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Current understanding of decision-making in adolescents with cancer: A narrative systematic review

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Abstract

Background: Policy guidance and bioethical literature urge the involvement of adolescents in decisions about their healthcare. It is uncertain how roles and expectations of adolescents, parents and healthcare professionals influence decision-making and to what extent this is considered in guidance.

Aims: To identify recent empirical research on decision-making regarding care and treatment in adolescent cancer: (1) to synthesise evidence to define the role of adolescents, parents and healthcare professionals in the decision-making process and (2) to identify gaps in research.

Design: A narrative systematic review of qualitative, quantitative and mixed-methods research. We adopted a textual approach to synthesis, using a theoretical framework of interactionism to interpret findings.

Data Sources: The databases MEDLINE, PsycINFO, SCOPUS, EMBASE and CINHAL were searched from 2001 through May 2015 for publications on decision-making for adolescents (13–19 years) with cancer.

Results: Twenty-eight articles were identified. Adolescents and parents initially find it difficult to participate in decision-making due to a lack of options in the face of protocol-driven care. Parent and adolescent preferences for information and response to loss of control vary between individuals and over time. No studies indicate parental or adolescent preference for a high degree of independence in decision-making.

Conclusion: Striving to make parents and adolescents fully informed or urge them towards more independence than they prefer may add to distress and confusion. This may interfere with their ability to participate in their preferred way in decisions about care and treatment. Future research should include analysis of on-ground interactions among parents, adolescents and clinicians across the trajectory.

Keywords

Cancer, adolescence, decision-making

What is already known about the topic?

- Decisions made by adolescents with cancer and their families have lifelong consequences.
- Guidance and bioethical literature increasingly advocate the participation of adolescents in decisions about their healthcare.
- Little guidance is offered to elucidate what this involvement looks like in practice, over time and across decisions for 13 to 19-year olds and their parents.

What this paper adds?

- This review enhances understanding of parents and adolescents' informational preferences as well as their actual and preferred roles in the decision-making process.

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- Adolescents exercise agency in decisions in a variety of ways but do not find a clearly defined role in decision-making comparable to that of parents and clinicians.
- No studies identified parental or adolescent preference for a high degree of independence in decision-making. Partnership and cooperation were most frequently stated or implied.

Implications for practice, theory or policy

- Assuming or advocating that all parents and adolescents desire to be or should be fully informed or independent in decision-making may increase their distress and confusion. This, in turn, may interfere with their ability to participate in their preferred way in decisions about care and treatment.

Introduction

Adolescents with cancer are both biologically and psychosocially distinct from children and older adults with the disease. National incident rates of teenage cancer are rising with some suggesting an increase of 50% in the last 30 years.[1] Outcomes for adolescents are poorer than for children and older adults. Five-year survival rates for acute lymphoid leukaemia, for example, decrease across by 30%–40% across the 10–19 years range.[2]

Undifferentiated from adult and paediatric populations in the past, there are limited psychosocial and biological data that attend specifically to 13 to 19-year olds. However, Weaver et al.[3] state that 'pediatric and adolescent age oncology patients and their families have identified their psychosocial care needs as both complex and unique from adult psychosocial care needs'.

It is increasingly being argued that the concepts of palliative care are a valuable resource in helping oncologists care for this population. Aimed at preventing and alleviating suffering, the use of palliative care concepts and skills is now thought to be appropriate from diagnosis forward, even in cases for which cure is likely.

One of the areas in which palliative care concepts provide a resource for the oncologist is in support of communication and decision-making. This is an area of high importance in the treatment of adolescent cancer. Decisions must be made about treatment, fertility preservation, transplant, enrolment in clinical trials, discontinuation of treatment and place of care and death when standard therapy has failed.

A first step towards the successful integration of palliative care principles is to analyse and understand decision-making in this population. This may reduce the possibility that despite the best of intentions, suffering is increased or prolonged through the application of principles, which do not respect the situation or align with the needs of participants.

Objectives

In this article, we report on a systematic narrative review of empirical research published internationally between 2001 and 2015 that illuminates the role of adolescents, parents or healthcare professionals (HCPs) in the decision-making processes surrounding care, treatment and future life. We sought to understand current qualitative, quantitative and mixed-methods research evidence on decision-making for adolescents (13–19 years) with cancer. We understand 'decision-making' to mean the process of interaction between two or more participants when information is processed and a judgement or conclusion is reached at any point across the disease trajectory.

We aimed (1) to identify recent empirical research that investigated decision-making regarding care and treatment in adolescent cancer, from the perspective of the adolescent, their parents and families or their HCPs; (2) to produce a narrative synthesis of existing evidence defining the participation, role and place of adolescents, parents and HCPs in the decision-making process; and (3) to identify gaps in the current literature in terms of methodology, perspective and design to inform future studies.

Method

Search strategy

We searched the databases MEDLINE, PSYCHINFO, SCOPUS, CINHAL and EMBASE to ensure inclusion of medical, social science and bioethics literature. For papers that were not accessible online, we contacted authors directly and requested copies. If authors failed to respond within 6 months, these papers were excluded.

We limited our search to papers published between 2001 and 2015. This time frame was chosen as 2001 saw the publication of the UK NICE Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer,[2] which set out to improve communication and informed choice with this age group.

We used the following search terms:

1. Cancer* including, leuk*emia or, lymphoma or neoplasm*;
2. Adolescen* including, p*ediatric or child or children;
3. 'Decision-making';

*=Truncation.

Inclusion/exclusion criteria

We included English-language qualitative, quantitative and mixed-method studies that focused on 13 to 19-year olds diagnosed with any form of cancer and dealt with decision-making about care, treatment and research participation over the course of illness. We also included articles that reported the perspective of the adolescent, HCP or parent(s) in isolation or in combination with one another. Retrospective studies were included if an adult participant was discussing decision-making with regard to care and treatment when he or she had been diagnosed with a cancer as an adolescent. We considered studies where patients aged 0–18 were investigated and included those studies where the mean age of participants was clearly reported and fell between 13 and 19 years as well as those where reporting was stratified by age such that findings for 13–19 year olds could be discerned.

We excluded papers which discussed adolescents who were not themselves diagnosed with cancer, those that discussed decisions about cancer screening or cancer prevention as well as participation in non-clinical studies and general texts on paediatric palliative care or cancer that did not focus specifically on 13 to 19-year olds or decision-making.

Papers identified from the initial database searches were screened for duplicates, which were removed. Citations were then screened for relevance and those that did not meet our inclusion criteria were removed. Full-text articles were independently screened by two reviewers (E.D., L.J.) and included articles were assessed for study quality (Figure 1).

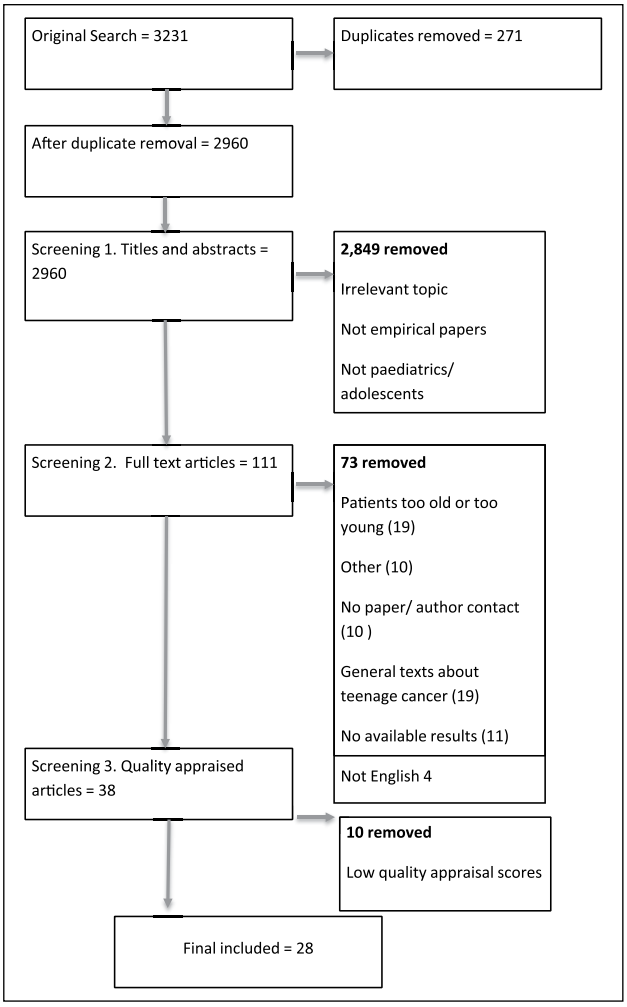

Figure 1. PRISMA flow chart.

Quality appraisal

Qualitative research was appraised using recommendations from the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist.[4] Mixed-methods and quantitative research was appraised using recommendations from Guyatt, Sackett and Cook's Users' guides to the medical literature II.[5,6] To produce a robust synthesis of findings, only studies deemed good quality (those scoring over 60% on the relevant appraisal tool) were included in the review. A total of 28 studies were retained and included in the analysis.

Method of synthesis

We used narrative synthesis, which is well suited to consideration of studies that are heterogeneous in method. Previous reviews have successfully used this approach to summarise existing research and to synthesise evidence on decision-making in a medical setting.[7] We have 'adopted a textual approach to the process of synthesis, to "tell the stories" of the included studies'[8] through a preliminary analysis, exploration of relationships and assessment of the robustness of the synthesis. In accordance with Popay's guidance (2006), we employ a theoretical framework of interactionism to interpret the findings.[8]

Theoretical perspective

We use interactionism as our overarching theoretical framework. By this we recognise the social world as a place where meaning is formed through interaction between individuals, in this case adolescents, parents and HCP.[9] We understand behaviour as more than individual responses and social rules; rather it is the product of human interaction, allowing the roles of adolescents, parents and HCPs to alter and develop over time and place.[10] It is supposed that people attempt to make sense of the world by viewing and interpreting themselves in the context of the behaviour and actions of others in any given situation.[9] Consequently, individuals are not seen as passive recipients of information but as active agents in the formation and interpretation of behaviour and action.[11,12] This interpretive narrative synthesis organises the current literature by focusing on the ways adolescents, parents and HCP

interpret their own roles and the roles of those around them, defining their place in the decision-making process.

Having a place in or participating in decision-making is understood here as being able to interact with others in a clinical consultation or an informed consent conference. The ability to interact and to have an impact on a decision-making interaction we refer to as agency, or self-efficacy (see Box 1). In framing consultations and the decision-making process in this way, we locate them within a general account of human behaviour and within the everyday lives of maturing children and their parents. This contrasts with approaches that construe clinical encounters as activities with their own unique rules.

Box 1. Defining agency.

Agency

Agency in interacting with others refers to the ability of a person through expressing a thought or a wish, for example, to make a difference to the activity in which he or she is engaged with others. Agency does not equate to power or authority or dominance. It is often exercised through negotiation, a process of give and take.[13,14]

Notably, interactional roles in these situations align with categories used to define populations in the various studies and with the participants identified in professional and ethical guidance, namely, adolescents, parent and HCP.

Results

The descriptive characteristics of the included studies and quality appraisal scores are presented in Table 1. A summary of study characteristics, including populations studied, is presented in Table 2. A model of synthesis results is presented in Figure 2.

Synthesis

The 28 studies included are heterogeneous in methods, in the nature of the data presented and in types of decisions and issues studied. The evidence ranges from records of audio- and video-taped consent conferences, retrospective surveys of parents, adolescents and HCPs, to reports of preferences and recommendations concerning the decision-making process. The evidence is a mixture of what was observed to have happened, what is recalled as having happened and what participants would like ideally to occur. Against a backdrop of interactionist theory we present a synthesis of these study findings, identifying to what extent adolescents, HCPs and parents are able to participate in decision-making.

The impact of protocols. A shared aspect of the experience of participation in decision-making is the impact of protocol-driven clinical treatment, following the diagnosis of a life-threatening cancer when initiating a treatment plan is thought to be in the best interests of all concerned.[20] Parents and adolescents experience a lack of choice because decisions are guided by a medical protocol.[19,35,39,42]

In describing their experiences at diagnosis, parents and adolescents report that the pace in consultations was too fast and that they lacked time to grasp what they were being told about protocols and treatment options, so that they could participate by asking questions.[15,19,22,35,41] Participants report a desire and a need to alter the pace of interaction in order to gain a place in the discussions and to establish agency.

The loss and re-establishment of agency. Parents' and adolescents' descriptions of their experience at diagnosis report a loss of control and agency in early interactions. Eight studies[18,19,23,25,28,29,35,39,41] report variously that parents (eight studies) and adolescent (one study) initially experience a lack of control, a feeling of loss of power or a sense of being overwhelmed, under time pressure and unable to participate in decisions.[15,20,35,38]

Kars et al.[25] identify parents striving for control as an issue continuing throughout the illness of their child. They found that 'Parents who lost their control surrendered their actorship' (p. 32). Woodgate and Yanofsky[39] report on parents faced with a decision about participation in clinical trials, usually immediately after diagnosis, experiencing feelings of distress and helplessness (p. 17). As a result, parents and adolescents put their trust in physicians; they tend to follow and agree with them. Parents report a sense that they would have signed anything. Stevens and Pletsch[35] go so far as to say 'The process of enrolling their children in clinical research was, therefore, not a calculated rational decision-making process of analysing the purpose and procedures and risks and benefits of particular research protocols' (p. 84). All of these findings reflect the participants' sense of self-efficacy or agency and the manner in which they are able to engage in making the decision under study.

Only one study[41] of parents reported no experience of a loss of power or agency, possibly attributable to the exclusive recruitment of parents considered 'veterans of the hospital'. Establishing or re-establishing agency in the clinical setting requires time and experience with the disease, the HCPs and the setting, something adolescents receiving palliative care may have opportunities to develop.

Six studies state that over time, with experience of the disease, agency is re-established as parents gain some sense of control.[18,19,23,35,41] Parents employ various strategies to establish their place in decision-making, for example, gathering information,[23] strategising to get more time to consider options[41] and equipping themselves with the skills to judge medical information.[18] Miller et al.[28] note

Table 1. Descriptive characteristics.

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Baker et al.[15]	2013/USA	57 parents and 20 patients (mean age 17)	Multisite, prospective descriptive interviews	Content analysis	6/10	Patient and parents want additional information about trials in different formats, they want more time to prepare and make decisions, they want straightforward and honest communication from a regularly available clinician
Broome and Richards[16]	2003/USA	34 children (8–22 years) with a diagnosis of diabetes or a haematological malignancy	Semi-structured interviews	Narrative analysis	10/10	Chronically ill children are willing to talk about involvement in trials and describe how relationships with others influence their decisions. They have faith in their parents to listen to them and make decisions for them. Cancer patients were markedly different as the physician approached child and parent together rather than parent first. They had a greater level of involvement in research decisions
Crawshaw et al.[17]	2009/UK	38 young adults diagnosed with cancer between 13 and 20 years old, aware of fertility affects and not currently on treatment	In-depth single interviews	Informed by grounded theory	8/10	Addressing fertility issues is important regardless of the options available, teenagers express clear wish to have a choice in who is involved in discussions. Girls are less likely to have issues raised than boys. Argue that assumptions about how much information on fertility the adolescent wants can be made based on the age of the adolescent
De Vries et al.[18]	2009/ Netherlands	14 physicians and 15 parents of male adolescents undergoing cancer treatment	In-depth semi-structured interviews		7.5/10	Physicians did not accept parents' strategic control around decisions relating to fertility preservation. Unlike other treatments, physicians spoke to child first regardless of parents' position on the matter
De Vries et al.[19]	2010/ Netherlands	15 paediatric haematologists/ oncologists	In-depth semi-structured interviews		7/10	Clinicians regard most adolescents as not capable of meaningfully participating in discussions about research. Clinicians do not always provide adolescents with all the information. Proxy consent is obtained and deemed sufficient. Clinicians judge treatment protocols as not harmful and in best interest of adolescent
De Vries et al.[20]	2013/ Netherlands	Parents, paediatric oncologists and 8- to 18-year-old (mean 13) cancer patients	One-to-one semi-structured in-depth interviews		8/10	All felt it is in the best interest to defer to medical judgement/protocols in beginning. There was recognition that as the disease progresses there is more choice and differences in what 'best interest' means. Parents reported little choice at diagnosis and the shock when they do have to make a decision about things like fertility preservation. Parents recognised that as the adolescents disease progresses they become 'layman-experts' and make more decisions. However physicians regard parents/children as having little influence on treatment protocols, claiming their influence starts with minor decisions
Hinds et al.[21]	2005/USA and Australia	20 patients aged 10–20 years	Interviews		8.10	These adolescents realised they were involved in an end-of-life decision, understood the consequences and were capable of participating in a complex decision process that involved risk to them and others. Decision factors most reported were relationship based, contradictory to existing development theories
Hokkanen et al.[22]	2004/Finland	Twenty 13- to 18-year olds currently living with cancer and attending a cancer adjustment camp	Focus groups		7/10	Adolescents stated that they felt HCPs asked them unnecessary questions and presented them with fake decisions and the illusion of control. They stated that information received in the early stages was irrelevant and they only needed it when treatment was over. They wanted practical advice on what they were allowed to do and how to cope with the disease, as well as more future-oriented information. Adolescents felt improvements were needed in staff, privacy and physical care facilities

(Continued)

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Holm et al.[23]	2003/USA	25 parents of 26 children who had completed treatment for cancer at least 1 year prior to the focus group	Focus groups (5–9 people)		7/10	Parents see themselves as advocates for their children, informing HCPs and keeping themselves informed during both diagnostic and treatment phases. They have a role in limiting actions of medical professionals and supporting them
Inglin et al.[24]	2011/ Switzerland	15 parents whose child died or was receiving palliative treatment in one of three diagnostic groups – cancer, neurological disorders and non-cancer/neurology	Qualitative interviews		7/10	Honesty and openness from HCPs considered essential by all parents when delivering difficult news. Parents appreciated when HCPs respected them as experts in taking care of their child and actively involved them in decision-making. Parents highly valued supportive home care and long-term bereavement care
Kars et al.[25]	2011/ Netherlands	44 parents of 23 children (6 months–18 years) with advanced and incurable cancer	One-time and repeated open interviews Multi-centre study		7/10	Parents don't accept death they deal with the loss, parents who made the transition to letting go had increased receptiveness to child's real situation and needs. Parents stated it is not a linear process from preservation to letting go. Feelings of loss begin in the EOL phase not post death. Parents delay recognising treatment has failed. Dominant perspective of parents influences the child's situation. Best interest for who argue that parents can act in ways that have negative consequences for the child. Professional focus should shift from decision-making to guiding process of relinquishing – from the preservation of the child to letting go
Kelly and Ganong[26]	2011/USA	15 custodial parents, non-residential parents and step parents who had previously made major treatment decisions for their child with cancer	Minimally structured interviews	Grounded theory	8/10	Parents focus on ill child until the crisis has passed. Biological parents 'step up' to responsibility, while their partners step back or are pushed away. Step-parents play a supportive role to their spouse if they are allowed to
Matsuoka and Narama[27]	2012/Japan	23 parents bereaved 1–3 years previously	Semi-structured open-ended retrospective interviews	Constant comparison analysis	5.5/10	How parents understand impending death is complex and impacts on decision-making. The key thought of parents is to protect and support their child. Parents argued that HCPs need to participate in EOL decision-making, and they needed to feel like they were parents. HCPs can help this to happen
Miller and Luce[28]	2011/USA	219 parents who made a decision about research or treatment for a child	Questionnaires – completed measures for external influence, distress, decision-making preference and coping		6.5/11	More external influence was associated with more hostility, uncertainty and confusion. Decision-making preference and coping style moderated the influence between external influence and distress
Miller and Nelson[29]	2012/USA	184 parents of children with cancer who made a decision about enrolling child in treatment protocol within previous 10 days	Questionnaires assessing voluntariness, external influence, concern of negative effects on care if disagreed, time pressure, information adequacy and demographics		6.5/11	Several groups of parents appear to be at risk for decreased voluntariness when making research or treatment decisions for their seriously ill children, including fathers, non-White parents and those with less education. Parental voluntariness may be enhanced by helping parents to mitigate the effects of unhelpful or unwanted influences by others and ensuring that their information needs are met

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Miller et al.[30]	2014/USA	61 patients aged 7–21 who were offered participation in a phase 1 trial	Audio-recorded consent conferences	Statistically coded	5/5	Mean proportion of informed consent conferences for trials in which the patient was involved was 43%. Proportion was greater with older patients. After controlling for age, the more patient to doctor communication, the more patients reported understanding
Olechnowicz et al.[31]	2002/USA	14 informed consent conferences involving children with leukaemia over age 7 parents and clinicians	Audio-recorded ICC and follow-up interviews with parents, clinicians completed a self-administered questionnaire		4.5/5	Who the clinician identified as the primary decision maker was not related to the age of the patient. Older patients asked more questions than young patients HCP interaction with patients based on a number of factors: patient age, disease status, training style and preferences. Parents asked significantly fewer questions if child was present
Pousset et al.[32]	2011/ Belgium	165 physicians who signed death certificates for 1- to 17-year olds	Anonymous population based post-mortem survey		8/11	Minor patients commonly kept in continuous deep sedation until death (21% non-sudden deaths, 53% sudden deaths). Indications that this is sometimes used with life-shortening intention without involving the patient
Simon et al.[33]	2003/USA	108 parents of children with leukaemia 21 – non-English-speaking 27 – English-speaking minority group 60 – English-speaking majority	Audio-recorded observations and interviews		4/5	Clinicians were more likely to omit certain information from discussions with non-English-speaking parents, relating to randomisation, right to withdraw and consent documentation. Significantly more non-English-speaking parents failed to grasp key aspects of informed consent. Parents in non-English group asked fewer questions. Consultations took on average the same amount of time, despite the added time normally required to speak through interpreters
Stenmarker et al.[34]	2010/ Sweden	10 paediatric oncology physicians with more than 10 years' experience	Interviews	Grounded theory	6.5/10	HCPs reported the decision burden for adolescents as they are at a stage calling for independence. They speak of the significance of seeking knowledge and information. They avoid identification with families and keep empathetic distance, dealing with their own attitudes to central life issues
Stevens and Pletsch[35]	2002/USA	12 mothers whose children had undergone BMT	Qualitative semi-structured interviews		6/10	Findings suggest that BMT is often a non-decision for mothers, as a life or death situation the voluntary nature of the decision is altered. Emotional trauma decreases mothers' ability to absorb information. Urgency further constricts mothers' time to understand and be informed. Mothers have the burden of responsibility, experiencing regret and recrimination once treatment begins
Talati et al.[36]	2010/USA	421 randomly selected general paediatricians and subspecialists from web-based directory	Online or mailed cross-sectional survey		8/11	Paediatrician's decisions to respect refusal from minors are multi-factorial. When prognosis is good, best interest dominates, when prognosis is bad parental authority (younger children) and minor autonomy (older children) dominates
Vrakking et al[37]	2005/ Netherlands	63 paediatricians 125 GPs 208 clinical specialists	Structured interviews about hypothetical cases – all questions answered on a Likert scale		6.5/11	A substantial proportion of Dutch physicians are willing to use lethal or potentially life-shortening drugs in children. Paediatricians are more willing than GPs to grant request from parent for ending life of unconscious child. Female and religious physicians are less likely. When parents disagree physicians are less likely to grant request of child

(Continued)

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Wicks and Mitchell[38]	2010/New Zealand	Ten 16- to 22-year olds diagnosed with cancer during adolescence	In-depth semi-structured interviews		6.5/10	Support for fostering involvement of young people. They reported experiencing a loss of control as the doctors took over, which lead to rebellion and non-adherence. Many factors could be implemented to enhance sense of control, for example, benefit finding, maintaining positive outlook, confidence, motivation, remaining focused
Woodgate and Yanofsky[39]	2010/Canada	31 parents of children with cancer (6 months post-diagnosis – 5 years after treatment completion)	In-depth, open-ended, semi-structured interviews		8/10	The suffering of parents is complicated by not only making decisions but by having to come to terms with them afterwards. This is made bearable by relationship with child/others/HCPs Parents experience is a relational process shaped by evolving intrapersonal, interpersonal and transpersonal relationships and communication. As such HCPs can help parents achieve sense of being a good parent
Yap et al.[40]	2010/USA	103 physicians	Cross-sectional questionnaire survey		7/11	Physicians believe providing information about phase 1 study entry to families is most important goal of informed consent process 64% report providing an unbiased description Females more likely than males to report influencing
Young et al.[41]	2010/USA	3 patients (13–22) 6 mothers (children U18) 6 physicians 8 nurses	Focus groups		7.5/10	All agree autonomy is paramount to conducting ethical research. Young people didn't talk about decision-making, but physicians did. Difference in status, role definition and information exchange were identified as important in the information consent process. Teenage patients described a loss of agency during informed consent process
Zwaanswijk et al.[42]	2007/ Netherlands	Seven patients aged 8–17, 11 parents and 18 survivors aged 8–17 at diagnosis	Online focus groups – three separate groups for patients, survivors and parents of current patients		7/10	All three highly valued open and honest communication, but not all adolescents wanted to know prognostic and survival rate information. Adolescents emphasised lack of information specifically for their age group. Majority of participants wanted decisions about treatment to be made in collaboration with HCPs and families. Survivors and patients believed they should be the ones to make the final decision. Parents and young people recognised the prescriptive protocols constrained their choice, as did lack of sufficient knowledge, lack of trust in physicians expertise, practical circumstances and feeling too ill or depressed to decide

HCPs: healthcare professionals; EOL: end of life; ICC: Informed Consent Conferences; BMT: bone marrow transplantation; GP: general physician.

Table 2. Summary characteristics.

Characteristic	Perspective studied			
	Healthcare professionals	Parents	Adolescents	Combination
Total number of studies	5[19,34,36,37]	11[23–30,33,35,39]	5[16,17,21,22,38]	6[15,18,20,31,41,42]
Methodology	Qualitative 2[19,34]	Qualitative 7[23–27,35,39]	Qualitative 5[16,17,21,22,38]	Qualitative 5[15,18,20,41,42]
	Quantitative 3[32,36,37]	Quantitative 2[28,29]		Mixed 1[31]
		Mixed 2[30,33]		
Methods of data gathering	Interviews 3[19,34]	Interviews 7[24–27,35,39]	Interviews 4[16,17,21,38]	Interviews 3[15,18,20,43]
	Survey/questionnaire 2[32,36]	Focus groups 1[23]		Observation 1[31]
		Questionnaire 2[29,30]	Focus groups 1[22]	Focus groups 2[41,42]
		Observation 2[30,33]		
Focus of article	Clinical trials 1[19]	Clinical trials 3[30,33,39]	Clinical trials 1[16]	Clinical trials 2[15,41]
	Treatments 1[36]	Treatments 3[23,26,29]	End of life 1[21]	Treatments 2[20,31]
	End of life 2[32,37]	End of life 6[24,25,28,44]	Fertility 1[17]	Fertility 1[18]
	Communication 1[34]	Communication 1[35]	Lived experience 2[22,38]	Communication 1[42]

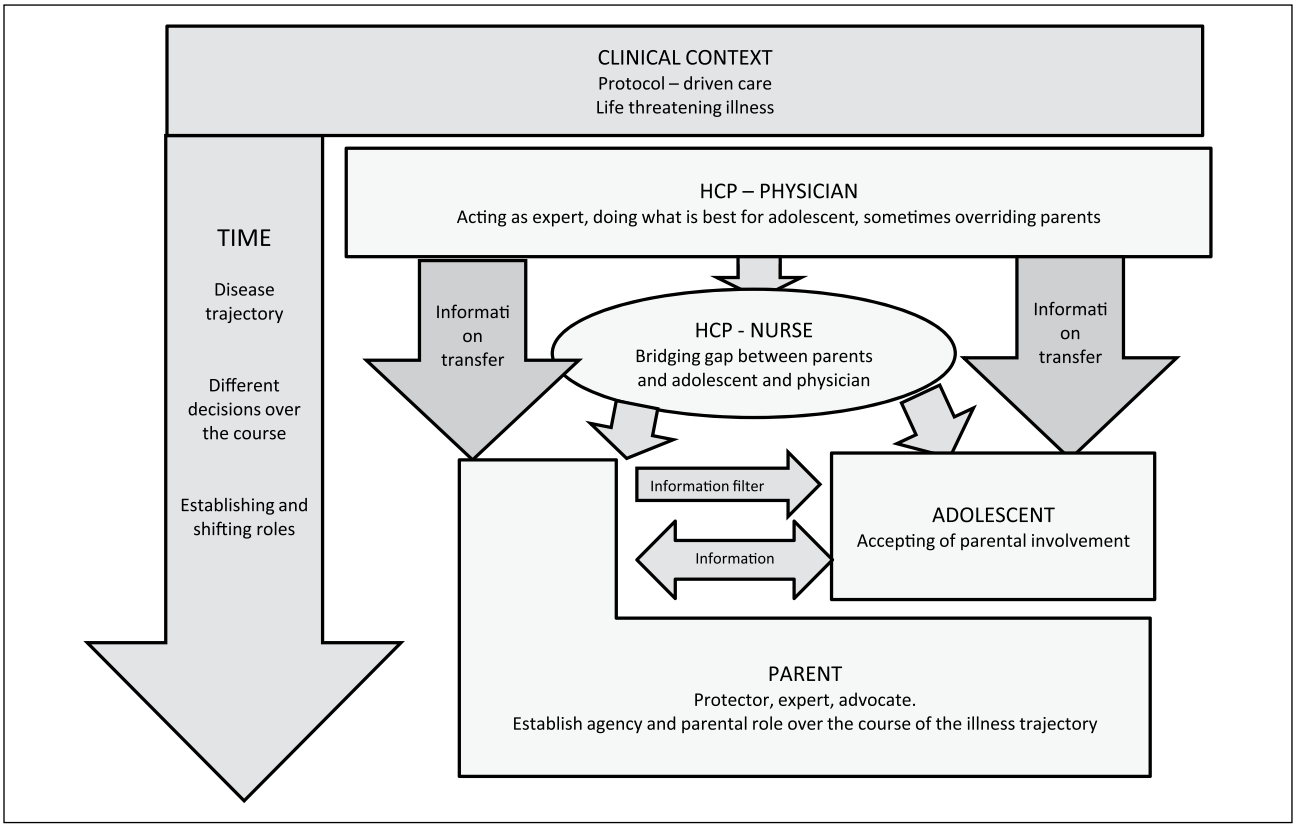

Figure 2. Model.

that parents of adolescents with a shorter duration of illness, and consequently less time to establish a role, experienced more distress.

Adolescents describe a loss of agency in decision-making about research trial participation,[41] feeling their power is reduced to their ability to sign the consent form once they attained legal majority. Adolescents also describe a loss of control, throughout the process of diagnosis and treatment.[38] De Vries et al.[19] focused on clinicians' views of adolescents, reporting that at diagnosis they are overwhelmed by their situation and thus are incapable of participating in decision-making; this was true even for older adolescents. The adolescents who were deemed capable were those facing relapse, that is, those who had experience with the disease and those who were likely to be receiving palliative care.

These studies document a critical difference between the reaction of parents and adolescents in response to loss of agency. Some adolescents can become less involved in decision-making as a means of coping with loss of control. This contrasts with the behaviour of parents which takes the form of struggling to re-establish agency within the process.

The role of adolescents, parents and HCPs. Role is an expression of how participants see themselves and how other participants see them. Adolescents, parental and HCP roles both guide and drive decision-making interactions (Model 1). Kars et al.'s[25] study of parental experience at the adolescents' end of life found that 'The need for control is immense and seems a precondition to fulfilling parental tasks' (p. 32). Thus, agency is required in order to realise one's role and meet expectations. Agency is lost when participants are unable to fulfil role-related behaviours and it is regained by asserting that role. Having a clear role and being able to express agency are interdependent.

Role of the adolescent. The studies reviewed provided few findings about the role of the adolescent. Young et al. report that adolescents had little to say about their role, deferring to parents or HCPs. They continue to state that the adolescent's role is a passive one, quoting one adolescents who stated his role was simply to sign consent forms (pp. 634, 637).[41]

Role of the parent. Different dimensions of the parental role are presented including parent as advocate, expert, protector of the adolescent and protector of family values.[16,20,23,27,39,41]

Holm et al.[23] found that advocacy was the overarching theme in parents' perception of their role in their child's healthcare. In the treatment phase, advocacy includes gathering and managing information, deciding about medical treatment, including limiting procedures and actively fostering good relations with medical staff. Young et al.[41] expand on the role of information gatherer and describe parents as actively and ardently seeking information from multiple sources, not limited to consultations.

Parents also assume the role of experts about their child's condition and quality of life, both as viewed by HCPs and by themselves.[18,24,26,37] Parents become protectors of family identity and values as well as of their child,[18] with adolescents expressing their trust in parents to make decisions on their behalf.[16]

Role of the HCP. Physician. Physicians are reported as regarding themselves as primary caregivers,[41] charged with doing what is best for the adolescent,[19] as experts, and as providers of information. This can extend to overriding parents when they deem it necessary.[19] Stenmarker et al.[34] suggest that HCPs also view themselves as the 'bearer of bad news', seeking knowledge and information as a central part of their role throughout the trajectory of their patient.

Parents recognised a difference in status between themselves and clinicians, requiring respect for physicians.[23] Physicians, by virtue of their status, were perceived as intimidating.[23] There was a lack of research identifying adolescents' perception of HCP's roles, or research referencing the relationship between adolescents and HCP.

Nurse. The reports on the role of nurses' role focus on bridging the relationship between parents and physicians.[41] In describing their interactions with parents and physicians during meetings aimed at establishing consent for treatments or trials, nurses use terms like 'witness', 'advisor', 'legal liaison', 'interpreter' and 'conduit of information'. Indeed a primary role reported is to ensure that parents and adolescents receive and understand all the information they need. They also wanted to ensure that adolescents were informed. Carrying this out, however, sometimes led to conflict with parents.[41]

Information preferences. Studies indicate that adolescents differ in the amount and type of information they prefer to receive, particularly about survival rates and prognosis.[42] Some adolescents state that early stage information was irrelevant because it was about issues arising after treatment had been completed. At the same time they express a preference for receiving more detailed information in subsequent consultations on 'here and now' matters and 'practical' matters (pp. 300, 331).[22] Crawshaw et al.[17] report that adolescents found 'broad-brush' information to be sufficient at first although parents, patients and survivors in that study all said that overall their preference was for being fully informed. Studies report the tailoring and limiting of information to adolescents and parents by HCPs.[19,41] Simon et al.[33] report this tailoring with non-English-speaking families in particular, stating clinicians were more likely to omit certain information from discussions with non-English-speaking parents, relating to randomisation, right to withdraw and consent documentation.

Miller and Nelson[29] suggest that both too much information and too little information are undesirable; both are negatively associated with parents' perception that they were in control of making a decision.

The studies reviewed indicate that parents exercise, or try to exercise, an influence on the type and presentation of information that adolescents receive. Young et al.[41] state that parents express a clear desire to control the kinds of information their children received and how it was delivered. Zwaanswijk et al.[42] state that parents shield children from upsetting information by excluding them from consultations. Desire for parental control of information is particularly evident in studies of decisions about fertility preservation. De Vries et al.[18] reported that 8 of 14 parents wanted 'to protect their child from this information, or at least wanted control over what was being discussed with their child' (p. 389).

Participation in practice. The participation of adolescents, parents and HCPs in the consultation itself was reported directly by several studies. In three studies,[30,31,33] informed consent conferences were audio and video taped. Miller et al.[30] report that a mean 36% of the conversation (by word count) was directed from HCP to adolescent (standard deviation (SD) = 31.23, range = 0–87.44). Communication from adolescents to HCP was substantially less, accounting for 3.21% of the total dialogue. Olechnowicz et al.[31] also report few questions being asked by the adolescent (mean 4 per conference). While these studies report on conferences where the adolescent and parent are present, in other studies discussions are held with adolescents or parents in isolation.

In a study of discussions of infertility risk and cryopreservation, De Vries et al.[19] reported that 'most' physicians spoke with parents about the subject before discussing with the adolescent. Still, 14 of the 15 said that they would then proceed to discuss the issue with the adolescent even in the face of clear objection from the parents. In the study by Crawshaw et al.,[17] 5 of 33 adolescents had fertility discussions without parents present. Based on the analysis of online focus groups, Zwaanswijk et al.[42] state that parents sometimes report having consultations without their child being present. Olechnowicz et al.[31] report that in the case of an 18-year-old patient, an informed consent conference was held with the adolescent alone and then a second conference was held with the parents alone.

Broome and Richards[16] report that with regard to a decision to participate in research, in a minority of cases the clinician approached the mother about the study first and the mother then approached the adolescent.

In several studies, parental involvement is explicitly recognised as acceptable to adolescents or even positive.[16,17] This involvement took the form of buffering information exchange between physician and adolescent[17] taking their views into account and making sure that they were represented.[16] Based on a post-mortem record review, Pousset et al.[32] express concern that a significant number of minors may have been unjustifiably excluded from their end-of-life decision-making.

Overall, the primary reason reported by parents and HCPs for excluding adolescents is the potentially upsetting or burdensome content of the discussion. Quotations from parents indicate that without exception parents' concerns were based on the specific issue before them – semen preservation, for example – rather than challenge to parental authority.

Studies consistently find that it is maturity and/or disease experience and not age that determines HCPs estimate of adolescents' ability to participate in decision-making and partake in discussions.[17,31,36,37,42] This may be the case even when adolescents are legal adults.

Who is regarded as primary decision maker? Several studies offer reports on who makes the final call in decisions relating to fertility, trial participation and treatment. Evidence for treatment decision-making varies with some suggesting HCPs make the decision,[20] others that parents and HCPs decide[22] or, as Talati et al.[36] state, 58% of HCPs believed the adolescent (over 16 years) is the primary decision maker.

Decisions relating to fertility were often assigned to the adolescent,[17] in spite of many parents' reluctance to have fertility discussed with their adolescent.[18] Studies of decisions to participate in clinical trials also show mixed results ranging from HCP paternalism[19] to parental directing[16,40,41] or active participation by adolescents in the decision.[16]

Preferred models of decision-making. When looking at decision-making overall, Baker et al.[15] find that the majority of parents 'prefer to share responsibility for decision-making with the physician' (p. 4158). Families want to know 'how an expert … would make a decision about trial participation if the expert shared the family's goals and values' (p. 4156).[15] In Zwaanswijk et al.,[42] the majority of participants preferred collaborative decision-making between adolescent, parent and HCP, with the adolescent making the final decision. These findings are consistent with the conclusions of Miller et al.;[28] using scores from a decision-making scale, they conclude that parents did not show a strong preference to control the decision-making process themselves.

Discussion

Key findings

In this review, we have assembled research evidence highlighting current understandings of decision-making in adolescents with cancer.

First, we found that at diagnosis, possibly on receipt of news of relapse, parents initially lose agency (Box 1) as a result of rigid care protocols. They subsequently re-establish agency acting in the role of advocate and protector. It is in their role as protector that parents sometimes try to control the information that the adolescent receives.

Second, we found that for adolescents there appears to be no such clear way in which they can establish agency in the decision-making process. One reported ironic feeling that his role was simply to sign consent forms. This in itself could constitute an obstacle to participation. Stated simply, this could indicate that in decision-making situations no one is sure, including the adolescents themselves, how the adolescent is to be involved. Of note, within current published research, data collected from adolescents directly were scarce accounting for only 12% of total subjects.

Third, we identified that parent and adolescent preference for shared decision-making was clear. Adolescents welcomed parental involvement and parents wanted to know HCPs' opinions. Neither parents nor adolescents showed a desire for a high degree of autonomy in decision-making. Maturity and disease experience, not age, is an important factor affecting attitudes of adults towards adolescents' participation. Hinds et al.[21] suggest that adolescent decision-making towards the end-of-life shows a maturity exceeding that predicted by developmental theories.

Preferences concerning information exchange in decision-making were by contrast variable. Adolescents differed with regard to the amount, the specificity and the timing of information that they received.

In practice, many adolescents reported expressing their views to their parents, who in turn represented the adolescent in decision-making. Adolescents seemed relatively satisfied with this process, when parents were aware of their views. In fertility preservation decisions, adolescents were more directly engaged by HCPs. More often, HCPs see parents rather than the adolescents as the primary figure in decision-making.

Robustness of the synthesis

Strengths. One of the strengths of this review is the inclusion of qualitative, quantitative and mixed-methods research. By acknowledging research from a variety of methodological approaches, we have been able to provide a more complete overview of the current evidence. We also assessed carefully the quality of each article identified and excluded those which failed to score over 60% on the appropriate critical appraisal tool.

Limitations. The included studies generally offer little information about sample selection (11 purposive sampling, 9 inadequate information including no response rate, 7 response rates $< 55\%$, 6 part of larger study, 4 had response rates above 70%); therefore, it is not possible to assess how representative these findings are of adolescent cancer, parent and HCP populations as a whole. Second, qualitative studies largely employed thematic analysis and there is a lack of clarity across studies with regard to the strength of emergent themes and their relative importance.

The nature of the research methods produced largely retrospective accounts of decisions made weeks, months and occasionally years ago. One participant had completed treatment 9 years prior to the study. In addition, the outcome of these decisions researched, the subsequent support received and the current status of their health/child's health or patient's health will influence how these decisions, and their role in making them, are then interpreted by participants and then reported. In conducting our review, we were reliant on the evidence selected and presented by the studies.

Studies identified originate from several countries, predominately the United States and the Netherlands. We recognise the disparity between and within these countries with regard to practice of shared decision-making as well as legal age of consent and assent and differences in practice with regard to the adolescent's participation in delivery of healthcare and in society. We also recognise the term adolescent, as a transition between childhood and adulthood, may have significantly different application in different cultures. These issues are beyond the scope of this review and are not attended to. Finally, due to limited resources, only English-language articles were included in this synthesis.

Clinical implications

The provision and receipt of information is a concept that arose in many studies. While some adolescents and parents retrieve as much knowledge as possible to maintain control, others limit the information they receive for the same reason. Within and between studies of adolescents, there are differences in preferences for information sharing, with some reporting a desire to know more and others content with minimal information. HCPs should be aware that adolescents might be asserting control by opting out of receiving certain information.

Research with adolescents themselves has highlighted a need for more information and more direct doctor–patient communication to help them understand what is happening, suggesting there may be a discrepancy in practice with regard to what the patient wants to know and how and when the HCPs and parents provide that information.

Miller et al.[28] report that few or no parents reported wanting to make healthcare decisions 'on their own'. Similarly, adolescents, regardless of age, report preferences for parental involvement in decision-making. A number of studies reported a parental or adolescent preference for shared decision-making (without defining that

term) and guidance from HCPs. If clinicians resist requests to offer their own opinions, they may be impeding the interaction with the parents and adolescents, making their deliberations more difficult as the parents and adolescents may feel more stressed, less confident and more confused without the guidance which they request.

Coyne et al.[43] set out to identify randomised controlled trial (RCT) studies examining the effects of shared decision-making interventions on the process of shared decision-making for 4 to 18-year olds with cancer. They were unable to identify any such studies, concluding among other things, that much 'evidence promoting young people's participation in decision-making is authored by policy makers and that we lack strong evidence from research that supports these recommendations'.[43] Taken together, our findings suggest a view that may differ from current ethical guidance and regulation that promote full information and minimal external influence for adolescents and parents, encouraging autonomy of the adolescent. Striving to impose this approach, particularly in the face of a poor prognosis, may add to distress and confusion, interfere with their agency and their ability to determine or participate as fully as they are able in decision-making about the course of their own/their child's healthcare.

Directions for future research

We found little evidence on the role of adolescents themselves in decision-making (data found in 11 of our included studies – 12% of total participants in these studies). We suggest that further work is needed to increase our understanding of how adolescents, and others, view the role of adolescents in making decisions for their own care and treatment both in principle and in practice. The importance of this focus is recognised in the appearance of recent work such as Weaver et al.,[45] published after the limits of our search. This study confirms the value of the perspective we have taken in this review. It reports that adolescents' 'overriding perspective of decisional involvement' is as an interactive process (p. 4423).

The majority of studies to date utilise similar methods, calling on semi-structured interviews, focus groups or surveys to elicit the views of parents, HCPs and occasionally adolescents on decisions that they have recently made. Although interview studies were often categorised as prospective,[15,16,21,22,25] they remain dependent on recall, employing interviews and focus groups anywhere between 7 days and years after a decision has been made. We found three studies that included observations of real-time interactions.[30,31,33] They focused on one decision at a single time point, thus suggesting that each party's role in decision-making can be understood by examining a single decision in isolation. Notably, none of these studies included interviews or informal conversations with adolescents themselves. It can be argued that such studies constrain understanding of participation in decision-making by categorising it as simply the amount of verbal communication, the number of questions asked or the amount of information given and ignoring the effect of time.

In this review, we have identified that important changes take place over time as parents and adolescents gain experience with the hospital and treatment protocols. The methodological consequence of this is that studies that seek to understand participation in decision-making must be longitudinal, beginning at diagnosis and documenting decision-making throughout the entire disease trajectory.

Conclusion

Striving to make parents and adolescents fully informed or to urge them towards more independence than they prefer may add to distress and confusion. This, in turn, may interfere with their ability to participate in decisions about care and treatment in their preferred way. Future research should include analysis of actual on-ground interactions among parents, adolescents and clinicians across the trajectory and decisions.

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