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Factors influencing the provision of End of Life care for adolescents and young adults with advanced cancer: a scoping review

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Review question/objectives

- Care service provision in adolescents and young adults with cancer during the EoL phase of care
- Experiences and perceptions of adolescents and young adults with cancer during the EoL phase of care
- Experience and perceptions of the health professionals and family members involved in their care.
- Practices/interventions used with adolescents and young adults with cancer during the EoL phase of care.

Background

This review will scope the literature relating to the provision of end of life care in adolescents and young adults with advanced cancer. It is estimated that there were around 173,000 cases of cancer diagnosed in adolescents and young adults (15-24 years) worldwide in 2008.¹ In the same time period for the 27 countries of the European Union there were 14,700 new cases.¹ In the UK in 2008-2010, an average of 2,214 adolescents and young adults (15-24 years) were diagnosed with cancer.¹ The incidence rates of all cancers for this population have been shown to be steadily increasing since the 1990s and 10-40% of adolescents and young adults (15-24 years) diagnosed with cancer, will progress to an incurable disease² with an estimated 86,000 deaths worldwide being reported in 2008.¹ In Europe this figure was estimated to be 2,500.¹ In 2008-2010, an average of 313 teenagers and young adults per year in the UK died from cancer.³ There is international recognition that not only is cancer in young people on the rise, but that improvements in outcomes of young people lag well behind advances achieved for both children and older adults in the past 30 years.⁴ Cohen-Gogo et al (2011) note that cancer is the third leading cause of death in adolescents and young adults.⁵ However little is known about how end-of-life unfolds for those who die of progressive disease.

Three interchangeable terms are often used to refer to End of Life (EoL) care which have distinct but overlapping meanings; hospice, palliative care and EoL care.⁶

Hospice is defined as “a program of care that supports the patients and family through the dying process and the surviving family members through bereavement”.⁷p164.

The World Health Organisation define palliative care as: “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and physical problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families”⁸ p.11.

Similarly the goals of EoL care are described as “preventing and managing symptoms and assisting the dying child or adolescent and his family members in finding comfort and meaning during this phase of care”.⁶ p.126.

Grinyer and Barbarchild (2011) suggest that end of life care is used to describe the care that focuses on preparation for an anticipated death and should promote clear and culturally sensitive communication to help patients and families understand the diagnosis, prognosis and treatment options available, including pain control and support systems for patients and their families which includes psychological and spiritual care.⁹ Grinyer and Barbarchild (2011) suggest that end of life care is used to describe the care that focuses on preparation for an anticipated death and should promote clear and culturally sensitive communication to help patients and families understand the diagnosis, prognosis and treatment options available, including pain control and support systems for patients and their families which includes psychological and spiritual care.⁹

Whilst a diagnosis of cancer may be considered traumatic and life-changing at any age, in adolescents and young adults it may have extra significance as it occurs during a critical and unique phase of the human life course.¹⁰ The threats associated with advanced cancer in young people can be expected to provoke strong emotions and prove challenging for all involved

The essential feature of effective and appropriate EoL¹⁰ care is a relevant concern for those close to the patient, as well as those providing the service. Palliative care for adolescents needs to take into account the normal physical and psychological changes associated with adolescence, including attainment of independence, social skills, peer acceptance and self-image building.²

In the article entitled “Improving Outcomes Guidance for Children and Young People” the age range of adolescents is defined as 15-24 years,¹¹ however some studies describe children from the age of 10 years as adolescents.^{12,13} Schrivers and Meijnders (2006) further define adolescence by the appearance of secondary sex characteristics and terminating with the cessation of somatic growth.² The World Health Organisation (2001) refers to individuals aged 10-19 years as adolescents and those aged 15-24 years as youth.¹⁴ Thomas et al (2006) note that in contrast to physical maturation, psychosocial maturation is highly variable but involves an increasing capacity for abstract thought enabling the realisation of concepts that lie outside of one’s immediate experience such as death.⁴ For the purpose of this scoping review an adolescent and young adult will be defined as being from 10 to 24 years.

An overview of research into EoL care for paediatric patients with cancer noted that substantial research gaps exist relating to the experiences of dying children and adolescents and their bereaved survivors, with the studies that have been conducted using retrospective, descriptive or pilot intervention designs and conducted in single institutional settings with small numbers of patients and omitting the perspective of the dying child.⁶ The participation rate of adolescents and young adults in Canada and the

United States has been shown to be considerably lower than children and older adults, with many aspects of the adolescents and young adults population being understudied.¹⁵ A search of the Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects (DARE), Joanna Briggs Institute (JBI) Library of Systematic Reviews and PubMed clinical queries identified that there were no existing systematic reviews addressing this topic, and only one related systematic review protocol which focused on children as opposed to adolescents and young adults.¹⁶

However, there has been a rapid expansion in interest around the needs of young people with cancer in recent years. Multi-professional groups such as Teenagers and Young Adults with Cancer (TYAC) (www.tyac.org.uk) have lobbied for greater awareness and members of the project team have been closely involved in this group and its activities. There has also been a rise in publications on the needs of this age group, including concerns about lack of clinical trials,¹⁷ the impact of adolescents and young adult cancer on parents and families,¹⁸ the place of death of young adults with cancer¹⁹ and the nature of specialist teenage cancer units.²⁰ Despite the unique nature of this age group's EoL support needs, there is a lack of empirical evidence currently available which supports the need for this scoping review. This scoping review will be informed by the work of Arksey and O'Malley (2005) who suggest a six stage methodological framework for conducting scoping reviews which includes: identifying the research question, searching for relevant studies, selecting studies, charting data, collating, summarising and reporting the results, and consulting with stakeholders to inform or validate study findings.²¹

Keywords

Adolescents; young adults; palliative; end of life care; cancer

Inclusion criteria

Types of participants

This scoping review will consider all studies that focus on adolescents and young adults aged 10 to 24 with advanced cancer and their families at the end stage of life. Studies will also be included where the adolescents and young people are part of a larger sample of patients with advanced cancer but where it is possible to accurately identify data that is from adolescents and young people separately. End stage of life is described as any care or service provision that focuses on the preparation for a death that is anticipated.⁹

Types of intervention(s)/phenomena of interest

This scoping review will consider all research studies that specifically address:

- Care service provision in adolescents and young adults with cancer during the EoL phase of care
- Experiences and perceptions of adolescents and young adults with advanced cancer during the EoL phase of care
- Experiences and perceptions of health professionals and family carers in relation to caring for adolescents and young adults with advanced cancer during the EoL phase of care
- Practices/interventions used with adolescents and young adults with cancer during the EoL phase of care, for example pain control, psychological and spiritual care.

Context

This scoping review will consider studies wherever End of life care is provided for adolescents and young adults with cancer. This will include, but is not exclusive to, hospitals, hospices, respite care homes, adolescents and young adults' home settings.

Types of Outcomes

This scoping review will consider all outcomes for the following

Primary outcomes

1. For the adolescents and young adults which could include
 - Control of pain and other symptoms
 - Place of death
 - Psychological, social issues and spiritual issues
 - Impact of EoL care
 - Decision making
 -

Secondary outcomes

2. For the family carer and health care professional which could include
 - Psychological, social issues and spiritual issues
 - Impact of EoL care
 - Preferences for where EoL care is provided
 - Decision making

Types of studies

This scoping review will consider both quantitative and qualitative data.

Quantitative

This scoping review will consider both experimental and observational study design including randomised controlled trials, non-randomised controlled trials, quasi-experimental, before and after studies, prospective and retrospective cohort studies; case control studies and analytical and descriptive cross sectional studies.

Qualitative

This scoping review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Exclusion criteria

- EoL care for adults over 25 years.
- EoL care for children under 10 years.
- Care provided for adolescents and young adults with cancer that is not focused towards end of life care.
- EoL care provided for adolescents and young adults for conditions other than cancer.

Search strategy

The search strategy aims to find both published and unpublished studies over the last 15 years from 1998 to 2013. A three-step search strategy will be used in this review.

Stage 1

This stage will involve an initial search of MEDLINE and CINAHL using preliminary keywords drawn from the natural language terms of the topic, followed by analysis of

the text words contained in the title and abstract, and of the index terms used to describe articles.

The preliminary keywords to be searched are:

1. Adolescents
2. Young adults
3. Teenagers
4. Palliative care
5. End of Life care
6. Cancer.

Stage 2

The text words contained in the title and abstract of relevant articles, along with the controlled language index terms used to describe the papers, will then be analysed to develop keywords for stage two. A second extensive search will then be undertaken of all keywords and index terms identified as relevant to the review across all included databases. Individual search strategies will be developed for each index using the different terminology of index thesauri.

Stage 3

References from retrieved articles will then be searched for additional studies for the final stage of the process. The journal Palliative Medicine will be hand-searched to ensure that any relevant papers that may not be indexed in the major databases are located.

The search will seek all published and unpublished studies to the present date. Only English language papers will be included in this review due to the limited resources available.

Databases

The databases to be searched for published material include:

- CINAHL
- MEDLINE
- British Nursing Index
- Cochrane Library
- EMBASE
- PsycINFO
- PsycARTICLES
- Web Of Knowledge
- TRIP
- ERIC
- Scopus

The sources to be searched for relevant unpublished material include:

- Open Grey (formerly SIGLE -System for Information on Grey Literature in Europe)
- Contacting authors, experts and organisations active within the phenomenon of interest to attempt to identify further published, un-published and ongoing studies.

Reference software will be used to manage the list of all the articles retrieved and all unnecessary duplications removed. Articles search will then be assessed for relevance to the review based on the information provided in the title, abstract and descriptor/MESH terms by two independent reviewers. Where any doubt exists, the full article will be retrieved. The full article will be retrieved for all studies that meet the inclusion criteria of the review. A screening tool to aid this process will be used. Based on full texts, two reviewers will examine independently whether the studies conform to the inclusion criteria. Disagreement will be resolved by discussion with a third reviewer. Multiple articles of the same study will be linked together and the information will be used for the decision concerning which studies are eligible for inclusion. Study authors will be contacted in case of ambiguity. Studies identified from reference list searches will be assessed for relevance based on the study title.

Methods of the Review

Assessment of methodological quality

The review to be performed here is a focused scoping review to locate and describe existing literature in relation to EoL care provision for adolescent and young adults with cancer. Scoping reviews typically do not include a quality assessment of included studies.^{22, 23} No attempt will be made to formally assess the quality of the individual included papers, although an overall brief summary will be provided.

Data extraction

Quantitative data will be extracted from papers in the review using the standardised data extraction tools from JBI-MAStARI (see Appendix 1). Two reviewers will extract data independently. Any disagreement will be resolved by discussion with a third reviewer. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Qualitative data will be extracted from papers in the review using the standardised data extraction tool from JBI-QARI (see Appendix 2). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives. This is in line with charting the data as outlined in stage four of Arskey and O'Malley's framework.²¹ Primary authors will be contacted for further information if further clarification of the data is required.

Data synthesis

As per a previous JBI scoping review²² the results will be discussed in narrative form. Findings from descriptive studies will, where possible, be synthesised and presented in a tabular summary with the aid of narrative and figures where appropriate. The approach described by Arskey and O'Malley²¹ will be followed with an overview of all the included material which will be summarized in tables and charts which map the literature. Literature will be tabulated using the following headings related to research design, geographical location, year of publication, characteristics of study population and the research outcomes.

Conflict of interest

There is no conflict of interest to report regarding this scoping review.

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Appendix 1: Data extraction tool: MASTARI

JBI Data Extraction Form for Experimental / Observational Studies

Reviewer Date

Author Year

Journal Record Number

Study Method

RCT Quasi-RCT Longitudinal

Retrospective Observational Other

Participants

Setting

Population

Sample size

Group A _____ Group B _____

Interventions

Intervention A

Intervention B

Authors Conclusions:

Reviewers Conclusions:

Study results

Dichotomous data

Outcome	Intervention () number / total number	Intervention () number / total number

Continuous data

Outcome	Intervention () number / total number	Intervention () number / total number

Appendix 2: Data extraction tool: QARI

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete

Yes

No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes

No