015)		the different aspects	addressed through survivorship
			of AYA life	programs. This allows for AYA to achieve
			throughout the	psychological and emotional wellbeing
			cancer journey.	while being able to to re-start
				educational or career pathways.
15	NICE improving outcomes	Document	The document sets -	- Appropriate psychosocial support for
	for children and young		out a blueprint for	children and young people including
	people		the NHS in improving	their families is complex and
			care services for	multidimensional. Support needs are
	(2005)		children a young	highly individual and will change as the
			people.	patient and families move through the
				different stages of the cancer pathway.
				Psychological services play a crucial role
				in all stages of the pathway including
				into adult life. The difficulty to provide
				adequate support is due to the heavy
				reliance on voluntary sector funding.
16	National Cancer Survivorship	Document	The document -	- NICE recommends lifelong contact with
	Initiative		reviewed the current	cancer centres though with increasing
			follow up processes	survivorship the capacity to continue
	(2010)		and how it could be	seems unlikely. Improving quality of life
			improved as the	is not just adding years to one's life but
			number of survivors	adding life to years ahead. A shift to a
			increases.	stratified pathway in lieu of a 'one size
				fits all' will allow professionals to tailor
				support to meet individual needs.
				Individuals should be encouraged to
				self-manage with the right tools and
				information from professionals.

Though it was evident that there is a paucity of articles pertaining to psychosocial related issues, it was disappointing that only 4/16 were qualitative studies. Fan and Eiser (2009) recognised social support as a means of enabling survivors to adjust to changes in their physical appearance, and may in the future play a critical role in improving the QoL for AYA following cancer treatment¹¹.

Kelly (2013) discussed the introduction of strategies and survivorship programs aimed at enhancing QoL and survivorship¹². The National Cancer Survivorship Initiative perceives QoL as not only adding years to one's life but adding life to years to come¹³. Teenage Cancer Trust (2015) also discussed the introduction of survivorship programs which may allow for AYA to achieve psychological and emotional wellbeing to be able to re-start educational or career pathways¹⁴.

Follow up for cancer survivors begins with regular clinic attendances for review by their oncologist; subsequently these reduce to bi-annual or annual visits. Where possible, all patients should be reviewed by an MDT and sufficient information provided to all patients to enable them to self-manage¹³. Support needs are highly individual and therefore providing a more stratified support pathway is necessary¹⁵. Current support channels for cancer survivors rely heavily on voluntary sector funding and therefore providing life-long support for all patients is impractical¹⁵. Establishing a discrete AYA oncology discipline with related training programs via community-led or internet-based initiatives may well impact positively on the lives of the survivors¹⁶.

The role of relationships, whether sexual or otherwise does ultimately impact the psychosocial wellbeing of the survivors^{12,17}. The significance of infertility was evident among the studies^{17,18,19}, therefore establishing methods of supporting those experiencing issues relating to infertility is crucial. Information provisions is necessary in supporting AYA in regards to coping mechanisms and the ability to self-manage, though this support should be widened to include family members and close relatives as all are impacted by the diagnosis.

Discussion

The importance of psychosocial needs combined with the psychological wellbeing of survivors can hinder the ability to overcome the impact of the cancer treatments. Interacting with friends enables survivors to reintegrate and regain confidence, allowing them to re-establish themselves back into normal life¹¹. The ability to sustain friendships during the transition emerged especially prominent, allowing adolescents to rise above the challenges and the residual effects of cancer treatment²⁰. Galán et al. (2016) provided evidence of friendships and relationships helping improve the psychosocial issues survivors face²¹. The fear of 'losing touch' and unable to socialise with friends can lead to isolation and act as a barrier to re-entering normality²². It was found that relying on friends for support especially those with experience with cancer was important and that having contact mutually benefitted AYA survivors²².

Teenage Cancer Trust (2015) provided evidence of friendships and relationships helping improve the psychosocial issues survivors face¹⁴. However, if the survivors do not have access to these individuals the ability to develop these relationships becomes much more difficult post-cancer treatment. The introduction of a buddy system or the establishment of key workers will allow for an increase accessibility of support throughout one's cancer journey. In order for health care professionals, carers or peers to adequately aid survivors, the correct training is required to equip them with the skills to best support adolescents. Extending training to family, friends and partners is equally as important as it will impact on the day-to-day lives of survivors. This would allow individuals to self-manage with the right tools and information which in turn would reduce the reliance of voluntary funding¹³.

NICE (2005) found that fertility and psychological issues were most common among survivors transitioning into normal life¹³. Though the NHS have begun to focus its agenda on developing means of combatting issues of infertility, anxiety and body image dissatisfaction, it is apparent that greater insight and investment is required to achieve the support necessary for a survivor to enter normality and succeed¹⁴.

Stinson et al. (2015) found that fear of infertility was a major theme among all the participants in the interviews, and access to care would ultimately improve psychosocial health of adolescents¹⁷. Results from Dudzinski (2004) identified that fertility issues were a major concern, which greatly impacts on the ability for survivors to envisage being a parent sometime in the future¹⁹. It is essential that resources are not all focussed on the development of the means of preserving female fertility, the introduction of counselling services will allow survivors to comprehend the challenges and discuss other options available.

Pacey (2007) followed the success of male fertility preservation and discussed different techniques that may in the future play a role in preserving fertility in female patients¹⁸. Oocyte cryopreservation and other techniques are now widely used to counter infertility in female cancer patients since this article's publication. An urgent referral is required for all those enrolled into the fertility preservation program with access also to counselling services to deliver necessary support.

Many AYA may appear to have managed well while on treatment, but the reality of the impact it has had on the patient only becomes apparent when they are no longer in contact with their treatment team, often referred to as 'hiatus in care' 23. Cancer

treatment can have a long-term effect on patients, therefore psychological and emotional wellbeing must be acknowledged at multiple stages following the completion of cancer treatment¹⁴. It is difficult to support AYA as young as 12-years-old to understand issues of infertility but more so ensuring capacity to make an informed decision to undergo fertility preserving treatment.

A 12-year-old may not have issues with dating or fertility but at a later stage in their life these issues will be more apparent, thus conducting follow ups consistently will enable those survivors to have access to support better suited to their needs¹⁷. It is often noted that psychological distress is missed during follow ups and therefore the implementation of screening for late effects as such can be beneficial^{24,25}.

A study reviewed the function of religion and spirituality for AYA as a means of support post-cancer treatment²⁶. Findings suggest that religion and spirituality can be used as a coping mechanism, often referred to as 'constructive coping', allowing one to grasp the meaning of the challenges they face²⁶. When AYA are able to draw upon a coping mechanism they assume to be effective, it improves their overall emotional wellbeing²². This will enable survivors to move on from the issues they face, and not be stuck with the residual effects of the cancer. Though, the effectiveness of religion and spirituality is yet to be investigated, it may be the method that could help those survivors cope with infertility and psychosocial issues.

Conclusion

The systematic review aimed to investigate the support needs for adolescents' post-cancer treatment. It was intended that the defined methodology and analysis would prove to form constructive conclusions.

The eagerness to continue a normal successful life post-cancer treatment seems to be over-shadowed by the fear of not being able to conceive offspring. This, in turn, can impact on the psychological wellbeing of survivors, thus signifying the need to develop ways in supporting these individuals. It is reassuring to note that progress has occurred and female fertility preserving treatment is now available. Although the issue of delaying treatment for fertility preservation may be detrimental to treatment outcomes.

The role of relationships and key workers were important to enabling survivors to self-manage. Though many articles detached the needs of survivors and support options, a more focussed all-inclusive study is required to fully conclude and redevelop the current recommendations for survivorship.

Body image dissatisfaction and anxiety were common among the survivors, restricting the ability for them to secure relationships. Studies have commended the role of friendships during the cancer treatment process but also as a means to coping with issues relating to survivorship. Using a coping mechanism thought to be beneficial by the survivor often improves their overall wellbeing. Other modes of support were also mentioned which include buddy system, religion and spirituality and survivorship groups, though greater research is required to understand the effectiveness of these methods. There has been a great deal of investment and specialisation in AYA cancer treatment and support, though improved use of resources is essential to providing optimal care.

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Ethical Standards

Due to the nature of the study attainment of ethical approval was not appropriate.

Conflicts of Interests

none

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Appendices

Appendix 1: CASP quality assesment tool

Appendix 1: CASP quality assesment tool

(A) Are the results of the review valid?
Screening Questions
Did the review address a clearly focused question? Yes Can't tell No
HINT: An issue can be 'focused' In terms of ● The population studied
The intervention given
The outcome considered
2. Did the authors look for the right type of papers?
○ Yes ○ Can't tell ○ No
HINT: 'The best sort of studies' would
Address the reviews question
• Have an appropriate study design (usually RCTs for papers evaluating interventions)
Is it worth continuing?
Detailed questions
3. Do you think all the important relevant studies were included?
HINT: Look for
Which bibliographic databases were used
Follow up from reference lists

Search for unpublished as well as published studies
Search for non-English language studies
4. Did the review's authors do enough to assess the quality of the included studies? Yes Can't tell No
HINT: The authors need to consider the rigour of the studies they have identified. Lack of
rigour may affect the studies' results. ("All that glisters is not gold" Merchant of Venice –
Act II Scene 7)
5. If the results of the review have been combined, was it reasonable to do so? Yes Can't tell No
HINT: Consider whether
The results were similar from study to study
• The results of all the included studies are clearly displayed • The results of the different
studies are similar
The reasons for any variations in results are discussed
(B) What are the results?
6. What are the overall results of the review?
Yes Can't tell No
HINT: Consider
 If you are clear about the review's 'bottom line' results

• Personal contact with experts

 What these are (numerically if appropriate)
 How were the results expressed (NNT, odds ratio etc)
7. How precise are the results?
HINT: Look at the confidence intervals, if given
(C) Will the results help locally?
8. Can the results be applied to the local population?
Yes Can't tell No
HINT: Consider whether
• The patients covered by the review could be sufficiently different to your population to
cause concern • Your local setting is likely to differ much from that of the review
9. Were all important outcomes considered?
HINT: Consider whether
• Is there other information you would like to have seen
10. Are the benefits worth the harms and costs?
Yes Can't tell No
HINT: Consider • Even if this is not addressed by the review, what do you think?