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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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Executive summary

Background

There is international recognition that cancer in young people is on the rise and that improvements in outcomes of young people lag well behind the advances achieved for both children and older adults over the past thirty years. Cancer is the third leading cause of death in adolescents and young adults, however, little is known about how end of life unfolds for those who die of progressive disease.

Objective

This scoping review sought to locate and describe literature relating to end of life care for adolescents and young adults with cancer.

Inclusion criteria

Types of participants

We considered studies that focused on adolescents and young adults aged 10-24 with advanced cancer at the end stage of life and those who care for them.

Types of intervention(s)/ phenomena of interest

We considered studies that focused on end of life care, including service provision, practices and interventions and the experiences and perceptions of adolescents and young adults with advanced cancer and their health professionals and family carers.

Types of studies

We included all quantitative and qualitative research designs

Types of outcome

The purpose of the review was to map existing literature on this topic and to identify what outcomes were being measured by current research.

Search strategy

A three-step search strategy was used in this review.

Methodological quality

This review is a scoping review to provide a broader picture of the existing literature on this topic. Hence, assessment of methodological quality was not performed to exclude studies based on quality scores.

Data collection

Data was extracted using extraction tools from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instruments (JBI-MAStARI) and the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

Data synthesis

The findings are presented in narrative form including tables and figures to aid in data presentation where appropriate.

Results

Twenty studies published in English were included in this review. Research designs were mainly descriptive and retrospective using data from case notes or medical records (n=8) and focus groups (n=4). There was a single randomised

controlled trial, four cross sectional surveys, two prospective cohort studies and one that used data from three studies to develop guidelines.

Conclusion

Relatively little research was located relating to experiences and perceptions of adolescents and young adults and their carers in relation to decision making and advanced care planning. The main focus of the research was medical record review and interviews with bereaved parents.

Implications for practice

The overall focus on retrospective data and the heterogeneous and descriptive nature of the studies makes recommendations for practice limited. Encouraging adolescents and young adults to participate in decisions about their end of life care through the use of advance care planning documents, introduced at a suitable stage of their illness, appears to be an appropriate way forward.

Implications for research

Future research should focus specifically on adolescents and young adults at the end of life and consider both their perspective and that of their carers, particularly with regard to decision making. Research should also focus on factors influencing appropriate place of death.

Keywords

Adolescents, Young adults, Teenagers, Palliative care, End of life care, Cancer

Introduction

Background

This review will scope the literature relating to the provision of end of life care in adolescents and young adults (AYA) 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 develop incurable disease[2] 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) noted 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

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". [7] p.164

Palliative Care

The World Health Organisation defines 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

The National Comprehensive Cancer Network (NCCN) clinical practice guidelines for adolescent and young adult oncology recognise that palliative care is accepted as a treatment to control symptoms, and reduce environmental and physical suffering at any stage of a life threatening illness.[9]

End of Life Care

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 their 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.[10]

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.

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.[11] 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 EoL[11] 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,[12] however some studies describe children from the age of 10 years as adolescents.[13,14] Schrijvers 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.[15] The NCCN defined an AYA as an individual aged 15-19 years at initial cancer diagnosis. 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 reflects this variation in the literature and will be defined as between 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. The reviewers commented that the studies had been conducted using retrospective, descriptive or pilot intervention designs and conducted in single institution 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.[16] A search of the Cochrane Database of Systematic Reviews, 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.[17]

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 the lack of clinical trials,[18] the impact of adolescents and young adult cancer on parents and families,[19] the place of death of young adults with cancer[20] and the nature of specialist teenage cancer units.[21] 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 and further research. 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.[22]

The objectives, inclusion criteria and methods of analysis for this review were specified in advance and documented in a protocol.[†]

Review question/objectives

This scoping review sought to locate and describe literature relating to EoL care provision to adolescents and young adults with cancer. The specific areas of investigation included

- End of life 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
- Experiences 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

Inclusion criteria

Types of participants

This scoping review considered all studies that focused on adolescents and young adults aged 10-24 with advanced cancer and their families at the end stage of life. Studies were also included where the adolescents and young people

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[†] Edwards et al (2013) Factors influencing the provision of End of Life care for adolescents and young adults with advanced cancer: a scoping review protocol JBI Database of Systematic Reviews & Implementation Reports 11(7) 386 - 399

were part of a larger sample of patients with advanced cancer but where it was possible to accurately identify data that was 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.[10]

Types of intervention(s)/phenomena of interest

This review considered all research studies that specifically addressed:

- End of life care service provision in adolescents and young adults with cancer during the End of life phase of care
- Experiences and perceptions of adolescents and young adults with advanced cancer during the End of life 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 End of life phase of care
- Practices/interventions used with adolescents and young adults with cancer during the End of life phase of care, for example pain control, psychological and spiritual care.

Context

This review considered studies wherever End of life care was provided for adolescents and young adults with cancer. This included, but was not exclusive to, hospitals, hospices, respite care homes, adolescents and young adults' home settings.

Types of studies

This review considered both quantitative and qualitative studies.

Quantitative

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

Types of Outcomes

The intention in this scoping review was to map the literature and represent the range of outcomes investigated in this topic. As such the scoping review considered 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 end of life 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 end of life care
    - Preferences for where end of life care is provided
    - Decision making

Exclusion Criteria

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

Search strategy

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

Stage 1

This stage involved 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 searched were;

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, were then analysed to develop keywords for stage two. A second extensive search was then undertaken of all keywords and index terms identified as relevant to the review across all included databases. The databases searched for published material included: CINAHL, MEDLINE, British Nursing Index, Cochrane Library, EMBASE, PsycINFO, PsycARTICLES, Web Of Knowledge, TRIP, ERIC, Scopus and The Joanna Briggs Institute (JBI) COnNECT+. The search terms included MeSH and 'free text' terms in combination and was adapted according to the particular database copy of the Medline search is provided as it represents the most complex and comprehensive of all strategies (Appendix 1)

The sources searched for relevant unpublished material included: Open Grey (formerly SIGLE -System for Information on Grey Literature in Europe), contacting authors (Pamela Hinds, Ann Grinyer) and experts (Sheila Payne), and organisations (together for short lives, CLIC Sergeant and the International observatory on End of Life Care) active within the phenomenon of interest to attempt to identify further published, un-published and ongoing studies and Dissertation Abstracts International

Stage 3

References from retrieved articles were then searched for additional studies for the final stage of the process. On the advice of lead researchers in the field the Journal of Palliative Medicine was hand-searched between 2012 and 2013 to ensure that any relevant papers that may not be indexed in the major databases were located.

The search sought all published and unpublished studies. Only English language papers were included in this review due to the limited resources available.

Reference software was used to manage the list of all the citations retrieved and all unnecessary duplications were removed. Articles searched were then 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 existed, the full article was retrieved. The full article was retrieved for all studies that met the inclusion criteria of the review. A screening tool to aid this process was used (see Appendix 2). Based on full texts, two reviewers examined independently whether the studies conformed to the inclusion criteria. Disagreement was resolved by discussion with a third reviewer. Multiple articles by the same authors that reported findings from the same study were linked together and the information was used for the decision concerning which studies were eligible for inclusion. Studies identified from reference list searches were assessed for relevance based on the study title. The full article was retrieved for all studies that met the inclusion criteria of the review

Method of the review

The review 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.[23,24] No attempt was made to formally assess the quality of the individual included papers, although an overall brief summary is provided.

Data extraction

Quantitative data was extracted from papers in the review using the standardised data extraction tools from JBI-MAStARI. Two reviewers extracted data independently. Disagreement was resolved by discussion with a third reviewer. The data extracted included specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Qualitative data was extracted from papers in the review using the standardised data extraction tool from JBI-QARI. The data extracted included 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 Arksey and O'Malley's framework.[22] Primary authors were contacted for further information if further clarification of the data was required.

Data synthesis

As per a previous JBI scoping review[23] the review findings are discussed in narrative form including tables. The approach described by Arksey and O'Malley[22] was followed and an overview of all the included material is summarised in tables and charts which map the literature. Literature was tabulated using the following headings: research design, geographical location, year of publication, characteristics of study population and the research outcomes.

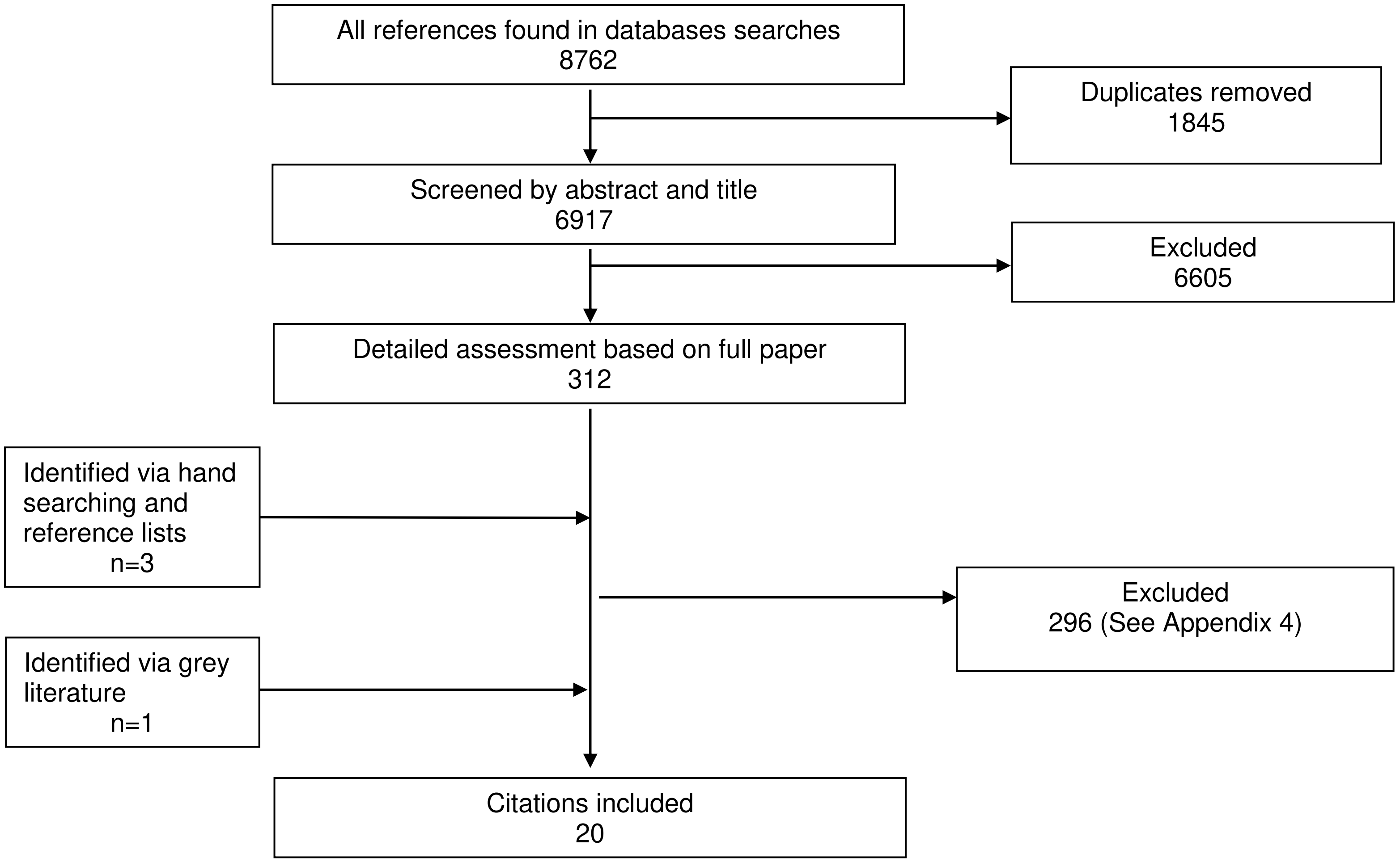
Review results

Description of studies

The database searches yielded a total of 6917 citations after duplicates were removed. The titles and abstracts for these 6917 citations were screened and 312 citations were considered for further detailed assessment of the full paper. yielding a total of 20 original citations for inclusion in this review, one of which was located through hand searching. A summary table which maps the literature is presented in Appendix 3.

A flow chart showing the number of citations at each stage is detailed below (Figure 1).

Figure 1: Flow chart of study selection



Results

Country of publication

Included studies were published between 2000 and 2013. The studies were conducted in USA (8)[12,13,24-28,30,34], France (2)[5,25], Australia (2)[26-28], Netherlands (1)[29], Sweden (1)[30], Germany (1)[31], UK (3)[20,32] and Canada (1)[33]. One study was conducted in both the USA and Australia.[29]

Age of sample

Only one study referred specifically to the sample as adolescents.[35] Two studies reported the age of the AYAs at diagnosis [26,30] and seven reported on age at death.[20,25,29,31,33,34,36,37] Three studies presented both age at diagnosis and age at death.[5,14,32] Two of the studies that followed AYAs prospectively through treatment at EoL reported the age of the sample at the time treatment commenced.[13,27] A further five studies reported the age of the AYA at the time that the research was undertaken.[28,38-41]

Ten studies were concerned with EoL issues for both children and adolescents[13,26,27,29,31-34,35,37] and it was possible to separate out the results for the adolescents: 12-19 years[33], 11-18 years[31], 15-21 years[35], 10-14 and 15-18 years[32] and for 13.2-21.3 years[37], 7 and younger, 7 to 12 and 12 and over with a mean age of 10.9 (SD 4.9 years)[29], 10-14, 15-19 and 20-24 years[13], 15-24 years[34] and individuals aged 13.4, 16.4, 18.7, 17.6.[27]

Seven papers were concerned solely with EoL issues for adolescents[5,14,20,25,26,30,39]. The reported age of the participants were 10-21 years[42], 14.2-24.2 years[5], 11-24 years[20], 15-25 years[25], 15-21 years[39],10-17 years[26], 9-15 and 16-25 years[30], 18-28 years (Mean 20.3 years)[38].

Sample size

The size of the sample varied widely from 4-130[5,14,25-29,31,33,37-41] for studies conducted in a single institution. One multi-centre study included 432 participants across 33 hospitals[13] and for data collected from four population based epidemiological studies numbers in each study were 195[30], 432[32]and 1997[20], 1,767[34] respectively. One survey undertaken by Jones et al 2006 was conducted on a sample of 131 Paediatric oncology social workers.[35]

Research design

Five studies used a retrospective case note review to obtain their information: survey of pain and palliative care databases[37]; charts, medical records, outpatient clinic nursing phone logs, and social work files on each patient[14]; Medical and nurses chart analysis[5]; Medical record review[13,26]. Four studies were of a retrospective descriptive design and were undertaken using focus groups of bereaved parents between 3 and 11 years after an AYAs' death[33]; questionnaires sent 1-3 years[29] or 4-9 years[30] after death, semi structured interviews with bereaved parents 2-6 years after death.[25] A further four were descriptive cross sectional surveys.[28,35,38,40,41]. Three studies were retrospective descriptive epidemiological studies using death registration data from cancer registries[20,32,34], two were prospective cohort studies[27,31] one randomised controlled trial[39] and one used data from three studies (one retrospective and two prospective descriptive) to develop guidelines for end of life decision making in pediatric oncology[41].

Period of data collection and EOL care

The time frame over which data was collected is shown below and ranged from 1 year to 10 years (see Table 1).

Table 1: Time frame over which was data collected in years

Author	Years (n)
Cohen-Gogo et al 2012[5]	1 year
De Graves and Aranda 2012[26]	1 year
Lyon et al 2013[39]	1 year
Anghelescu et al 2010[37]	1.5 years
Noyes and Irving 2011[27]	3 years -
Montel et al 2009[25]	3 years
Wiener et al 2012[38]	3.5 years
Janssen et al 2000[31]	4 years
Bell et al 2010[42]	5 years
Higginson and Thompson 2003[20]	5 years
Orsey et al 2009[13]	5 years
Surkan et al 2006[30]	6 years
Shah et al 2011[32]	8 years
NCIN 2011[34]	9 years
Cataudella and Zelcer 2012[33]	10 years
Theunissen et al 2007[29]	10 years
Hinds et al 2009[40]	N/A
Hinds et al 2001[41]	N/A
Hinds et al 2005[28]	N/A
Jones 2006[35]	N/A

N/A – not applicable

Only 5 of the studies defined the time period for EoL[5,13,30,37,42], ranging from the last week of life[5,13], last month of life[30], last 3 months of life [37] or time from initial EoL discussion to death, categorised as 0-14 days / 15-30 days / 31-60 days/ 61-179 days / 180-880 days.[42] Two studies defined EoL as the start of palliative treatment and then recorded time until death occurred: 6 hours to 22 days[27], 1-26 months [31]. Three studies looked at place of death only[20,25,32] and EoL was not defined in 3 studies[26,33,35]. For the study by Theunissen et al 2007[29] the only information given was for palliative care which was defined as a shift in the goal from cure to palliation but no actual time points were reported. Three studies looked at EoL decision making, within the previous 7 days[28] or previous 72 hours[40] and was not defined by Hinds et al 2001[41] . A further two studies asked adolescents with cancer to consider decisions around advanced care planning at the EoL.[38,39].

Location of research

The majority of research was conducted at a single site in a children's hospital with the exception of Orsey et al and Hinds et al 2005[13,28] or data was extracted from tumour registries or death registrations (see Table 2). More specific hospital based locations were reported by Surkan et al 2006[30] (24% children's oncology ward, 10% intensive care unit, 5% another ward, 3% adult ward) and Cohen-Gogo et al 2011[5] (44.4% Pediatric department 6% local hospital, adult palliative care unit 4.4%, intensive care unit 4.4%).

Table 2: Location of research

Noyes and Irving 2011[27]	Royal Children's Hospital – oncology Unit Queensland and Northern New South Wales
Orsey et al 2009[13]	Pediatric Health Information System database for 38 children's hospitals located throughout the USA
Janssen et al 2000[31]	Children's Hospitals of Bonn, Dusseldorf and Wuppertal
Hinds et al 2001[41]	N/A
Hinds et al 2009[40]	St Jude Children's Research Hospital in Memphis
Hinds et al 2005[28]	St Jude Children's Research Hospital in Memphis Sydney Children's Hospital In Sydney
Surkan et al 2006[30]	Swedish Cause of Death Register
Theunissen et al 2007[29]	Department of Pediatric Haematology/Oncology of the Radboud University Nijmegen Medical Centre
Cataudella and Zelcer 2012[33]	Patient tumour registry for south western Ontario

Higginson & Thompson 2003[20]	Death registrations in England and Wales
NCIN 2011[34]	National Cancer Repository in England (excluding London and South East England)
Shah et al 2011[32]	National Registry of Childhood Tumours for England
Anghelescu et al 2010[37]	St Jude Children's Research Hospital in Memphis
Bell et al 2010[42]	Midwestern tertiary care centre
De Graves and Aranda 2012[26]	Single tertiary paediatric centre
Cohen-Gogo et al 2012[5]	Pediatric and Adolescent Oncology Department at the Institut Gustave Roussy
Montel et al 2009[25]	Paediatric Oncology Department of a regional cancer centre
Jones 2006[35]	N/A
Lyon et al 2013[39]	Pediatric oncology program
Wiener et al 2012[38]	Pediatric Oncology Branch from the National Cancer Institute

The analysis is presented with regard to the four objectives proposed for this review: EoL care service provision (n=8), Experiences and perceptions of AYAs (n=3), Experiences and perceptions of health care professionals and family members (n=7), Practices/interventions used with AYAs with cancer during the EoL phase of care (n=4). Studies in multiple categories are counted for each category in which they feature.

1. EoL care service provision

The studies that discussed care service provision focused primarily on place of death, this included investigation of a number of influencing factors.

Place of Death

The location of death varied according to the individual wishes and needs of the child and their family and was investigated in 8 studies.[5,20, 25,26,30,32,34,42]

Table 3: Location of place of death for AYAs

Country, Author, Age	**Hospital**	**Home**	**Hospice**	**Other**	**Missing**
USA Bell et al 2010[42] 10-21 years	58%	16%			29%
France Cohen-Gogo et al 2012[5] 14-26 years	76.5%	8.8		4.4%*	11.2%
England and Wales Higginson and Thompson 2003					

16-24 years	57.7%	30.4%	9.4%	2.4%	
England					
Shah et al 2011[32]					
10-14 years	46%	47%	7%		
15-19 years	38%	54%	8%		
England (excluding London and South East England)					
NCIN 2011[34]					
15-24 years	52%	32%	13%[a]	3%[c]	
France					
Montel et al 2009[25]					
15-25 years	90.5%				
Sweden					
Surkan et al 2006[30]	64%	36%		2%[b]	
Australia					
De Graves and Aranda 2012[26]					
10-16 years	45%	55%			

a : hospice or specialist palliative care unit b: foreign country, c: care home or other place

Four studies evaluated factors influencing place of death[20,30,32,34]. The population based study by Surkan et al 2006[30] in Sweden investigated associations between a number of demographic variables and home as the place where the AYA was cared for during the last month and died. Dying at home was found to be strongly related to type of malignancy. Specifically patients with leukaemia or lymphoma were much less likely to die at home and the authors suggest that this could be because they require blood products more frequently than AYAs with other types of malignancies. There were also strong significant associations between parents and AYAs' awareness about death (four specific variables) with death at home and care at home in the last month. The four variables were: i) intellectually realising that their AYA would die ($p<0.05$); ii) emotionally realising that AYA would die ($p=0.2$), iii) parents who sensed that their AYA was aware of his/her own imminent death ($p<0.01$); iv) parents getting information that their AYAs’ illness was incurable a month or more before death ($p<0.01$).

In the much larger population based studies of all cancer deaths in England and Wales during 1995 to 1999[20] and in England during 1999-2006; multivariate analysis found that home death was less likely with increasing age ($p<0.05$)[20], for young women ($p<0.05$)[20], for patients with leukaemia or lymphoma rather than solid tumours ($p<0.05$) [20,32], more likely where access to local services (school, shops, general practitioner) was good ($p<0.05$)[20] and those treated at a Childhood Cancer Research Group centre.[32] Dying in hospital was more likely for those dying within six months of diagnosis and those from ethnic minorities or deprived backgrounds.[32]

Data from the National Cancer Intelligence network explored patterns of place of death among children, teenagers and young adults with cancer in England who died during 2000-2009 (NCIN 2011). It was found that death of patients with leukaemia or lymphoma was more likely to occur in hospital whereas the highest proportion dying in their own homes was for bone tumours. For those aged 15-24 years the proportion dying in a hospice or SPCU was higher for patients with melanoma and carcinoma. There was no statistically significant variation in place of death by deprivation or Asian ethnic background for those aged 15-24 years whereas there was for children aged 0-14 years ($p>0.05$).

Only one study sought to investigate families' motivations concerning place of death. Thematic analysis was reported for the positive and negative motivations concerning their AYAs' place of death, end of life care quality of care in hospital and home.[25] Positive motivations for home death included influence of cultural background and personal belief, to let the AYA die in his usual environment close to his family and to be close to the AYA even after death. The negative motivations for home death included the memory of the dead AYA, personal history, to protect the siblings and fear of regretting something. Positive representations of quality of hospital care included the belief that the best care is obtained in the hospital and the availability of nursing staff. The negative representations of quality of hospital care included harmful effects of treatment, lack of organisation, incompetent nursing staff, lack of humanity in patient care and the risk of developing nosocomial disease.[25] Only 43% of families were informed of the existence of home hospitalisation and only 14% were informed about the palliative care mobile unit. But in reality families said that they did not choose place of death as death was sudden, but would have chosen the hospital.[25]

2) Experiences and perceptions of AYA

Only three studies sought the experiences or perspective of the AYA concerning issues at the EoL.[28,38,39]

Decision Making

A study by Hinds (2005) investigated the factors influencing EoL care decisions and the EoL care preferences of twenty AYAs (10-20 years), who were interviewed within 7 days of their participation in one of three types of end-of-life decisions.[28] The characteristics of competent decision making were that they were able to identify death as an outcome of their decision and as such recognised that they were taking part in making decisions about the end of their own life and what this ultimately meant. Hinds concluded that the AYAs realised that they were involved in an EoL decision, understood the consequences of this decision and were capable of participating in a complex decision process involving risks to themselves and others.

Advanced Care Planning

A number of documents have been developed to help encourage discussions about EoL choices with children and adults with life limiting conditions. In previous studies Wiener and colleagues evaluated "Five Wishes", an adult advanced care planning (ACP) guide that had been used in the AYA population and developed an AYA- specific ACP guide called "My Thoughts, My Wishes, My Voice" ("MT MW MV") for AYA's living with HIV and recurrent cancer[43]. Further research was conducted to assess and compare the usefulness of these two ACP guides to see if any improvements could be made.[38] Fifty two participants with metastatic or recurrent cancer or HIV/infection were included. Participants were presented with random pages of the document and asked to rank 25 items on several factors including how likely they would be to complete each statement. They were provided with two wishes written in similar formats and asked how appropriate they felt each was for someone their age. Qualitative information was gathered regarding document preferences regarding wording, layout, colour, design and additional content. Fifty-four percent of respondents indicated a preference to complete "MT MW MV", 37% preferred "Five Wishes" and 9% did not express a preference. Males were more likely to prefer "Five Wishes "than females. There were no significant differences by diagnosis, race/ethnicity or age group for overall document preference. Participants preferred "MT MV MV" to discuss how they would like to be treated but preferred "Five Wishes " when discussing their comfort.

Lyon et al (2013) conducted a randomised controlled trial of adolescents with cancer and their families and engaged in discussions to identify and share patients' preferences for hypothetical care plans if the disease progressed. The approach termed Family –Centred ACP presented hypothetical scenarios to the intervention group using three tools i) The Lyon family-centred advanced care planning survey, ii) The respecting choices interview and iii) Five Wishes survey. The control group participants were given a brochure with information on ACP but they did not participate in any discussions using the three tools. The family-centred ACP adolescents thought they were significantly better informed about EoL decisions than the control group participants.[39]

3) Experiences and perceptions of health care professionals and family members

Three papers included the perspective of the healthcare professional[28,35,41]. One of these compared the experiences and perceptions of healthcare professionals, parents and AYAs with regard to the factors influencing decision making during EoL[28]. One paper combined data from across three studies in order to develop guidelines for end of life decision making in pediatric oncology.[41] Three studies were parent reports only[29,33,40], one investigated the psychological experiences of their AYAs[33] , one the physical, psychological and social symptoms[29] and what makes a good parent.[41]

Healthcare professionals

Decision making

Hinds (2005) interviewed 14 physicians, 19 parents and 20 AYAs and described the factors that influenced EoL decisions, comparing those considered by patients, parents and physicians. The factors most frequently mentioned by physicians as influencing EoL decisions were the patients' prognosis and comorbid conditions and patient and family preferences.[28]

Interview data from across three studies was analysed to develop guidelines for end of life decision making in pediatric oncology.[41] Three separate guidelines were derived from the three sources, for the healthcare team to use with parents, adolescent patients and each other with end of life decision making. The agreement across the studies regarding influencing factors were information on health and disease status of the patient, curative options having been attempted, trusting the healthcare team and feeling support from the health care provided.

Psychosocial needs

Jones 2006[35] reported focus group and survey responses from social workers regarding their perceptions of the psychosocial needs of pediatric oncology patients at the end of life. The needs of children and adolescents were compared. The social workers rated 13 of the 20 items in the survey more highly for adolescents than for children ($p<0.05$). These items were control over treatment decisions, choice of where to die, medical information, education about the disease and structured conversations. The 20 items on the survey accounted for 57% of the total variance in end of life needs.[35]

Parents

Decision Making

Hinds 2005, as discussed earlier, interviewed 19 parents of 20 AYAs aged 10-20 years. The factors most frequently mentioned by parents as influencing EOL decisions were 'continuing to try for a cure for longer', 'trusting staff and being supported by them' and 'deciding as my child prefers'.[28]

Another study by the same authors [40] asked the question "What makes a good parent to my dying child?" Sixty two parents of fifty eight patients with a mean age of 11.3 years, who had made one of three EoL decisions during the previous 72 hours responded to open ended questions about the definition of a good parent and how clinicians could help them fulfil this role. The age rage for the children and AYAs in this study was from 0.6-21.6 so the results could not be delineated between application to children and AYAs. Making informed, unselfish decisions in the child/AYAs interest, remaining at the child/AYAs' side, showing that they are cherished, teaching the child/AYA to make good decisions, advocating for the child and promoting the child/AYA’s health were identified as important aspects. The parents were also asked to describe the actions from staff that would help in their efforts to be a good parent to their child/AYA. Fifteen clinician strategies were identified that help parents to be part of making these decisions on behalf of a child/AYA the most frequent theme being “all that can be done is being done?” appreciating that the family were already receiving the best possible care.

Psychological experiences

Cataudella and Zelcer 2012[33] undertook focus groups with bereaved parents to categorise parents’ perceptions of their AYAs’ psychological experiences at EoL. Three categories were defined: intrapsychic changes, intrapersonal changes and post-traumatic growth. The category intrapsychic changes included two sub categories, ‘emotional & cognitive changes’ and ‘awareness of impending death’. Quotes from the AYAs (10-19) were used to illustrate all of the categories developed. For ‘emotional and cognitive changes’ parents reported that many of the negative emotions experienced by AYA were attributed to physical changes due to disease progression or medication. Cognitive and behavioural sequelae were also reported by many parents. For ‘awareness of impending death’, the majority of parents thought that their AYAs’ awareness of impending death was expressed indirectly through comments, behaviours or gestures. Most parents of younger AYAs thought they knew they were going to die. The category intrapersonal changes included the two sub categories ‘being treated as normal not sick by others’ and ‘remaining connected with others’. For being ‘treated as normal’ parents shared the importance their AYAs placed on wanting to live normally and being treated like normal peers/siblings e.g. attending school and participating in school and social activities. Adolescents and Young Adults desired to be goal-orientated and have a drive to meet developmental milestones more urgently than peers. For ‘remaining connected with others’, most parents reported that children and adolescents in the last month of life wanted and looked forward to contact with close ones; relationships developed between staff and their child helped facilitate discussions about death and dying. The final category was post-traumatic growth and parents commonly described a wisdom beyond their child’s years in accepting their situation, findings ways to have closure with others and in being worried about others in their own situation. Many parents described how their child showed increased strength in coping with aversive treatments/procedures, in accepting developmental achievement regressions, in finding meaning from normal things and in maintaining hope. Coping strategies were taking an active role in decision making and use of humour.

Symptoms

Parents of children whose deceased child (mean age of 10.9 years) had received palliative care for terminal cancer between 1999 and 2002 (n=32/40) in the Netherlands completed questionnaires which sought to examine physical, psychological and social symptoms during the palliative phase.[29] The mean number of physical symptoms per child during the palliative phase was 6.3 (SD 2.7). There were no statistically significant differences in the number of physical and psychological symptoms of the children among the different tumour types ($p>0.05$). The mean number of psychological symptoms of the children varied significantly among the different age groups ($p<0.005$). Post hoc comparison analysis revealed that children older than 12 years suffered from more psychological problems than children younger than 7 years. Loss of perspective, fear of physical symptoms and death and feelings of guilt were more frequently reported in the group above 12 years of age. The mean number of psychological symptoms per child during the palliative phase was 3.2 (SD 2.2). Mean number of psychological symptoms per couple of parents child during the palliative phase was 5.5(SD 1.9). The study also reported that half of the children (50%) did not attend school for lessons during the palliative phase.

4) Practices/interventions used during EOL care

One of the goals of palliative care is to control symptoms,[44] with pain control a major focus of AYA palliative care[45]. Three studies reported on pain control; one was a prospective cohort study[27] and the other two used a retrospective design.[13,37] . One further study investigated control of a variety of physical symptoms control through a retrospective review of medical notes.[31]

The study by Noyes and Irving 2001[27] reported on the experience at one children's hospital of the use of transdermal fentanyl for pain relief in pediatric oncology palliative care. The authors described transdermal fentanyl as offering a non invasive approach to the management of patients with chronic cancer pain with ease of administration and reduction in opioid side effects. Patients were eligible for treatment if they had progressive malignant disease, opioid-sensitive and stable pain, a minimum daily oral morphine requirement of 30mg/day, experiencing side effects from oral opioids or poor compliance with oral medication. All four adolescents either had oral opioid side effects or poor oral compliance. Duration of previous oral opioid therapy in the four adolescents ranged from 4-10 days. The authors noted that older patients were reluctant to take immediate release morphine as they did not wish to experience the associated drowsiness. One adolescent patient in particular (17y 6m male) was reported to have experienced excellent pain relief with fentanyl which impacted positively on his mobility. The efficacy of fentanyl was judged as 'good' (defined as patient only requiring occasional or up to two rescue doses of morphine per day) in all four adolescents with no adverse reactions and all four continued with fentanyl until death

All pediatric patients aged 0-24 years treated at 38 children's hospitals located throughout the US were included in the study by Orsey et al 2009.[13] The dataset was extracted using clinical information contained within the Pediatric Health Information System and the consisted of 1,466 patients across 33 hospitals. To aim of the study was to assess variation in opioid prescription during the last week among a cohort of pediatric oncology patients who while hospitalised. The likelihood of a daily opioid prescription during the hospitalised portion of the last week of life varied by three patient-level characteristics: patient age, broad category of cancer diagnosis) and length of hospital stay. Those aged 10-14 years were most likely to receive daily opioids, those with brain tumours significantly less likely to and those who died within 3 days of hospitalisation more significantly likely. Opioid prescription during the hospitalised portion of the last week of life was found to vary substantially among hospitals, even after adjustment for clinical characteristics of the patients. In the multilevel multivariate logistic regression model patients between the ages of 10 and 19 years were most likely to have daily opioid prescription.[13]

Anghelescu et al (2010) examined the impact of epidural and peripheral nerve block catheters on pain control in children and young adults with cancer within the last 3 months of life over an 18 month period obtained information from pain and palliative care databases.[37]

Seven adolescents were included and separate results were reported for each of the participants. A description of the clinical characteristic of each of the patients and the interventions for pain management were recorded but no further discussion for the young adult population was provided.[37]

Janssen et al (2000) reported on the experiences of using Boswellic acids in the palliative therapy of children and AYAs with progressive or relapsed brain tumours over a 4 year period in one hospital in Germany. The sample included 8 adolescents (11-18 years) of which 2 had stated subjective relief of symptoms, other adolescents had noted a reduction in headache(n=1), an increase in muscular strength (n=2), an improvement in hemiparesis (n=2) and cachexia (n=1).[31]

Discussion

Setting

This scoping review included 20 studies published over a fourteen year period that investigated or described issues related to end of life care in adolescents and yound adults with terminal cancer. The vast majority of available literature was based primarily on medical record review of deceased patients, interviews with bereaved parents 3-12 years after the AYA's death, and to a lesser extent staff observations. Studies to date of EoL care for AYAs have used retrospective, descriptive designs, been conducted in single institutions and have included small numbers of patients. With the exception of a very small number of studies the perspective of the dying AYA has not been explored. This has also been reported for previous reviews for paediatric oncology patients (mainly chidren) with cancer at EoL.[6,28] A number of papers were excluded from the scoping review beacause it was not possible to determine which findings were derived from the adolecent age group or because the findings specific to adolescent oncology partipants could not be distinguished from those of other non oncology related partipcants.

Only seven out of the 20 papers dealt solely with AYAs with cancer The current state of research reflects the way that cancer care is ”splintered” beyween paediatric and adult oncologists.[16] Adolescents and young adults with cancer can be treated at either paediatric or adult cancer centres.[51] In the UK since the 1990’s a number ofcomprehensive AYA units have been developed. There are a few units in Australia and Europe, however although AYA units are in development in North America and Canada no dedicated physical units currently exist across the United States.[51-52] Albritton and Bleyer 2003[53] suggest that the choice of specialism would vary on a case wise basis, depending on the nature of the tumour but that in reality the referrals are often haphazard. The literature suggests that referral decisions reflect the judgment of the referring physician[16,43] familiarity with a specific referral instititution[16] as well as patient age at diagnosis[16,43] and type of cancer.[16] In some instances the early adolescents are referred to paediatric oncologists and older adolescents seen by a variety of specialists depending on their presenting symptoms.[45]

EoL Care

The aim of palliative care for AYA is to enhance the quality life for both the AYA and the family and should begin when an AYA is diagnosed with a life-limiting or life threatening condition.[45]

End of life care involves the management of physical and psychological symptoms, including relief of suffering from adverse effects of treatment, discussion about the place of death, improved quality of life for patients and their families and support of family.[46-47] Ramphall et al (2011) suggests that in paediatric and adult institutions, there is often a lack of awareness or focus on many psychosocial issues AYAs face as they would be surrounded by patients much older or younger than themselves.[16] Adolescents and young adults as individuals undergo developmental stages marked by rapid changes in cognitive and emotional growth and if psychological and supportive care are to be delievered appropriately then these issues must be taken into consideration.[47-48] Such psychosocial issues for AYAs include being able to maintain an active and independent life, coping with treatment related side effects and stress, seeking and understanding informaton, accepting cancer and maintainng a positive attitude.[49] A stakeholder group working as part of a recent review conducted by

Pritchard et al 2011 identifed the key issues and priorities for AYAs which were: i) psychosocial needs of the patient, family and friends and caregivers, ii) transition to palliative care-when, how and where, iii) resources required for the patient, family and healthcare system and iv) advocacy (Health care professionals are required to advocate for the needs of this population and increase awareness within hospitals, communities and government).[50]

For such issues to be considered more research needs to be conducted with AYAs themselves. Trying to obtain information retrospectively from medical records to answer such questions has proved to be challenging with very little information of what specific services or treatments both physical and psychological had been given during the EOL/palliative phase being reported.[26]

Place of Death

The AYA and the family should be able to decide where they would like palliative treatment and ultimately place of death to take place, for example home, hospital or hospice.[45] Even in countries where data were available huge variance exists and there is still little rigorous research that documents parents and AYAs preference. Appropriate facilities including hospice and home care at EoL vary considerably from country to country and needs to be taken into account.

Advanced Care planning

An advance care planning document may be appropriate and helpful for terminally ill AYA patients with metastatic cancer.[43] They give the AYA the opportunity to express and capture preferences.[38,54-55] and may be an aid in initiating EOL discussions between patients, families and clinicians.[43] Allowing AYA involvement in ACP can help parents and health care agents make informed decisions, alleviate distress, avoid regret and could improve the patient's quality of life by taking into consideration their religious, cultural and familial values and beliefs.[57-58] Such documents exist for the adult population but few resources exist to aid AYAs in addressing their changing physical, emotional and social needs and wishes around EoL.[38] Two studies[38-39] explored issues around the use of ACP documents for AYAs. As a result of the work by Wiener and colleagues[38] a new guide has been produced called "Voicing My Choices: A Planning Guide for Adolescents and Young Adults" which incorporated what the AYAs felt was important to them in enabling EOL discussions.[59] The approach used by Lyon and colleagues[39] showed that using a number of Family-centred ACP tools combined with hypothetical scenarios resulted in adolescents being better informed about EOL options, improved parents' understanding of the AYAs preferences and more agreement between parents and patients about limiting treatment.[39]. Previous work by the same authors regarding EoL decision making for adolescents with and without a chronic illness which included AYAs with cancer found that across all chronic illnesses AYAs would prefer to discuss their wishes later in the course of their illness with only 16% wanting to do this when actually dying.[60]

Limitations of the review

This is a scoping review to present the current range of evidence relating to end of life care for adolescents and young adults with cancer. The aim of the review was not to provide generalisable conclusions other than that related to the current state of knowledge, but to identify the range of evidence available. The heterogeneous and descriptive nature of the quantitative studies meant we were unable to synthesise the work in a meta-analysis. No qualitative studies were located. Studies were limited to those published in English only.

Conclusion

The aim of this scoping review was to gather information that sheds light on the EoL care provided to AYAs with cancer. We were particularly interested in the factors that influence care provision, the experiences and perceptions of AYAs their family carers and health professionals and effective practices and interventions that support this group. Very few studies investigated interventions including pain control, and this may be because very few EoL studies focus specifically on the need of AYAs, they are instead included in studies with adults and younger children.

With regard to factors influencing care and experiences and perceptions, only one author Hinds[28] interviewed AYAs, their parents and health professionals involved in their care, who had been faced with actual decisions about their EoL care. The need for AYAs to be involved in decision making and care planning has been identified through the development of advanced care planning documents aimed specifically at AYAs such as “Voicing My Choices: A Planning Guide for Adolescents and Young Adults”[43] and this raises questions for future studies, whether investigating AYAs wishes through this approach is more feasible than when AYAs are at the EoL stage of care.

Conflicts of interest

None to declare.

Implications for practice

Despite the limited research presented, providing AYAs and their family carers with sound information regarding the EoL care options available to them appears to be a significant way forward. Where AYAs have made EoL decisions they appear to exhibit competent decision making and they should be provided with this opportunity through the use of advance care planning documents at a suitable stage of their illness.

Implications for research

Clarification is necessary to enable future studies to be compared and synthesised, this should include clear identification of the age group involved, their diagnosis and stage of treatment. Future research should focus specifically on adolescents and young adults at the end of life and consider both their perspective and that of their carers, both families and health care professionals, particularly with regard to decision making; this may necessitate using hypothetical care planning scenarios. There is an overall lack of in depth qualitative studies that explore the needs and requirements of AYAs receiving or anticipating to receive end of life care. Whilst retrospective data documenting place of death is important to plan future care services, research should also focus what factors impact on the choice of home, hospice or hospital care on to determine the appropriate place of death and where end of life care should be provided on an individual basis that considers culture, the type of care required and the needs of both AYAs and their families. Further research needs to be undertaken to determine effective interventions and strategies for AYAs to address issues such as control of pain and other symptoms at EoL where adult and paediatric regimes do not meet the specific needs of the AYA.

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Appendix 1: Medline Search Strategy

Undertaken 30/08/2012

Search Number	Search Terms	Results
1	exp Adolescent/	1493907
2	Adolescen*.mp	1514363
3	Teen*.mp	18671
4	exp Young Adult/	240434
5	“Young adult*”.mp	281277
6	“Young person”.mp	511
7	“young people”.mp	13152
8	Juvenile*.mp	13152
9	AYA.mp	98
10	“young patient*”.mp	16757
11	“young wom#n”.mp	18721
12	“young m#n”.mp	12835
13	Youngster*	1863
14	Youth.mp	27424
15	exp Child/	1452938
16	Child*.mp	1721558
17	P?ediatric.mp	172878
18	1/18 OR	2697023
19	exp Neoplasms/	2379037
20	Cancer*.mp	911589
21	Malignan*.mp	357236
22	Neoplasm*.mp	1954182
23	Leuk?emia	238762
24	Melanoma.mp	85994
25	Lymphoma*.mp	168070
26	Tumo?r.mp	1091468
27	Carcino*.mp	679368
28	Oncolog*.mp	74909
29	Sarcoma*.mp	89517
30	19/29 OR	2906464
31	exp Terminal Care/	38375
32	exp Palliative Care/	36852
33	exp Terminally Ill	5057
34	exp Hospice Care	4163
35	EOL.mp	541
36	(end adj5 life).mp	10804
37	(terminal adj2 care).mp	19967
38	(dying adj2 child*).mp	628
39	(terminal adj2 ill*).mp	1412
40	31/39 OR	75045
41	18 AND 30 AND 40	2521
42	Limit 41 to (English language and yr=”1992-Current” and humans	**1584**

Appendix 2: Screening Tool

Reference: ____ Country_________________

First Reviewer____________________ Second Reviewer________________________

	Yes	No	
End of Life Care	☐	☐	
Adolescents (16-24 years)	☐	☐	**exclude**
Included with children	☐	mean (years)	range (years)
Included with adults	☐	mean (years)	range (years)
Included with children & adults	☐	mean (years)	range (years)
Separate results reported for TYA	☐	☐	**exclude**
Research	☐	☐	**exclude**
Review article	☐		
Cancer	☐	☐	**exclude**
Included with other conditions	☐		

If included then

Research Design

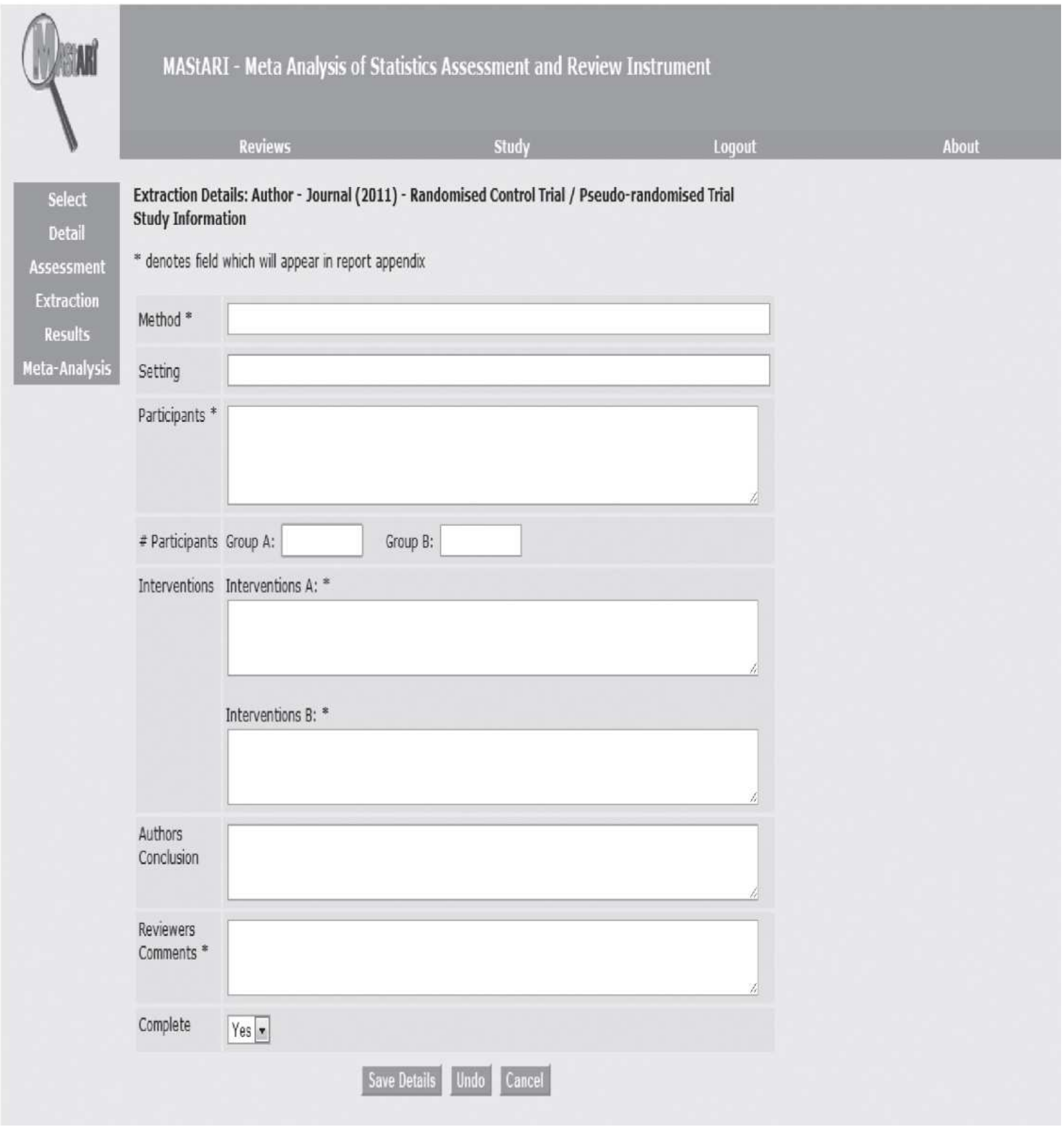
Quantitative	☐	Specify…………………………………………………………………….
Qualitative	☐	Specify…………………………………………………………………….

Participants

Adolescents (16-24 years)	☐	Mean (years)…………	Range (years)…………………
Parents	☐		
Siblings	☐		
Health Professionals	☐	Specify……………………………………………………………………	

Type of cancer Specify……………………………………………………………………………….

Appendix 3: Data Extraction Tool : MAStARI



Extraction Details: Author - Journal (2011) - Randomised Control Trial / Pseudo-randomised Trial
Study Information

* denotes field which will appear in report appendix

Method *
Setting
Participants *
\# Participants Group A: Group B:
Interventions Interventions A: *
Interventions B: *
Authors Conclusion
Reviewers Comments *
Complete Yes

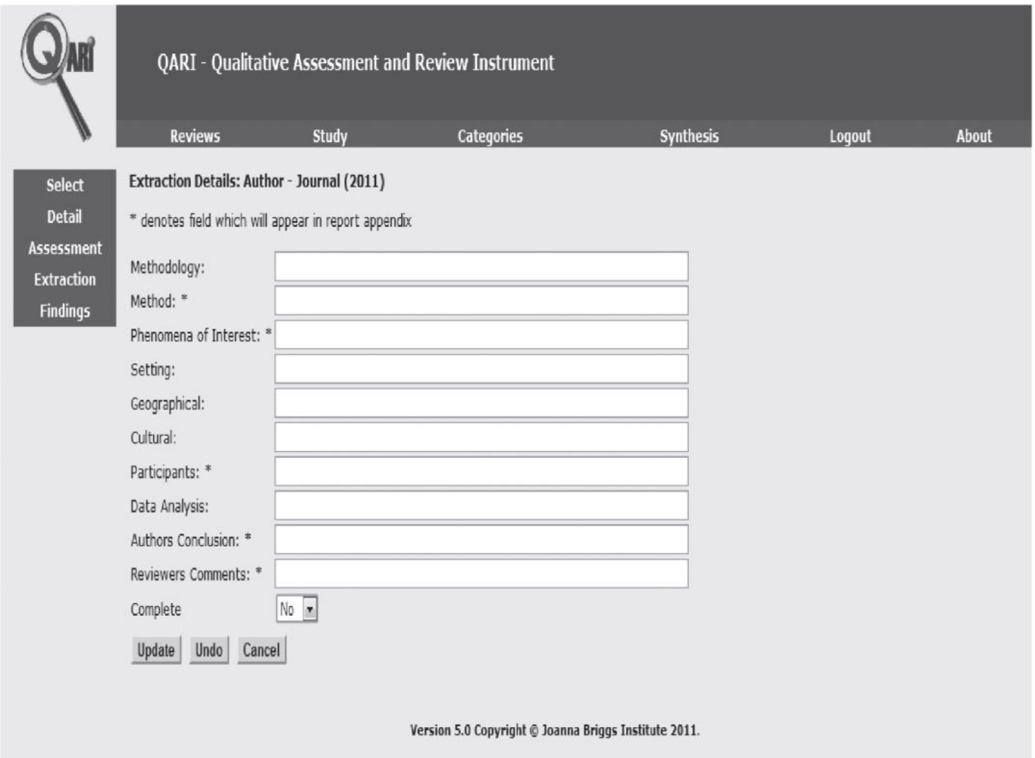
Dichotomous Results for: Author - Journal (2011)

Intervention	Result	
	n	N
New Abbreviation		
V		
New Abbreviation		

Continuous Results for: Author - Journal (2011)

Intervention	Result		
	Mean	SD	N
New Abbreviation			
V			
New Abbreviation			

Appendix 4: Data extraction tool: QARI



Extraction Details: Author - Journal (2011)

* denotes field which will appear in report appendix

Methodology:
Method: *
Phenomena of Interest: *
Setting:
Geographical:
Cultural:
Participants: *
Data Analysis:
Authors Conclusion: *
Reviewers Comments: *
Complete: No

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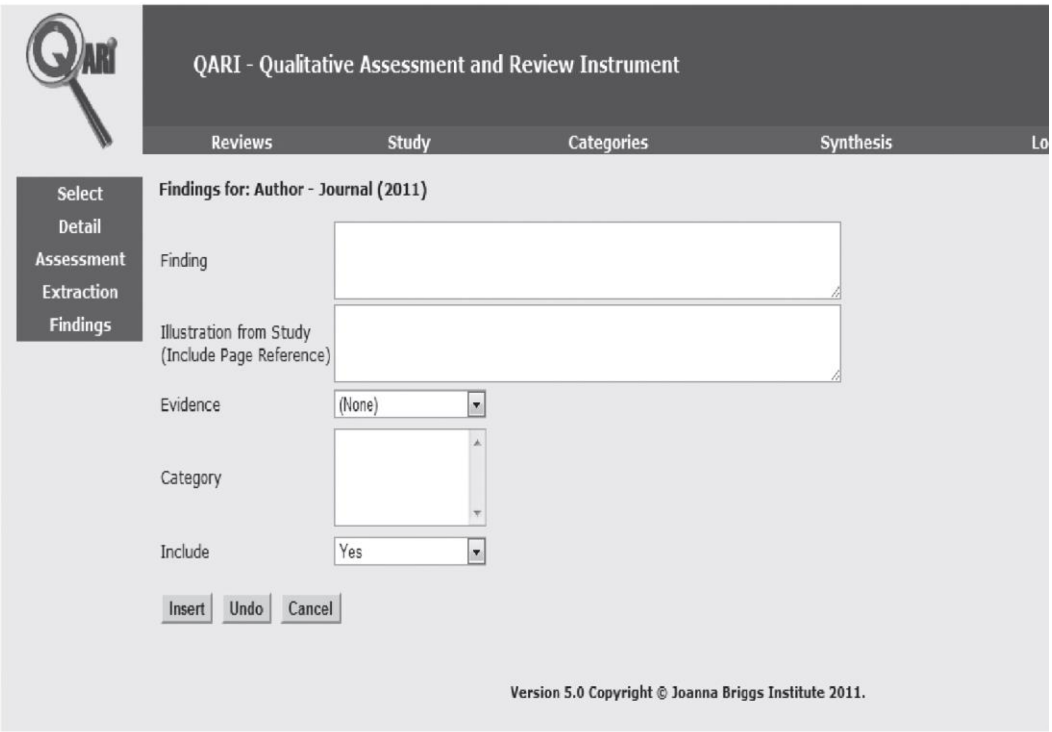

Findings for: Author - Journal (2011)

Finding
Illustration from Study (Include Page Reference)
Evidence: (None)
Category
Include: Yes

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Appendix 5: Included studies table

Author, Year of publication Country, Source of data, Aims	**Design & Methods**	**Population**	**Age**
Noyes and Irving 2011[27] Australia Royal Children's Hospital – oncology Unit Queensland and Northern New South Wales To report on the experience at one children's hospital in the use of transdermal fentanyl for pain relief in pediatric oncology palliative care	**Prospective cohort** Time frame EOL Treatment time Palliative treatment to death 6 hours to 22 days	Children (n=9) and adolescents (n=4) in receipt of palliative care for progressive malignant disease between March 1997 and December 1999 Cancer Diagnosis Leukaemia (n=1) Solid tumours (n=3) Treatment Transdermal fentanyl	Age at treatment (years) 3.9-18.7 years Separate results were provided for all participants 13 years 4months 16 years 4 months 18 years 7 months 17 years 6 months
Orsey et al 2009[13] USA Pediatric Health Information System database for 38 children's hospitals located throughout the USA To assess variation in opioid prescription during the last week among a cohort of pediatric oncology patients who while hospitalised	**Retrospective cohort** Retrospective review of medical notes 1 week pre death Time frame EOL Opioid medications during last week of life	Children and adolescents treated at 33 hospitals between 2001 and 2005 Cancer Diagnosis Leukaemia & Lymphoma (n=734) Brain (n=235) Bone and soft tissue (n=107) Other (n=350) Treatment Opioids	Age at treatment (years) 0-24 years (n=1466) 10-14 years (n=322) 15-19 years (n=340) 20-24 years (n=60)

Janssen et al 2000[31] Germany Children's Hospitals of Bonn, Dusseldorf and Wuppertal To report experiences with Boswellic acids in the palliative therapy of children with progressive or relapsed brain tumours	**Retrospective cohort** Retrospective review of medical notes Time frame EOL Median treatment time 9 months Range 1-26 months	Children and adolescents treated at four children's hospitals between 1995 and 1998 Cancer Diagnosis Brain tumours (100%) Treatment Boswellic acids	Age at death (years) 0.5-18 years (n=19) 11-13 years (n=5) 14-18 years (n=3)
Hinds et al 2001[41] USA To use three sources to develop guidelines for end of life decision making in pediatric oncology	**Study 1** Retrospective descriptive Open-ended interview questions via telephone & a 15 item questionnaire for parents. Face to face interviews with health professionals. **Study 2** Prospective descriptive study Interviews **Study 3** Prospective descriptive, cross sectional, three site international feasibility study	**Study1** Parents (n=39/83) of patients (n=37) at a pediatric oncology institution who had died in the previous 6-24 months and corresponding healthcare professionals (n=37) **Study 2** Parents (n=52) from 51 families, and one 18 years old patient making her own decision and adolescents (n=9/15 physicians (n=22/24) **Study 3** Parents (n=43) who had made an end of life decision within the past few hours to 3 weeks.	**Study 1** Age at death (years) Hinds et al (1997) Mean 13.27 (SD 5.10) Range 1.7-23.8 years **Study 2** Age at treatment (years) 15-18 years **Study 3** Age at death (years) Not specified

Hinds et al 2005[28] Australia, USA St Jude Children's Research Hospital in Memphis Sydney Children's Hospital In Sydney To identify the preferences of children and adolescents with advanced cancer about their end of life care and the factors that influenced their decisions	**Descriptive** **Cross sectional survey** Interviews Time frame EOL End of life decision making within the previous 7 days	Children and adolescents from one pediatric oncology centre (n=20) and their parents and physicians Cancer diagnosis Refractory slid tumour (n=12) Brain tumour (n=4) Leukemia (n=4)	Age at time of study (years) 10-20 years Mean 17 years and 4 months
Hinds et al 2009[40] USA St Jude Children's Research Hospital in Memphis To explicate the meaning of being a good parent to a child with incurable cancer	**Descriptive** **Cross sectional survey** Interviews Time frame EOL End of life decision making within previous 72 hours	Parents of patients had made a non curative treatment decision during the previous 72 hours. 62 parents of 58 patients participated. Cancer diagnosis Solid tumour (n=30) Brain tumour (n=21) Leukemia (n=7)	Age at time of study (years) Mean age 11.3 (SD 6.2) Median 11.4 Range 0.6-21.6 years
Surkan et al 2006[30] Sweden Swedish Cause of Death Register To assess the relationship between place of the child's end of life care in relation to several possible predictors related to parental; awareness of the child's impending death. To examine symptom relief relative	**Retrospective descriptive** Questionnaire (365 items) Time frame EoL EoL defined as last month of life and parents sent	Parents of children (n=254) and adolescents (n=195) (diagnosed with cancer before 17 years and dying before 24 years between 1992 and 1997 Cancer diagnosis Brain tumour (n=150) Leukemia or lymphoma (n=141) Sarcoma or neuroblastoma (n=87) Other malignant disease (n=41)	Age at diagnosis (years) 9-15 years (n=97) 16-24 years (n=98)

to place of end of life care EoL home care and parental awareness of impending death			
Theunissen et al 2007[29]Netherlands Department of Pediatric Haematology/Oncology of the Radboud University Nijmegen Medical Centre To examine physical, psychological and social symptoms of children with cancer and their parents during the palliative phase	**Retrospective descriptive** Questionnaires Time frame EoL Palliative care defined as shift in the goal from cure to palliation	Parents of children whose deceased child had received palliative care for terminal cancer between 1999 and 2002 (n=32/40) Cancer Diagnosis Leukemia / MDS (n=10) Brian tumour (n=10) Other solid tumours (n=12)	Age at death (years) Mean 10.9 (SD 4.9)
Cataudella and Zelcer 2012[33] Canada Patient tumour registry for south western Ontario To explore the psychological experiences of children with brain tumours at the end of life	**Retrospective descriptive** Focus groups of bereaved parents Time Frame EOL Mean = 5 years Median 5.5 years	Parents of children (n=24) who have died from a brain tumour from 1996-2006 Cancer Diagnosis Brain tumours (100%)	Age at death 1-5 years (n=3) 8-11 years (n=3) 12-19 years (n=11)
Higginson and Thompson 2003[20] United Kingdom Death registrations in England and Wales To investigate the associations between place of death and potential explanatory variables for children and young people who die from cancer	**Retrospective descriptive** Retrospective data analysis for all cancer deaths from death registrations in England & Wales 1995-1999	Children, adolescents & young adults who died from cancer 1995-1999 Cancer Diagnosis Brain cancer (n=176) Leukaemia & Lymphoma (n=379) Bone and soft tissue (n=259) Endocrine glands other than thyroid (n=20) Hodgkin's disease (n=70) Kidney and other urinary cancer	Age at death (years) 0-15 years n=1725 of which 11-15 years n=525 16-24 years n= 1472 of which 16-20 years n=712 of which 21-24 years n=760

		(n=10) Melanoma (n=51) Female genital organs (n=52) Testis (n=36) Other (n=419)	
Shah et al 2011[32] United Kingdom National Registry of Childhood Tumours for England To describe patterns of care and to evaluate factors influencing place of death for children who died after a diagnosis of cancer in England during 1999-2006	**Retrospective descriptive** Retrospective data analysis for all registrations of children who were diagnosed with cancer and died during 1999-2006	Children (n=1864) under 15 years who were diagnosed with cancer and who died under the age of 20 years <u>Cancer Diagnosis</u> Brain and spinal tumours (n=640) All leukaemias (n=456) ALL (n=236) AML (n=140) Soft tissue sarcomas (n=180) Sympathetic nervous system tumours (n=175) Bone tumours (n=135) Lymphomas (n=112) Renal tumours (n=71) Hepatic tumours (n=38) Epithelial tumours (n=37) Germ call and gonadal tumours (n=13) Other and unspecified malignant neoplasm (n=7)	<u>Age at death (years)</u> 10-14 years (n=503) 15-19 years (n=179)
NCIN 2011[34] To determine place of death for children , teenagers and young	**Retrospective descriptive**	Children, teenagers and young adults who died from cancer 2000-2009	<u>Age at death (years)</u> Under 15 years (n=1,454) 15 -24 years (n=1,767)

adults with Cancer in England UK	Retrospective data analysis for all cancer deaths from the National Cancer Data Repository in England (excluding London and South East England) 2000-2009		
Anghelescu et al 2010[37] USA St Jude Children's Research Hospital in Memphis To examine the impact of epidural and peripheral nerve block catheters on pain control in children and young adults with cancer within the last 3 months of life	**Retrospective cohort** Survey of pain and palliative care databases <u>Time frame EOL</u> 3 months preceding death	Children and young adults who had epidural and/or peripheral nerve block catheters for pain control at the end of life between May 2008 and October 2009 <u>Cancer diagnosis</u> Solid tumours (n=9) Lymphoma (n=1) <u>Treatment</u> Epidural and/or peripheral nerve block catheters for pain control	<u>Age at death (years)</u> 4.4-21.3 years (n=10) 13.2-21.3 years (n=7) Separate results were reported for each participant. <u>Pain Control</u> Description of the clinical characteristic of each of the patients and the interventions for pain management. <u>Place of death</u> Death location (Preferred: home (n=6), hospital (n=1), Actual: home (n=6), hospital (n-1) Four adolescents died with a catheter in place, two at home.
Bell et al 2010[42] USA Midwestern tertiary care centre To explore the EoL experiences of adolescents dying from cancer,	**Retrospective cohort** Data obtained from charts, medical records, outpatient clinic nursing phone logs, and social work files on each	Adolescents between 10-21 years treated from 1982 to 2004 and who subsequently died between 2000 and 2005 <u>Cancer Diagnosis</u> Leukaemia & Lymphoma (n=40)	<u>Age at diagnosis</u> 0.53-19 years Mean 11.2 (SD 4.5) years) <u>Age at death (years)</u> 10-21 years (n=103) Mean 14.4 (SD 2.9) years

including place of death, medications used at EOL, and initiation of EOL discussions between health professionals and adolescents during early, middle and late adolescence and their families	patient Time frame EOL EOL defined as time from initial EOL discussion to death and categorised as 0-14 days 15-30 days 31-60 days 61-179 days 180-880 days But numbers of adolescents in each category not reported	Solid tumour (n=39) CNS / brain tumour (n=10)	Early adolescence 10-13 early (n=42) Middle adolescence 14-17 years (n=44) Late adolescence 18-21 years (n=17)
De Graves and Aranda 2012[26] Australia Single tertiary paediatric centre To explore the extent in which the shift from cure to palliation is reflected in the child's medical record	**Retrospective cohort** Medical record review In depth content analysis Time frame EOL Period of EOL care not defined data was collected from medical notes from diagnosis to death	Children (n=18: adolescents n=9) with cancer who died from disease progression during 1999 Cancer Diagnosis Myoepithelial tumour (n=1) Ewing's sarcoma (n=1) Acute lymphoid lymphoma (n=2) Burkitt's lymphoma (n=1) Osteosarcoma (n=1) Brainstem glioma (n=1) Cerebral glioblastoma (n=1) Primitive neuro ectodermal tumour (n=1) Medulloblastoma (n=1)	Age at diagnosis Mean age 7.5 years Range 0.7 - 16 10-13 years (n=5) 14-16 years(n=4) Age at death Mean 10 years Range 3-17 10-13 years (n=3) 14-17 years (n=6)
Cohen-Gogo et al 2012[5] France Pediatric and Adolescent Oncology Department at the Institut Gustave	**Retrospective cohort** Medical and nurses chart analysis	Patients over the age of 13 years who had consulted at least once and died between January 2007 and December 2008 (n=45)	Age at diagnosis (years) Median 15.9 Range 5.2-24.2 years Age at death (years)

Roussy To provide broad baseline information about clinical history and patterns of EOL care of AYA in one adolescent unit	Time frame Clinical history of cancer and cancer treatment, patterns of physical symptoms collected during last week of life Time Frame EOL Last month of life	Cancer Diagnosis Sarcomas (n=19) Brain tumours (n=16) Leukaemia & Lymphoma (n=3) Other solid tumours (n=7)	Median 18.8 years Range 14.2-26.2 years
Montel et al 2009[25] France Paediatric Oncology Department of a regional cancer centre To study the place of death of adolescents and young adults treated within Institute Curie (Cancer Centre) and to identity some of the determinants of the choice of place of death	**Retrospective cohort** Semi structured interviews Socio-demographic data also extracted from medical notes Time frame EOL not defined	Parents and/or partners of adolescents/young adults aged between 15-25 who died between 2000-2003 (n=21) Cancer Diagnosis Ewing sarcoma (n=7) Oestosarcoma (n= 6) Rhadomysacroma (n=3) Chondosracoma (n=1) Neurobastoma (n=1) Malignant temporal tumour (n=1) Neuroectodermal tumour (n=1) Pulmonary adenocarcinoma (n=1)	Age at death (years) 19 years ± 5 years
Jones 2006[35] USA Social workers perspectives on the needs of children with cancer and their families at the end of life	**Descriptive** **Cross sectional survey** Questionnaire with open ended questions Time frame EOL Not defined	Paediatric oncology social workers (n=131)	Psychosocial needs of children (0-14 years) and adolescents (15-21 years)
Lyon et al 2013[39] USA	**Randomised controlled trial (RCT)**	Adolescents aged 14-21 years with cancer (n=30) their surrogates or families enrolled	Age at time of study Mean 16.3 / Mode 14 years Range 14-21 years

Pediatric oncology program To examine the efficacy of family centred advanced care planning (ACP)	2 group RCT in a paediatric oncology program At baseline all participants given ACP brochure **Intervention (I)** - 3 sessions of approx. 60 mins weekly to go through ACP document (n=17). **Control (C)**- Did not receive 3 session-facilitated conversation but standard care (n=13) Completed the same assessments at the same 5 time points <u>Time Frame EOL</u> Not defined	between January 2011 and March 2012 <u>Cancer Diagnosis</u> Leukaemias (n=14) Lymphoma (n=2) Solid tumour (n=6) Brain tumour (n=8)	
Wiener et al 2012[38] USA Pediatric Oncology Branch from the National Cancer Institute To assess and compare the usefulness, helpfulness and stress associated with receiving a previously adapted ACP guide My Thoughts, my Wishes, My Voice	**Descriptive** **Cross sectional survey** <u>ACP tool development</u> A 5-point Likert-type scale evaluating the degree of helpfulness and stressfulness of each wish contained within a previously adapted advance care planning	Adolescents aged 16-28 years living with recurrent or metastatic cancer (n=26) or HIV (n=26) between March 2008 – August 2011 <u>Cancer Diagnosis</u> Recurrent or metastatic cancer (n=26)	<u>Age at time of study</u> Mean 20.3 years Range 16-28 years

(MTMWMV) in comparisons with the widely used adult document Five Wishes by AYS's living with a serious illness	guide, (MTMWMV) in comparison with the widely used document Five Wishes by adolescents and young adults living with a serious illness. <ins>Time Frame EOL</ins> Not defined		

Key: AYA – Adolescents and young adults, CCLG – Children's Cancer and Leukaemia Group

Appendix 6: Reasons for excluding studies

Reasons for exclusion	**n**
Children included with adolescents -data not presented separately	70
Adolescents included with adults - data not presented separately	47
Data related to children only, not adolescents	24
Adolescents included with children and adults-data not presented separately	14
Not EoL	38
Not research	23
Not cancer	6
Unavailable	4
Adults	10
Adolescent carers	2
Individual Case studies	28
Same study published multiple times	14
Review Paper	16
Total	296