

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<u>http://bmjopen.bmj.com</u>).

If you have any questions on BMJ Open's open peer review process please email <u>info.bmjopen@bmj.com</u>

BMJ Open

Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

en-2023-080024 al research p-2023 h, Deborah; University of Cambridge, Department of Public Health hary Care
p-2023 h, Deborah; University of Cambridge, Department of Public Health ary Care
h, Deborah; University of Cambridge, Department of Public Health ary Care
ary Care
, Rachel; University College London Hospitals NHS Foundation CNMAR; s, Anna; University of Cambridge insky, Robbie; University of Cambridge Ella; University of Cambridge er, Helen; Cambridge University Hospitals NHS Foundation Trust Luke; Cambridge University Hospitals NHS Foundation Trust
cents < Adolescent, Decision Making, EDUCATION & TRAINING ledical Education & Training), ONCOLOGY





I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our <u>licence</u>.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which <u>Creative Commons</u> licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

terez oni

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies



Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

Deborah J Critoph MSc, Rachel M Taylor PhD, Anna Spathis MD, Robbie Duschinsky PhD, Helen Hatcher MD PhD, Ella Clyne, Isla Kuhn MSc, Luke AM Smith

Deborah Critoph, PhD student, Department of Public Health & Primary Care, University of Cambridge

Rachel Taylor, Director of the CNMAR, Centre for Nurse, Midwife and Allied Health Profession Led Research, University College London Hospitals NHS Foundation Trust, London, NW1 2PG

Anna Spathis, Assistant Professor, Department of Public Health and Primary Care, University of Cambridge

Robbie Duschinsky, Professor of Social Science & Health, Department of Public Health & Primary Care, University of Cambridge

Helen Hatcher, Consultant in Medical and TYA Oncology, Clinical and Regional Lead for Sarcoma and Young People with Cancer, Clinical Director EoE TYAc ODN

Ella Clyne, Medical Student, University of Cambridge

Isla Kuhn, Head of Medical Library Services, University of Cambridge Medical Library

Luke Smith, Junior Clinical Fellow in TYA Haematology and Oncology, Cambridge University Hospitals NHS Foundation Trust

Correspondence: Deborah Critoph, dc625@medschl.cam.ac.uk

Keywords: Teenagers and young adults with cancer (TYAC), adolescents, triadic communication, communication, supporters, third person, parents, support network, health care, professionals, experiences, impact.

Abstract = 299/300 Word count = 3928 Number of tables = 4 Number of figures = 1

Abstract

Background

Although most young people have limited encounters with healthcare, around 2,500 young people in the United Kingdom (UK) are diagnosed with cancer each year. Clinical communication needs of teenagers and young adults with cancer (TYAC) are increasingly recognised to differ significantly from younger children and older adults. Triadic communication refers to the presence of a third party, such as a parent, carer, or companion in clinical encounters and is a key feature of TYAC care.

Aim

We sought to understand who is present with TYACs, synthesise TYACs experiences of triadic communication with HCPs and supporter(s), and explore the impact of triadic communication for TYACs. We generated three research questions to focus this review:

Review questions:

- 1. Who is present with TYACs in healthcare consultations/communication? For example, who are the supporters?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact of a TYAC's supporter being present in the communication?

Methods

We conducted a systematic review and narrative synthesis of empirical evidence published since 2005. An inductive thematic analysis was undertaken to identify the main, recurrent, and important data across the studies in answering each research question.

Results

A total of 7,727 studies were identified in the search, of which 33 fulfilled the inclusion criteria. We found that mothers were the most common supporter in clinical communication encounters. The experience of communication in the presence of a third person is paradoxical in nature – the supporter can help or hinder the involvement of the young person in their care. Overall, young people are not included in communication and decisions about their care to the level they want.

Conclusion

Triadic communication in TYAC is common, complex, and dynamic. Due to the degree of challenge and nuances raised, HCPs need further training on effective triadic communication.

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

PROSPERO registration CRD42022374528

Strengths & limitations of this study

- We searched systematically and thoroughly for eligible studies, but this is not a wellindexed field of research, and therefore it is possible that some relevant studies were not included in the review.
- We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in some countries (between 29 to 39).
- We only included papers published in English and the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics.
- International representation was seen in the eligible studies and TYAC ages were included across the entirety of the specified UK age range.
- Studies represented the journey throughout the cancer experience from diagnosis to survivorship and end of life care.

Introduction

Adolescence is a time of transition where young people navigate monumental physical, cognitive, emotional, and behavioural milestones to develop a sense of self-identity and gain independence. Although most young people have limited encounters with healthcare, around 2,500 young people in the United Kingdom (UK) are diagnosed with cancer each year, which is the leading cause of non-traumatic death in young people in the United States (US) and Europe.(1) Teenagers and young adults with cancer (TYACs) have unique healthcare needs and there has been an international drive to develop developmentally appropriate evidence-based specialist care, provided by appropriately trained healthcare professionals (HCPs).(2)

Communication with TYACs can be particularly challenging: a life-limiting condition intersects an age associated with emotional reactivity and variable maturity. TYACs clinical communication needs are increasingly recognised to differ significantly from younger children and older adults. Research indicates TYACs can have little meaningful involvement in conversations with HCPs: almost half of children and young people reported not being involved in decisions about their care.(3) HCPs recognise this and consider young people amongst the hardest patients to communicate with.(4) However, HCPs receive little training about how best to manage these clinical encounters. TYACs who are not heard or understood can be labelled as 'challenging', 'hard to reach' and 'disengaged'. This may adversely impact care and contribute to poor physical and psychological outcomes. Despite these issues, there are limited opportunities for formal postgraduate education in communication with TYACs for HCPs, with most training being ad hoc and not interprofessional.(5,6) Effective communication with TYACs has been recognised as a key national research priority. In a UKwide survey of young patients' own research priorities, communication was a striking crosscutting theme.(7)

Recent research into clinical communication with TYACs has offered some insight into the complexities of communication with this specialist patient group. (8-12) Yet one area that has received less attention is triadic communication. Triadic communication refers to the presence of a third party, such as a parent, carer, or companion in clinical encounters (13) and the presence of such a person was found to occur in 87% of TYAC consultations.(11) As a commonly occurring form of communication in TYAC care, there is a need to understand the theoretical basis and relevance of triadic communication to clinical practice. For the purposes of this review, we refer to this third person as a supporter. Triadic communication literature from children and older adults exists. (14-17) Notably this includes a meta-analytic review of provider-patient-companion of adults, (18) one large systematic review of physician-patientcompanion communication and decision-making in adults (19) and one review of doctorparent-child communication.(20) Whilst informative, these studies are with children and adults, not this unique age-group of emerging adulthood with a significant life threatening diagnosis such as cancer. Also, these studies focus on doctor-patient-third person communication, whereas TYAC care involves a range of interdisciplinary professionals. This review aims to understand what is known about triadic communication with TYACs in healthcare communication.

Aim

We sought to understand who is present with TYACs, synthesise TYACs experiences of triadic communication with HCPs and supporter(s), and develop insights into the impact of triadic communication for TYACs.

Review questions:

- 1. Who is the supporter present with TYACs in healthcare consultations and communication?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact on a TYAC's supporter being present in the communication?

Methods

We conducted a systematic review and narrative synthesis (21,22) of empirical evidence published since 2005, the year of publication of the National Institute for Care Excellence (NICE) Improving Outcomes Guidance, the guidance document underpinning TYAC services in England.(2) The review protocol was prospectively registered with PROSPERO (CRD42022374528). We designed the search to identify and map the available evidence using a broad scope to gain an overview of the pertinent literature, identify knowledge gaps and clarify concepts. The search strategy was developed and refined with an information scientist (I.K.). Keywords were generated across five strands detailed in Table 1, with strands combined with the Boolean operator 'AND'. The search was conducted across five databases: Medline, CINAHL, Embase, PsycINFO and AMED (supplemental file).

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Table 1. Search Terms

|--|

TYA cancer or TYA oncology or teenage and young adult adj5 cancer or teenage and
young adult adj5 oncology or teenage* adj5 cancer or teenage* adj5 oncology or
adolescen* adj 5 cancer or adolescen* adj 5 oncology or young people adj 5 cancer or
young people adj 5 oncology
Strand 2 – communication
Cancer OR oncology OR malignancy OR leukaemia OR lymphoma
Strand 3 – supporters
Communication skills OR communicat* OR discuss* OR disclos* OR inform* OR interact
OR relationship building OR decision making OR communication tools OR
communication aids OR psychosocial assessment
Strand 4 - impact
affect OR effect OR influence OR result OR resultant OR impact
Strand 5 - experience
encounter OR involvement OR occurrence OR feel OR "go through" OR experience*
TYAC: teenage and young adult with cancer

Database searches were compiled and de-duplicated in Mendeley, abstracts were screened in Rayyan by two researchers (D.J.C and L.A.M.S.), and 155 full articles were read by three researchers (L.A.M.S., D.J.C., and R.M.T) for eligibility of inclusion in the final analysis, with disagreements resolved by discussion. Papers were included if: they presented empirical research published after 2005; participants had malignant disease, diagnosed aged 13-24 years (for over 50% of participants); the research addressed any area of clinical communication; and the research included supporters (parents, partners, carers, friends etc). Papers were excluded if they were: conference abstracts, unpublished articles, systematic reviews, single case studies, validation research methodology, studies using retrospective documentation in clinical notes, articles focusing on information needs rather than communication skills, or were not in English.

A review-specific data extraction form was used to record participant characteristics and methods from each included paper and results relevant to the three review questions. The final number of included articles totalled 33, the remaining 122 were excluded based on the participants' ages, focus on HCPs or information giving. In tandem to the data extraction process, two members of the review team (E.C. and D.J.C.) independently assessed each paper in terms of its internal validity, appropriateness, and contribution to answering the review questions, using a review-specific version of Gough's Weight of Evidence criteria.(23) Discrepancies in assessment decisions were discussed between reviewers and final scores were agreed through consensus.

Extracted data were entered into Excel to aid the narrative synthesis of the included papers.(21,22) All articles, irrespective of relevance and quality, were included in the review. However, those rated 'medium' and 'high' were given greater weight in the synthesis. An inductive thematic analysis was undertaken to identify the main, recurrent, and important

data across the studies related to answering each research question. D.J.C. and E.C. explored heterogeneity across the studies. The integration of results from studies utilising different methods and epistemological positions was supported by L.A.M.S. and R.M.T., and consensus in synthesis was reached. The synthesis was further refined through discussion of the review of results and their implications with clinicians, interdisciplinary academic audiences, and all of the co-authors.

Results

A total of 7,727 studies were identified in the search, of which 33 fulfilled the inclusion criteria (Figure 1). The included articles are summarised in Table 2. (table 2 uploaded separately)

All points across the cancer trajectory were represented in the final papers: diagnosis (n=6); (12,24–28) on treatment (n=17); (29–45) end of treatment (completed within one year) (n=2); (46,47) survivorship (more than one-year post-treatment) (n=2); (5,48) and end of life care (n=5). (49–53) One study included patients at more than one point along the cancer care continuum. (54) Most studies (n=18) were conducted in the US (24,27,28,30,34–36,38–45,49,51,53) other countries included the UK, (25,31,32) Australia, (37,47,48) Norway, (12,52) Israel, (46) Iran, (29) Mexico, (50) France, (33) Denmark, (26) and Taiwan, (54) one study recruited from three European countries. (5) Studies used predominantly qualitative methods (n=29) but there were two mixed methods studies and two using quantitative methods. Weight of evidence criteria indicated four were high evidence, (24,30,34,44) twenty-two were medium (5,12,25,27-29,31-33,35,36,38-41,43,45,46,48-50,54) and seven were low evidence. (26,37,42,47,51-53)

The categories used to separate the age groups were lower adolescence (11-14 years), middle adolescence (15-17 years), upper adolescence (18-21 years) and emerging adulthood (22 onwards). Of the papers where the age range at diagnosis could be deduced, the majority of these (19 out of 24) spanned three or more age categories (Table 3). All the papers spanned two or more age categories. In nine of the papers, the age ranges at diagnosis were not available (as age at diagnosis was expressed as a mean or median). Given these factors, it is difficult to ascertain whether any between age group differences exist.

Table 3 – Age range of patients at diagnosis

Category	Number of papers
Lower and middle adolescence	4
Lower, middle, and upper adolescence	8
Lower, middle, upper adolescence and emerging adulthood	6
Middle and upper adolescence	1
Middle, upper adolescence and emerging adulthood	5
Not specified	9

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Who is present with TYACs in healthcare consultations and communication?

The majority of supporters were mothers (63.5%). When combined, parents represented nearly all the supporters in the included studies (93.5%), see Table 4. Non-parental supporters (2.6%) included partners, sisters, aunts, and grandmothers. The remaining supporters were not categorised due to insufficient information in the article's demographics data (3.9%).(52,53)

Table 4 – Table of supporters

Supporter type	Number of supporters	Percentage quoted to 1
		decimal place (%)
"Mother"	342	63.5
"Father"	122	22.6
"Both parents"	20	3.7
"parents" no further	20	3.7
specification		
"Grandmother"	2	0.4
"Sister"	3	0.6
"Partner"	3	0.6
"Aunt"	3	0.6
"supporters" no further specification	21	3.9
"other"	3	0.6
Total	539	100.2

What are TYACs' experiences of communication with the supporter present?

The presence of supporters was concurrently helpful and challenging for TYACs. Supporters undertook several helpful roles and responsibilities: they asked questions on behalf of the TYAC, retained information from HCPs, acted as a conduit of information between the TYAC and HCP, and acted as a "sounding board" for the young person.(25,30,44) Some supporters promoted self-advocacy and autonomy for the young person (27,38,40,45). Some reported symptoms on their behalf (44) and proactively negotiated changes to treatment schedules in the interest of the young person.(38)

Findings also suggested that young people could experience limited or ineffective communication in the presence of a supporter. Communication could be directed towards the supporter, not the young person.(27,30,35) Supporters could receive information in the absence of the TYAC and subsequently filter the content before delivering the information to TYACs.(29,32,33,54): *"The parents had hidden a truth that was not theirs to hide"* p533.(33) This reflected the broader predicament that supporters' priorities at times might have competed with those of young people. (25,33,49,50) Supporters could dominate the communication encounter, for instance, parents were seen to interrupt young people, especially when time was limited. (50) Frederick et al found the mean time for adolescent to

clinician communication was only 5.5% of the total consultation and parent conversation turns directed towards clinicians comprised a mean of 37.5% of all conversation turns. Clinicians directed most communication at the parent rather than the adolescent and none of the clinicians offered patients the opportunity to speak with them alone. (34)

Mutual protectionism appeared to occur, with TYACs and supporters seeking to protect each other from difficult information leading to non-disclosure when both were present. A diagnosis of cancer is devastating for the young person, supporter(s), family, and the wider social network. Repeatedly, there were references to reduced disclosure between the young person and their supporter, in an attempt to shield each other from emotional distress.(12,30,35,37,38,40,44,52) TYACs could experience discomfort and guilt in seeing parents tearful and worried, and felt a burden in response to observing the emotions of supporters.(37,38,51) Some TYACs sought to limit this by withholding concerns to protect their supporters: "I couldn't talk to mum about my concerns because I didn't want to hurt her" p 37.(37) In equal measure, supporters were characterised as working hard to stay in control of emotions, be strong and stay in the "now", and they channelled energy into helping.(12,30) Yet this could contribute to an environment of non-disclosure that had the potential to create future communication challenges, such as supporters not knowing the young person's wishes. Examples of this were evident within the end of life care studies. (51,52) Friebert et al found that 86% of young people wanted to receive prognostic information as soon as possible but only 39% of families knew that. (51) Similarly, Jacobs et al found that young people's end of life wishes were not known by their families. (52) In instances where the young person may not be able to communicate, it may help families relieve the impossible burden of making difficult decisions or feelings of regret, if the young person's perspective and wishes are known.(53)

What is the impact of a TYAC's supporter being present in the communication?

Supporters have the potential to facilitate, complicate or obstruct the young person's involvement in decision-making. Involvement had a positive impact on recall,(41) and may improve autonomy, efficacy, adherence, and future self-management.(24) However, the participation of supporters may be experienced as stressful by TYAC as they may become side-lined. (25,39,54) The presence of supporters impacted the young person's level of involvement in decision-making in several ways. In some cases, supporters empowered TYACs to make decisions by withholding their opinion (27) and deferring the final decision to TYACs.(30) However, supporters and TYACs did not perceive decision-making in the same way.(46) Supporters believed that young people oversaw decisions about their care; however, this was not what young people recounted.(24) TYACs reported a lack of communication and limited involvement in decisions (24,29,45) associated later with decisional regret.(24,36)

Deferral of communication and decisions from the young person to supporters was commonplace.(27,30,35) When supporters responded to this pathway of communication, young people then did not see a need to participate in decisions, knowing that their supporter was taking the mantle.(35) In parallel, clinicians were found to direct communication towards supporters and in extreme cases young people were completely excluded from communication and decisions. (29,34,46) An atmosphere characterised by a lack of trust, unanswered questions and uncertainty contributed to the exclusion of young people who Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

 then sought information from other sources.(29,35,38) Not allowing TYACs to choose their involvement in decision-making violated their autonomy, and increased distrust or resentment of providers and supporters and resulted in lower treatment adherence.(29,35,38)

The decisional involvement preferences of young people were not static: they were context and environment dependent. At diagnosis, heightened emotions and poor health rendered young people unable to engage in communication. (24,25,27,30,36,40) TYACs expressed a desire to be involved in decision making at different levels: some wanted limited involvement from their supporter(s) so they could take the leading role in consultations and their care; (55) several wanted collaboration with supporters and clinicians; (26,27,43) and some completely relied on supporters and HCP's to make decisions on their behalf. (44,45) Davies et al described this as agency, the ability to make free and independent choices. They highlighted the normality of this fluctuation between personal (acting independently), proxy (decisions made on behalf of someone) and collective (decisions are shared) decision making. Whilst this was not always linear, it was part of the cancer trajectory and demonstrated the fluctuating personal agency for TYACs.(31) Some young people reported that supporters and clinicians decided on the their level of involvement in communication and decision-making, (54) and TYACs commented that they did not feel the decision was theirs. (46) Decisional involvement was an interactive, complex, and multifaceted process within the context of the triad, and young people often wanted to be in control of their level of involvement. (28,30) The evidence highlighted that in the presence of a supporter, young people's choice in the their level of involvement in decisions was challenged and not routinely achieved.

Most TYACs felt that it was important for the healthcare team to communicate with them directly and openly.(29,30,32,37,38,48,49) Time alone helped facilitate communication between TYAC and HCP, to ensure that the young person's needs were fully met.(30,35) However, time alone with HCPs was not routinely integrated as a part of consultations with TYACs. (34,47) In fact, clinicians were reported as frequently speaking more to parents and TYACs received limited communication from HCPs.(27,30,34,35) In the presence of supporters, as well as withholding concerning information, young people reported feeling discomfort when discussing sensitive topics such as sex or fertility preservation.(27,35)

Young people wanted time alone to communicate with HCPs directly for a variety of reasons. This private line of communication offered a sense of personal agency and allowed them to feel "in the loop" and promoted a sense of autonomy that was threatened by the cancer diagnosis, particularly at the point of diagnosis.(31,49) Young people wanted space to think and privacy during the cancer journey; private lines of communication with HCPs actively promoted this.(30,38,44,45) It also enabled HCPs to get to know the young person and allowed them to ask questions that they may be reluctant to ask in the presence of their supporter, because of embarrassment or emotional shielding.(30) Darabos et al found that 87.5% of oncology providers considered it important to talk to the TYAC without their parents present.(30) Whilst the importance has been highlighted within the data it is also evident that this does not happen as part of routine clinical practice. This could be for several reasons such as not wanting to challenge rules of authority, uncertainty around how best to ask a parent to leave and lack of confidence when communicating with a young person alone.

Discussion

Principal Findings

Who is present with TYACs in healthcare consultations and communication? For example, who are the supporters?

The included papers in our review demonstrated that most supporters were parents, more commonly mothers. The frequent presence of mothers in consultations is consistent with previous findings. For example, in a UK study in which TYAC nominated a caregiver, 85% were parents, and of those 80% were female.(56) We note that there is a paucity of data for non-parental supporters, and this may represent a reality of clinical practice or a bias towards TYAC-parental dyads over other relational-dyads in this field of research to date.

What are TYACs' experiences of communication with the supporter present?

TYACs experienced supporters facilitating communication by obtaining information, asking questions, advocating, and supporting personal agency of the young person; conversely supporters could hinder communication by gatekeeping information, or dominating communication and thereby rendering young people as bystanders. Young people experienced negative emotions in response to witnessing their supporters in distress.

What is the impact of a TYAC's supporter being present in the communication?

Bidirectional non-disclosure was a coping strategy used by both TYACs and supporters to protect one another from concerns and emotional burden. This limited HCPs ability to effectively assess ideas, concerns, and expectations from both parties when together. In the presence of supporters some young people were less informed, which could impair their ability to engage in decision-making conversations.

Meaning of the study

This is the first review to look specifically at triadic communication in teenagers and young adults with cancer and has demonstrated that there is a paucity of evidence focussed specifically on triadic communication with TYACs. Of the thirty-three studies in the review only one third included all three parties in the triadic communication encounter. However, the review has enabled us to provide answers to the review questions and identify knowledge gaps, including a lack of theory describing triadic communication. Some preliminary theoretical models, such as family involvement in interpersonal healthcare processes,(57) depict the interaction pathways between patients, families and HCP and hypothesise the influence of family on interpersonal processes and outcomes of medical consultations.

The data has clearly identified that parents are the predominating supporter for TYACs, which may be surprising given the inclusion of participants up to the age of 25. Parents can play a significant role when a young person is diagnosed with cancer. Developmentally, a major characteristic that differentiates TYACs from younger children or older adults is the Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

progressive increase in their desire and capacity for independence, personal agency, and autonomy. This process is disrupted by a cancer diagnosis: increased parental presence can be perceived as intrusive and reflect reversion to an earlier family dynamic, anchoring adolescents in dependency, restricting self-exploration, and limiting development of a TYACs internal value and belief system.(37,58–60) This has been phrased as "retreating to family" and can impede the maintenance of sustaining a network of peers and cancer negatively impacts peer relationships.(39,61,62) Young people may often be accepting of this, particularly in the early stages of the cancer diagnosis. However, the presence of parents alters the experience and impact of communication with HCPs. It is important to highlight that there is limited literature on TYAC communication encounters with supporters other than parents.(59,63,64) Partners felt relegated to a supporting role by a parent, and mothers struggled to relinquish their existing role as primary supporter.(59,64) It is relevant to note that the participants in these three studies were in their early 20's.

A key impact of triadic communication is that young people may not be involved in decision making to the level they want. This is consistent with related paediatric oncology literature which consistently reports children's limited participation in decision-making. (65–67) Clinicians attempted to protect children from 'too much' information because of the perception that children are not capable or too vulnerable.(17) The important difference between paediatric and TYAC populations are the legal and ethical obligations towards TYACs who are autonomous, capacitous patients rather than to parents with parental responsibility.

The findings of this review demonstrate the presence of a supporter impacts the involvement of young people in healthcare decisions. Therefore, there are legal and ethical issues, which are critically important, both in research and clinically in TYAC care particularly related to informed consent, capacity, and autonomy. The law relating to children and young people is complex and differs across the UK and internationally. The General Medical Council guidelines in the UK state, "the patient must be the first concern". (68) HCPs have ethical and legal obligations outlined in UK best practice guidance, statute, and case law.(69) In the UK, parents can legally make decisions for children under 16 years unless the child disagrees and is deemed 'Gillick Competent'. (70) Moreover, studies have shown children aged 14 and older can approach the level of understanding of adults.(71,72) In contrast, people aged 16 and above are legally able to make decisions for themselves in the UK and are automatically assumed to have capacity (73) and therefore, HCPs must communicate with them in developmentally appropriate ways. Clinicians face a challenge in identifying the best way to communicate with TYACs and their supporter (s). TYACs need parental involvement whilst simultaneously desiring autonomy (35) necessitating careful balancing of the needs of both parties to ensure that the young person is not relegated to a non-participant status.

Strengths and weaknesses

Our review had a number of limitations. We searched systematically and thoroughly for eligible studies, but this is not a well-indexed field of research, and therefore it is possible that some relevant studies were not included in the review. We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in

some countries (between 29 to 39). We also only included papers published in English and therefore papers reflect practices in primarily North America, Australia and Europe, the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics and where the healthcare culture may be different, e.g., more paternalistic. Despite these limitations, international representation was seen in the eligible studies, TYAC ages were included across the entirety of the specified UK age range and studies represented the journey throughout the cancer experience.

Implications for clinicians and policy makers

Given the degree of challenge and nuance raised, HCPs need training on effective triadic communication. Fourneret concluded that the relationship between TYACs, their parents and HCPs "as being the most difficult one in oncology".(33) Professionals described challenges communicating with both TYACs and parents, especially when loyalties were torn between the two.(5) However, training is currently ad hoc and not interdisciplinary.(74–77) Furthermore, HCPs can find it difficult to apply teaching in this area in clinical practice.(52,78) HCPs need education and training to navigate triadic communication to optimise involvement of the young person whilst attending to a supporter's needs. Experiential learning is the gold standard in teaching methods for clinical communication and is designed to bring about changes in learners' skills. These evidence-based methods are through small group, problem-based simulation in a classroom, with repeated practise and rehearsal of skills under observation with detailed and descriptive feedback. This is arguably warranted here.(79,80)

Triadic communication is a key feature of TYAC care but requires further attention and inclusion in future iterations of key policy documents and guidelines such as the Blueprint of Care (BoC).(81) The BoC is a UK document that helps shape and deliver developmentally appropriate care to TYAC. However, it is recognised that age is poorly correlated with developmental maturity and therefore any communication framework needs to be specific to TYACs, recognising the transitional nature of adolescence meaning a one size fits all approach is likely inadequate.

Unanswered questions and future research

Future research is warranted to triangulate triadic perspectives and understand more about the interactional dynamics of these complex communication encounters. A key research need is investigating how best to support decision-making whilst engaging supporters, understanding their priorities and information needs may conflict.(30,35,36,39) Conflict management must also be understood in the emotional context of young adult oncology. How to effectively educate HCPs to communicate within the triad, to ensure the young person and the supporters needs are met is a priority. This needs to include how best we facilitate time alone between young patients and HCPs. Continued development and utilisation of comprehensive triadic theoretical frameworks may provide guidance and direction for future research, allowing for greater integration and progress with this diverse research area and commonly occurring form of healthcare communication.

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

Conclusion

Triadic communication is a pivotal component of communicating with TYACs and the presence of supporters impacts clinical communication both positively and negatively. Young people desire a sense of personal agency, autonomy and control related to information flow and decision making. This includes private lines of communication with HCPs without the presence of supporters. HCPs recognise the importance of time alone with young people; however this does not translate to clinical practice. Therefore, further research on communication dynamics is needed to allow for the development of bespoke, TYAC focussed clinical communication. This then needs to be formally embedded in national guidance and postgraduate training for HCPs working in TYAC care to allow equitable access for TYACs.

Author Contributions:

DC, LS and RT were involved in developing the protocol; DC, IK and LS coordinated the running of the study and were responsible for data acquisition; DC, LS, RT and EC contributed to the analysis; DC drafted the manuscript. All authors have critically reviewed the manuscript for important intellectual content and have read and agreed to the published version of the manuscript. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest: The authors declare no conflict of interest.

Ethics Approval:

This was a systematic review and therefore ethics approval was not required.

Funding:

This paper presents work supported by the Wellcome Trust, (grant number G115288) under its Programme PhD for healthcare professionals course awarded to the first author Deborah Critoph, University of Cambridge. The views expressed are those of the author (s) and not necessarily those of the Wellcome Trust.

Data availability statement:

All data relevant to the study are included in the article or uploaded as supplementary information. No previously unpublished primary data are included in the paper. All data relevant to the systematic review are included in the paper or uploaded as supplementary information.

References:

- 1. Cancer Research UK. Young peoples' cancers incidence statistics [Internet]. 2016 [cited 2019 Jul 10]. Available from: https://www.cancerresearchuk.org/healthprofessional/cancer-statistics/young-people-cancers/incidence
- 2. National Institute of Health and Clinical Excellence. Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer National Institute for Health and Clinical Excellence [Internet]. Nice. 2005. 198 p. Available from: https://www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-childrenand-young-people-with-cancer-update-pdf-773378893
- 3. Care Quality Commission., NHS Patient Survey Programme. 2018 Children and Young People's patient experience survey. Statistical Release. 2019;(November).
- 4. White B, Viner RM. Improving communication with adolescents. Arch Dis Child Educ Pract Ed. 2012;97(3):93–7.
- Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer [Internet]. 2016;63(8):1423–30. Available from: http://aplib.com/incurren//10.1002//JSSN/1545_5017

http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017 Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and

- Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and Shaped by Health Care Professionals Caring for Adolescents and Young Adults with Cancer? J Adolesc Young Adult Oncol. 2021;10(5):503–11.
- Gibson F, Aldiss S, Fern LA, Phillips B, Gravestock H, Malik S, et al. Reporting the whole story: Analysis of the "out-of-scope" questions from the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership Survey. Health Expect. 2021;
- Smith LAM, Critoph DJ, Hatcher HM. How Can Health Care Professionals Communicate Effectively with Adolescent and Young Adults Who Have Completed Cancer Treatment? A Systematic Review. J Adolesc Young Adult Oncol [Internet].
 2020 Jan 14; Available from: https://doi.org/10.1089/jayao.2019.0133

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

1 2 3 4 5 6	
7 8 9 10 11	
12 13 14 15 16 17	
18 19 20 21 22	
23 24 25 26 27 28	
29 30 31 32 33	
34 35 36 37 38 39	
40 41 42 43 44	
45 46 47 48 49 50	
50 51 52 53 54 55	
56 57 58 59 60	

1

- 9. Reid J, McKeaveney C, Martin P. Communicating with Adolescents and Young Adults about Cancer-Associated Weight Loss. Curr Oncol Rep. 2019;21(2):6.
 - Phillips CR, Haase JE. A Connectedness Primer for Healthcare Providers: Adolescents/Young Adult Cancer Survivors' Perspectives on Behaviors That Foster Connectedness during Cancer Treatment and the Resulting Positive Outcomes. J Adolesc Young Adult Oncol [Internet]. 2018;7(2):174–80. Available from: http://www.liebertpub.com/products/product.aspx?pid=387
 - Mellblom A V, Finset A, Korsvold L, Loge JH, Ruud E, Lie HC. Emotional concerns in follow-up consultations between paediatric oncologists and adolescent survivors: a video-based observational study. Psychooncology [Internet]. 2014 Dec;23(12):1365– 72. Available from:

https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=109768272&site=ehost-live

12. Korsvold L, Mellblom AV, Finset A, Ruud E, Lie HC. A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members. European Journal of Oncology Nursing [Internet]. 2017;26:1–8. Available from:

https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=cin20&AN= 120589318&site=ehost-live&custid=ns123475

- Ward A, Critoph D, Westacott R, Williams R, Dogra N. A collaboration on teaching and assessing triadic consultation skills. PEC Innovation [Internet]. 2022;1(October):100091. Available from: https://doi.org/10.1016/j.pecinn.2022.100091
- 14. van Staa AL. Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: The added value of mixed methods research. Patient Educ Couns. 2011;82(3):455–64.
- 15. Cahill P, Papageorgiou A. Triadic communication in the primary care paediatric consultation: A review of the literature. British Journal of General Practice. 2007;57(544):904–11.
- 16. Maras M. Hidden in plain sight. Int J Psychiatry Med. 2022;57(6):481–5.
 - 17. Young B, Dixon-woods M, Windridge KC, Heney D. Study of Patients and Parents. Br Med J. 2003;326(7384):305.
 - Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review. Soc Sci Med [Internet]. 2011;72(6):823–31. Available from: http://dx.doi.org/10.1016/j.socscimed.2011.01.015
 - 19. Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, et al. Physicianpatient-companion communication and decision-making: A systematic review of triadic medical consultations. Patient Educ Couns. 2013;91(1):3–13.
 - 20. Tates K, Meeuwesen L. Doctor-parent-child communication. A (re)view of the literature. Soc Sci Med. 2001;52(6):839–51.
 - 21. Popay J, Roberts, H SA et al. Guidance on the Conduct of Narrative Synthesis in Systematic Reviews.
- 22. Petticrew M RH. Systematic Reviews in the social sciences. In: Systematic reviews in the social sciences [Internet]. Available from: https://onlinelibrary.wiley.com/doi/book/10.1002/9780470754887

1		
2 3	23.	Gough D. Weight of Evidence: a framework for the appraisal of the quality and
4	25.	relevance of evidence. 2007 [cited 2023 Jul 2]; Available from:
5		https://www.tandfonline.com/action/journalInformation?journalCode=rred20
6	24	
7 8	24.	Barakat LP, Schwartz LA, Reilly A, Deatrick JA, Balis F. A Qualitative Study of Phase III
8 9		Cancer Clinical Trial Enrollment Decision-Making: Perspectives from Adolescents,
10		Young Adults, Caregivers, and Providers. J Adolesc Young Adult Oncol. 2014;3(1):3–
11		11.
12	25.	Hart RI, Cameron DA, Cowie FJ, Harden J, Heaney NB, Rankin D, et al. The challenges
13		of making informed decisions about treatment and trial participation following a
14		cancer diagnosis: a qualitative study involving adolescents and young adults with
15		cancer and their caregivers. BMC Health Serv Res. 2020;20(1).
16 17	26.	Ingersgaard MV, Tulstrup M, Larsen HB, Schmiegelow Kjeld AO - Ingersgaard MVO
17 18	20.	http://orcid. org/0000 0002 7037 2104. A qualitative study of decision-making on
18		
20		Phase III randomized clinical trial participation in paediatric oncology: Adolescents'
21		and parents' perspectives and preferences. J Adv Nurs. 2018;74(1):110–8.
22	27.	Olsavsky AL, Theroux CI, Dattilo TM, Klosky JL, O'Brien SH, Quinn GP, et al. Family
23		communication about fertility preservation in adolescent males newly diagnosed with
24		cancer. Pediatr Blood Cancer. 2021;68(7).
25 26	28.	Weaver MS, Baker JN, Gibson D V, Gattuso JS, Hinds PS, Gibson D V, et al. "Being a
20		good patient" during times of illness as defined by adolescent patients with cancer.
28		Cancer [Internet]. 2016 Jul 15;122(14):2224–33. Available from:
29		http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142
30	29.	Bahrami M, Namnabati M, Mokarian F, Oujian P, Arbon P. Information-sharing
31		challenges between adolescents with cancer, their parents and health care providers:
32		a qualitative study. Supportive Care in Cancer [Internet]. 2017;25(5):1587–96.
33 34		Available from:
35		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
36		AN=122279626&site=ehost-live
37	20	
38	30.	Darabos K, Berger AJ, Barakat LP, Schwartz LA. Cancer-Related Decision-Making
39		Among Adolescents, Young Adults, Caregivers, and Oncology Providers. Qual Health
40		Res. 2021 Nov 1;31(13):2355–63.
41 42	31.	Davies J, Kelly D, Hannigan B. "Life then", "life interrupted", "life reclaimed": The
42 43		fluctuation of agency in teenagers and young adults with cancer. Eur J Oncol Nurs.
44		2018;36(100885136):48–55.
45	32.	Fern LA, Taylor RM, Whelan J, Pearce S, Grew T, Brooman K, et al. The Art of Age-
46		Appropriate Care. Cancer Nurs [Internet]. 2013;36(5):E27–38. Available from:
47		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
48		AN=110243702&site=ehost-live
49 50	33.	Fourneret E. Breaking Bad News about Cancer to Adolescents and Young Adults: The
50 51	55.	French Experience. J Law Med [Internet]. 2018 [cited 2021 Nov 22];25(2):530–7.
52		Available from: https://pubmed.ncbi.nlm.nih.gov/29978652/
53	24	• • • • •
54	34.	Frederick NN, Mack JW. Adolescent patient involvement in discussions about
55		relapsed or refractory cancer with oncology clinicians. Pediatr Blood Cancer
56		[Internet]. 2018;65(4):1. Available from:
57		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
58 59		AN=128132562&site=ehost-live
59 60		

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

4

5

6 7

8

9

10

11

12 13

14

15

16

17

18 19

20

21

22

23 24

25

26

27

28 29

30

31

32

33

34 35

36

37

38

39

40 41

42

43

44

45 46

47

48

49

50

51 52

53

54

55

56 57

58

59

60

35. Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. Proc SIGCHI Conf Hum Factor Comput Syst [Internet]. 2016 May 7 [cited 2018 Jun 2];2016:5337–49. Available from: http://www.ncbi.nlm.nih.gov/pubmed/28164178 Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients' 36. Experiences With Treatment Decision-making. Pediatrics. 2019;143(5). 37. Patterson P, Millar B, Desille N, McDonald F. The Unmet Needs of Emerging Adults With a Cancer Diagnosis A Qualitative Study. Cancer Nurs. 2012;35(3):E32-40. 38. Pennant S, Lee SC, Holm S, Triplett KN, Howe-Martin L, Campbell R, et al. The Role of Social Support in Adolescent/Young Adults Coping with Cancer Treatment. Children [Internet]. 2020;7(1):1–25. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=142468088&site=ehost-live 39. Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. 3 Dimensions of Treatment Decision Making in Adolescents and Young Adults With Cancer. Cancer Nurs [Internet]. 2020 Nov;43(6):436–45. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=146822019&site=ehost-live 40. Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. Day-to-Day Decision Making by Adolescents and Young Adults with Cancer. Journal of Pediatric Hematology/Oncology Nursing [Internet]. 2022;39(5):290–303. Available from: https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=medl&AN=35538622 https://cambridgeprimo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM services page?sid=OVID:m edline&id=pmid:35538622&id=doi:10.1177%2F27527530211068718&issn= 41. Zarnegar S, Gosiengfiao Y, Rademaker A, Casey R, Albritton KH. Recall of Fertility Discussion by Adolescent Female Cancer Patients: A Survey-Based Pilot Study. J Adolesc Young Adult Oncol [Internet]. 2018 Apr;7(2):249–53. Available from: http://www.liebertpub.com/products/product.aspx?pid=387 42. Viola A, Taggi-Pinto A, Sahler OJZ, Alderfer MA, Devine KA, Ed M, et al. Problemsolving skills, parent-adolescent communication, dyadic functioning, and distress among adolescents with cancer. Pediatr Blood Cancer. 2018;65(5). 43. Weaver MS, Baker JN, Gibson DV, Gattuso JS, Sykes AD, Hinds PS. Adolescents' preferences for treatment decisional involvement during their cancer. Cancer [Internet]. 2015;121(24):4416–24. Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142 Sisk BA, Keenan M, Kaye EC, Baker JN, Mack JW, DuBois JM. Co-management of 44. communication and care in adolescent and young adult oncology. Pediatr Blood Cancer [Internet]. 2022;69(10):e29813. Available from: https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=mesx&AN=35719025 https://cambridgeprimo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM services page?sid=OVID:m edline&id=pmid:35719025&id=doi:10.1002%2Fpbc.29813&issn=1545-500 45. Sisk BA, Keenan M, Schulz GL, Kaye E, Baker JN, Mack JW, et al. Interdependent functions of communication with adolescents and young adults in oncology. Pediatr Blood Cancer [Internet]. 2022; Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017

et].	-
	-
g	Protected by
J	/ copyri
xt&	yht, inc
):m	luding
0&	Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining
20	rieur (/ nd data
0&	ABES)
ces	
0&	ng, and
ing	ES) . ining, Al training, and similar technologies.
	es.

46.	Barlevy D, Wangmo T, Ash S, Elger BS, Ravitsky V. Oncofertility decision making: Findings from Israeli adolescents and parents. J Adolesc Young Adult Oncol [Internet]. 2019;8(1):74–83. Available from: https://www.proquest.com/scholarly- journals/oncofertility-decision-making-findings-israeli/docview/2426222863/se-
	2?accountid=47868
47.	Sawyer SM, McNeil R, Thompson K, Orme LM, McCarthy MAOSSM; O http://orcid. org/0000 0002 9095 358X, Sawyer SM, et al. Developmentally appropriate care for adolescents and young adults with cancer: how well is Australia doing? Supportive Care in Cancer [Internet]. 2019;27(5):1783–92. Available from: http://link.springer.de/link/service/journals/00520/index.htm
48.	Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among child and adolescent cancer survivors and their parents: A qualitative analysis. J Psychosoc Oncol. 2016;34(5):347–62.
49.	Ananth P, Mun S, Reffat N, Li R, Sedghi T, Avery M, et al. A Stakeholder-Driven Qualitative Study to Define High Quality End-of-Life Care for Children With Cancer. J Pain Symptom Manage [Internet]. 2021;62(3):492–502. Available from: https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=med19&AN=33556497 https://cambridge- primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m edline&id=pmid:33556497&id=doi:10.1016%2Fj.jpainsymman.2021.01.
50.	Cicero-Oneto CE, Valdez-Martinez E, Bedolla M. Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study. BMC Med Ethics [Internet]. 2017;18:74. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=127010047&site=ehost-live
51.	Friebert S, Grossoehme DH, Baker JN, Needle J, Thompkins JD, Cheng YI, et al. Congruence Gaps Between Adolescents With Cancer and Their Families Regarding Values, Goals, and Beliefs About End-of-Life Care. JAMA Netw Open [Internet]. 2020 May 19;e205424–e205424. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=143389091&site=ehost-live
52.	Jacobs S, Perez J, Cheng YI, Sill A, Wang J, Lyon ME. Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. Pediatr Blood Cancer [Internet]. 2015;62(4):710–4. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=109777063&site=ehost-live
53.	Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-centered advance care planning for teens with cancer. JAMA Pediatr. 2013;167(5):460–7.
54.	Wu LM, Chiou SS, Lin PC, Liao YM, Su HL. Decisional conflicts, anxiety, and perceptions of shared decision-making in cancer treatment trajectory among adolescents with cancer: A longitudinal study. Journal of Nursing Scholarship. 2022;54(5):589–97.
55.	Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients' Experiences With Treatment Decision-making. Pediatrics. 2019;143(5).
56.	Martins A, Alvarez-Galvez J, Fern LA, Vindrola-Padros C, Barber JA, Gibson F, et al. The BRIGHTLIGHT National Survey of the Impact of Specialist Teenage and Young Adult

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

2 3	
3 4	
5	
6	
7	
8 9	
10	
11	
12	
13 14	
14	
16	
17	
18 19	
20	
21	
22	
23	
24 25	
26	
27	
28	
29 30	
31	
32	
33	
34 35	
36	
37	
38	
39 40	
40 41	
42	
43	
44 45	
45 46	
47	
48	
49	
50 51	
52	
53	
54	
55 56	
56 57	
58	
59	
60	

1

Cancer Care on Caregivers' Information and Support Needs. Cancer Nurs. 2021;44(3):235–43.

- 57. Dalton JM. Development and testing of the theory of collaborative decision-making in nursing practice for triads. J Adv Nurs. 2003;41(1):22–33.
- 58. Grinyer A. Young people living with cancer:implications for policy and practice. Open University Press; 2007. 182 p.
- 59. Moules NJ, Laing CM, Estefan A, Schulte F, Guilcher GMT. "Family Is Who They Say They Are"(a): Examining the Effects of Cancer on the Romantic Partners of Adolescents and Young Adults. J Fam Nurs. 2018;24(3):374–404.
- 60. Silva M, Barretta F, Luksch R, Terenziani M, Casanova M, Spreafico F, et al. Adolescents with cancer on privacy: Fact-finding survey on the need for confidentiality and space. Tumori. 2021 Oct 1;107(5):452–7.
- 61. KM B, Smith A, Schmidt S, TH K, Zebrack B, CF L, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. Cancer (0008543X) [Internet]. 2012 Oct 15;118(20):5155–62. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=104372613&site=ehost-live
- 62. Pyke-Grimm KA, Franck LS, Patterson Kelly K, Halpern-Felsher B, Goldsby RE, Kleiman A, et al. Treatment Decision-Making Involvement in Adolescents and Young Adults With Cancer. Oncol Nurs Forum [Internet]. 2019;46(1):E22–37. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=133553348&site=ehost-live
- 63. Davies J. The experience and role of partners in helping to meet the support needs of adolescents and young adults with cancer. Journal of Advanced Nursing (John Wiley & Sons, Inc) [Internet]. 2019 May;75(5):1119–25. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=135934208&site=ehost-live
- 64. Iannarino NT. "It's My Job Now, I Guess": Biographical disruption and communication work in supporters of young adult cancer survivors. Commun Monogr [Internet]. 2018;85(4):491–514. Available from: https://doi.org/10.1080/03637751.2018.1468916
- 65. Coyne I, Amory A, Gibson F, Kiernan G. Information-sharing between healthcare professionals, parents and children with cancer: More than a matter of information exchange. Eur J Cancer Care (Engl). 2016;25(1):141–56.
- 66. de Vries MC, Wit JM, Engberts DP, Kaspers GJL, van Leeuwen E. Pediatric Oncologists' Attitudes Towards Involving Adolescents in Decision-Making Concerning Research Participation. Pediatr Blood Cancer. 2010;55(1):123–8.
- Frederick NN, Bingen K, Bober SL, Cherven B, Xu X, Quinn GP, et al. Pediatric oncology clinician communication about sexual health with adolescents and young adults: A report from the children's oncology group. Cancer Med [Internet]. 2021;10(15):5110–9. Available from:

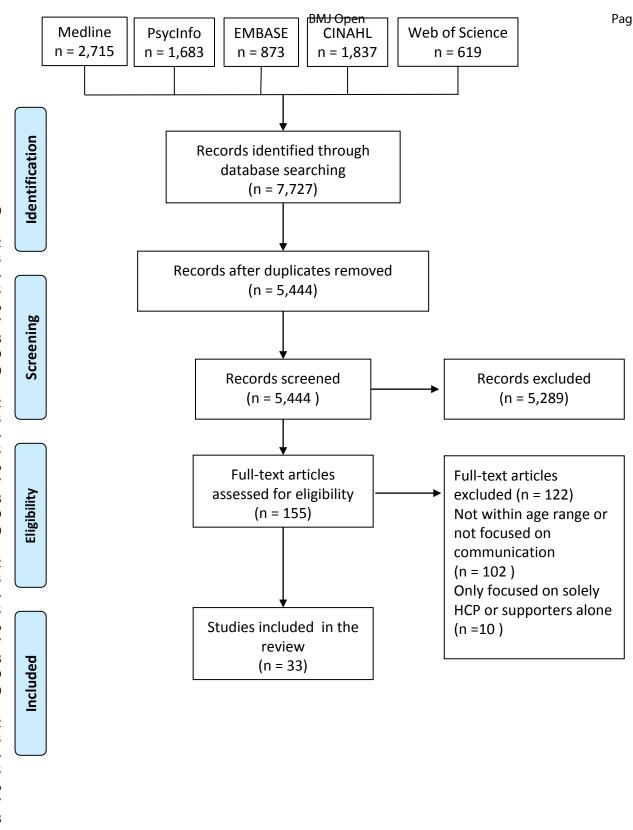
https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=med20&AN=34128352 https://cambridge-

primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m edline&id=pmid:34128352&id=doi:10.1002%2Fcam4.4077&issn=2045-76

2		
3	68.	General Medical Council. (
4	08.	
5		Doctors [Internet]. 2018;1
б		guidance/ethical-guidance
7	69.	British Medical Associatior
8		BMA.org.uk [Internet]. 202
9	70.	Gillick T. Gillick competend
10 11		capacity and The Gillick ca
11	71.	Joffe S, Fernandez C V., Pe
12	, 1.	children with cancer in dec
14		
15		Pediatrics. 2006;149(6).
16	72.	Mårtenson EK, Fägerskiöld
17		health care. J Clin Nurs. 20
18	73.	Department for Constitution
19		Mental Capactity Act 2005
20	74.	Lea S, Gibson F, Taylor RM
21		Shaped by Health Care Pro
22		Cancer? J Adolesc Young A
23 24	75.	_
25	75.	Essig S, Steiner C, Kuehni C
26		Adolescent Cancer Care: A
27		2016;63(8):1423–30.
28	76.	Essig S, Steiner C, Kühne T,
29		Training for Professionals
30		Participants' Needs: A Pilo
31		4;8(3):354–62.
32	77.	Coad J, Smith J, Pontin D, C
33	77.	Advanced Communication
34 35		
35 36		Pediatric Oncology Nursing
37	78.	Ruhe KM, Badarau DO, Bra
38		Participation in pediatric o
39		Psychooncology. 2016;25(
40	79.	Blackmore A, Kasfiki EV, Pu
41		communication skills: A sy
42		BMJ Simul Technol Enhance
43	80.	Mahoney P, Macfarlane S,
44	00.	•
45		education. Teaching in Hig
46 47		from: https://doi.org/10.1
47 48	81.	Smith S, Mooney S, Cable I
49		young adults with cancer S
50		https://www.teenagecanc
51		pdf
52		•
53		
54		
55		
56		
57		
58 59		
59 60		

- Guidance for All Doctors. 0-18 Years: Guidance for All 1. Available from: https://www.gmc-uk.org/ethicale-for-doctors/0-18-years/making-decisions#paragraph-29 n. Children and young people toolkit A toolkit for doctors. 21; Available from: https://www.bma.org.uk ce What is Gillick Here 's what you need to know about se. 2022; ntz RD, Ungar DR, Mathew NA, Turner CW, et al. Involving cision-making about research participation. Journal of AM. A review of children's decision-making competence in 08;17(23):3131-41. onal Affairs. Mental Capactity Act 2005: Code of Practice. : Code of Practice. 2007;1–301. . Holistic Competence": How Is it Developed, Shared, and ofessionals Caring for Adolescents and Young Adults with dult Oncol. 2021;10(5):503-11. E, Weber H, Kiss A. Improving Communication in Multiperspective Study. Pediatr Blood Cancer. Kremens B, Langewitz W, Kiss A. Communication Skills Working with Adolescent Patients with Cancer Based on t. https://home.liebertpub.com/jayao. 2019 Jun Gibson F. Consult, Negotiate, and Involve: Evaluation of an Skills Program for Health Care Professionals. Journal of g. 2018 Jul 1;35(4):296–307. azzola P, Hengartner H, Elger BS, Wangmo T, et al. oncology: views of child and adolescent patients. 9):1036-42. urva M. Simulation-based education to improve stematic review and identification of current best practice. : Learn. 2018;4(4):159–64. Ajjawi R. A qualitative synthesis of video feedback in higher her Education [Internet]. 2019;24(2):157–79. Available 080/13562517.2018.1471457 M, Taylor RM. THE BLUEPRINT OF CARE for teenagers and Second edition. 2016; Available from:
 - ertrust.org/sites/default/files/BlueprintOfCare 2ndEdition.

Page 22 of 47



23 of 47				BMJ Open		6/bmjopen-2023-080024 cted by copyright, ings Key finde
First author			<u>]</u> Study Type - analysis method	Summary o	f Articles	יז-2023-080 opyright, i
(year)	Title	Setting	Data collection	Focus	Participant Characteristics [¥]	Key find gs R
Ananth (2021)	A Stakeholder- Driven Qualitative Study to Define High Quality End- Of-Life Care for Children with Cancer	USA Multicentre	Qualitative - <u>thematic analysis</u> Semi-structured interviews and focus groups.	To explore end of life care (EOLC) priorities for children with cancer and their families.	 <u>54 participants:</u> 10 AYACs (age range: 17-23 years) 25 parents (including 12 bereaved parents) 19 healthcare professionals 	Important to gave direct communication with the child or young person regarding decision- making. Interdisco line y care with integrated teams is vital for high patient of life care. Continuity of health of professionals was positive. AYACs of the professionals may be hesitant.
Bahrami (2017)	Information Sharing Challenges Between Adolescents with Cancer, their Parents and Health Care Providers: A Qualitative Study	Iran Single centre	Qualitative descriptive- exploratory study - <u>grounded theory</u> <u>analysis</u> Semi-structured interviews.		33 participants: 12 AYACs (age range at interview: 15-20 years, within 1 year of diagnosis) 6 supporters 6 healthcare professionals	 AYACs feet they are excluded from information- sharing sections between parents and healthcare profession s. This leads to disaffiliation, confusion and AYACs seek information from 'inferior' sources. Parents were often the first receivers of information allowing them to act as gatekeepers controlling information to flow to AYACs. Parents may want to sheld AYACs from bad news. Trust and homesty are the foundations of effective communication between AYACs and healthcare professionals. AYACs reacted negatively towards dianonesty.
Barakat (2014)	A Qualitative Study of Phase III Cancer Clinical Trial Enrollment Decision Making Perspectives from AYAC, Caregivers and Providers		Qualitative - <u>thematic analysis</u> <i>Semi-structured</i> <i>interviews</i> .	Clinical trial enrollment.	40 participants: 13 AYACs (age range: 15- 21 years) 16 supporters 11 healthcare professionals	 Four patterns of decision-making patterns identified: 1. AYAC abdicates to caregiver, 2. Caregiver based and AYAC approved, 3. Collaborative, 4. AYAC in marge of decision-making. Caregivers parceived AYAC to be in charge of decision making most of the time whereas the AYACs selt that "AYAC abdicates to carer" was the most common form of decision making. Distress and poor health limited AYAC involvement in the decision. Development and emotional maturity facilitated involvement.
		For pe	eer review only - ht	tp://bmjopen.bmj.o	com/site/about/guidelines.xl	ntml de l

As in other Bultural contexts, Israeli adolesc and parents demonstrate multifac decision methics with respect to oncoferti	A significant finding from this st suggests that health professional shy fi discussing posthumous planning cryoposerved materials with adolese cancer patents and their parents. 5 out of AYAS that the decision was not theirs that it was instead the parents' or the pysici to make the clinician - explicit or imp recompositions from the clinician stror influence clinician making. No decisional re- expressing by any members of the dyad.		
<u>35 participants</u> 16 AYACs (age range 12- 16 years)	19 parents	13 paediatric oncologists 13 parents or primary carers 6 AYACs (age range 13-18 years)	com/site/about/guidelines.xh
BMJ Open To understand adolescent oncofertilty	decision making in Israel, from perspectives of parents and adolescents	on therapeutic futility	:p://bmjopen.bmj.c
Qualitative- thematic analysis	semi-structured interviews	Qualitative - thematic analysis Semi-structured interviews	er review only - htt
Israel Single centre	л _с	Mexico Multicentre	For pe
Oncofertility decision making: findings from	Israeli adolescents and parents	Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study	
Barlevy (2019)		Cicero- Oneto (2017)	

Page 25 of 4	7			BMJ Open 66 bm jopen 50 cop						
1 2 3 4 5 5 7 3 9 10 11 12 13 14 15 16 17 18 19 20 21	Darabos (2021)	Cancer Related Decision Making Among AYAC, Care Givers and Oncology Providers	USA Single centre	Qualitative – content analysis with hypothesis coding Semi-structured interviews.	Decision-making and triadic communication	30 Participants: 11 AYACs (age range: 15- 24 years) 11 supporters 8 healthcare professionals	 Four decision making patterns were identified: AYAC deven, Collaborative, Deferrated parents, Provider based, AYA/Caregiver-approved. Collaborative decision-making and AYAC-driven decisions were most commonly described. There was recognition that some decision-making aday/context dependent. AYACs were more likely to drive decisions regarding apportive care than treatment related decisions. AYACs and caregivers explained how cognitive and caregivers			
22 23 24 25 26 27 28 29 30	Davies (2019)	'Life then', 'life interrupted', 'life reclaimed': the fluctuation of agency in teenagers and young adults with cancer	UK single centre	qualitative - thematic analysis case studies - multiple interviews		22 participants 5 AYACs (16-24 years) 5 parents carers (2 fathers, 3 mothers, 1 couple), 5 healthcare professionals (4 nurses and 1 oncology consultant) 5 other supporters (1 boyfriend, 1 girlfriend, 1 aunt, 2 friends)	Agency Luciates over time within cases and between cases. Agency can fluctuate between personal proxy and collective perspectives. Personal agency is high prior to diagnosis, decrease after diagnosis and is reclaimed after treatments in on treatments of the second sec			
31 32 33 34 35 36 37 38 39 40 41	Ellis (2016)	Fertility concerns among child and adolescent survivors and parents: a qualitative study	Australia single centre	Qualitative semi-structured telephone interviews	recently off treatment and	97 participants from 45 families 19 AYACs (age range 7-17 at diagnosis, mean age 13.3) 44 mothers and 34 fathers	reported and conversations about fertility were frequently interrupted to discuss illness and treatment. These fertility discussions were not then continues once the AYAC was off treatment m			
11 12 13 14 15 16 17			For pe	eer review only - ht	tp://bmjopen.bmj.c	com/site/about/guidelines.xh	bliographique 3 Itml de I			

				BMJ Open		Cted by copynalizing can	Page 26
Essig (2016)	Improving Communication in Adolescent Cancer Care: A Multiperspective Study	Germany, Austria, Switzerland Number of centres not stated	Qualitative – inductive thematic analysis Focus groups.	Explore effective communication with AYACs for communication skills training.	54 participants: 16 AYACs (age range: 13-19 years) 8 parents 30 healthcare professionals	adolessents are cogniti lack the abgity to make AYACs teel closs of auto Age-appenpinete environm Effective communication type of protessional (i.e Adolescents enegatively when: 1. They are indifferent 2. They point is cont 3. They will be professional comments in when: 1. They are professional comments in when: 1. They are professional comments and the teat the appropriate way. 2. They den't take the	nomy. ents are important. differs depending on the ., doctor vs nurse) affect communication flict with treatment arents. s negatively affect e adolescent in an age- adolescent seriously. information or withhold
Fern (2013)	The Art of Age- Appropriate Care	UK Number of centres not stated	Qualitative – <u>thematic analysis</u> <i>Peer-to-peer</i> <i>interviews, field</i> <i>notes and spider</i> <i>diagrams from</i> <i>focus groups.</i>	Review a conceptual model of AYACs' cancer care experiences.	11 participants: 11 AYACs (age range: 13- 25 years)	 Engagement. Individually tailored. Support unproxied by AYACs and not want information was revealed by a service of continuity of hereits. 	on of their stated needs: l information. by parents/family. rmation to be directed at rassing when sensitive d in the presence of their nealthcare professionals tisfaction and irritation
		For pe	eer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xl	ntml de	4

je 27 of 47	7			BMJ Open BMJ Open-2					
	Fourneret (2018)	Breaking bad news about cancer to adolescents and young adults: the french experience	Multicentre	qualitative semi- structured interviews	Explore the effectiveness and implementation of the French announcement protocol in 7 french paediatric oncology centres	90 participants 27 AYACs (21 were 14-17 and 6 were 18-22) 30 parents (16 mothers, 5 fathers, 9 parents together at the appointment) 33 healthcare professionals	Parents and AYACs have different needs - both of which needs to be accounted for when breaking bad newson Awkward and premature announcements were noted The anneuncement consultation – young patients were dever alone when informed of their disease either with parents (n=31) (parents were informed thefore their child 10 out of 31 times - this was in the parents so they can better support the charge were the bad news is broken) or close family method ber/sibling or boyfriend or girlfriend (n=2).000000000000000000000000000000000000		
	Frederick (2018)	Adolescent Patient Involvement in Discussions About Relapsed or Refractory Cancer with Oncology Clinicians.	USA Single centre	Qualitative – <u>content analysis</u> <i>Audiotaped</i> <i>conversations</i> .	Breaking bad news of relapsed or refractory cancer.	75 participants: 11 AYACs (age range: 12.6-17.5 years) 44 supporters 20 healthcare professionals	 Adolescent patients' involvement in conversations about alapsed or refractory cancer is limited. Adolescents were accompanied by one (27%) two (64%) in more than two (18%) family members in the discussion. Adolescents poke 3.5% of words compared to 66.9% elimitians and 30% parents. No conversations included instances in which the clinicians' g asked adolescents for their communication preferences or desired role in decision-making. 		
	Friebert (2020)	Congruence gaps between adolescents with cancer and their families regarding values, goals and beliefs about end- of-life care	USA multicentre	Qualitative cross- sectional study	End of life care	126 parent-AYAC dyads AYACs (14-20 years, mean age 16.9)	Young people wanted early information (86%) but only 32% families knew this. Families understanding of what was important to their adolescents when dealing with their own dying was excellent for wanting honest answers from their physician and understanding treatment choices but poor for dying a natural death and being off machines that extend life, if dying. Parents do not know what AYACs want at the end of life		
			For po	eer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xł	ntml de		

Page 28 of 47

				BMJ Open		cted by cop
Hart (2020)	The Challenges of Making Informed Decisions About Treatment and Trial Participation Following Cancer: A Qualitative Study with Adolescent and Young Adults with Cancer and Care Givers	UK Multicentre	Qualitative – thematic analysis Semi-structured interviews.	treatment and	33 participants: 18 AYACs (age range: 16- 24 years) 15 supporters	AYACs struggled to process information around diagnosis, exacerbated by symptom burden, emotions, and the fast pace of clinical activity. Some AYACs disengaged from conversation topics which were distressing. There are limited options for 'real' decision- making at diagnosis. However, many preferred this when they were already overwhelmed by emotions and the second by the recommendation of the second by the recommendation
Hong (2016)	Care Partnerships: toward technology to support teen's participation in their health care	US multicentre	Qualitative semi-structured interviews and observations	To investigate how technology can support the partnerships between AYACs, parents and clinicians when the AYAC is experiencing complex chronic illness	33 interviews. 15 with AYACs (13 of whom had cancer. age range 13-17) 15 parents (10 mothers, 1 fathers, 1 aunt and 2 fathers and mothers together) 8 clinician caregivers	interest of a Participatity faced challenges concerning: 1) a structure of a sensitive 2) a some unicating emotionally sensitive and a sen
Ingersgaard (2018)	A qualitative study on decision-making on Phase III randomized clinical trial participation in paediatric oncology: adolescents' and parents' perspectives and preferences	Denmark	qualitative exploratory study - in-depth semi- structured interviews with thematic analysis	To explore patients' and AYACs' motivs for accepting/ declining participation in the AL2008 trial and adolescents' involvement in decision making	16 participants 5 AYACs (age range 12-16) 6 parents of AYACs 5 parents of children aged 3- 10 years with cancer	 Key there is in the clinicians in the clinicians in the clinicians in the clinicians in the generation of cure contrated of the clinicians in the generation of cure contrated of the clinicians in the generation of cure contrated of the clinicians in the generation of the clinicians in the generation of the clinicians in the clinicians
		For pe	eer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xh	at Agence Bibliographique de l

Page	29	of	47
------	----	----	----

47			BMJ Open		Adolesconts Swith cancer were comfortable
Jacobs Adolescent en life preference congruence w their parents' preferences: r of a survey of adolescents w cancer	and n ults	Qualitative three sessions of dyadic interviews	To explore AYACs' end of life preferences and to assess the congruence of these preferences with the parents' beliefs	17 adolescent/ family dyads 17 AYACs (age range 14- 21, 71% under 18)	Adolescents with cancer were comfortable discussing FOL, and the majority preferred to talk about FOL issues before they are facing EOL. There were substantive areas of agreement between adolescents and their surrogates, but important facets of adolescents' EOL wishes were for known by their families, reinforcing the importance of eliciting individual preference and engaging dyads so parents can unders and their children's wishes. 53% of AYAC framework spoken about their end of life preference but 82% considered it important to let their Byed ones know their wishes.
Korsvold A content ana (2017) of emotional concerns expr at the time of receiving a ca diagnosis: An observational of consultation with adolesce young adult patients and th family member	ssed cer udy and ir	exploratory mixed methods study audio recorded consultations	To investigate the emotional concerns of AYACs at the time of diagnosis and how to quantify how healthcare professionals respond	<u>18 participants</u> 9 AYACs (age range 13-23 Present with mother (n=9), father (n=1), sister (n=1) or mother and father (n=2)	Four main themes of emotional concerns
Lyon Family-Cente (2013) Advance Care Planning for T With Cancer	single centre	Qualitative a randomised control pilot study	To examine the efficacy of family-centres ACP	30 dyads mean age of AYACs 16 17 were randomised to intervention and 13 were randomised to control 87% of surrogates were biological parents and were female	The model (AGP) increased congruence in the triad compared in the control standard of care group- so it is key. The family centres ACP AYACs reported for ling more informed that the control group
	For	peer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xl	raphique 7

				BMJ Open	L	A majority of AYACs (58%) want to sha
Mack (2019)	Adolescent and Young Adult Cancer Patients' Experiences with Treatment Decision-Making	USA Single Centre	Quantitative – multivariate analysis, logistic regression Surveys at diagnosis, 4 and 12 months.	Treatment decision-making	203 participants: 203 AYACs (age range: 15- 29 years)	A majority of AYACs (58%) want to sha decision-making with oncologists. The remainder overe split between the AYA wanting pumary responsibility in decision making (20%) or wanting their oncologist have gimmery responsibility (22%). A lower opportion of younger AYACs want sole responsibility but this did not achie statistic significance (P = 0.07). The majority 90%) of AYACs who lived with parent of 90%) of AYACs who lived with parent of 90%) of AYACs who lived with parent of 90% (either collaborative or considerin their of 90%). Younger of Cs (15-17 years) were more like to want of the relative to their parents b were and once likely to be less involved the they wanted to be relative to their parents. Decision of correct was less likely among AYAC who the spon oncologists completely, and whe report of the parent oncologists understood what w important of them when treatment started.
Olsavsky (2021)	Family communication about fertility preservation in adolescent males newly diagnosed with cancer	USA	Qualitative	To explore fertility preservation communication among mothers, fathers and their male adolescents newly diagnosed with cancer.	87 participants: 33 AYAC aged 12-25 32 mothers 22 fathers Representing 37 families in total.	 Five process themes: (1) Raiange on health care team and soci support networks to facilitate FP decision (need just by parents), (2) wighod ing parental opinion and deferring the decision to the adolescent, (3) easy of communication, (4) communication barriers and facilitators, (5) not being present or not remembering details of Conversations. Four content themes: (1) proference for biological parenthood (grad digreenthood), (2) consideration of future partner of AYAC desire for biological parenthood, (3) sperm wanking whilst it is a viable option, (4) openness to alternative parenthood options
		For pe	eer review only - ht	ttp://bmjopen.bmj.	com/site/about/guidelines.xh	Bibliographique ntml de l

Page 31 of 47				BMJ Open		cted by c	experience poses the potential for
1 Pattersor 2 (2012) 3 (2012) 4 5 6 7 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 —	The Unmet Needs of Emerging Adults With a Cancer Diagnosis	Australia	Qualitative	Aim to contribute to the limited research base and inform our understanding of the needs of emerging adults with a diagnosis of cancer from a developmental perspective that appreciates the key transitional tasks of emerging adulthood identified by Arnett	14 AYAC aged 20-25,	achievemen achievemen The needing into six the daily light renegotiation These the requirement 1. b into a and a and 3. Al taning 3. Al taning	interpersonal support, identity on the four requirements for adulthood. of hese emerging adults were grouped mess; information, healthcare provision, ng interpersonal support, identity on and emotional distress. Set of adulthood. The solution of adulthood. The solution of a set of
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47		For p			:om/site/about/guideline	s.xhtml	סיין on June 13, 2025 at Agence Bibliographique de I

				BMJ Oper	1	Themes of support included; presence,
(2020) Supp Adol Adul	Role of Social oort in lescent/Young lts Coping with eer Treatment		Qualitative	To explore specific actions that help AYAC and what behaviours they want from their social supports	20 Participants: 10 AYAC ages 15-26, mean age 18.9 years 10 parents	 Theme of support included; presence, distraction, positive attitude, maintaining AYACS autonomy, communication and advocated. Mothes were the most noted family support. AYAC patients can differ in their preferences throughout treatment and this can, at times, appear contradictory. AYAC patients can differ in their preferences throughout treatment and this can, at times, appear contradictory. AYAC patients of want autonomy and independence, but appreciate help with daily tasks from their parents. They express the desire for privacy, but also value poysical presence and communication Parents much oscillate between being involved in and starring to their AYAC child's needs during areatment while allowing space for independence and autonomy. The mode of the should be the preferences and needs throughout the course of treatment and asking them about both individual and social preferences, which may change frequently.
Grimm Treat (2020) Maki Adol	tment Decision ing in lescents and ng Adults with	USA Multicentre	Qualitative – ethnographic Semi-structured interviews, field notes.	Explore the preferences of AYACs for involvement in healthcare decisions	16 participants: 16 AYACs (age range: 14.7-20 years)	Emotions around diagnosis inhibit information receptiveness and ability to engage in treatment decisions (especially important decisions). Initially AYACs struggle with the jargon and plethom of medical terms which are being used. They have bimited knowledge which limits their questions, this increases over time. The importance of decisions differs from one AYACs to the next. Also, some decisions are seen abhaving only one 'real' option. AYACs engaged in minor decisions much earlier in their treatment, and some began engaging in more important decisions later in treatment. AYACs could adopt an active (sole decision maker), collaborative (with healthcare professional s/supporters) or passive (healthcare professional s/supporters as decision makers)
						html de

Page 33 of 43	7				BMJ Open		Factors Figure the involvement of AYAC in
1 2 3 4 5 6 7 8 9 10 11 12 13 14	Pyke- Grimm (2022)	Day-to-Day Decision Making by Adolescents and Young Adults with Cancer	USA	Qualitative Interpretive focused ethnography within the socio- logic tradition, informed by symbolic interactionism	To explore involvement of AYAs with cancer in day-to- day decisions affected by their cancer and treatment.	<u>16 Participants:</u> 16 AYAC aged 15-20 (at time of interview - with an average of one year from diagnosis)	decision making such as the type of decision, the point in the cancer journey. They want to be involved. Four day to day decision making categories were identified: inental mindset, self care practices, self-actionary and negotiating relationships. Parents were offen present and staying strong was a rector for the theme across mental mindset and negotiating relationships. HCP are offen the focus of the focus of the terms of the focus of the terms of the focus of the terms of terms of the terms of terms of the terms of terms of terms of terms of the terms of te
15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sawyer (2019)	Developmentally Appropriate Care for Adolescents and Young Adults with Cancer: How Well is Australia Doing?	Australasia Multicentre	Quantitative – <u>Chi-squared and</u> <u>Fisher's exact test</u> Single time point survey.		196 participants: 196 AYACs (age range: 15 25 years)	 >90% of the action of the second state of the second
31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47			For pe	eer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xł	ne 13, 2025 at Agence Bibliographique de I ntml 11

Building	1	BMJ Oper				
 Building reprint the second second	37 participants: 37 AYACs (age range: 12- 20 years; mean: 16 years)	Define communication functions from perspective of AYACs.	Qualitative – content analysis Semi-structured interviews.	USA Multicentre	Interdependent Functions of Communication with Adolescents and Young Adults in Oncology	
Agence Bibliographique 12 tml de I	.com/site/about/guidelines.xh	tp://bmjopen.bmj	eer review only - ht	For p		

Page	35	of	47
------	----	----	----

3MJ (Open
-------	------

Page 35 of 47					BMJ Open		There are 6 20 co-manage with
1 S 2 3 4 5 6 7 8 9 10 11 12 13 14 15	Sisk (2022)	Co-management of communication and care in adolescent and young adult oncology	USA	Qualitative Semi-structured interviews	Study aimed to learn how AYAs and parents shared and delegated roles in communication and care during and after treatment for cancer	37 Participants: 37 AYAC aged 12-24 Mean age 16 years	There are 6 Soles that AYAC co-manage with parents managing information, managing social and monogonal needs, managing health, advocacy and empowerment, making decisions and managing logistics. Five fagors, that influence AYAC roles in communication were: AYAC agence Clinical and areagement Emotional and physical well-being Personal and physical well-being Personal and areagement of the adoles of the sole of th
16 V 17 (2 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33	/iola 2018)	Problem-solving skills, parent- adolescent communication, dyadic functioning, and distress among adolescents with cancer	USA	Mixed methods study		39 Parents - 79.5 % mothers	Better addissent problem solving skills and better parent boolem solving skills were associated with low ridolescent distress. Parents addinate communication problems. The most commonly endorsed cancer-related problem was "not talking about what to do if the AYAC gool significantly worse'. Parents correct better problem solving ability and better ayactic functioning than their adolescent.
רר	Veaver 2016)	"Being a Good Patient" During Times of Illness as Defined by Adolescent Patients With Cancer	USA	Qualitative - semantic content analysis Semi-structured interviews		40 participants AYAC ages 12-19 Mean age of 15.5 years	The concepts of adherence and compliance were the primary phrases used to describe the good patient role but always within the context of a relationship. Of note: A total of 23 adolescents requested to be interviewed alone with the interviewe (57.5%)
41 42 43 44 45 46 47			For pe	eer review only - ht	tp://bmjopen.bmj.	com/site/about/guidelines.xł	ographique 13 ntml de

				BMJ Open		6/bmjopen-2
Weaver (2015)	Adolescents' Preferences for Treatment Decisional Involvement During Their Cancer	USA Multicentre	Qualitative – semantic content analysis Semi-structured interviews.	Investigate AYACs' decision-making preferences and how supports and healthcare professionals can support involvement.	40 participants: 40 AYACs (age range at interview: 12-18.9 years; 0.5-6 months from diagnosis/relapse) NB: 34 AYACs primary diagnosis, 6 AYACs relapse.	 AYACs indicated a spectrum of preferred decisional joles, with the most common being an actively ingolved role (65%), although a shared decision-making approach was still valued. AYACs decognized that situational and social contexts might shift their preferred level of involvement in medical decisions. Although addrescents wanted to be involved in decision bey also expressed an appreciation of family is they also expressed and expressed and
Wu (2021)	Decisional conflicts, anxiety, and perceptions of shared decision- making in cancer treatment trajectory among adolescents with cancer: A longitudinal study	Taiwan	Qualitative. An explanatory mixed method was used, incorporating questionnaires and individual interviews.	To describe the perception on levels of decision-making during cancer treatment for adolescents with cancer and examine the trajectory of their decisional conflict	44 participants: 22 AYAC 11 male and 11 female mean age 15.39 22 Supporters: father n=1 mothers n=12 both n=6 other n=3	Difference as of participation in shared decision making (50) during the treatment trajectory were for the system of the highest decisional conflict and diagnosis. Roles in heathcare communication varied from direct articipation to indirect involvement. Overall, aparecipants reported that doctors and parente, davided their level of involvement, communication and or decision making.
Zarnegar et al (2018)	Recall of Fertility Discussion by Adolescent Female Cancer Patients: A Survey- Based Pilot Study	USA	Qualitative	To assess: recall of a fertility discussion, satisfaction with fertility knowledge, and identify factors that may influence recall.	19 participants: 19 AYAC aged 13-18 years and a mean age of 15.6	 42% and 2% of AYAC did not recall discussion regarding geatment related infertility or fertility preservation during initial treatment planning. 63% of AYAC reported that parents made all or most of the decisions whereas 30.8% reported making decisions with parents. Key Finding A greater percentage of AYAC who reported making a joint decision with parents recalled 71% of fertility discussions than those who reported parents made most or all of

Supplementary File – Search strategy and history

Searches run November 2022

Limited to 2005 onwards, and to English language only.

<text>

Medline (via Ovid)

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to November 23, 2022>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "caregiver*" or spouse* or supporter* or support network*).ti,ab. or parents/ or fathers/ or mothers/ or spouses/ or caregivers/ or siblings/ or friends/ or legal guardians/ 1074121

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 cancer) or (adolescen* adj3 cancer) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or (soung adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (soung adult" adj3 h?ematol*) or (young adult adj3 h?ematol*) or (soung adult" adj3 h?ematol*) or (young adult adj3 h?ematol*) or (soung adult" adj3 lymphom*) or (soung adult adj3 lymphom*) or (soung adult" adj3 lymphom*) or (soung adult adj3 lymphom*)).ti,ab. or (soung adult adj3 lymphom*) or (soung adult adj3 lymphom*)).ti,ab. or (soung adult adj2 lymphom*)).ti,ab. or (soung adult) adsessent/ or exp soung adult) adsessent/ or exp soung adult) adsessent/ soung adult) adsessent/ soung advit(soung advit) adsessesses advit(soung advit(soung advit(soung advit(soung

3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp communication/ or exp disclosure/ or exp information dissemination/ or exp physician-patient relations/ 5715959

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 12406352

5 1 and 2 and 3 and 4 3380

6 limit 5 to (english language and yr="2005 -Current") 2715

Embase (via Ovid)

Embase <1974 to 2022 November 23>

1 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp *adolescent/ or exp *young adult/) and exp *neoplasm/) 9638

2 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp *interpersonal communication/ or exp *professional-patient relationship/ or exp *information dissemination/ or exp *conversation/ 6997005

3 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or *parent/ or *father/ or *mother/ or *spouse/ or *caregiver/ or *social worker/ or *sibling/ or *friend/ or *legal guardian/ 1339977

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 15453173

5 1 and 2 and 3 and 4 939

6 limit 5 to (english language and yr="2005 -Current") 873

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Psy	cInfo (via Ebscohost)			
#	Query	Limiters/Expanders	Last Run Via	Results
511	S1 AND S2 AND S7 AND S8	Limiters - Publication Year: 2005-2022 Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	1,683
S10	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	1,981
S9	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,017
58	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	3,366,619
S7	(S5) or (S3)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	13,719
S6	S4 AND S5	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research Databases	13,275

BMJ Open

1					
2					
3				Coorde Corroen Desig	
4			Search modes - Boolean/Phrase	Search Screen - Basic Search	
5			DUDIEdity Fillase	Database - APA	
6				PsycInfo	
7				i syeimo	
8 9			Expanders - Apply		
9 10			equivalent subjects		
11			Narrow by		
12			SubjectAge: -		
13			adolescence (13-17		
14			yrs)		
15			Narrow by	Interface - EBSCOhost	
16		((DE "neoplasms" OR DE "Benign Neoplasms" OR	SubjectAge: - young		
17		DE "Breast Neoplasms" OR DE "Endocrine	adulthood (18-29	Search Screen - Basic	
18		Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous	yrs) Search modes -	Search Database - APA	
19	S 5	System Neoplasms" OR DE "Terminal Cancer"))	Boolean/Phrase	PsycInfo	13,275
20	30	System Neoplasms ON DE Terminal cancer //	DooleanyFillase	rsycino	13,275
21				Interface - EBSCOhost	
22 23		((DE "neoplasms" OR DE "Benign Neoplasms" OR		Research Databases	
23 24		DE "Breast Neoplasms" OR DE "Endocrine	Expanders - Apply	Search Screen - Basic	
24		Neoplasms" OR DE "Leukemias" OR DE	equivalent subjects	Search	
26		"Melanoma" OR DE "Metastasis" OR DE "Nervous	Search modes -	Database - APA	
27	S4	System Neoplasms" OR DE "Terminal Cancer"))	Boolean/Phrase	PsycInfo	58,767
28		("TYA cancer" or "TYA oncology" or "AYA cancer"			
29		or "AYA oncology" or ("young adult" n3 (cancer or			
30		oncology or leuk?em* or lymphom* or			
31		h?ematol*)) or ("teenage and young adult" n3			
32		cancer) or ("teenage and young adult" n3			
33		oncology) or (teenage* n3 cancer) or (teenage* n3			
34		oncology) or (adolescen* n3 cancer) or 🧼 🧹			
35 36		(adolescen* n3 oncology) or ("young people" n3			
30 37		cancer) or ("young people" n3 oncology) or			
38		("teenage and young adult" n3 leuk?emia*) or			
39		(teenage* n3 leuk?emia*) or (adolescen* n3			
40		leuk?emia*) or ("young people" n3 leuk?emia*) or			
41		("young adult" n3 leuk?emia*) or ("teenage and			
42		young adult" n3 h?ematol*) or (teenage* n3		Interface - EBSCOhost	
43		h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult"		Research Databases	
44		n3 h?ematol*) or ("teenage and young adult" n3	Expanders - Apply	Search Screen - Basic	
45		lymphom*) or (teenage* n3 lymphom*) or	equivalent subjects	Search	
46		(adolescen* n3 lymphom*) or ("young people" n3	Search modes -	Database - APA	
47	S 3	lymphom*) or ("young adult" n3 lymphom*))	Boolean/Phrase	PsycInfo	1,864
48					,
49 50		(Communicat* or Disclos* or inform* or Interact*		Interface - EBSCOhost	
51		or relationship* or Conversation* or Dialogue* or		Research Databases	
52		triad* or Interview* or consult* or "decision	Expanders - Apply	Search Screen - Basic	
53		making") or DE "communication" OR DE	equivalent subjects	Search	
54	ເາ	"information dissemination" OR DE "conversation"	Search modes -	Database - APA	2 122 000
55	S2	CONVERSACION	Boolean/Phrase	PsycInfo	2,423,980
56		(Parent* or guardian* or mother* or father* or	Expanders - Apply	Interface - EBSCOhost	
57		partner or wife or wives or husband* or	equivalent subjects	Research Databases	
58		boyfriend* or girlfriend* or sibling* or friend* or	Search modes -	Search Screen - Basic	
59	S1	teacher* or social worker* or carer* or "third	Boolean/Phrase	Search	894,375
60					

person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR DE "parents" OR DE "mothers" OR DE "fathers" OR DE "spouses" OR DE "wives" OR DE "husbands" OR DE "siblings" OR DE "significant others" OR DE "social workers" OR DE "guardianship" OR DE "caregivers"

CINAHL (via Ebscohost)

Thursday, November 24, 2022 6:21:27 PM

.				D !!
#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,837
S6	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,866
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,106

Database - APA PsycInfo

S4	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,016,184
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young adult" n3 lymphom*) or (adolescen* n3 lymphom*) or (adolescen* n3 lymphom*) or (myoung adult" n3 lymphom*) or (myoung adul	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	59,927
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or MH "communication+" OR MH "discussion" OR MH	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	2,016,086

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

2
J ∧
4
3 4 5 6 7 8 9 10
0
/
8
9
10 11 12
11
12 13
13
14
15
16
17
18
19
12 13 14 15 16 17 18 19 20
21
าา
22 23
24
22 23 24 25 26 27 28 29 30
26
27
28
20
29
20 21
31 22
32 33
33
34 35 36 37 38 39
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
55 56
50 57
57 58
58 59
59

60

1 2

	"conversation" OR (MH "Professional- Patient Relations+") (Parent* or guardian* or mother* or		Search Database - CINAHL	
S1	father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	544,991

Web of Science Core Collection

Web of Science Search Strategy (v0.1)

Database: Web of Science Core Collection PLICZ

Entitlements:

- WOS.IC: 1993 to 2022
- WOS.CCR: 1985 to 2022
- WOS.SCI: 1900 to 2022
- WOS.AHCI: 1975 to 2022
- WOS.BHCI: 2008 to 2022
- WOS.BSCI: 2008 to 2022
- WOS.ESCI: 2017 to 2022
- WOS.ISTP: 1990 to 2022
- WOS.SSCI: 1956 to 2022
- WOS.ISSHP: 1990 to 2022

Searches:

1: TS=(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) Results: 2129759

2: TS=("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" near/3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" near/3 cancer) or ("teenage and young adult" near/3 oncology) or (teenage* near/3 cancer) or (teenage* near/3 oncology) or (adolescen* near/3 cancer) or (adolescen*

near/3 oncology) or ("young people" near/3 cancer) or ("young people" near/3 oncology) or ("teenage and young adult" near/3 leuk?emia*) or (teenage* near/3 leuk?emia*) or (adolescen* near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("teenage and young adult" near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (adolescen* near/3 h?ematol*) or ("young people" near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("teenage and young adult" near/3 lymphom*) or (teenage* near/3 lymphom*) or (adolescen* near/3 lymphom*) or ("young people" near/3 lymphom*) or ("young adult" near/3 lymphom*)) Results: 7793

3: TS=(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") Results: 11889093

4: TS= (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*) Results: 24306121

5: #4 AND #3 AND #2 AND #1

Results: 684

6: #4 AND #3 AND #2 AND #1

Results: 684

7: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) Results: 644

8: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) and English (Languages) Results: 619



PRISMA 2020 Checklist

		BMJ Open	Page 46 of 4
PRISM	/A 20	BMJ Open de	
Section and Topic	ltem #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT		See the PRISMA 2020 for Abstracts checklist.	
Abstract	2		Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pages 3 and 4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted.	Page 4 and supplementa file
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 4, Table 1 and supplementa file 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how mathy reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation golds used in the process.	Page 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each geport, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, detate of automation tools used in the process.	Pages 4 and 5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with act outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which the sults to collect.	Page 5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, durding sources). Describe any assumptions made about any missing or unclear information.	Page 5
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presenta b n of results.	Page 5
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 5
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing sum	Page 5
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 5
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used a	Page 5

Page 47 of 47

PRISMA 2020

	BMJ Open
20 Checklist	

Section and Topic	ltem #	Checklist item	Location where item is reported
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup adalysis, meta-regression).	Pages 5 ar 6
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not applicable
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bigs).	Not applicable
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Not applicable
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the search to studies included in the review, ideally using a flow diagram.	Figure 1 page 6
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they was book cluded.	Figure 1 page 6
Study characteristics	17	Cite each included study and present its characteristics.	Table 2 – summary o articles pages
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Not report
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) a geffect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Not applicable
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Not applicable
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summare estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Not applicable
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Not applicable
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis asses	Not applicable
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not applicable
DISCUSSION		<u>o</u> g	
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 10 and 11
	23b	Discuss any limitations of the evidence included in the review. For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	Pages 11 and 12

cted by copyrigh 6/bmjopen-2023-



PRISMA 2020 Checklist

		BMJ Open de by jog	Page 48 of 47
PRIS	MA 20	BMJ Open وتقط by copyrigh D20 Checklist والمعادية عند المعادية والمعادية والم	
Section and Topic	ltem #	Checklist item	Location where item is reported
	23c	Discuss any limitations of the review processes used.	Pages 11 and 12
	23d	Discuss implications of the results for practice, policy, and future research.	Page 12
OTHER INFORMA	TION		
Registration and	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 3
protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Supplemental file
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not appliable
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 13
Competing interests	26	Declare any competing interests of review authors.	Page 13
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms to be found: template data collection forms to be found at a collection form to be found at a collection forms to be found at a collection form to be found at a collection form. The found at a collection form to be found at a collection at a collection form to be found at a collection at a c	Page 13
		Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting system For more information, visit: http://www.prisma-statement.org/ and similar technologies For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	
		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	

BMJ Open

BMJ Open

Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

Journal:	BMJ Open
Manuscript ID	bmjopen-2023-080024.R1
Article Type:	Original research
Date Submitted by the Author:	10-Jan-2024
Complete List of Authors:	Critoph, Deborah; University of Cambridge, Department of Public Health & Primary Care Taylor, Rachel; University College London Hospitals NHS Foundation Trust, CNMAR; Spathis, Anna; University of Cambridge Duschinsky, Robbie; University of Cambridge Hatcher, Helen; Cambridge University Hospitals NHS Foundation Trust Clyne, Ella; University of Cambridge Kuhn, Isla; University of Cambridge, Medical Library, School of Clinical Medicine Smith, Luke; Cambridge University Hospitals NHS Foundation Trust
Primary Subject Heading :	Communication
Secondary Subject Heading:	Communication, Oncology, Patient-centred medicine, Paediatrics, Medical education and training
Keywords:	Adolescents < Adolescent, Decision Making, EDUCATION & TRAINING (see Medical Education & Training), ONCOLOGY

SCHOLARONE[™] Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our <u>licence</u>.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which <u>Creative Commons</u> licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

terez oni

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies

Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

Deborah J Critoph MSc, Rachel M Taylor PhD, Anna Spathis MD, Robbie Duschinsky PhD, Helen Hatcher MD PhD, Ella Clyne, Isla Kuhn MSc, Luke AM Smith

Deborah Critoph, PhD student, Department of Public Health & Primary Care, University of Cambridge

Rachel Taylor, Director of the CNMAR, Centre for Nurse, Midwife and Allied Health Profession Led Research, University College London Hospitals NHS Foundation Trust, London, NW1 2PG

Anna Spathis, Assistant Professor, Department of Public Health and Primary Care, University of Cambridge

Robbie Duschinsky, Professor of Social Science & Health, Department of Public Health & Primary Care, University of Cambridge

Helen Hatcher, Consultant in Medical and TYA Oncology, Clinical and Regional Lead for Sarcoma and Young People with Cancer, Clinical Director EoE TYAc ODN

Ella Clyne, Medical Student, University of Cambridge

Isla Kuhn, Head of Medical Library Services, University of Cambridge Medical Library

Luke Smith, Junior Clinical Fellow in TYA Haematology and Oncology, Cambridge University Hospitals NHS Foundation Trust

Corresponding author: Deborah Critoph, dc625@cam.ac.uk

Keywords: Teenagers and young adults with cancer (TYAC), adolescents, triadic communication, communication, supporters, third person, parents, support network, health care, professionals, experiences, impact.

Abstract = 290/300 Word count = 4,468 Number of tables = 4 Number of figures = 1

Abstract

Objectives

Clinical communication needs of teenagers and young adults with cancer (TYAC) are increasingly recognised to differ significantly from younger children and older adults. We sought to understand who is present with TYACs, TYACs experiences of triadic communication and its impact. We generated three research questions to focus this review:

- 1. Who is present with TYACs in healthcare consultations/communication?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact of a TYAC's supporter being present in the communication?

Design

Systematic review with narrative synthesis.

Data sources

The search was conducted across six databases: Medline, CINAHL, Embase, PsycINFO, Web of Science and AMED for all publications up to December 2023.

Eligibility criteria for selecting studies

Included papers were empirical research published after 2005; participants had malignant disease, diagnosed aged 13-24 years (for over 50% of participants); the research addressed any area of clinical communication.

Data extraction and synthesis

Three independent reviewers undertook full text screening. A review-specific data extraction form was used to record participant characteristics and methods from each included paper and results relevant to the three review questions.

Results

A total of 8,480 studies were identified in the search, of which 36 fulfilled the inclusion criteria. We found that mothers were the most common supporter present in clinical communication encounters. TYACs experiences of triadic communication are paradoxical in nature – the supporter can help or hinder the involvement of the young person in care related communication. Overall, young people are not included in clinical communication and decisions at their preferred level.

Conclusion

Triadic communication in TYAC care is common, complex, and dynamic. Due to the degree of challenge and nuances raised, HCPs need further training on effective triadic communication.

PROSPERO registration number CRD42022374528

Strengths & limitations of this study

- We searched systematically and thoroughly for eligible studies, but this is not a wellindexed field of research, and therefore it is possible that some relevant studies were not included in the review.
- We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in some countries (between 29 to 39).
- We only included papers published in English and the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics.
- International representation was seen in the eligible studies and TYAC ages were included across the entirety of the specified UK age range.
- Studies represented the journey throughout the cancer experience from diagnosis to survivorship and end of life care.

Introduction

Adolescence is a time of transition where young people navigate monumental physical, cognitive, emotional, and behavioural milestones to develop a sense of self-identity and gain independence. Although most young people have limited encounters with healthcare, around 2,500 young people in the United Kingdom (UK) are diagnosed with cancer each year, which is the leading cause of non-traumatic death in young people in the United States (US) and Europe.(1) Teenagers and young adults with cancer (TYACs) have unique healthcare needs and there has been an international drive to develop developmentally appropriate evidence-based specialist care, provided by appropriately trained healthcare professionals (HCPs).(2)

Communication with TYACs can be particularly challenging: a life-limiting condition intersects an age associated with emotional reactivity and variable maturity. TYACs clinical communication needs are increasingly recognised to differ significantly from younger children and older adults. Research indicates TYACs can have little meaningful involvement in conversations with HCPs: almost half of children and young people reported not being involved in decisions about their care.(3) HCPs recognise this and consider young people amongst the hardest patients to communicate with.(4) However, HCPs receive little training about how best to manage these clinical encounters. TYACs perceive that HCPs do not make efforts to understand how their cancer impacts their life outside of the healthcare setting. As a result, they may withdraw and subsequently be labelled as 'challenging', 'hard to reach' and 'disengaged'. This may adversely impact care and contribute to poor physical and psychological outcomes. Despite these issues, there are limited opportunities for formal postgraduate education in communication with TYACs for HCPs, with most training being ad hoc and not interprofessional. (5,6) Effective communication with TYACs has been recognised as a key national research priority. In a UK-wide survey of young patients' own research priorities, communication was a striking cross-cutting theme.(7)

Recent research into clinical communication with TYACs has offered some insight into the complexities of communication with this specialist patient group.(8-12) Yet one area that has

BMJ Open

 received less attention is triadic communication. Triadic communication refers to the presence of a third party, such as a parent, carer, or companion in clinical encounters (13) and the presence of such a person was found to occur in 87% of TYAC consultations.(11) As a commonly occurring form of communication in TYAC care, there is a need to understand the theoretical basis and relevance of triadic communication to clinical practice. For the purposes of this review, we refer to this third person as a supporter. Triadic communication literature from children and older adults exists. (14–17) Notably this includes a meta-analytic review of provider-patient-companion of adults,(18) one large systematic review of physician-patient-companion.(20) Whilst informative, these studies are with children and adults, not this unique age-group of emerging adulthood with a significant life threatening diagnosis such as cancer. Also, these studies focus on doctor-patient-third person communication, whereas TYAC care involves a range of interdisciplinary professionals. This review aims to understand what is known about triadic communication with TYACs in healthcare communication.

Aim

We sought to understand who is present with TYACs, synthesise TYACs experiences of triadic communication with HCPs and supporter(s), and develop insights into the impact of triadic communication for TYACs.

Review questions:

- 1. Who is the supporter present with TYACs in healthcare consultations and communication?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact on a TYAC's supporter being present in the communication?

Methods

We conducted a systematic review and narrative synthesis (21,22) of empirical evidence published since 2005, the year of publication of the National Institute for Care Excellence (NICE) Improving Outcomes Guidance, the guidance document underpinning TYAC services in England.(2) The review protocol was prospectively registered with PROSPERO (CRD42022374528). We designed the search to identify and map the available evidence using a broad scope to gain an overview of the pertinent literature, identify knowledge gaps and clarify concepts. The search strategy was developed and refined with an information scientist (I.K.). Keywords were generated across five strands detailed in Table 1, with strands combined with the Boolean operator 'AND'. The search was conducted across six databases: Medline, CINAHL, Embase, PsycINFO, Web of Science and AMED (supplemental file).

Table 1. Search Terms

Strand 1 – TYAC

TYA cancer or TYA oncology or teenage and young adult adj5 cancer or teenage and young adult adj5 oncology or teenage* adj5 cancer or teenage* adj5 oncology or adolescen* adj 5 cancer or adolescen* adj 5 oncology or young people adj 5 cancer or young people adj 5 oncology Strand 2 – communication Communication skills OR communicat* OR discuss* OR disclos* OR inform* OR interact OR relationship building OR decision making OR communication tools OR communication aids OR psychosocial assessment Strand 3 – supporters Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*. Strand 4 - impact affect OR effect OR influence OR result OR resultant OR impact Strand 5 - experience encounter OR involvement OR occurrence OR feel OR "go through" OR experience*

TYAC: teenage and young adult with cancer

Database searches were compiled and de-duplicated in Mendeley, abstracts were screened in Rayyan by two researchers (D.J.C and L.A.M.S.), and 172 full articles were read by three researchers (L.A.M.S., D.J.C., and R.M.T) for eligibility of inclusion in the final analysis, with disagreements resolved by discussion. Papers were included if: they presented empirical research published after 2005; participants had malignant disease, diagnosed aged 13-24 years (for over 50% of participants); the research addressed any area of clinical communication; and the research included supporters (parents, partners, carers, friends etc). Papers were excluded if they were: conference abstracts, unpublished articles, systematic reviews, single case studies, validation research methodology, studies using retrospective documentation in clinical notes, articles focusing on information needs rather than communication skills, or were not in English.

A review-specific data extraction form was used to record participant characteristics and methods from each included paper and results relevant to the three review questions. The final number of included articles totalled 36, the remaining 136 were excluded based on the participants' ages, focus on HCPs or information giving. In tandem to the data extraction process, two members of the review team (E.C. and D.J.C.) independently assessed each paper in terms of its internal validity, appropriateness, and contribution to answering the review questions, using a review-specific version of Gough's Weight of Evidence criteria.(23) Discrepancies in assessment decisions were discussed between reviewers and final scores were agreed through consensus.

Extracted data were entered into Excel to aid the narrative synthesis of the included papers. (21,22) All articles, irrespective of relevance and quality, were included in the review.

 However, those rated 'medium' and 'high' were given greater weight in the synthesis. An inductive thematic analysis was undertaken to identify the main, recurrent, and important data across the studies related to answering each research question. D.J.C. and E.C. explored heterogeneity across the studies. The integration of results from studies utilising different methods and epistemological positions was supported by L.A.M.S. and R.M.T., and consensus in synthesis was reached. The synthesis was further refined through discussion of the review of results and their implications with clinicians, interdisciplinary academic audiences, and all of the co-authors.

Patient and Public Involvement Statement

None

Results

A total of 8,480 studies were identified in the search, of which 36 fulfilled the inclusion criteria (Figure 1). The included articles are summarised in Table 2. (table 2 uploaded separately)

All points across the cancer trajectory were represented in the final papers: diagnosis (n=7); (12,24–29) on treatment (n=17); (30–46) end of treatment (completed within one year) (n=2); (47,48) survivorship (more than one-year post-treatment) (n=2); (5,49) and end of life care (n=5). (50–54) Three studies included patients at more than one point along the cancer care continuum. (55–57) Most studies (n=19) were conducted in the US (24,27–29,31,35–37,39–46,50,52,54) other countries included the UK, (25,32,33) Australia, (38,48,49,57) Norway, (12,53) Israel, (47) Iran, (30) Mexico, (51) France, (34) Denmark, (26) Korea (56) and Taiwan, (55) one study recruited from three European countries. (5) Studies used predominantly qualitative methods (n=32) but there were two mixed methods studies and two using quantitative methods. Weight of evidence (WoE) criteria indicated five were high evidence, (24,31,35,45,56) twenty-four were medium (5,12,25,27–30,32–34,36,37,39–42,44,46,47,49–51,55,57) and seven were low evidence. (26,38,43,48,52–54) We used Gough's review specific criteria to weight the quality of each paper. (23) To do this, we used three parameters:

- A) The integrity of the evidence on its own terms
- B) The appropriateness of the method for answering the review questions
- C) The appropriateness of the focus or relevance for answering the review questions

Each of the above was either rated as low, medium, or high. These 3 parameters were combined to create WoE D which was the overall rating seen above and is the extent to which a study contributes evidence to answering the review questions. Factors that made the method highly appropriate included the use of semi-structured interviews to understand TYAC experiences and speaking to the TYAC and supporter separately. The high scoring papers included papers that focussed on communication in the triad, but this only occurred in 10 papers. In 9 papers the age at diagnosis was not specified and this decreased the weighting of these papers. (5,34–36,50–54)

Of the included studies just less than one third researched the triad (n=10) of TYAC, supporters and HCP (5,24,30–32,34–36,50,51), one third TYAC only (n=12)

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

(28,29,33,37,38,40–42,44–46,48) and just over a third TYAC and supporters (n=14). (12,25–27,39,43,47,49,52–57)

Table 3 Study population

Participants included in the study and numbers of papers included for each of the three participant groups

Triad? Dyad? Single?	Who is studied in the paper?	Number of papers
Triad	TYAC, supporter, HCA	10
Dyad	TYAC and supporter	14
Single	TYAC only	12

The categories used to separate the age groups were lower adolescence (11-14 years), middle adolescence (15-17 years), upper adolescence (18-21 years) and emerging adulthood (22 onwards). Of the papers where the age range at diagnosis could be deduced, the majority of these (21 out of 24) spanned three or more age categories. All the papers spanned two or more age categories. In nine of the papers, the age ranges at diagnosis were not available (as age at diagnosis was expressed as a mean or median). Given these factors, it is difficult to ascertain whether any between age group differences exist.

Who is present with TYACs in healthcare consultations and communication?

The majority of supporters were mothers (68.9%). When combined, parents represented nearly all the supporters in the included studies (94.6%), see Table 4. Non-parental supporters (1.8%) included partners, sisters, aunts, and grandmothers. The remaining supporters were not categorised due to insufficient information in the article's demographics data (3.9%).(53,54)

Table 4 Supporter Demographics

Details of the supporter demographics and percentages of within the included publications

Supporter type	Number of supporters	Percentage quoted to 1 decimal place (%)
"Mother"	453	68.9
"Father"	128	19.5
"Both parents"	20	3.0
"Parents" no further specification	20	3.0
"Stepmother"	1	0.2
"Grandmother"	2	0.3
"Sister"	3	0.5
"Partner"	3	0.5

2	
3	
4	
5	
6 7	
6 7 8	
9	
10	
11	
12	
13	
14	
15	
16	
17	
18 19	
20	
20	
22	
22 23 24	
24	
25	
26	
27	
28	
29	
30 31	
32	
33	
34	
35	
36	
37	
38	
39	
40 41	
41	
43	
44	
45	
46	
47	
48	
49 50	
50 51	
51 52	
52 53	
54	
55	
56	
57	
58	
59	
60	

"Aunt"	3	0.5
"Supporters" no further specification	21	3.2
"Other"	3	0.5
Total	657	100.1

What are TYACs' experiences of communication with the supporter present?

The presence of supporters was concurrently helpful and challenging for TYACs. Supporters undertook several helpful roles and responsibilities: they asked questions on behalf of the TYAC, retained information from HCPs, acted as a conduit of information between the TYAC and HCP, and acted as a "sounding board" for the young person.(25,31,45) Some supporters promoted self-advocacy and autonomy for the young person.(27,39,41,46,57) Some reported symptoms on their behalf (45) and proactively negotiated changes to treatment schedules in the interest of the young person.(39)

Findings also suggested that young people could experience limited or ineffective communication in the presence of a supporter. Communication could be directed towards the supporter, not the young person.(27,29,31,36) Supporters could receive information in the absence of the TYAC and subsequently filter the content before delivering the information to TYACs.(30,33,34,55,56): *"The parents had hidden a truth that was not theirs to hide"* p533.(34) This reflected the broader predicament that supporters' priorities at times might have competed with those of young people. (25,34,50,51) Supporters could dominate the communication encounter, for instance, parents were seen to interrupt young people, especially when time was limited. (51) Frederick et al found the mean time for adolescent to clinician communication was only 5.5% of the total consultation and parent conversation turns directed most communication at the parent rather than the adolescent and spoke for 66.9% of the conversation and none of the clinicians offered patients the opportunity to speak with them alone. (35)

Mutual protectionism appeared to occur, with TYACs and supporters seeking to protect each other from difficult information leading to non-disclosure when both were present. A diagnosis of cancer is devastating for the young person, supporter(s), family, and the wider social network. Repeatedly, there were references to reduced disclosure between the young person and their supporter, in an attempt to shield each other from emotional distress.(12,31,36,38,39,41,45,53,56) TYACs could experience discomfort and guilt in seeing parents tearful and worried, and felt a burden in response to observing the emotions of supporters.(38,39,52) Some TYACs sought to limit this by withholding concerns to protect their supporters: "*I couldn't talk to mum about my concerns because I didn't want to hurt her*" p 37.(38) In equal measure, supporters were characterised as working hard to stay in control of emotions, be strong and stay in the "now", and they channelled energy into helping.(12,31,56) Yet this could contribute to an environment of non-disclosure that had the potential to create future communication challenges, such as supporters not knowing the young person's wishes. Examples of this were evident within the end of life care studies.(52,53) Friebert et al found that 86% of young people wanted to receive prognostic information as soon as possible but only 39% of families knew that.(52) Similarly, Jacobs et al found that young people's end of life wishes were not known by their families.(53) In instances where the young person may not be able to communicate, it may help families relieve the impossible burden of making difficult decisions or feelings of regret, if the young person's perspective and wishes are known.(54)

What is the impact of a TYAC's supporter being present in the communication?

Supporters have the potential to facilitate, complicate or obstruct the young person's involvement in decision-making. Involvement had a positive impact on recall,(42) and may improve autonomy, efficacy, adherence, and future self-management.(24,57) However, the participation of supporters may be experienced as stressful by TYAC as they may become side-lined. (25,40,55) The presence of supporters impacted the young person's level of involvement in decision-making in several ways. In some cases, supporters empowered TYACs to make decisions by withholding their opinion (27) and deferring the final decision to TYACs.(31) However, supporters and TYACs did not perceive decision-making in the same way.(47,56) Supporters believed that young people oversaw decisions about their care; however, this was not what young people recounted.(24) TYACs reported a lack of communication and limited involvement in decisions (24,29,30,46) associated later with decisional regret.(24,37)

Deferral of communication and decisions from the young person to supporters was commonplace.(27,31,36) When supporters responded to this pathway of communication, young people then did not see a need to participate in decisions, knowing that their supporter was taking the mantle. (36) In parallel, clinicians were found to direct communication towards supporters and in extreme cases young people were completely excluded from communication and decisions. (29,30,35,47) An atmosphere characterised by a lack of trust, unanswered questions and uncertainty contributed to the exclusion of young people who then sought information from other sources. (30, 36, 39, 56) Not allowing TYACs to choose their involvement in decision-making violated their autonomy, and increased distrust or providers and supporters resulted in resentment of and lower treatment adherence.(30,36,39)

The decisional involvement preferences of young people were not static: they were context and environment dependent. At diagnosis, heightened emotions and poor health rendered young people unable to engage in communication. (24,25,27,29,31,37,41) TYACs expressed a desire to be involved in decision making at different levels: some wanted limited involvement from their supporter(s) so they could take the leading role in consultations and their care;(58) several wanted collaboration with supporters and clinicians;(26,27,44,57) and some completely relied on supporters and HCP's to make decisions on their behalf.(45,46) Davies et al described this as agency, the ability to make free and independent choices. They highlighted the normality of this fluctuation between personal (acting independently), proxy (decisions made on behalf of someone) and collective (decisions are shared) decision making. Whilst this was not always linear, it was part of the cancer trajectory and demonstrated the fluctuating personal agency for TYACs.(32) Some young people reported that supporters and clinicians decided on the their level of involvement in communication and decision-

making,(55) and TYACs commented that they did not feel the decision was theirs.(47) Decisional involvement was an interactive, complex, and multifaceted process within the context of the triad, and young people often wanted to be in control of their level of involvement.(28,31) The evidence highlighted that in the presence of a supporter, young people's choice in the their level of involvement in decisions was challenged and not routinely achieved.

Most TYACs felt that it was important for the healthcare team to communicate with them directly and openly.(30,31,33,38,39,49,50) Time alone helped facilitate communication between TYAC and HCP, to ensure that the young person's needs were fully met.(31,36) However, time alone with HCPs was not routinely integrated as a part of consultations with TYACs. (35,48) In fact, clinicians were reported as frequently speaking more to parents and TYACs received limited communication from HCPs.(27,31,35,36) In the presence of supporters, as well as withholding concerning information, young people reported feeling discomfort when discussing sensitive topics such as sex or fertility preservation.(27,36)

Young people wanted time alone to communicate with HCPs directly for a variety of reasons. This private line of communication offered a sense of personal agency and allowed them to feel "in the loop" and promoted a sense of autonomy that was threatened by the cancer diagnosis, particularly at the point of diagnosis.(32,50) Young people wanted space to think and privacy during the cancer journey; private lines of communication with HCPs actively promoted this.(31,39,45,46) It also enabled HCPs to get to know the young person and allowed them to ask questions that they may be reluctant to ask in the presence of their supporter, because of embarrassment or emotional shielding.(31) Darabos et al found that 87.5% of oncology providers considered it important to talk to the TYAC without their parents present.(31) Whilst the importance has been highlighted within the data it is also evident that this does not happen as part of routine clinical practice. This could be for several reasons such as not wanting to challenge rules of authority, uncertainty around how best to ask a parent to leave and lack of confidence when communicating with a young person alone.

Discussion

Principal Findings

Who is present with TYACs in healthcare consultations and communication? For example, who are the supporters?

The included papers in our review demonstrated that most supporters were parents, more commonly mothers. The frequent presence of mothers in consultations is consistent with previous findings. For example, in a UK study in which TYAC nominated a caregiver, 85% were parents, and of those 80% were female.(59) We note that there is a paucity of data for non-parental supporters, and this may represent a reality of clinical practice or a bias towards TYAC-parental dyads over other relational-dyads in this field of research to date.

What are TYACs' s present?

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

TYACs experienced supporters facilitating communication by obtaining information, asking questions, advocating, and supporting personal agency of the young person; conversely supporters could hinder communication by gatekeeping information, or dominating communication and thereby rendering young people as bystanders. Young people experienced negative emotions in response to witnessing their supporters in distress.

What is the impact of a TYAC's supporter being present in the communication?

Bidirectional non-disclosure was a coping strategy used by both TYACs and supporters to protect one another from concerns and emotional burden. This limited HCPs ability to effectively assess ideas, concerns, and expectations from both parties when together. In the presence of supporters some young people were less informed, which could impair their ability to engage in decision-making conversations.

Meaning of the study

This is the first review to look specifically at triadic communication in teenagers and young adults with cancer and has demonstrated that there is a paucity of evidence focussed specifically on triadic communication with TYACs. Of the thirty-six studies in the review less than one third included all three parties in the triadic communication encounter. However, the review has enabled us to provide answers to the review questions and identify knowledge gaps, including a lack of theory describing triadic communication. Some preliminary theoretical models, such as family involvement in interpersonal healthcare processes,(60) depict the interaction pathways between patients, families and HCP and hypothesise the influence of family on interpersonal processes and outcomes of medical consultations.

The data has clearly identified that parents are the predominating supporter for TYACs, which may be surprising given the inclusion of participants up to the age of 25. Parents can play a significant role when a young person is diagnosed with cancer. Developmentally, a major characteristic that differentiates TYACs from younger children or older adults is the progressive increase in their desire and capacity for independence, personal agency, and autonomy. This process is disrupted by a cancer diagnosis: increased parental presence can be perceived as intrusive and reflect reversion to an earlier family dynamic, anchoring TYACs in dependency, restricting self-exploration, and limiting their developing of an internal value and belief system. (38,61–63) This has been phrased as 'retreating to family' and can negatively impact peer relationships by impeding development and maintenance of a peer network.(40,64,65) Young people may often be accepting of this, particularly in the early stages of the cancer diagnosis. However, as this review demonstrates, the presence of parents alters the experience and impact of communication with HCPs. It is important to highlight that there is limited literature on TYAC communication encounters with supporters other than parents.(62,66,67) Partners felt relegated to a non-participatory role by a parent, and mothers struggled to relinquish their existing role as primary supporter. (62,67) It is relevant to note that the participants in these three studies were in their early 20's.

A key impact of triadic communication is that young people may not be involved in decision making to the level they want. This is consistent with related paediatric oncology literature

which consistently reports children's limited participation in decision-making. (68–70) Clinicians attempted to protect children from 'too much' information because of the perception that children are not capable or too vulnerable.(17) The important difference between paediatric and TYAC populations are the legal and ethical obligations towards TYACs who are autonomous, capacitous patients rather than to parents with parental responsibility.

The findings of this review demonstrate the presence of a supporter impacts the involvement of young people in healthcare decisions. Therefore, there are legal and ethical issues, which are critically important, both in research and clinically in TYAC care particularly related to informed consent, capacity, and autonomy. The law relating to children and young people is complex and differs across the UK and internationally. The General Medical Council guidelines in the UK state, "the patient must be the first concern".(71) HCPs have ethical and legal obligations outlined in UK best practice guidance, statute, and case law. (72) In the UK, parents can legally make decisions for children under 16 years unless the child disagrees and is deemed 'Gillick Competent'.(73) Moreover, studies have shown children aged 14 and older can approach the level of understanding of adults.(74,75) In contrast, people aged 16 and above are legally able to make decisions for themselves in the UK and are automatically assumed to have capacity (76) and therefore, HCPs must communicate with them in developmentally appropriate ways. Clinicians face a challenge in identifying the best way to communicate with TYACs and their supporter (s). TYACs need parental involvement whilst simultaneously desiring autonomy (36) necessitating careful balancing of the needs of both parties to ensure that the young person is not relegated to a non-participant status.

Strengths and weaknesses

Our review had a number of limitations. We searched systematically and thoroughly for eligible studies, but this is not a well-indexed field of research, and therefore it is possible that some relevant studies were not included in the review. We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in some countries (between 29 to 39). We also only included papers published in English and therefore papers reflect practices in primarily North America, Australia and Europe, the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics and where the healthcare culture may be different, e.g., more paternalistic. Despite these limitations, international representation was seen in the eligible studies, TYAC ages were included across the entirety of the specified UK age range and studies represented the journey throughout the cancer experience.

Implications for clinicians and policy makers

Given the degree of challenge and nuance raised, HCPs need training on effective triadic communication. Fourneret concluded that the relationship between TYACs, their parents and HCPs "as being the most difficult one in oncology".(34) Professionals described challenges communicating with both TYACs and parents, especially when loyalties were torn between the two.(5) However, training is currently ad hoc and not interdisciplinary.(77–80)

Furthermore, HCPs can find it difficult to apply teaching in this area in clinical practice.(53,81) HCPs need education and training to navigate triadic communication to optimise involvement of the young person whilst attending to a supporter's needs. Experiential learning is the gold standard in teaching methods for clinical communication and is designed to bring about changes in learners' skills. These evidence-based methods are through small group, problembased simulation in a classroom, with repeated practise and rehearsal of skills under observation with detailed and descriptive feedback. This is arguably warranted here.(82,83)

Triadic communication is a key feature of TYAC care but requires further attention and inclusion in future iterations of key policy documents and guidelines such as the Blueprint of Care (BoC).(84) The BoC is a UK document that helps shape and deliver developmentally appropriate care to TYAC. However, it is recognised that age is poorly correlated with developmental maturity and therefore any communication framework needs to be specific to TYACs, recognising the transitional nature of adolescence meaning a one size fits all approach is likely inadequate.

Unanswered questions and future research

Future research is warranted to triangulate triadic perspectives and understand more about the interactional dynamics of these complex communication encounters. A key research need is investigating how best to support decision-making whilst engaging supporters, understanding their priorities and information needs may conflict.(31,36,37,40) Conflict management must also be understood in the emotional context of young adult oncology. How to effectively educate HCPs to communicate within the triad, to ensure the young person and the supporters needs are met is a priority. This needs to include how best we facilitate time alone between young patients and HCPs. Continued development and utilisation of comprehensive triadic theoretical frameworks may provide guidance and direction for future research, allowing for greater integration and progress with this diverse research area and commonly occurring form of healthcare communication.

Conclusion

Triadic communication is a pivotal component of communicating with TYACs and the presence of supporters impacts clinical communication both positively and negatively. Young people desire a sense of personal agency, autonomy and control related to information flow and decision making. This includes private lines of communication with HCPs without the presence of supporters. HCPs recognise the importance of time alone with young people; however this does not translate to clinical practice. Therefore, further research on communication dynamics is needed to allow for the development of bespoke, TYAC focussed clinical communication. This then needs to be formally embedded in national guidance and postgraduate training for HCPs working in TYAC care to allow equitable access for TYACs.

1 2 3	
4 5 6 7 8 9 10 11 12 13 14	A D ai in m qi in
15 16 17	Ca Th
18 19 20 21	Et Ti
22 23 24 25 26 27 28 29 30	Fu Th it: Cu ex Cl
31 32 33 34 35 36 37 38	D A in re in
39 40 41	Fi
42 43 44	Fi
44 45 46	Ta
47 48	Ta
49 50 51 52 53	Ta Pa pa
54 55 56 57 58 59	Ta Di
60	

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Author Contributions: DC, LS and RT were involved in developing the protocol; DC, IK and LS coordinated the running of the study and were responsible for data acquisition; DC, LS, RT and EC contributed to the analysis; DC drafted the manuscript. All authors have critically reviewed the manuscript for important intellectual content and have read and agreed to the published version of the manuscript. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Conflicts of Interest: The authors declare no conflict of interest.

Ethics Approval:

This was a systematic review and therefore ethics approval was not required.

Funding:

This paper presents work supported by the Wellcome Trust, (grant number G115288) under its Programme PhD for healthcare professionals course awarded to the first author Deborah Critoph, University of Cambridge. R.M.T. is partially funded through UCLH Charity. The views expressed are those of the author (s) and not necessarily those of the Wellcome Trust or UCLH Charity.

Data availability statement:

All data relevant to the study are included in the article or uploaded as supplementary information. No previously unpublished primary data are included in the paper. All data relevant to the systematic review are included in the paper or uploaded as supplementary information.

Figure Legends:

Figure 1: PRISMA Flow diagram

Table 1: Search terms

Table 2: Summary of articles

Table 3: Study Population

Participants included in the study and numbers of papers included for each of the three participant groups

Table 4: Supporter DemographicsDetails of the supporter demographics and percentages of within the included publications

References:

- 1. Cancer Research UK. Young peoples' cancers incidence statistics [Internet]. 2016 [cited 2019 Jul 10]. Available from: https://www.cancerresearchuk.org/healthprofessional/cancer-statistics/young-people-cancers/incidence
- 2. National Institute of Health and Clinical Excellence. Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer National Institute for Health and Clinical Excellence [Internet]. Nice. 2005. 198 p. Available from: https://www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-childrenand-young-people-with-cancer-update-pdf-773378893
- 3. Care Quality Commission., NHS Patient Survey Programme. 2018 Children and Young People's patient experience survey. Statistical Release. 2019;(November).
- 4. White B, Viner RM. Improving communication with adolescents. Arch Dis Child Educ Pract Ed. 2012;97(3):93–7.
- Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer [Internet]. 2016;63(8):1423–30. Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017
- 6. Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and Shaped by Health Care Professionals Caring for Adolescents and Young Adults with Cancer? J Adolesc Young Adult Oncol. 2021;10(5):503–11.
- Gibson F, Aldiss S, Fern LA, Phillips B, Gravestock H, Malik S, et al. Reporting the whole story: Analysis of the "out-of-scope" questions from the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership Survey. Health Expect. 2021;
- Smith LAM, Critoph DJ, Hatcher HM. How Can Health Care Professionals Communicate Effectively with Adolescent and Young Adults Who Have Completed Cancer Treatment? A Systematic Review. J Adolesc Young Adult Oncol [Internet]. 2020 Jan 14; Available from: https://doi.org/10.1089/jayao.2019.0133
- 9. Reid J, McKeaveney C, Martin P. Communicating with Adolescents and Young Adults about Cancer-Associated Weight Loss. Curr Oncol Rep. 2019;21(2):6.
- Phillips CR, Haase JE. A Connectedness Primer for Healthcare Providers: Adolescents/Young Adult Cancer Survivors' Perspectives on Behaviors That Foster Connectedness during Cancer Treatment and the Resulting Positive Outcomes. J Adolesc Young Adult Oncol [Internet]. 2018;7(2):174–80. Available from: http://www.liebertpub.com/products/product.aspx?pid=387
- Mellblom A V, Finset A, Korsvold L, Loge JH, Ruud E, Lie HC. Emotional concerns in follow-up consultations between paediatric oncologists and adolescent survivors: a video-based observational study. Psychooncology [Internet]. 2014 Dec;23(12):1365– 72. Available from:

https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=109768272&site=ehost-live

12. Korsvold L, Mellblom AV, Finset A, Ruud E, Lie HC. A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members. European Journal of Oncology Nursing [Internet]. 2017;26:1–8. Available

2		
3		from:
4		
5		https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=cin20&AN=
6		120589318&site=ehost-live&custid=ns123475
7	13.	Ward A, Critoph D, Westacott R, Williams R, Dogra N. A collaboration on teaching and
8		assessing triadic consultation skills. PEC Innovation [Internet].
9 10		2022;1(October):100091. Available from:
10 11		https://doi.org/10.1016/j.pecinn.2022.100091
12	14.	van Staa AL. Unraveling triadic communication in hospital consultations with
13		adolescents with chronic conditions: The added value of mixed methods research.
14		Patient Educ Couns. 2011;82(3):455–64.
15	1 -	
16	15.	Cahill P, Papageorgiou A. Triadic communication in the primary care paediatric
17		consultation: A review of the literature. British Journal of General Practice.
18		2007;57(544):904–11.
19	16.	Maras M. Hidden in plain sight. Int J Psychiatry Med. 2022;57(6):481–5.
20 21	17.	Young B, Dixon-woods M, Windridge KC, Heney D. Study of Patients and Parents. Br
21		Med J. 2003;326(7384):305.
23	18.	Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review.
24		Soc Sci Med [Internet]. 2011;72(6):823–31. Available from:
25		http://dx.doi.org/10.1016/j.socscimed.2011.01.015
26	19.	Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, et al. Physician-
27	19.	
28		patient-companion communication and decision-making: A systematic review of
29		triadic medical consultations. Patient Educ Couns. 2013;91(1):3–13.
30 31	20.	Tates K, Meeuwesen L. Doctor-parent-child communication. A (re)view of the
32		literature. Soc Sci Med. 2001;52(6):839–51.
33	21.	Popay J, Roberts, H SA et al. Guidance on the Conduct of Narrative Synthesis in
34		Systematic Reviews.
35	22.	Petticrew M RH. Systematic Reviews in the social sciences. In: Systematic reviews in
36		the social sciences [Internet]. Available from:
37		https://onlinelibrary.wiley.com/doi/book/10.1002/9780470754887
38	23.	Gough D. Weight of Evidence: a framework for the appraisal of the quality and
39 40	25.	relevance of evidence. 2007 [cited 2023 Jul 2]; Available from:
40 41		
42	~ .	https://www.tandfonline.com/action/journalInformation?journalCode=rred20
43	24.	Barakat LP, Schwartz LA, Reilly A, Deatrick JA, Balis F. A Qualitative Study of Phase III
44		Cancer Clinical Trial Enrollment Decision-Making: Perspectives from Adolescents,
45		Young Adults, Caregivers, and Providers. J Adolesc Young Adult Oncol. 2014;3(1):3–
46		11.
47	25.	Hart RI, Cameron DA, Cowie FJ, Harden J, Heaney NB, Rankin D, et al. The challenges
48		of making informed decisions about treatment and trial participation following a
49 50		cancer diagnosis: a qualitative study involving adolescents and young adults with
50		cancer and their caregivers. BMC Health Serv Res. 2020;20(1).
52	26.	Ingersgaard MV, Tulstrup M, Larsen HB, Schmiegelow Kjeld AO - Ingersgaard MVO
53	20.	http://orcid. org/0000 0002 7037 2104. A qualitative study of decision-making on
54		
55		Phase III randomized clinical trial participation in paediatric oncology: Adolescents'
56		and parents' perspectives and preferences. J Adv Nurs. 2018;74(1):110–8.
57 58	27.	Olsavsky AL, Theroux CI, Dattilo TM, Klosky JL, O'Brien SH, Quinn GP, et al. Family
58 59		communication about fertility preservation in adolescent males newly diagnosed with
59 60		cancer. Pediatr Blood Cancer. 2021;68(7).

Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

2 3	
4	
5 6	
7	
8 9	
10	
11 12	
13	
14 15	
16	
17 18	
19	
20 21	
22	
23 24	
25	
26 27	
28	
29 30	
30 31	
32 33	
34	
35	
36 37	
38	
39 40	
41	
42 43	
44	
45 46	
47	
48 49	
50	
51 52	
53	
54 55	
56	
57 58	
59	
60	

1

- 28. Weaver MS, Baker JN, Gibson D V, Gattuso JS, Hinds PS, Gibson D V, et al. "Being a good patient" during times of illness as defined by adolescent patients with cancer. Cancer [Internet]. 2016 Jul 15;122(14):2224–33. Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142
 - Mobley EM, Thomas SM, Brailsford J, Ochoa CY, Miller K, Applebaum A, et al. Clinical Trial Participation: A Qualitative Study of Adolescents and Younger Adults Recently Diagnosed with Cancer. J Adolesc Young Adult Oncol. 2023 Jun 1;12(3):303–13.
 - 30. Bahrami M, Namnabati M, Mokarian F, Oujian P, Arbon P. Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study. Supportive Care in Cancer [Internet]. 2017;25(5):1587–96. Available from:

https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=122279626&site=ehost-live

- 31. Darabos K, Berger AJ, Barakat LP, Schwartz LA. Cancer-Related Decision-Making Among Adolescents, Young Adults, Caregivers, and Oncology Providers. Qual Health Res. 2021 Nov 1;31(13):2355–63.
- Davies J, Kelly D, Hannigan B. "Life then", "life interrupted", "life reclaimed": The fluctuation of agency in teenagers and young adults with cancer. Eur J Oncol Nurs. 2018;36(100885136):48–55.
- 33. Fern LA, Taylor RM, Whelan J, Pearce S, Grew T, Brooman K, et al. The Art of Age-Appropriate Care. Cancer Nurs [Internet]. 2013;36(5):E27–38. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=110243702&site=ehost-live
- Fourneret E. Breaking Bad News about Cancer to Adolescents and Young Adults: The French Experience. J Law Med [Internet]. 2018 [cited 2021 Nov 22];25(2):530–7.
 Available from: https://pubmed.ncbi.nlm.nih.gov/29978652/
- 35. Frederick NN, Mack JW. Adolescent patient involvement in discussions about relapsed or refractory cancer with oncology clinicians. Pediatr Blood Cancer [Internet]. 2018;65(4):1. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=128132562&site=ehost-live
- 36. Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. Proc SIGCHI Conf Hum Factor Comput Syst [Internet]. 2016 May 7 [cited 2018 Jun 2];2016:5337–49. Available from: http://www.ncbi.nlm.nih.gov/pubmed/28164178
- 37. Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients' Experiences With Treatment Decision-making. Pediatrics. 2019;143(5).
- 38. Patterson P, Millar B, Desille N, McDonald F. The Unmet Needs of Emerging Adults With a Cancer Diagnosis A Qualitative Study. Cancer Nurs. 2012;35(3):E32–40.
- Pennant S, Lee SC, Holm S, Triplett KN, Howe-Martin L, Campbell R, et al. The Role of Social Support in Adolescent/Young Adults Coping with Cancer Treatment. Children [Internet]. 2020;7(1):1–25. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=142468088&site=ehost-live
 - 40. Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. 3 Dimensions of Treatment Decision Making in Adolescents and Young Adults With Cancer. Cancer Nurs [Internet]. 2020 Nov;43(6):436–45. Available from:

1		
2		
3		
4		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
5		AN=146822019&site=ehost-live
6	41.	Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. Day-to-Day
7		Decision Making by Adolescents and Young Adults with Cancer. Journal of Pediatric
8		Hematology/Oncology Nursing [Internet]. 2022;39(5):290–303. Available from:
9		https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&
10		D=medl&AN=35538622 https://cambridge-
11		primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m
12 13		
13		edline&id=pmid:35538622&id=doi:10.1177%2F27527530211068718&issn=
15	42.	Zarnegar S, Gosiengfiao Y, Rademaker A, Casey R, Albritton KH. Recall of Fertility
16		Discussion by Adolescent Female Cancer Patients: A Survey-Based Pilot Study. J
17		Adolesc Young Adult Oncol [Internet]. 2018 Apr;7(2):249–53. Available from:
18		http://www.liebertpub.com/products/product.aspx?pid=387
19	43.	Viola A, Taggi-Pinto A, Sahler OJZ, Alderfer MA, Devine KA, Ed M, et al. Problem-
20		solving skills, parent-adolescent communication, dyadic functioning, and distress
21		among adolescents with cancer. Pediatr Blood Cancer. 2018;65(5).
22	ЛЛ	Weaver MS, Baker JN, Gibson D V, Gattuso JS, Sykes AD, Hinds PS. Adolescents'
23 24	44.	
24 25		preferences for treatment decisional involvement during their cancer. Cancer
26		[Internet]. 2015;121(24):4416–24. Available from:
27		http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142
28	45.	Sisk BA, Keenan M, Kaye EC, Baker JN, Mack JW, DuBois JM. Co-management of
29		communication and care in adolescent and young adult oncology. Pediatr Blood
30		Cancer [Internet]. 2022;69(10):e29813. Available from:
31		https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&
32		D=mesx&AN=35719025 https://cambridge-
33 34		primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m
35		edline&id=pmid:35719025&id=doi:10.1002%2Fpbc.29813&issn=1545-500
36	40	
37	46.	Sisk BA, Keenan M, Schulz GL, Kaye E, Baker JN, Mack JW, et al. Interdependent
38		functions of communication with adolescents and young adults in oncology. Pediatr
39		Blood Cancer [Internet]. 2022; Available from:
40		http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017
41	47.	Barlevy D, Wangmo T, Ash S, Elger BS, Ravitsky V. Oncofertility decision making:
42		Findings from Israeli adolescents and parents. J Adolesc Young Adult Oncol [Internet].
43 44		2019;8(1):74–83. Available from: https://www.proquest.com/scholarly-
44 45		journals/oncofertility-decision-making-findings-israeli/docview/2426222863/se-
46		2?accountid=47868
47	48.	Sawyer SM, McNeil R, Thompson K, Orme LM, McCarthy MAOSSM; O http://orcid.
48	40.	
49		org/0000 0002 9095 358X, Sawyer SM, et al. Developmentally appropriate care for
50		adolescents and young adults with cancer: how well is Australia doing? Supportive
51		Care in Cancer [Internet]. 2019;27(5):1783–92. Available from:
52		http://link.springer.de/link/service/journals/00520/index.htm
53 54	49.	Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among
54 55		child and adolescent cancer survivors and their parents: A qualitative analysis. J
56		Psychosoc Oncol. 2016;34(5):347–62.
57	50.	Ananth P, Mun S, Reffat N, Li R, Sedghi T, Avery M, et al. A Stakeholder-Driven
58	20.	Qualitative Study to Define High Quality End-of-Life Care for Children With Cancer. J
59		Pain Symptom Manage [Internet]. 2021;62(3):492–502. Available from:
60		1 and symptom Manage [internet]. 2021,02(3).432–302. Available 11011.

	https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&
	D=med19&AN=33556497 https://cambridge-
	primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m
	edline&id=pmid:33556497&id=doi:10.1016%2Fj.jpainsymman.2021.01.
51.	Cicero-Oneto CE, Valdez-Martinez E, Bedolla M. Decision-making on therapeutic
	futility in Mexican adolescents with cancer: a qualitative study. BMC Med Ethics [Internet]. 2017;18:74. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
	AN=127010047&site=ehost-live
52.	Friebert S, Grossoehme DH, Baker JN, Needle J, Thompkins JD, Cheng YI, et al.
	Congruence Gaps Between Adolescents With Cancer and Their Families Regarding
	Values, Goals, and Beliefs About End-of-Life Care. JAMA Netw Open [Internet]. 2020
	May 19;e205424–e205424. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
	AN=143389091&site=ehost-live
53.	Jacobs S, Perez J, Cheng YI, Sill A, Wang J, Lyon ME. Adolescent end of life preferences
	and congruence with their parents' preferences: Results of a survey of adolescents
	with cancer. Pediatr Blood Cancer [Internet]. 2015;62(4):710–4. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
	AN=109777063&site=ehost-live
54.	Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-centered advance care planning
	for teens with cancer. JAMA Pediatr. 2013;167(5):460–7.
55.	Wu LM, Chiou SS, Lin PC, Liao YM, Su HL. Decisional conflicts, anxiety, and
	perceptions of shared decision-making in cancer treatment trajectory among
	adolescents with cancer: A longitudinal study. Journal of Nursing Scholarship.
	2022;54(5):589–97.
56.	Son H, Miller LE. Family Communication About Cancer in Korea: A Dyadic Analysis of
	Parent-Adolescent Conversation. Glob Qual Nurs Res. 2023 Jan 1;10.
57.	Glackin A, Marino JL, Peate M, McNeil R, Orme LM, McCarthy MC, et al. Experiences
	of Oncofertility Decision-Making and Care in a National Sample of Adolescent and
	Young Adult Cancer Patients and Parents. J Adolesc Young Adult Oncol. 2023;
58.	Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients'
	Experiences With Treatment Decision-making. Pediatrics. 2019;143(5).
59.	Martins A, Alvarez-Galvez J, Fern LA, Vindrola-Padros C, Barber JA, Gibson F, et al. The
	BRIGHTLIGHT National Survey of the Impact of Specialist Teenage and Young Adult
	Cancer Care on Caregivers' Information and Support Needs. Cancer Nurs.
	2021;44(3):235–43.
60.	Dalton JM. Development and testing of the theory of collaborative decision-making in
	nursing practice for triads. J Adv Nurs. 2003;41(1):22–33.
61.	Grinyer A. Young people living with cancer:implications for policy and practice. Open
	University Press; 2007. 182 p.
62.	Moules NJ, Laing CM, Estefan A, Schulte F, Guilcher GMT. "Family Is Who They Say
	They Are"(a): Examining the Effects of Cancer on the Romantic Partners of
	Adolescents and Young Adults. J Fam Nurs. 2018;24(3):374–404.
63.	Silva M, Barretta F, Luksch R, Terenziani M, Casanova M, Spreafico F, et al.
	Adolescents with cancer on privacy: Fact-finding survey on the need for
	confidentiality and space. Tumori. 2021 Oct 1;107(5):452–7.

64.	KM B, Smith A, Schmidt S, TH K, Zebrack B, CF L, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult.
	Cancer (0008543X) [Internet]. 2012 Oct 15;118(20):5155–62. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
	AN=104372613&site=ehost-live
65.	Pyke-Grimm KA, Franck LS, Patterson Kelly K, Halpern-Felsher B, Goldsby RE, Kleiman
	A, et al. Treatment Decision-Making Involvement in Adolescents and Young Adults
	With Cancer. Oncol Nurs Forum [Internet]. 2019;46(1):E22–37. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=133553348&site=ehost-live
66.	Davies J. The experience and role of partners in helping to meet the support needs of
	adolescents and young adults with cancer. Journal of Advanced Nursing (John Wiley & Sons, Inc) [Internet]. 2019 May;75(5):1119–25. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
	AN=135934208&site=ehost-live
67.	Iannarino NT. "It's My Job Now, I Guess": Biographical disruption and communication
	work in supporters of young adult cancer survivors. Commun Monogr [Internet].
	2018;85(4):491–514. Available from:
	https://doi.org/10.1080/03637751.2018.1468916
68.	Coyne I, Amory A, Gibson F, Kiernan G. Information-sharing between healthcare
	professionals, parents and children with cancer: More than a matter of information
~~	exchange. Eur J Cancer Care (Engl). 2016;25(1):141–56.
69.	de Vries MC, Wit JM, Engberts DP, Kaspers GJL, van Leeuwen E. Pediatric Oncologists'
	Attitudes Towards Involving Adolescents in Decision-Making Concerning Research
70.	Participation. Pediatr Blood Cancer. 2010;55(1):123–8.
70.	Frederick NN, Bingen K, Bober SL, Cherven B, Xu X, Quinn GP, et al. Pediatric oncology clinician communication about sexual health with adolescents and young adults: A
	report from the children's oncology group. Cancer Med [Internet]. 2021;10(15):5110–
	9. Available from:
	https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&
	D=med20&AN=34128352 https://cambridge-
	primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM services page?sid=OVID:m
	edline&id=pmid:34128352&id=doi:10.1002%2Fcam4.4077&issn=2045-76
71.	General Medical Council. Guidance for All Doctors. 0-18 Years: Guidance for All
	Doctors [Internet]. 2018;11. Available from: https://www.gmc-uk.org/ethical-
	guidance/ethical-guidance-for-doctors/0-18-years/making-decisions#paragraph-29
72.	British Medical Association. Children and young people toolkit A toolkit for doctors.
	BMA.org.uk [Internet]. 2021; Available from: https://www.bma.org.uk
73.	Gillick T. Gillick competence What is Gillick Here's what you need to know about
	capacity and The Gillick case. 2022;
74.	Joffe S, Fernandez C V., Pentz RD, Ungar DR, Mathew NA, Turner CW, et al. Involving
	children with cancer in decision-making about research participation. Journal of
	Pediatrics. 2006;149(6).
75.	Mårtenson EK, Fägerskiöld AM. A review of children's decision-making competence in
76	health care. J Clin Nurs. 2008;17(23):3131–41.
76.	Department for Constitutional Affairs. Mental Capactity Act 2005: Code of Practice. Mental Capactity Act 2005: Code of Practice. 2007;1–301.
	$\mathbf{M} \in \mathbf{M} \subset \mathbf{A} \cup $

- 77. Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and Shaped by Health Care Professionals Caring for Adolescents and Young Adults with Cancer? J Adolesc Young Adult Oncol. 2021;10(5):503–11.
 - Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer. 2016;63(8):1423–30.

- 79. Essig S, Steiner C, Kühne T, Kremens B, Langewitz W, Kiss A. Communication Skills Training for Professionals Working with Adolescent Patients with Cancer Based on Participants' Needs: A Pilot. https://home.liebertpub.com/jayao. 2019 Jun 4;8(3):354–62.
- 80. Coad J, Smith J, Pontin D, Gibson F. Consult, Negotiate, and Involve: Evaluation of an Advanced Communication Skills Program for Health Care Professionals. Journal of Pediatric Oncology Nursing. 2018 Jul 1;35(4):296–307.
- 81. Ruhe KM, Badarau DO, Brazzola P, Hengartner H, Elger BS, Wangmo T, et al. Participation in pediatric oncology: views of child and adolescent patients. Psychooncology. 2016;25(9):1036–42.
- Blackmore A, Kasfiki EV, Purva M. Simulation-based education to improve communication skills: A systematic review and identification of current best practice.
 BMJ Simul Technol Enhanc Learn. 2018;4(4):159–64.
- 83. Mahoney P, Macfarlane S, Ajjawi R. A qualitative synthesis of video feedback in higher education. Teaching in Higher Education [Internet]. 2019;24(2):157–79. Available from: https://doi.org/10.1080/13562517.2018.1471457
- 84. Smith S, Mooney S, Cable M, Taylor RM. THE BLUEPRINT OF CARE for teenagers and young adults with cancer Second edition. 2016; Available from: https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition. pdf

UNIVERSITY of York Centre for Reviews and Dissemination

Systematic review

A list of fields that can be edited in an update can be found here

1. * Review title.

PROSPERO

Give the title of the review in English

What is the impact and experience on communication for teenagers and young adults with cancer when

supporters are present during healthcare consultations?

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

05/12/2022

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

07/08/2023

5. * Stage of review at time of this submission.

This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

Update this field each time any amendments are made to a published record.

The review has not yet started: Yes

Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

National Institute for Health Research

International prospective register of systematic reviews	He	alth Research
Review stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No
Provide any other relevant information about the stage of the review he	ere.	

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Deborah Critoph

PROSPERO

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Mrs Critoph

7. * Named contact email.

Give the electronic email address of the named contact.

dc625@medschl.cam.ac.uk

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

Forvie Site

Addenbrookes Hospital

Department of Public Health and Primary Care

University of Cambridge

Cambridge

CB2 OPY

PROSPERO

International prospective register of systematic reviews

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+44 (0)1223 330300

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Cambridge

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Mrs Deborah Critoph. University of Cambridge Dr Luke Smith. Cambridge University NHS Hospital Trust Assistant/Associate Professor Rachel Taylor. University College London Assistant/Associate Professor Anna Spathis. University of Cambridge Assistant/Associate Professor Robbie Duschinsky. University of Cambridge Dr Helen Hatcher. Cambridge University NHS Hospital Trust Mrs Isla Kuhn. Cambridge University

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

Wellcome Trust

Grant number(s)

State the funder, grant or award number and the date of award

XXxed commentionest 2222497 721/21/e/52 sionals PhD 01/10/2022 - 30/06/2026

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

PROSPERO International prospective register of systematic reviews

National Institute for Health Research

not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

When a subpop flex make present with teenagers and young adults with cancer what is the impact on the

communication dynamics and the experiences of care for the young person?

Research Questions:

1. Who is present with teenagers and young adults with cancer in healthcare communication? For example,

who are the supporters, how often do they attend and in what context?

2. What are the teenagers and young adults experiences of care with the supporter being present?

3. What is the impact of a supporter being present in the communication?

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

State Chersher With Druid in:

- Embase via Ovid
- CINAHL via EBSCO
- PsycINFO via EBSCO
- Web of Science Core Collection.

Searches will be limited by date, English language and human studies.

Prattisipantsitbaid:malignant disease (or BMT for non-malignant disease)

Diagnosis aged 13-24 at the time of the study (for over 50% participants)

Articles focussing on any area of clinical communication

Supporters - parents, romantic partners, friends, informal carers etc.

Papers published after 2005.

Exclusion criteria:

PROSPERO

Non-English language

Systematic reviews

Conference abstracts

Articles focusing on information needs rather than communication skills.

International prospective register of systematic reviews

Unpublished articles

Validation research methodology

Single case studies

Studies using retrospective documentation in clinical notes.

Additional search strategy information can be found in the attached PDF document (link provided below).

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/374528_STRATEGY_20221205.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

The disease is a cancer diagnosis, this includes all oncological and haematological malignant diagnoses.

PROSPERO International prospective register of systematic reviews

National Institute for Health Research

This is in the teenage and young adult cancer (TYAC) population, ages 13-24 birthday as per UK age ranges for the TYAC speciality.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Prattisipartsitead:malignant disease (or BMT for non-malignant disease)

Diagnosis aged 13-24 at the time of the study (for over 50% participants)

Articles focussing on any area of clinical communication

Supporters - parents, romantic partners, friends, informal carers etc.

Papers published after 2005.

Exclusion criteria:

Non-English language

Systematic reviews

Conference abstracts

oeer terit Articles focusing on information needs rather than communication skills.

Unpublished articles

Validation research methodology

Single case studies

Studies using retrospective documentation in clinical notes.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

All interventions, any frameworks or assessment tools related to communication would be included in the review.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared

(e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Any relevant comparator.

PROSPERO

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

We expect data returned will largely be qualitative, however will support the use of quantitative data where

athaitsabseudy designs that are not eligible for inclusion in the review include:

International prospective register of systematic reviews

Systematic reviews, validation research methodology, single case studies and studies using retrospective

documentation in clinical notes.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Teenagers and young adults with cancer can be treated as in-patients and as outpatients and hospices, all

settings will be included in the literature review. The cancer journey is complex including significant time

points and transitions; at diagnosis, on treatment, relapse, completed treatment, survivorship and end of life

care. All parts of the cancer journey if relevant will be included in the systematic review.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

To gain a greater understanding of who the supporters may be when present with a TYAC. What context are

they with the TYAC - when an inpatient, at outpatient appointments and what sort of roles do they play -

Totige in passing enstanding hole of the fact in the f

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

PROSPERO International prospective register of systematic reviews

National Institute for Health Research

Page 30 of 75

None.

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

26.chageeextraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

All paper titles and abstracts will be assessed for eligibility by one independent reviewer, DC, and at least 25% of the papers (a random sample) assessed by a second independent reviewer, LS. The systematic literature review software Rayyan will be used to support this. Any papers where inclusion eligibility is unclear will be reviewed by a second independent reviewer with any disagreements on eligibility resolved by achieving consensus; a third independent reviewer will assess the eligibility of papers if needed. Full text review will be completed by the same three blinded reviewers and disagreements resolved by discussion.

Data extraction will be undertaken by one independent reviewer, DC using an Excel spreadsheet and reviewed by all paper authors. The data to be extracted will be:

1. Authors

- 2. Year of publication
- 3. Study location
- 4. Title
- 5. Study aims

6. Who were the supporters: a.) informal carers/support network b.) parents, romantic partners, friends, siblings.

7. Setting (treatment setting)

8. Point in the cancer journey: a.) pre diagnosis b.) diagnosis (up to 2 months) c.) treatment d.) survivorship (up to 2 years) e.) survivorship (up to 5 years) f.) survivorship (longer than 5 years)

9. Study type: a.) qualitative b.) quantitative c.) multi-method

- International prospective register of systematic reviews
- 10. Participant characteristics: a.) TYAC b.) HCP c.) supporters
- 11. Ages of patients at diagnosis extract what information they give
- 12. Ages of patients at the time of the research extract what information they give
- 13. Key findings

PROSPERO

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

QualitätäviseatidielesvillilbeaaseseedusisigghteRAJArgunideRindsqfBjzzs/Conjupzeis.omj.com/content/suppl/2012

/01/12/bmjopen-2011-000138.DC1/BMJ_Open_IMG_Physician_Migration_RATS_Checklist.pdf).

Studies will be assessed using the Mixed Methods Appraisal Tool (MMAT).

Quality assessment will be completed by three reviewers. Disagreements will be discussed for consensus.

Article quality and risk of bias will be included in the review publication.

28.chatrgedgy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If metaanalysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

We have planned a narrative synthesis. Study findings will be synthesised based on the reoccurring themes identified within included publications. This method will aid our inductive research synthesis and seek to

generate new insights and recommendations in this previously unexplored area. Our approach will follow the

fo Explored and the statistic set of the set

• Developing a preliminary synthesis of findings of included studies

- Assessing the robustness of the synthesis
- Developing a theory of how the intervention works, why and for whom

Three researchers, DC, LS and RT, will analyse the extracted data from included papers. Data will be fully extracted into an Excel spreadsheet by DC as detailed in Q26, tabulating the study findings as the first step in the narrative synthesis of qualitative and quantitative data. This will allow us to answer research question one: Who are the supporters and in what context. By extracting data related to patient ages, we will also be

National Institute for Health Research

PROSPERO International prospective register of systematic reviews

able to narratively synthase data for commonalities and differences by age categorised as per lower adolescence, middle adolescence, and upper adolescence. We hypothesise that as the age of the TYAC increases, the person in the role of a supporter may change from a parent to another important person. We will also be able to identify and describe if there is a difference in supporter, and role of supporter, at different time points in the cancer trajectory. We hypothesise that TYAC may need more from a supporter in the earlier stages of the cancer experience.

We are anticipating a reasonable number of publications in this review. It is likely that triadic communication is not the primary focus of most of the research studies, but may form part of the findings presented. We are also anticipating mainly qualitative research to detail experiences of communication, and our aim will be to draw the findings from a wide range of individual studies, with diverse methods, together to answer the research questions. We hypothesise that communication experiences for TYAC when a supporter is present are both helpful and unhelpful.

These steps detailed above will be used iteratively. The three researchers will all seek to undertake these steps and come together at regular intervals to review and debate insights, refine the narrative synthesis and reach conclusions by consensus. Researcher triangulation, of three unique backgrounds – doctor, nurse researcher in TYAC, and PhD student, will reduce researcher bias.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach. It is likely that the final publications that meet the inclusion criteria will be including patients across a wider age range than this review is specifically looking at (13-24). It will therefore be critical to establish the focus with his likely charteria be used by the state of patient:

Lower adolescence - 13-16

Middle adolescence - 16-19

Upper adolescent - 19-24

There may be similarities in themes across the subgroups and differences and this will need to form part of the analysis and be presented clearly.

Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

2 3

4 5

10

11 12

13 14

15

16 17

18

19 20

21

22 23

24

25 26

27 28

29

30 31

32 33

34

35 36

37

38 39

40

41 42

43

44 45

46 47

48

49 50

51 52

53

54 55

56

57 58

59

60

A supplementary table will be created to identify which age range each publication focussed on to aid

accessibility for the reader.

PROSPERO

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

International prospective register of systematic reviews

Type of review Cost effectiveness No Diagnostic No Epidemiologic No Individual patient data (IPD) meta-analysis No Intervention No Living systematic review No Meta-analysis No Methodology No Narrative synthesis Yes Network meta-analysis No Pre-clinical No Prevention No Prognostic No Prospective meta-analysis (PMA) No Review of reviews No

NHS National Institute for Health Research

International prospective register of systematic reviews Service delivery No Synthesis of qualitative studies No Systematic review Yes Other No OPPER REVIEW ONLY Health area of the review Alcohol/substance misuse/abuse No Blood and immune system No Cancer Yes Cardiovascular No Care of the elderly No Child health Yes Complementary therapies No COVID-19 No Crime and justice No Dental No Digestive system No Ear, nose and throat No Education No

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

PROSPERO

Page 35	of 75 BMJ Open	
	PROSPERO	NHS National Institute for
1	International prospective register of systematic reviews	Health Research
2 3	Endocrine and metabolic disorders	
4	No	
5 6		
7	Eye disorders	
8	No	
9 10	General interest	
11	Yes	
12	Genetics	
13 14	No	
15		
16	Health inequalities/health equity	
17 18	No	
19	Infections and infestations	
20	No	
21 22		
23	International development	
24	No	
25 26	Mental health and behavioural conditions	
27	No	
28	Musculoskeletal	
29 30	No	
31		
32	Neurological	
33 34	No	
35	Nursing	
36	No	
37 38	No Nursing No Obstetrics and gynaecology No Oral health No Palliative care No	
39	No	
40 41		
42	Oral health	
43	No	
44 45	Palliative care	
46	No	
47	Perioperative care	
48 49	No	
50		
51	Physiotherapy	
52 53	No	
55	Pregnancy and childbirth	
55	No	
56 57	Public health (including social determinants of health)	
58	Yes	
59		
60	Rehabilitation	

NHS
National Institute for
Health Research

International prospective register of systematic reviews	Health
No	
Respiratory disorders No	
Service delivery Yes	
Skin disorders No	
Social care No	
Surgery No	
Tropical Medicine No	
Urological No	
Wounds, injuries and accidents	
Violence and abuse No	

31. Language.

PROSPERO

 Select each language individually to add it to the list below, use the bin icon to remove any added in error. English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in

PROSPERO International prospective register of systematic reviews

Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible. Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

This will be published in the peer reviewed journal, European Journal of Cancer Care with open access. The results of the literature review will also be shared at national level via the professional organisation - TYAC. It will be shared at international, national and local conferences and shared via OrcID, Research gate and professional twitter accounts to share this publication and findings widely.

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Teenagers and young adults with cancer; TYAC; Adolescents; Triadic communication; Communication;

Supporters; Third person; Parents; Support network; Health care professionals; Experiences; Impact

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

The systematic review that underpins this line of enquiry by three of the same authors can be found here:

DOI: 10.1089/jayao.2019.0133

This is not an update of an existing review but adding to the growing knowledge base related to



Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

PROSPERO International prospective register of systematic reviews

National Institute for Health Research

communicating with teenagers and young adults with cancer.

38. * Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing so this field is not editable for initial submission.

Please provide anticipated publication date

Review_Ongoing

39. Anay gelditional information.

Provide any other information relevant to the registration of this review.

Please note this is a re-submission with revisions made to questions 26 and 28.

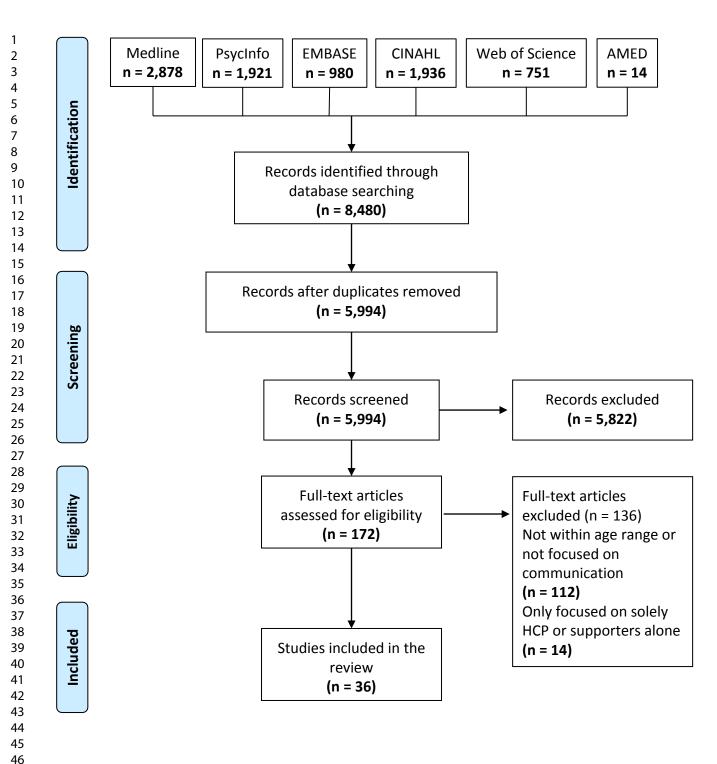
40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

Page 39 of 75

BMJ Open



BMJ Open

				В	MJ Open		Vbmjop	Page 40
			Study Type -	Table 2. St	ummary of Articles		6/bmjopen-2023-08002	
<i>First author</i> (year)	Title	Setting	analysis method Data collection	Focus	Participant Characteristics	Key findings	inc. 3002	WoE Score
Ananth (2021)	A Stakeholder- Driven Qualitative Study to Define High Quality End- Of-Life Care for Children with Cancer	USA Multicentre	Qualitative - thematic analysis Semi-structured interviews and focus groups.	To explore end of life care (EOLC) priorities for children with cancer and their families.	-	Important to have child or youn making. Interdisciplinary c for high quality healthcare profe AYACs would pre	direct communication with the person regarding decision- the network of the second second the second second second second second second second second second second second second second second	
Bahrami (2017)	Information Sharing Challenges Between Adolescents with Cancer, their Parents and Health Care Providers: A Qualitative Study	Iran Single centre	Qualitative descriptive- exploratory study - grounded theory analysis Semi-structured interviews.	Information sharing between AYACs, parents and health professionals.	33 participants: 12 AYACs (age range at interview: 15-20 years, within 1 year of diagnosis) 6 supporters 6 healthcare professionals	AYACs feel they sharing sessions professionals. confusion and 'inferior' source Parents were often allowing them t information to want to shield A Trust and honesty communication	A cluded from information- be seen parents and healthcare leads to disaffiliation, cleads to dis	
(2014)	A Qualitative Study of Phase III Cancer Clinical Trial Enrollment Decision Making Perspectives from AYAC, Caregivers and Providers		Qualitative - thematic analysis Semi-structured interviews.	Clinical trial enrollment.	40 participants: 13 AYACs (age range: 15- 21 years) 16 supporters 11 healthcare professionals	identified: 1. AYAC abdicate 2. Caregiver based 3. Collaborative, 4. AYAC in charge Caregivers perceid decision making AYACs felt that the most common Distress and po- involvement in the	AYAC approved, of decision-making. and AYAC to be in charge of asyof the time whereas the AYAC abdicates to carer" was form of decision making. bor Ahealth limited AYAC he decision. d enactional maturity facilitated	
			For peer review	only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml	Bibliographique de l	1

Pag	e 41 of 75				E	BMJ Open	6/bmjopen- <i>-</i> cted by cop	
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	Barlevy (2019)	Oncofertility decision making: findings from Israeli adolescents and parents	Israel Single centre	Qualitative- thematic analysis semi-structured interviews	To understand adolescent oncofertilty decision making in Israel, from perspectives of parents and adolescents	 <u>35 participants</u> 16 AYACs (age range 12- 16 years) 19 parents 	As in other cultural contexts, Israeli adolescents Medium and parents demonstrate multifaceted decision making, will respect to oncofertility. A significant finding from this study suggests that health professional shy from discussing posthumous planning of cryopreserved of materials with adolescent cancer patients and their parents. 5 out of 16 AYAs felt that the decision was not theirs and that it was insteaded parents' or the pysicians' to make. Some parents'	
16 17 18 19 20 21 22 23 24 25 26 27	Cicero- Oneto (2017)	Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study	Mexico Multicentre	Qualitative - thematic analysis Semi-structured interviews	Decision making on therapeutic futility	32 Participants 13 paediatric oncologists 13 parents or primary carers 6 AYACs (age range 13-18 years)	 Four themes were and field Medium 1. flow of a farmation to inform decision making a provide and stakeholder involved in decision making 2. disclosure of a and stakeholder involved in decision making 4. barriers and facilitators to decision making a provide and stakeholder involved in decision making a provide and stakeholder involved and stakeholder involved in decision making a provide and stakeholder involved and stakeholder involved	
28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47				For peer review	v only - http://bmjc	open.bmj.com/site/about/guid	on June 13, 2025 at Agence Bibliographique	

Page 42 of 75

					В	MJ Open	6/bmjopen	Page 42 of 7
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	Darabos (2021)	Cancer Related Decision Making Among AYAC, Care Givers and Oncology Providers	USA Single centre	Qualitative – content analysis with hypothesis coding Semi-structured interviews.	Decision-making and triadic communication	30 Participants: 11 AYACs (age range: 15- 24 years) 11 supporters 8 healthcare professionals	 Four decision-making betterns were identified: AYAC driven Collaborative Deferral to parents Provider-based A&A/Caregiver-approved. Collaborative decision-making and AYAC-driven decisions were most commonly described. There was recognized on that some decision-making was dayed the ext dependent. AYACs were most commonly described decisions. AYACs and caregiver explained how cognitive and emotional coping the explained how cognitive to a stronger relation the explained how cognitive. Direct and honest the explained how cognitive. Direct and honest the explained how cognitive. Direct and honest the explained how cognitive. 	High
22 23 24 25 26 27 28 29 30	Davies (2019)	'Life then', 'life interrupted', 'life reclaimed': the fluctuation of agency in teenagers and young adults with cancer	UK single centre	qualitative - thematic analysis case studies - multiple interviews	Fluctuation of agency across time and between cases	22 participants 5 AYACs (16-24 years) 5 parents carers (2 fathers, 3 mothers, 1 couple), 5 healthcare professionals (4 nurses and 1 oncology consultant) 5 other supporters (1 boyfriend, 1 girlfriend, 1 aunt, 2 friends)	Agency fluctuates ≥ over time within cases and between cases. Agency can fluctuate between personal, proxy and collective perspectives. Personal agency g is nigh prior to diagnosis, decreases after diagnosis and is reclaimed after treatment.	Medium
31 32 33 34 35 36 37 38 39 40	Ellis (2016)	Fertility concerns among child and adolescent survivors and parents: a qualitative study	Australia single centre	Qualitative semi-structured telephone interviews	recently off treatment and	97 participants from 45 families 19 AYACs (age range 7-17 at diagnosis, mean age 13.3) 44 mothers and 34 fathers	reported and conversations about fertility were frequently interrupted to discuss illness and treatment. These fersility discussions were not then continues once the AYAC was off treatment	Medium
41 42 43 44 45 46 47				For peer review	only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml B delines.xhtml C	3

Pag	e 43 of 75				E	BMJ Open	Decision-making ricar20 cause conflict when	
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	Essig (2016)	Improving Communication in Adolescent Cancer Care: A Multiperspective Study	Germany, Austria, Switzerland Number of centres not stated	Qualitative – inductive thematic analysis Focus groups.	Explore effective communication with AYACs for communication skills training.	 54 participants: 16 AYACs (age range: 13-19 years) 8 parents 30 healthcare professionals 	 Decision-making care cause conflict when adolescents are toggittively mature but legally lack the ability to make decisions. AYACs feel a loss of actonomy. Age-appropriate environments are important. Effective communication differs depending on the type of professional T.e., doctor vs nurse) Adolescents negative affect communication when: They are indifferent. There priorities conflict with treatment They conflict with graents. Healthcare professionals negatively affect communication where: They don't take the adolescent seriously. They give tog part information or withhold important intogenetion 	Medium
20 21 22 23 24 25 26 27 28 29 30 31 32	Fern (2013)	The Art of Age- Appropriate Care	UK Number of centres not stated	Qualitative – thematic analysis Peer-to-peer interviews, field notes and spider diagrams from focus groups.	Review a conceptual model of AYACs' cancer care experiences.	11 participants: 11 AYACs (age range: 13- 25 years)	 Young people misse the kept at the centre of interactions in tecognition of their stated needs: 1. Engagement and the stated information. 2. Individually and the stated information. 3. Support unprivated by parents/family. AYACs did not want information to be directed at parents but at them. AYACs found it emparrassing when sensitive information was revealed in the presence of their parents. Lack of continuity of healthcare professionals leads to AYACs dissatisfaction and irritation having to repeat their cancer story. 	Medium
33 34 35 36 37 38 39 40 41 42 43 44 45 46 47				For peer review	v only - http://bmjo	pen.bmj.com/site/about/gui	logies. idelines.xhtml	4

					E	BMJ Open	6/bmjopen-⁄	Page 44 of
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	Fourneret (2018)	Breaking bad news about cancer to adolescents and young adults: the french experience	France Multicentre	qualitative semi- structured interviews	Explore the effectiveness and implementation of the French announcement protocol in 7 french paediatric oncology centres	90 participants 27 AYACs (21 were 14-17 and 6 were 18-22) 30 parents (16 mothers, 5 fathers, 9 parents together at the appointment) 33 healthcare professionals	Parents and AYACs have different needs - both of which need to be accounted for when breaking bad news. Awkward and premature announcements were noted The announcement consultation – young patients were never alone when informed of their disease; either with parents (n=31) (parents were informed before there child 10 out of 31 times - this was motivated by a compassionate goal of preparing the parents vare is broken) or close family member/ and is or boyfriend or girlfriend (n=2). Some parents with an discussed - but the key quality needed in the triad is mutual trust HCP found parents or sence helpful in the study. HCPs should show meature the triad of the study. HCPs should show meature the triad of the study.	Medium
21 22 23 24 25 26 27 28 29 30	Frederick (2018)	Adolescent Patient Involvement in Discussions About Relapsed or Refractory Cancer with Oncology Clinicians.	USA Single centre	Qualitative – content analysis Audiotaped conversations.	Breaking bad news of relapsed or refractory cancer.	 <u>75 participants:</u> 11 AYACs (age range: 12.6-17.5 years) 44 supporters 20 healthcare professionals 	Adolescent patiens involvement in conversations about relapsed refractory cancer is limited. Adolescents were accompanied by one (27%) two (64%) or more than two (18%) family members in the discussion Adolescents spoke 3.3% of words compared to 66.9% clinicians and 30% parents. No conversations included instances in which the clinicians' as feed of adolescents for their communication preferences or desired role in decision-making	High
31 32 33 34 35 36 37 38 39 40 41	Friebert (2020)	Congruence gaps between adolescents with cancer and their families regarding values, goals and beliefs about end- of-life care	USA multicentre	Qualitative cross- sectional study	End of life care	<u>126 participants:</u> 126 parent-AYAC dyads AYACs (14-20 years, mean age 16.9)	Young people warsed early information (86%) but only 39% fanglies, knew this. Families understanding of when was important to their adolescents when dealing with their own dying was excellent for wanting bonest answers from their physician and under anding treatment choices but poor for dying an natural death and being off machines that external life, if dying. Parents do not know what AYACs want at the end of life	Low
41 42 43 44 45 46				For peer review	only - http://bmjo	pen.bmj.com/site/about/guid	delines.xhtml de	5

Pag	e 45 of 75				В	MJ Open	6/bmjope	
1 2 3 4 5 6 7 8 9 10 11 12 13 14	Glackin (2023)	Experiences of Oncofertility Decision-Making and Care in a National Sample of Adolescent and Young Adult Cancer Patients and Parents	Australasia multicentre	Qualitative – cross sectional survey. Reflexive thematic analysis	Oncofertility decision making	210 participants: 99 AYACs (age range 15- 25 years) 111 parents 41 AYAC parent dyads from the same family	Four themes were then died: emotional care needs; parent-AYA dynamics including autonomy and agendcy; decision making considerations including values and practicalities; and reflections on on constituity and follow-up. Both AYAC and parents placed importanceon AYA autonomy in fertility decision-making but, but many AYAC appectated the role of parents in providing supper and guidance throughout the process. Healthcare professionals are encouraged to autonomously and supper AYA's around fertility decision making withile concurrently offering opportunities the opport.	Low
15 16 17 18 19 20 21 22 23 24 25 26 27 28	Hart (2020)	The Challenges of Making Informed Decisions About Treatment and Trial Participation Following Cancer: A Qualitative Study with Adolescent and Young Adults with Cancer and Care Givers	UK Multicentre	Qualitative – <u>thematic analysis</u> <i>Semi-structured</i> <i>interviews</i> .	treatment and trial participation – at diagnosis.	33 participants: 18 AYACs (age range: 16- 24 years) 15 supporters	AYACs struggled by grocess information around diagnosis, exact and diagnosis, exact and diagnosis, exact and the pace of clinical activity. Some AYACs displayed from conversation topics which we have tressing. There are limited from sfor 'real' decision- making at diagnosis. However, many preferred this when they were already overwhelmed by emotions/symptoms. For trial enrollment, many AYACs allowed themselves to be steered by the recommendation of the healthcape professional who recruited them, thinking they were acting in their best interests.	Medium
28 29 30 31 32 33 34 35 36 37 38 39	Hong (2016)	Care Partnerships: toward technology to support teen's participation in their health care	US multicentre	Qualitative semi-structured interviews and observations		33 interviews. 15 with AYACs (13 of whom had cancer. age range 13-17) 15 parents (10 mothers, 1 fathers, 1 aunt and 2 fathers and mothers together) 8 clinician caregivers	 Participants faced analynges concerning: Teens' limited participation in their care communicating emotionally sensitive information managing physical and emotional responses Time alone with clinicans was important. Mutual protectionism or the need to "emotionally protect eachother" was prevalent. 	Medium
40 41 42 43 44 45 46 47				For peer review	r only - http://bmjo	pen.bmj.com/site/about/gui	Bi bliographique delines.xhtml delines.xhtml	6

Page 46 of 75

BMJ Open

					E	BMJ Open	6/bmjope	Page 46 of
1 2 4 5 6 7 8 9 10 11	Ingersgaard (2018)	A qualitative study on decision-making on Phase III randomized clinical trial participation in paediatric oncology: adolescents' and parents' perspectives and preferences	Denmark	qualitative exploratory study - in-depth semi- structured interviews with thematic analysis	To explore patients' and AYACs' motivs for accepting/ declining participation in the AL2008 trial and adolescents' involvement in decision making	 <u>16 participants</u> 5 AYACs (age range 12-16) 6 parents of AYACs 5 parents of children aged 3-10 years with cancer 	 altruism availing to help future AYACs trust in the cligicians individuate parceptions of cure contratoxicity adolescents as active participants in the decision making process parental responsibility and authority the difficients of uncertainty 	Low
12 13 14 15 16 17 18 19 20 21 22 23 24	Jacobs (2015)	Adolescent end of life preferences and congruence with their parents' preferences: results of a survey of adolescents with cancer	Norway	Qualitative three sessions of dyadic interviews	To explore AYACs' end of life preferences and to assess the congruence of these preferences with the parents' beliefs	17 adolescent/ family dyads 17 AYACs (age range 14- 21, 71% under 18)	Adolescents with the majority preferred to talk about EOL in the majority preferences, but important facets if adolescents' EOL wishes were not known if adolescents' EOL wishes adolescents' EOL wishes were not known if adolescents' EOL wishes adolescents' EOL wishes adolescents' EOL wishes adolescents' EOL wishes' adolescents' eol adolescents	Low
25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41						C A	n.bmj.com/ on June 13, 2025 at Agence Bibliographique ng, and similar technologies.	
42 43 44 45 46				For peer review	only - http://bmjo	ppen.bmj.com/site/about/guid		7

Page 4	47 of 75				В	MJ Open	Four major the metal and the m
,	Corsvold 2017)	A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members		exploratory mixed methods study audio recorded consultations	To investigate the emotional concerns of AYACs at the time of diagnosis and how to quantify how healthcare professionals respond	9 AYACs (age range 13-23) Present with mother (n=9), father (n=1), sister (n=1) or mother and father (n=2)	 Four major themes 20 of emotional concerns Medium expressed by ArApatients and their family members during consultations for a cancer diagnosis: 1) side effects/late effects or infertility, 2) "what happens in the near future/practical aspects", or a same formal concerns aspects of the concerns of the conc
21 L: 22 (2 23 24 25 26 27	.yon 2013)	Family-Centered Advance Care Planning for Teens With Cancer	USA single centre	Qualitative a randomised control pilot study	To examine the efficacy of family-centres ACP	30 dyads mean age of AYACs 16 17 were randomised to intervention and 13 were randomised to control 87% of surrogates were biological parents and were female	so it is key. The family centres ACP AYACs reported feeling note informed that the control group
28 — 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46				For peer review	v only - http://bmjo	pen.bmj.com/site/about/guic	on June 13, 2025 at Agence Bibliographique

					E	BMJ Open	6/bmjopen-j	Page 48
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	Mack (2019)	Adolescent and Young Adult Cancer Patients' Experiences with Treatment Decision-Making	USA Single Centre	Quantitative – <u>multivariate</u> <u>analysis, logistic</u> <u>regression</u> Surveys at diagnosis, 4 and 12 months.	Treatment decision-making	203 AYACs (age range: 15- 29 years)	A majority of $A_{\mathbf{X}} \times A_{\mathbf{R}} \times (58\%)$ want to share	
22 23 24 25 26 27 28 29 30 31 32	Mobley (2023)	Clinical Trial Participation: A qualitative study of Adolescents and Younger Adults Recently Diagnosed with Cancer	USA	Qualitative Grounded theory analysis of semi- structured interviews	Clinical trial participation	9 AYACs (age range 16-20)	of timing, decisional jole, and emotional impact Informing participation involved decision-making processes, specific knowledge, understanding and external infraence. Participant relationships emphasized the importance of communication and relationships with providers and parents. Patient determinants centered on motives from different perspectives pre-conceived attitudes, and understanding of CCTs	
33 34 35 36 37 38 39 40 41 42 43 44 45 46 47				For peer review	/ only - http://bmjc	open.bmj.com/site/about/guid	2025 at Agence Bibliographique gies.	9

Pag	Page 49 of 75 BMJ Open ¹ Olsavsky Family USA Qualitative To explore <u>87 participants:</u> Five process the process							
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17	Olsavsky (2021)	Family communication about fertility preservation in adolescent males newly diagnosed with cancer	USA	Qualitative	To explore fertility preservation communication among mothers, fathers and their male adolescents newly diagnosed with cancer.	 <u>87 participants:</u> 33 AYAC aged 12-25 32 mothers 22 fathers Representing 37 families in total. 	 Reliance of health care team and social support network to facilitate FP decisions (noted just by parents), withholding parental opinion and deferring the decision to the adolescent, ease of compunitation, communication berriers and facilitators, not being provide the provided of FP conversions. Four content the set of the provided of the parenthood (or grandparenthold). consideration of future partner of AVAC's 	Medium
 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 						open.bmj.com/site/about/guide	from http://bmjopen.bmj.com/ on June 13, 2025 at Agence Bibliographique (ABES) . ta mining, Al training, and similar technologies.	10

				В	MJ Open	6/bmjopen-2 cted by cop	Pag
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26	Patterson (2012)	The Unmet Needs of Emerging Adults With a Cancer Diagnosis	Qualitative	inform our understanding of the needs of emerging adults with a diagnosis of cancer from a developmental perspective that appreciates the key transitional tasks of emerging adulthood	14 Participants: 14 AYAC aged 20-25, average age of 22	 A cancer experience poses the potential for significant impacts on the four requirements for achievement of adulthood. The needs of these emerging adults were grouped into six themes; information, healthcare provision, daily living, increasing directly to the four requirements of adulthood. These themes related directly to the four requirements of adulthood. The task are capting responsibility for oneself compassions the importance of empower and with HCP. The task are capting on personal beliefs and value and philights the importance of keeping are advected on the importance of maximum and provide the importance of maximising Ar AC autonomy in relation to support responsibility the importance of maximising and advect of the importance of maximising are advected on the importance of maximising ar	
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47			For peer reviev		pen.bmj.com/site/about/g	similar technologies. uidelines.xhtml	11

Pag	je 51 of 75	BMJ Open do pen								
$\begin{array}{c}1\\2\\3\\4\\5\\6\\7\\8\\9\\10\\11\\12\\13\\14\\15\\16\\17\\18\\19\\20\\21\\22\\324\\25\\26\\27\\28\\9\\30\\31\\32\\33\\4\\35\\36\\7\\38\\9\\40\\41\end{array}$	Pennant (2020)	The Role of Social Support in Adolescent/Young Adults Coping with Cancer Treatment		Qualitative	To explore specific actions that help AYAC and what behaviours they want from their social supports	20 Participants: 10 AYAC ages 15-26 , mean age 18.9 years 10 parents	Themes of support included; presence,	Medium		
	Pyke- Grimm (2020)	3 Dimensions of Treatment Decision Making in Adolescents and Young Adults with Cancer.	USA Multicentre	Qualitative – ethnographic Semi-structured interviews, field notes.	Explore the preferences of AYACs for involvement in healthcare decisions	<u>16 participants:</u> 16 AYACs (age range: 14.7-20 years)	Emotions around diamosis inhibit information receptiveness and ability to engage in treatment decisions (especially important decisions). Initially AYACs struggle with the jargon and plethora of medical erms which are being used. They have limited knowledge which limits their questions, this increases over time. The importance of decisions differs from one AYACs to the best Also, some decisions are seen as having only one 'real' option. AYACs engaged moor decisions much earlier in their treatment, and some began engaging in more important decisions later in treatment. AYACs could adopte an active (sole decision maker), collaborative (with healthcare professionals/supporters) or passive (healthcare professionals/supporters as decision makers) role.	Medium		
41 42 43 44 45 46				For peer review	v only - http://bmjo	open.bmj.com/site/about/gui	idelines.xhtml	12		

					E	8MJ Open	6/bmjope	Page 52 of
1 2 3 4 5 6 7 8 9 10 11 12 13 14	Pyke- Grimm (2022)	Day-to-Day Decision Making by Adolescents and Young Adults with Cancer	USA	Qualitative Interpretive focused ethnography within the socio- logic tradition, informed by symbolic interactionism	To explore involvement of AYAs with cancer in day-to- day decisions affected by their cancer and treatment.	<u>16 Participants:</u> 16 AYAC aged 15-20 (at time of interview - with an average of one year from diagnosis)	 Factors influence the providence of AYAC in decision making such as the type of decision, the point in the cancer bourney. They want to be involved. Four day to day decision making categories were identified: mendial mindset, self care practices, self-advocacy and negotiating relationships. Parents were often present and staying strong was a recurring the second second recurring the second second recurring the second second recurring the second se	Medium
 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 	Sawyer (2019)	Developmentally Appropriate Care for Adolescents and Young Adults with Cancer: How Well is Australia Doing?	Australasia Multicentre	Quantitative – <u>Chi-squared and</u> <u>Fisher's exact test</u> Single time point survey.		196 participants: 196 AYACs (age range: 15- 25 years)	 >90% of AYACs are to be a state of the second of	Low
 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 							ıne 13, 2025 at Agence Bibliographique schnologies.	13
45 46 47				For peer review	only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml	

Pag	e 53 of 75				l	BMJ Open	Building relation to the second secon	
$\begin{array}{c}1\\2\\3\\4\\5\\6\\7\\8\\9\\10\\11\\12\\13\\14\\15\\16\\17\\18\\19\\20\\21\\22\\23\\24\\25\\26\\27\\28\\29\\30\\31\\32\\33\\4\\35\end{array}$	with A	ons of unication dolescents oung Adults	USA Multicentre	Qualitative – content analysis Semi-structured interviews.	Define communication functions from perspective of AYACs.	37 participants: 37 AYACs (age range: 12- 20 years; mean: 16 years)	 competence, remainly, empathy, and showing care and concert. We n clinicians demonstrated these attributes AYACs described feelings of trust in the clinicians ability and intent to care for them. Exchanging information: providing accurate and transparent information; and pacing of information, and palancing communication between parents and transparency is important. How we transparency could be burdensome. Exploring uncertainties and fears of the future mad AYACs feel bases araitation between AYACs for exploring the prepared and decreasing anxiety. There are araitation between AYACs for exploring the prepared and whether healthcare professionals should emain present and or give AYACs often feel that reatment related decisions realistically only have one choice giving a sense of powerlessness. They played a greater role in decisions outside of reatment related areas. While some AYACs preferred very passive or active roles most deciribed an interdependent process of communication involving them, their parents, and the clinicians. Parents often served as a conduit and buffer of communication between the AYAC and healthcare professional. Many described the integral role of parents in communication regardless of their age. 	High
36 37 38 39 40 41 42 43 44 45 46 47				For peer reviev	v only - http://bmjo	open.bmj.com/site/about/gui	delines.xhtml	14

2022) Co-management of		Qualitative	Study aimed to	37 Participants:	There are 6 roles, that AYAC co-manage with	Medium
communication an care in adolescent and young adult oncology	d	Semi-structured interviews	learn how AYAs and parents shared and delegated roles in communication and care during and after treatment for cancer	37 AYAC aged 12-24 Mean age 16 years	parents; managing information, managing social and emotional. meds, managing health, advocacy and empowerment, making decisions and managing legistrys. Five factors that influence AYAC roles in communication over AYAC agency Clinical encourage manual Emotional and physical well-being Personality, prefer were Insights and skills of and values Insights and skills of and values There are multiple boots fits of engagement of the adolescent.	
2023) Family Communication About Cancer in Korea: A Dyad Analysis of Parent-Adolescen Conversation		Qualitative descriptive study	The aim was to understand communication experiences of Korean AYAC and their parents in the context of young adult cancer.	14 participants: 7 AYAC (ages 14-19 years) and 7 parent pairs	subthemes. Different expectations for parent-adolescent communication hattenges and limited sharing and progress in the conversation. This study offers is is got into different communication expectations and preferences between Korean adolescents and parents, and reasons for communication challenges, while emphasizing the individualized assessment of parent-adolescent communication between them.	
					June 13, 2025 at Agence Bibliographique de technologies.	15

Pag	e 55 of 75			6/bmjope				
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	Viola (2018)	Problem-solving skills, parent- adolescent communication, dyadic functioning, and distress among adolescents with cancer	USA	Mixed methods study	The aim was to describe and assess how intrapersonal (i.e., problem-solving ability) and social–ecological factors (i.e., cancer- related communication with parents and parent–adolescent dyadic relationship quality) are associated with adolescent adjustment (i.e., distress).	78 participants: 39 AYAC and 39 parent pairs AYAC 14-20 mean age 16.1 39 Parents - 79.5 % mothers	The most commonly endorsed cancer-related problem was "net taking about what to do if the AYAC got signed that y worse". Parents reported better problem solving ability and better dyadic function of the solving than their adolescent. to text and data the solving ability and the solving than their adolescent.	
20 21 22 23 24 25	Weaver (2016)	"Being a Good Patient" During Times of Illness as Defined by Adolescent Patients With Cancer	USA	Qualitative - semantic content analysis Semi-structured interviews		40 participants AYAC ages 12-19 Mean age of 15.5 years	The concepts of a strance and compliance were the primary phases used to describe the good patient role, bulkalways within the context of a relationship. Of note: A total of 23 adolescents requested to be interviewed alone with the interviewer (57,5%)	Medium
26 27 28 29 30 31 32 33 34 35 36 37 38 39	Weaver (2015)	Adolescents' Preferences for Treatment Decisional Involvement During Their Cancer	USA Multicentre	Qualitative – <u>semantic content</u> <u>analysis</u> Semi-structured interviews.	healthcare	40 participants: 40 AYACs (age range at interview: 12-18.9 years; 0.5-6 months from diagnosis/relapse) NB: 34 AYACs primary diagnosis, 6 AYACs relapse.	 AYACs indicates as spectrum of preferred decisional roles with the most common being an actively involved role (65%), although a shared decision-making approach was still valued. AYACs recognized that situational and social contexts might shift their preferred level of involvement in bedgal decisions. Although adolescents wanted to be involved in decisions, they also oppressed an appreciation of family insight, parental presence, and clinician guidance. AYACs can retrospectively identify their preferences for inclosion in medical decision-making, and even when preferring involvement, they value the input of trusted others. 	
40 41 42 43 44 45 46 47				For peer review	v only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml	16

					В	MJ Open	6/bmjopen- <i>:</i> octed by cop	Page 56 of 75
1 2 3 4 5 6 7 8 9 10 11 12	Wu (2021)	Decisional conflicts, anxiety, and perceptions of shared decision- making in cancer treatment trajectory among adolescents with cancer: A longitudinal study	Taiwan	Qualitative. An explanatory mixed method was used, incorporating questionnaires and individual interviews.	To describe the perception on levels of decision-making during cancer treatment for adolescents with cancer and examine the trajectory of their decisional conflict	44 participants: 22 AYAC 11 male and 11 female mean age 15.39 22 Supporters: father n=1 mothers n=12 both n=6 other n=3	Different levels of participation in shared dec making (SDM) Huring the treatment trajed were found. Participants experienced the highest decisi conflict during dagnosis. Roles in healthcase communication varied direct participation to indirect involvement. Overall, participation to indirect involvement. Overall, participation to indirect of involvem communication area or decision making.	ctory ional from
 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 	al (2018)				To assess: recall of a fertility discussion, satisfaction with fertility knowledge, and identify factors that may influence recall.		42% and 52% of AVAC record and that parents made a most of the decision whereas 30.8% reported making decision and parents. Key Finding - A grade parents. Key Finding - A grade parents and the parents of AYAC reported making and the parents and the paren	tility ng. Ill or orted who rents hose Il of
43 44 45 46 47				For peer review	r only - http://bmjo	pen.bmj.com/site/about/gui	idelines.xhtml e	17

Update – December 2023 Medline

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to December 19, 2023>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or parents/ or fathers/ or mothers/ or spouses/ or caregivers/ or siblings/ or friends/ or legal guardians/ 1148168

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp adolescent/ or exp young adult/) and exp neoplasms/) 337284

3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp communication/ or exp disclosure/ or exp information dissemination/ or exp physician-patient relations/ 6147070

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 13278879

- 5 1 and 2 and 3 and 4 3519
- 6 limit 5 to english language 3399

7 (202211* or 202212* or 2023* or 2024*).dp. or (202211* or 202212* or 2023* or 2024*).ez. or (202211* or 202212* or 2023* or 2024*).ed. or (202211* or 202212* or 2023* or 2024*).ep. 1958643

8 6 and 7 163

Embase

Embase <1974 to 2023 December 19>

BMJ Open

1 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp *adolescent/ or exp *young adult/) and exp *neoplasm/) 10359

2 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp *interpersonal communication/ or exp *professional-patient relationship/ or exp *information dissemination/ or exp *conversation/ 7565603

3 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or *parent/ or *father/ or *mother/ or *spouse/ or *caregiver/ or *social worker/ or *sibling/ or *friend/ or *legal guardian/ 1440315

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 16593794

5 1 and 2 and 3 and 4 1032

6 limit 5 to english language 1010

7 (202211* or 202212* or 2023* or 2024*).dc. or (202211* or 202212* or 2023* or 2024*).dd. or (202211* or 202212* or 2023* or 2024*).dp.2647560

8 6 and 7 107

PsycINFO (via Ebsco)

			Last Run		
#		Query	Limiters/Expanders	Via	Results
			Limiters - Publication Date: 20221101- 20241231 Expanders - Apply equivalent subjects Search modes -	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA	
S1	1	S1 AND S2 AND S7 AND S8	Boolean/Phrase	PsycInfo	238
S1	LO	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Narrow by	Interface - EBSCOhost Research	6,315

		Language: - english Search modes - Boolean/Phrase	Databases Search Screen - Basic Search Database - APA PsycInfo	
		Expanders - Apply	Interface - EBSCOhost Research Databases Search Screen - Basic Search	
		equivalent subjects Search modes -	Database - APA	
S9	S1 AND S2 AND S7 AND S8	Boolean/Phrase	APA PsycInfo	6,549
	(affect* or effect* or influenc* or resultant or		Interface - EBSCOhost Research Databases Search Screen - Basic	
	impact* or perception* or perspective* or	Expanders - Apply	Search	
	encounter* or preference or opinion or involvement or occurance* or feel or "go	equivalent subjects Search modes -	Database - APA	
S8	through" or experienc*)	Boolean/Phrase	PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic	3,524,144
		Expanders - Apply 🧹	Search	
		equivalent subjects	Database -	
S7	(S5) or (S3)	Search modes - Boolean/Phrase	APA PsycInfo	62,557
			Interface - EBSCOhost Research Databases Search Screen - Basic	
		Expanders - Apply	Search	
		equivalent subjects Search modes -	Database - APA	
S6	S4 AND S5	Boolean/Phrase	APA PsycInfo	62,384
			-,	,

\$5	((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,384
S4	((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,384
53	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or (teenage and young adult" n3 h?ematol*) or ("teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("young adult" n3 lymphom*) or (teenage* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,072
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or DE "communication" OR DE "information dissemination" OR DE "conversation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,545,968

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1	
2 3	
4	
5 6	
7	
8 9	
10	
11 12	
13 14	
14	
16 17	
18	
19 20	
21	
22 23	
24 25	
26	
27 28	
29	
30 31	
32 33	
34	
35 36	
37	
38 39	
40	
41 42	
43 44	
45	
46 47	
48 49	
50	
51 52	
53	
54 55	
56	
57 58	
59 60	

	(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR DE "parents" OR DE "mothers" OR DE "fathers" OR DE "spouses" OR DE "wives" OR DE "husbands" OR DE "siblings" OR DE "significant others" OR DE "social workers" OR DE "guardianship" OR DE	Expanders - Apply equivalent subjects Search modes -	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA	
S1	"caregivers"	Boolean/Phrase	PsycInfo	937,154

CINAHL (via Ebsco)

Wednesday, December 20, 2023 4:07:56 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S3 AND S4	Limiters - Publication Date: 20221101- 20241231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	99
S 6	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,152
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,189

S4	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,149,468
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("young people" n3 lymphom*) or (adolescen* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young adult" n3 lymphom*)) OR ((MH "adolescence+" OR MH "young adult+") AND (MH "neoplasms+"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	61,263
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or MH "communication+" OR MH "discussion" OR MH "conversation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	2,080,061

OR (MH "Professional-Patient Relations+")		Search Database - CINAHL	
S1 caregiver* or "care-giver*" or spouse* or chaperone*) OR MH "parents" OR	Expanders - Apply equivalent subjects Search modes -	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	567,768

Web of Science Core Collection

Web of Science Search Strategy (v0.1)

Database: Web of Science Core Collection

Entitlements:

- WOS.IC: 1993 to 2023
- WOS.CCR: 1985 to 2023
- WOS.SCI: 1900 to 2023
- WOS.AHCI: 1975 to 2023
- WOS.BHCI: 2008 to 2023
- WOS.BSCI: 2008 to 2023
- WOS.ESCI: 2018 to 2023
- WOS.ISTP: 1990 to 2023
- WOS.SSCI: 1956 to 2023
- WOS.ISSHP: 1990 to 2023

Searches:

1: TS=(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) Date Run: Wed Dec 20 2023 16:03:59 GMT+0000 (Greenwich Mean Time) Results: 2283955

2: TS=("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" near/3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" near/3 cancer) or ("teenage and young adult" near/3 oncology) or (teenage*

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

near/3 cancer) or (teenage* near/3 oncology) or (adolescen* near/3 cancer) or (adolescen*

2
_
3
4
5
6
7
/
8
9
10
11
12
13
14
15
16
17
18
10
19
20
21
22
23
24
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
58 59
60

1

near/3 oncology) or ("young people" near/3 cancer) or ("young people" near/3 oncology) or ("teenage and young adult" near/3 leuk?emia*) or (teenage* near/3 leuk?emia*) or (adolescen* near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("teenage and young adult" near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (adolescen* near/3 h?ematol*) or ("young people" near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("young people" near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("teenage and young adult" near/3 lymphom*) or (teenage* near/3 lymphom*) or (adolescen* near/3 lymphom*) or ("young people" near/3 lymphom*) or ("young adult" near/3 lymphom*)) Date Run: Wed
Dec 20 2023 16:04:06 GMT+0000 (Greenwich Mean Time) Results: 8540
3: TS=(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") Date Run: Wed Dec 20 2023 16:04:13 GMT+0000 (Greenwich Mean Time) Results: 12748181
4: TS= (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*) Date Run: Wed Dec 20 2023 16:04:19 GMT+0000 (Greenwich Mean Time) Results: 26006930
5: #4 AND #3 AND #2 AND #1 Date Run: Wed Dec 20 2023 16:04:26
GMT+0000 (Greenwich Mean Time) Results: 764
6: #4 AND #3 AND #2 AND #1 and English (Languages) Date Run:
Wed Dec 20 2023 16:04:35 GMT+0000 (Greenwich Mean Time)Results: 737
7: #4 AND #3 AND #2 AND #1 and English (Languages) and 2022 or 2023 (Publication Years) Date Run: Wed Dec 20 2023 16:04:39 GMT+0000 (Greenwich
Mean Time) Results: 132

AMED via Ovid

AMED (Allied and Complementary Medicine) <1985 to October 2023>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. 14291

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3

1 2 3 4 5 6 7 8 9 10 11 12 13 14	 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. 120 3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. 60609 4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 143225 5 1 and 2 and 3 and 4 19 6 limit 5 to yr="2005 -Current" 14
15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40	
41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	

First run – November 2022 Medline (via Ovid)

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to November 23, 2022>

(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "caregiver*" or spouse* or supporter* or support network*).ti,ab. or parents/ or fathers/ or mothers/ or spouses/ or caregivers/ or siblings/ or friends/ or legal guardians/

(TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp adolescent/ or exp young adult/) and exp neoplasms/) 333070

(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp communication/ or exp disclosure/ or exp information dissemination/ or exp physician-patient relations/

(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab.

- 1 and 2 and 3 and 4
- limit 5 to (english language and yr="2005 -Current")

Embase (via Ovid)

Embase <1974 to 2022 November 23>

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

1 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp *adolescent/ or exp *young adult/) and exp *neoplasm/) 9638

2 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp *interpersonal communication/ or exp *professional-patient relationship/ or exp *information dissemination/ or exp *conversation/ 6997005

3 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or *parent/ or *father/ or *mother/ or *spouse/ or *caregiver/ or *social worker/ or *sibling/ or *friend/ or *legal guardian/ 1339977

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 15453173

5 1 and 2 and 3 and 4 939

6 limit 5 to (english language and yr="2005 -Current") 873

PsycInfo (via Ebscohost)

, .				
#	Query	Limiters/Expanders	Last Run Via	Results
		Limiters - Publication Year: 2005-2022		
		Expanders - Apply equivalent subjects Narrow by	Interface - EBSCOhost Research Databases Search Screen - Basic	
644		Language: - english Search modes -	Search Database - APA	4 602
S11	S1 AND S2 AND S7 AND S8	Boolean/Phrase Expanders - Apply equivalent subjects Narrow by	PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic	1,683
S10	S1 AND S2 AND S7 AND S8	Language: - english	Search	1,981

		Search modes - Boolean/Phrase	Database - APA PsycInfo		
S9	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,017	
58	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	3,366,619	
 S7	(S5) or (S3)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	13,719	
S6	S4 AND S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	13,275	
		Expanders - Apply equivalent subjects Narrow by SubjectAge: - adolescence (13-17 yrs) Narrow by	Interface - EBSCOhost		
	((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous	SubjectAge: - young adulthood (18-29 yrs) Search modes -	Research Databases Search Screen - Basic Search Database - APA		
S5 S4	System Neoplasms" OR DE "Terminal Cancer")) ((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	Boolean/Phrase Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	13,275 58,767	
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	1,864	

S2

S1

2,423,980

894,375

(adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*))		
(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or DE "communication" OR DE "information dissemination" OR DE "conversation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo
(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR DE "parents" OR DE "mothers" OR DE "fathers" OR DE "spouses" OR DE "wives" OR DE "husbands" OR DE "siblings" OR DE "significant others" OR DE "social workers" OR DE "guardianship" OR DE "caregivers"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo

CINAHL (via Ebscohost) Accessibility Information and Tips

Print Search History

Thursday, November 24, 2022 6:21:27 PM

(adolescen* n3 oncology) or ("young people" n3

("teenage and young adult" n3 leuk?emia*) or

leuk?emia*) or ("young people" n3 leuk?emia*) or

("young adult" n3 leuk?emia*) or ("teenage and

("young people" n3 h?ematol*) or ("young adult"

n3 h?ematol*) or ("teenage and young adult" n3

(teenage* n3 leuk?emia*) or (adolescen* n3

young adult" n3 h?ematol*) or (teenage* n3

h?ematol*) or (adolescen* n3 h?ematol*) or

lymphom*) or (teenage* n3 lymphom*) or

cancer) or ("young people" n3 oncology) or

#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,837

S6	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,866
\$5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,106
S4	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,016,184
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	59,927

Protected by copyri
Protected by copyright, including for uses related to text and data mining, Al tr
g, Al training, and similar technolog

	<pre>leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("teenage and young adult" n3 lymphom*) or (teenage* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*) or ("young adult" n3 lymphom*) OR ((MH "adolescence+" OR MH "young adult+") AND (MH "neoplasms+"))</pre>			
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or MH "communication+" OR MH "discussion" OR MH "conversation" OR (MH "Professional- Patient Relations+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,016,0
S1	(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR MH "parents" OR MH "mothers" OR MH "fathers" OR MH "spouses" OR MH "siblings" OR MH "teachers" OR MH "social workers" OR MH "caregivers"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	544,99

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Web of Science Core Collection

Web of Science Search Strategy (v0.1)

Database: Web of Science Core Collection

Entitlements:

 - WOS.IC: 1993 to 2022

- WOS.CCR: 1985 to 2022

Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

- WOS.SCI: 1900 to 2022
 WOS.AHCI: 1975 to 2022
 WOS.BHCI: 2008 to 2022
 WOS.BSCI: 2008 to 2022
 WOS.ESCI: 2017 to 2022
 WOS.ISTP: 1990 to 2022
- WOS.SSCI: 1956 to 2022
- WOS.ISSHP: 1990 to 2022

Searches:

1: TS=(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) Results: 2129759

Results: 2129759

2: TS=("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" near/3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" near/3 cancer) or ("teenage and young adult" near/3 oncology) or (teenage* near/3 cancer) or (teenage* near/3 oncology) or (adolescen* near/3 cancer) or (adolescen* near/3 oncology) or ("young people" near/3 cancer) or ("young people" near/3 cancer) or ("teenage and young adult" near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or (adolescen* near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("teenage and young adult" near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (teenage* near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("young adult" near/3 lymphom*) or (teenage* near/3 lymphom*) or ("young adult" near/3 lymphom*) or ("young adult" near/3 lymphom*)) Results: 7793

3: TS=(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") Results: 11889093

4: TS= (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*) Results: 24306121

5: #4 AND #3 AND #2 AND #1	Results: 684

6: #4 AND #3 AND #2 AND #1

7: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) Results: 644

Results: 684

8: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or (Publication Years) and English (Languages)

or



47

PRISMA 2020 Checklist

		BMJ Open	Page 74 of 2
PRISM	MA 20	BMJ Open de brijopen-2023- D20 Checklist	
Section and Topic	ltem #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT		See the PRISMA 2020 for Abstracts checklist.	
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pages 3 and 4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 4
METHODS	1	t pe	
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to the date when each source was last searched or consulted.	Page 4 and supplementa file
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 4, Table 1
			and supplementa file 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many regiewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation gols used in the process.	Page 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each epoint, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, detate of automation tools used in the process.	Pages 4 and 5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with act outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which to collect.	Page 5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, ounding sources). Describe any assumptions made about any missing or unclear information.	Page 5
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 5
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 5
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing sum	Page 5
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 5
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was per ormed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used a	Page 5

47

PRISMA 2020 Checklist

age 75 of 75		BMJ Open de				
ge 75 of 75 BMJ Open Star PRISMA 2020 Checklist PRISMA 2020 Checklist Star						
Section and Topic	ltem #	Checklist item	Location where item is reported			
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup adalysis, meta-regression).	Pages 5 and 6			
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not applicable			
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bigses).	Not applicable			
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Not applicable			
RESULTS						
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to t	Figure 1 page 6			
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they was cluded.	Figure 1 page 6			
Study characteristics	17	Cite each included study and present its characteristics.	Table 2 – summary of articles pages			
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Not reported			
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) a geffect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Not applicable			
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Not applicable			
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summare estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Not applicable			
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Not applicable			
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable			
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis asses	Not applicable			
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not applicable			
DISCUSSION						
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 10 and 11			
, , ,	23b	Discuss any limitations of the evidence included in the review. For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	Pages 11 and 12			



PRISMA 2020 Checklist

			BMJ Open d by op	Page 76 of 75				
1	PRISM	BMJ Open de by copyrigh Page 76 of Page 76 of Page 76 of Page 76 of Print Page 76 of Pag						
3 4 5	Section and Topic	ltem #	Checklist item	Location where item is reported				
6 7		23c	Discuss any limitations of the review processes used.	Pages 11 and 12				
8		23d	Discuss implications of the results for practice, policy, and future research.	Page 12				
9 10	OTHER INFORMAT	ION	es s a					
11	Registration and	24a	Provide registration information for the review, including register name and registration number, or state that the was not registered.	Page 3				
12 13	protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Supplemental file				
14		24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not appliable				
15	Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the eview.	Page 13				
16 17 18	Competing interests	26	Declare any competing interests of review authors.	Page 13				
19 20 21	Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms are a extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Page 13				
24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44	From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic diviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71 For more information, visit: http://www.prisma-statement.org/							

BMJ Open

BMJ Open

Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

Journal:	BMJ Open
Manuscript ID	bmjopen-2023-080024.R2
Article Type:	Original research
Date Submitted by the Author:	30-Jan-2024
Complete List of Authors:	Critoph, Deborah; University of Cambridge, Department of Public Health & Primary Care Taylor, Rachel; University College London Hospitals NHS Foundation Trust, CNMAR; Spathis, Anna; University of Cambridge Duschinsky, Robbie; University of Cambridge Hatcher, Helen; Cambridge University Hospitals NHS Foundation Trust Clyne, Ella; University of Cambridge Kuhn, Isla; University of Cambridge, Medical Library, School of Clinical Medicine Smith, Luke; Cambridge University Hospitals NHS Foundation Trust
Primary Subject Heading :	Communication
Secondary Subject Heading:	Communication, Oncology, Patient-centred medicine, Paediatrics, Medical education and training
Keywords:	Adolescents < Adolescent, Decision Making, EDUCATION & TRAINING (see Medical Education & Training), ONCOLOGY

SCHOLARONE[™] Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our <u>licence</u>.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which <u>Creative Commons</u> licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

terez oni

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies

Triadic communication with teenagers and young adults with cancer: a systematic literature review: "Make me feel like I'm not the third person"

Deborah J Critoph MSc, Rachel M Taylor PhD, Anna Spathis MD, Robbie Duschinsky PhD, Helen Hatcher MD PhD, Ella Clyne, Isla Kuhn MSc, Luke AM Smith

Deborah Critoph, PhD student, Department of Public Health & Primary Care, University of Cambridge

Rachel Taylor, Director of the CNMAR, Centre for Nurse, Midwife and Allied Health Profession Led Research, University College London Hospitals NHS Foundation Trust, London, NW1 2PG

Anna Spathis, Assistant Professor, Department of Public Health and Primary Care, University of Cambridge

Robbie Duschinsky, Professor of Social Science & Health, Department of Public Health & Primary Care, University of Cambridge

Helen Hatcher, Consultant in Medical and TYA Oncology, Clinical and Regional Lead for Sarcoma and Young People with Cancer, Clinical Director EoE TYAc ODN

Ella Clyne, Medical Student, University of Cambridge

Isla Kuhn, Head of Medical Library Services, University of Cambridge Medical Library

Luke Smith, Junior Clinical Fellow in TYA Haematology and Oncology, Cambridge University Hospitals NHS Foundation Trust

Corresponding author: Deborah Critoph, dc625@cam.ac.uk

Keywords: Teenagers and young adults with cancer (TYAC), adolescents, triadic communication, communication, supporters, third person, parents, support network, health care, professionals, experiences, impact.

Abstract = 290/300 Word count = 4,468 Number of tables = 4 Number of figures = 1

Abstract

Objectives

Clinical communication needs of teenagers and young adults with cancer (TYAC) are increasingly recognised to differ significantly from younger children and older adults. We sought to understand who is present with TYACs, TYACs experiences of triadic communication and its impact. We generated three research questions to focus this review:

- 1. Who is present with TYACs in healthcare consultations/communication?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact of a TYAC's supporter being present in the communication?

Design

Systematic review with narrative synthesis.

Data sources

The search was conducted across six databases: Medline, CINAHL, Embase, PsycINFO, Web of Science and AMED for all publications up to December 2023.

Eligibility criteria for selecting studies

Included papers were empirical research published after 2005; participants had malignant disease, diagnosed aged 13-24 years (for over 50% of participants); the research addressed any area of clinical communication.

Data extraction and synthesis

Three independent reviewers undertook full text screening. A review-specific data extraction form was used to record participant characteristics and methods from each included paper and results relevant to the three review questions.

Results

A total of 8,480 studies were identified in the search, of which 36 fulfilled the inclusion criteria. We found that mothers were the most common supporter present in clinical communication encounters. TYACs experiences of triadic communication are paradoxical in nature – the supporter can help or hinder the involvement of the young person in care related communication. Overall, young people are not included in clinical communication and decisions at their preferred level.

Conclusion

Triadic communication in TYAC care is common, complex, and dynamic. Due to the degree of challenge and nuances raised, HCPs need further training on effective triadic communication.

PROSPERO registration number CRD42022374528

Strengths & limitations of this study

- We searched systematically and thoroughly for eligible studies, but this is not a wellindexed field of research, and therefore it is possible that some relevant studies were not included in the review.
- We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in some countries (between 29 to 39).
- We only included papers published in English and the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics.
- International representation was seen in the eligible studies and TYAC ages were included across the entirety of the specified UK age range.
- Studies represented the journey throughout the cancer experience from diagnosis to survivorship and end of life care.

Introduction

Adolescence is a time of transition where young people navigate monumental physical, cognitive, emotional, and behavioural milestones to develop a sense of self-identity and gain independence. Although most young people have limited encounters with healthcare, around 2,500 young people in the United Kingdom (UK) are diagnosed with cancer each year, which is the leading cause of non-traumatic death in young people in the United States (US) and Europe.(1) Teenagers and young adults with cancer (TYACs) have unique healthcare needs and there has been an international drive to develop developmentally appropriate evidence-based specialist care, provided by appropriately trained healthcare professionals (HCPs).(2)

Communication with TYACs can be particularly challenging: a life-limiting condition intersects an age associated with emotional reactivity and variable maturity. TYACs clinical communication needs are increasingly recognised to differ significantly from younger children and older adults. Research indicates TYACs can have little meaningful involvement in conversations with HCPs: almost half of children and young people reported not being involved in decisions about their care.(3) HCPs recognise this and consider young people amongst the hardest patients to communicate with.(4) However, HCPs receive little training about how best to manage these clinical encounters. TYACs perceive that HCPs do not make efforts to understand how their cancer impacts their life outside of the healthcare setting. As a result, they may withdraw and subsequently be labelled as 'challenging', 'hard to reach' and 'disengaged'. This may adversely impact care and contribute to poor physical and psychological outcomes. Despite these issues, there are limited opportunities for formal postgraduate education in communication with TYACs for HCPs, with most training being ad hoc and not interprofessional. (5,6) Effective communication with TYACs has been recognised as a key national research priority. In a UK-wide survey of young patients' own research priorities, communication was a striking cross-cutting theme.(7)

Recent research into clinical communication with TYACs has offered some insight into the complexities of communication with this specialist patient group.(8-12) Yet one area that has

BMJ Open

 received less attention is triadic communication. Triadic communication refers to the presence of a third party, such as a parent, carer, or companion in clinical encounters (13) and the presence of such a person was found to occur in 87% of TYAC consultations.(11) As a commonly occurring form of communication in TYAC care, there is a need to understand the theoretical basis and relevance of triadic communication to clinical practice. For the purposes of this review, we refer to this third person as a supporter. Triadic communication literature from children and older adults exists. (14–17) Notably this includes a meta-analytic review of provider-patient-companion of adults,(18) one large systematic review of physician-patient-companion.(20) Whilst informative, these studies are with children and adults, not this unique age-group of emerging adulthood with a significant life threatening diagnosis such as cancer. Also, these studies focus on doctor-patient-third person communication, whereas TYAC care involves a range of interdisciplinary professionals. This review aims to understand what is known about triadic communication with TYACs in healthcare communication.

Aim

We sought to understand who is present with TYACs, synthesise TYACs experiences of triadic communication with HCPs and supporter(s), and develop insights into the impact of triadic communication for TYACs.

Review questions:

- 1. Who is the supporter present with TYACs in healthcare consultations and communication?
- 2. What are TYACs' experiences of communication with the supporter present?
- 3. What is the impact on a TYAC's supporter being present in the communication?

Methods

We conducted a systematic review and narrative synthesis (21,22) of empirical evidence published since 2005, the year of publication of the National Institute for Care Excellence (NICE) Improving Outcomes Guidance, the guidance document underpinning TYAC services in England.(2) The review protocol was prospectively registered with PROSPERO (CRD42022374528). We designed the search to identify and map the available evidence using a broad scope to gain an overview of the pertinent literature, identify knowledge gaps and clarify concepts. The search strategy was developed and refined with an information scientist (I.K.). Keywords were generated across five strands detailed in Table 1, with strands combined with the Boolean operator 'AND'. The search was conducted across six databases: Medline, CINAHL, Embase, PsycINFO, Web of Science and AMED (supplementary file 1).

Table 1. Search Terms

Strand 1 – TYAC

TYA cancer or TYA oncology or teenage and young adult adj5 cancer or teenage and young adult adj5 oncology or teenage* adj5 cancer or teenage* adj5 oncology or adolescen* adj 5 cancer or adolescen* adj 5 oncology or young people adj 5 cancer or young people adj 5 oncology Strand 2 – communication Communication skills OR communicat* OR discuss* OR disclos* OR inform* OR interact OR relationship building OR decision making OR communication tools OR communication aids OR psychosocial assessment Strand 3 – supporters Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*. Strand 4 - impact affect OR effect OR influence OR result OR resultant OR impact Strand 5 - experience encounter OR involvement OR occurrence OR feel OR "go through" OR experience* TYAC: teenage and young adult with cancer

Database searches were compiled and de-duplicated in Mendeley, abstracts were screened in Rayyan by two researchers (D.J.C and L.A.M.S.), and 172 full articles were read by three researchers (L.A.M.S., D.J.C., and R.M.T) for eligibility of inclusion in the final analysis, with disagreements resolved by discussion. Papers were included if: they presented empirical research published after 2005; participants had malignant disease, diagnosed aged 13-24 years (for over 50% of participants); the research addressed any area of clinical communication; and the research included supporters (parents, partners, carers, friends etc). Papers were excluded if they were: conference abstracts, unpublished articles, systematic reviews, single case studies, validation research methodology, studies using retrospective documentation in clinical notes, articles focusing on information needs rather than communication skills, or were not in English.

A review-specific data extraction form was used to record participant characteristics and methods from each included paper and results relevant to the three review questions. The final number of included articles totalled 36, the remaining 136 were excluded based on the participants' ages, focus on HCPs or information giving. In tandem to the data extraction process, two members of the review team (E.C. and D.J.C.) independently assessed each paper in terms of its internal validity, appropriateness, and contribution to answering the review questions, using a review-specific version of Gough's Weight of Evidence criteria.(23) Discrepancies in assessment decisions were discussed between reviewers and final scores were agreed through consensus.

Extracted data were entered into Excel to aid the narrative synthesis of the included papers.(21,22) All articles, irrespective of relevance and quality, were included in the review.

 However, those rated 'medium' and 'high' were given greater weight in the synthesis. An inductive thematic analysis was undertaken to identify the main, recurrent, and important data across the studies related to answering each research question. D.J.C. and E.C. explored heterogeneity across the studies. The integration of results from studies utilising different methods and epistemological positions was supported by L.A.M.S. and R.M.T., and consensus in synthesis was reached. The synthesis was further refined through discussion of the review of results and their implications with clinicians, interdisciplinary academic audiences, and all of the co-authors.

Patient and Public Involvement Statement

None

Results

A total of 8,480 studies were identified in the search, of which 36 fulfilled the inclusion criteria (Figure 1). The included articles are summarised in Table 2. (table 2 uploaded separately)

All points across the cancer trajectory were represented in the final papers: diagnosis (n=7); (12,24–29) on treatment (n=17); (30–46) end of treatment (completed within one year) (n=2); (47,48) survivorship (more than one-year post-treatment) (n=2); (5,49) and end of life care (n=5). (50–54) Three studies included patients at more than one point along the cancer care continuum. (55–57) Most studies (n=19) were conducted in the US (24,27–29,31,35–37,39–46,50,52,54) other countries included the UK, (25,32,33) Australia, (38,48,49,57) Norway, (12,53) Israel, (47) Iran, (30) Mexico, (51) France, (34) Denmark, (26) Korea (56) and Taiwan, (55) one study recruited from three European countries. (5) Studies used predominantly qualitative methods (n=32) but there were two mixed methods studies and two using quantitative methods. Weight of evidence (WoE) criteria indicated five were high evidence, (24,31,35,45,56) twenty-four were medium (5,12,25,27–30,32–34,36,37,39–42,44,46,47,49–51,55,57) and seven were low evidence. (26,38,43,48,52–54) We used Gough's review specific criteria to weight the quality of each paper. (23) To do this, we used three parameters:

- A) The integrity of the evidence on its own terms
- B) The appropriateness of the method for answering the review questions
- C) The appropriateness of the focus or relevance for answering the review questions

Each of the above was either rated as low, medium, or high. These 3 parameters were combined to create WoE D which was the overall rating seen above and is the extent to which a study contributes evidence to answering the review questions. Factors that made the method highly appropriate included the use of semi-structured interviews to understand TYAC experiences and speaking to the TYAC and supporter separately. The high scoring papers included papers that focussed on communication in the triad, but this only occurred in 10 papers. In 9 papers the age at diagnosis was not specified and this decreased the weighting of these papers. (5,34–36,50–54)

Of the included studies just less than one third researched the triad (n=10) of TYAC, supporters and HCP (5,24,30–32,34–36,50,51), one third TYAC only (n=12)

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

(28,29,33,37,38,40–42,44–46,48) and just over a third TYAC and supporters (n=14). (12,25–27,39,43,47,49,52–57)

Table 3 Study population

Participants included in the study and numbers of papers included for each of the three participant groups

Triad? Dyad? Single?	Who is studied in the paper?	Number of papers	References
Triad	TYAC, supporter, HCA	10	(5,24,30–32,34– 36,50,51)
Dyad	TYAC and supporter	14	(12,25– 27,39,43,47,49,52–57)
Single	TYAC only	12	(28,29,33,37,38,40– 42,44–46,48)

The categories used to separate the age groups were lower adolescence (11-14 years), middle adolescence (15-17 years), upper adolescence (18-21 years) and emerging adulthood (22 onwards). Of the papers where the age range at diagnosis could be deduced, the majority of these (21 out of 24) spanned three or more age categories. All the papers spanned two or more age categories. In nine of the papers, the age ranges at diagnosis were not available (as age at diagnosis was expressed as a mean or median). Given these factors, it is difficult to ascertain whether any between age group differences exist.

Who is present with TYACs in healthcare consultations and communication?

The majority of supporters were mothers (68.9%). When combined, parents represented nearly all the supporters in the included studies (94.6%), see Table 4. Non-parental supporters (1.8%) included partners, sisters, aunts, and grandmothers. The remaining supporters were not categorised due to insufficient information in the article's demographics data (3.9%).(53,54)



Table 4 Supporter Demographics

Details of the supporter demographics and percentages of within the included publications

Supporter type	Number of supporters	Percentage quoted to 1 decimal place (%)	References
"Mother"	453	68.9	(5,12,24–27,30– 32,34,36,39,43,47,49– 52,54,55)
"Father"	128	19.5	(5,12,25–27,30– 32,34,36,39,43,47,49– 52,55–57)
"Both parents"	20	3.0	(12,32,34,36,55)
"Parents" no further specification	20	3.0	(35)
"Stepmother"	1	0.2	(57)
"Grandmother"	2	0.3	(24)
"Sister"	3	0.5	(12,30,51)
"Partner"	3	0.5	(25,52)
"Aunt"	3	0.5	(36,51,52)
"Supporters" no	21	3.2	(53,54)
further specification			
"Other"	3	0.5	(55)
Total	657	100.1	

What are TYACs' experiences of communication with the supporter present?

The presence of supporters was concurrently helpful and challenging for TYACs. Supporters undertook several helpful roles and responsibilities: they asked questions on behalf of the TYAC, retained information from HCPs, acted as a conduit of information between the TYAC and HCP, and acted as a "sounding board" for the young person.(25,31,45) Some supporters promoted self-advocacy and autonomy for the young person.(27,39,41,46,57) Some reported symptoms on their behalf (45) and proactively negotiated changes to treatment schedules in the interest of the young person.(39)

Findings also suggested that young people could experience limited or ineffective communication in the presence of a supporter. Communication could be directed towards the supporter, not the young person.(27,29,31,36) Supporters could receive information in the absence of the TYAC and subsequently filter the content before delivering the information to TYACs.(30,33,34,55,56): *"The parents had hidden a truth that was not theirs to hide"* p533.(34) This reflected the broader predicament that supporters' priorities at times might have competed with those of young people. (25,34,50,51) Supporters could dominate the communication encounter, for instance, parents were seen to interrupt young people, especially when time was limited. (51) Frederick et al found the mean time for adolescent to clinician communication was only 5.5% of the total consultation and parent conversation

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

turns directed towards clinicians comprised a mean of 37.5% of all conversation turns. Clinicians directed most communication at the parent rather than the adolescent and spoke for 66.9% of the conversation and none of the clinicians offered patients the opportunity to speak with them alone. (35)

Mutual protectionism appeared to occur, with TYACs and supporters seeking to protect each other from difficult information leading to non-disclosure when both were present. A diagnosis of cancer is devastating for the young person, supporter(s), family, and the wider social network. Repeatedly, there were references to reduced disclosure between the young person and their supporter, in an attempt to shield each other from emotional distress.(12,31,36,38,39,41,45,53,56) TYACs could experience discomfort and guilt in seeing parents tearful and worried, and felt a burden in response to observing the emotions of supporters.(38,39,52) Some TYACs sought to limit this by withholding concerns to protect their supporters: "I couldn't talk to mum about my concerns because I didn't want to hurt her" p 37.(38) In equal measure, supporters were characterised as working hard to stay in control of emotions, be strong and stay in the "now", and they channelled energy into helping. (12,31,56) Yet this could contribute to an environment of non-disclosure that had the potential to create future communication challenges, such as supporters not knowing the young person's wishes. Examples of this were evident within the end of life care studies.(52,53) Friebert et al found that 86% of young people wanted to receive prognostic information as soon as possible but only 39% of families knew that. (52) Similarly, Jacobs et al found that young people's end of life wishes were not known by their families.(53) In instances where the young person may not be able to communicate, it may help families relieve the impossible burden of making difficult decisions or feelings of regret, if the young person's perspective and wishes are known.(54)

What is the impact of a TYAC's supporter being present in the communication?

Supporters have the potential to facilitate, complicate or obstruct the young person's involvement in decision-making. Involvement had a positive impact on recall,(42) and may improve autonomy, efficacy, adherence, and future self-management.(24,57) However, the participation of supporters may be experienced as stressful by TYAC as they may become side-lined. (25,40,55) The presence of supporters impacted the young person's level of involvement in decision-making in several ways. In some cases, supporters empowered TYACs to make decisions by withholding their opinion (27) and deferring the final decision to TYACs.(31) However, supporters and TYACs did not perceive decisions about their care; however, this was not what young people recounted.(24) TYACs reported a lack of communication and limited involvement in decisions (24,29,30,46) associated later with decisional regret.(24,37)

Deferral of communication and decisions from the young person to supporters was commonplace. (27,31,36) When supporters responded to this pathway of communication, young people then did not see a need to participate in decisions, knowing that their supporter was taking the mantle. (36) In parallel, clinicians were found to direct communication towards supporters and in extreme cases young people were completely excluded from communication and decisions. (29,30,35,47) An atmosphere characterised by a lack of trust,

 unanswered questions and uncertainty contributed to the exclusion of young people who then sought information from other sources.(30,36,39,56) Not allowing TYACs to choose their involvement in decision-making violated their autonomy, and increased distrust or resentment of providers and supporters and resulted in lower treatment adherence.(30,36,39)

The decisional involvement preferences of young people were not static: they were context and environment dependent. At diagnosis, heightened emotions and poor health rendered young people unable to engage in communication. (24,25,27,29,31,37,41) TYACs expressed a desire to be involved in decision making at different levels: some wanted limited involvement from their supporter(s) so they could take the leading role in consultations and their care; (58) several wanted collaboration with supporters and clinicians; (26,27,44,57) and some completely relied on supporters and HCP's to make decisions on their behalf.(45,46) Davies et al described this as agency, the ability to make free and independent choices. They highlighted the normality of this fluctuation between personal (acting independently), proxy (decisions made on behalf of someone) and collective (decisions are shared) decision making. Whilst this was not always linear, it was part of the cancer trajectory and demonstrated the fluctuating personal agency for TYACs.(32) Some young people reported that supporters and clinicians decided on the their level of involvement in communication and decisionmaking, (55) and TYACs commented that they did not feel the decision was theirs. (47) Decisional involvement was an interactive, complex, and multifaceted process within the context of the triad, and young people often wanted to be in control of their level of involvement.(28,31) The evidence highlighted that in the presence of a supporter, young people's choice in the their level of involvement in decisions was challenged and not routinely achieved.

Most TYACs felt that it was important for the healthcare team to communicate with them directly and openly.(30,31,33,38,39,49,50) Time alone helped facilitate communication between TYAC and HCP, to ensure that the young person's needs were fully met.(31,36) However, time alone with HCPs was not routinely integrated as a part of consultations with TYACs. (35,48) In fact, clinicians were reported as frequently speaking more to parents and TYACs received limited communication from HCPs.(27,31,35,36) In the presence of supporters, as well as withholding concerning information, young people reported feeling discomfort when discussing sensitive topics such as sex or fertility preservation.(27,36)

Young people wanted time alone to communicate with HCPs directly for a variety of reasons. This private line of communication offered a sense of personal agency and allowed them to feel "in the loop" and promoted a sense of autonomy that was threatened by the cancer diagnosis, particularly at the point of diagnosis.(32,50) Young people wanted space to think and privacy during the cancer journey; private lines of communication with HCPs actively promoted this.(31,39,45,46) It also enabled HCPs to get to know the young person and allowed them to ask questions that they may be reluctant to ask in the presence of their supporter, because of embarrassment or emotional shielding.(31) Darabos et al found that 87.5% of oncology providers considered it important to talk to the TYAC without their parents present.(31) Whilst the importance has been highlighted within the data it is also evident that this does not happen as part of routine clinical practice. This could be for several reasons such

as not wanting to challenge rules of authority, uncertainty around how best to ask a parent to leave and lack of confidence when communicating with a young person alone.

Discussion

Principal Findings

Who is present with TYACs in healthcare consultations and communication? For example, who are the supporters?

The included papers in our review demonstrated that most supporters were parents, more commonly mothers. The frequent presence of mothers in consultations is consistent with previous findings. For example, in a UK study in which TYAC nominated a caregiver, 85% were parents, and of those 80% were female.(59) We note that there is a paucity of data for non-parental supporters, and this may represent a reality of clinical practice or a bias towards TYAC-parental dyads over other relational-dyads in this field of research to date.

What are TYACs' experiences of communication with the supporter present?

TYACs experienced supporters facilitating communication by obtaining information, asking questions, advocating, and supporting personal agency of the young person; conversely supporters could hinder communication by gatekeeping information, or dominating communication and thereby rendering young people as bystanders. Young people experienced negative emotions in response to witnessing their supporters in distress.

What is the impact of a TYAC's supporter being present in the communication?

Bidirectional non-disclosure was a coping strategy used by both TYACs and supporters to protect one another from concerns and emotional burden. This limited HCPs ability to effectively assess ideas, concerns, and expectations from both parties when together. In the presence of supporters some young people were less informed, which could impair their ability to engage in decision-making conversations.

Meaning of the study

This is the first review to look specifically at triadic communication in teenagers and young adults with cancer and has demonstrated that there is a paucity of evidence focussed specifically on triadic communication with TYACs. Of the thirty-six studies in the review less than one third included all three parties in the triadic communication encounter. However, the review has enabled us to provide answers to the review questions and identify knowledge gaps, including a lack of theory describing triadic communication. Some preliminary theoretical models, such as family involvement in interpersonal healthcare processes,(60) depict the interaction pathways between patients, families and HCP and hypothesise the influence of family on interpersonal processes and outcomes of medical consultations.

The data has clearly identified that parents are the predominating supporter for TYACs, which may be surprising given the inclusion of participants up to the age of 25. Parents can play a significant role when a young person is diagnosed with cancer. Developmentally, a major characteristic that differentiates TYACs from younger children or older adults is the progressive increase in their desire and capacity for independence, personal agency, and autonomy. This process is disrupted by a cancer diagnosis: increased parental presence can be perceived as intrusive and reflect reversion to an earlier family dynamic, anchoring TYACs in dependency, restricting self-exploration, and limiting their developing of an internal value and belief system.(38,61–63) This has been phrased as 'retreating to family' and can negatively impact peer relationships by impeding development and maintenance of a peer network.(40,64,65) Young people may often be accepting of this, particularly in the early stages of the cancer diagnosis. However, as this review demonstrates, the presence of parents alters the experience and impact of communication with HCPs. It is important to highlight that there is limited literature on TYAC communication encounters with supporters other than parents.(62,66,67) Partners felt relegated to a non-participatory role by a parent, and mothers struggled to relinquish their existing role as primary supporter. (62,67) It is relevant to note that the participants in these three studies were in their early 20's.

A key impact of triadic communication is that young people may not be involved in decision making to the level they want. This is consistent with related paediatric oncology literature which consistently reports children's limited participation in decision-making. (68–70) Clinicians attempted to protect children from 'too much' information because of the perception that children are not capable or too vulnerable.(17) The important difference between paediatric and TYAC populations are the legal and ethical obligations towards TYACs who are autonomous, capacitous patients rather than to parents with parental responsibility.

The findings of this review demonstrate the presence of a supporter impacts the involvement of young people in healthcare decisions. Therefore, there are legal and ethical issues, which are critically important, both in research and clinically in TYAC care particularly related to informed consent, capacity, and autonomy. The law relating to children and young people is complex and differs across the UK and internationally. The General Medical Council guidelines in the UK state, "the patient must be the first concern".(71) HCPs have ethical and legal obligations outlined in UK best practice guidance, statute, and case law. (72) In the UK, parents can legally make decisions for children under 16 years unless the child disagrees and is deemed 'Gillick Competent'. (73) Moreover, studies have shown children aged 14 and older can approach the level of understanding of adults.(74,75) In contrast, people aged 16 and above are legally able to make decisions for themselves in the UK and are automatically assumed to have capacity (76) and therefore, HCPs must communicate with them in developmentally appropriate ways. Clinicians face a challenge in identifying the best way to communicate with TYACs and their supporter (s). TYACs need parental involvement whilst simultaneously desiring autonomy (36) necessitating careful balancing of the needs of both parties to ensure that the young person is not relegated to a non-participant status.

Strengths and weaknesses

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

Our review had a number of limitations. We searched systematically and thoroughly for eligible studies, but this is not a well-indexed field of research, and therefore it is possible that some relevant studies were not included in the review. We limited the review to a UK TYAC age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to aged 24 only and not necessarily the age of young adulthood used in some countries (between 29 to 39). We also only included papers published in English and therefore papers reflect practices in primarily North America, Australia and Europe, the results may not be applicable to other countries especially where cultural differences affect parental-TYAC or other familial/romantic relational dynamics and where the healthcare culture may be different, e.g., more paternalistic. Despite these limitations, international representation was seen in the eligible studies, TYAC ages were included across the entirety of the specified UK age range and studies represented the journey throughout the cancer experience.

Implications for clinicians and policy makers

Given the degree of challenge and nuance raised, HCPs need training on effective triadic communication. Fourneret concluded that the relationship between TYACs, their parents and HCPs "as being the most difficult one in oncology".(34) Professionals described challenges communicating with both TYACs and parents, especially when loyalties were torn between the two.(5) However, training is currently ad hoc and not interdisciplinary.(77–80) Furthermore, HCPs can find it difficult to apply teaching in this area in clinical practice.(53,81) HCPs need education and training to navigate triadic communication to optimise involvement of the young person whilst attending to a supporter's needs. Experiential learning is the gold standard in teaching methods for clinical communication and is designed to bring about changes in learners' skills. These evidence-based methods are through small group, problembased simulation in a classroom, with repeated practise and rehearsal of skills under observation with detailed and descriptive feedback. This is arguably warranted here.(82,83)

Triadic communication is a key feature of TYAC care but requires further attention and inclusion in future iterations of key policy documents and guidelines such as the Blueprint of Care (BoC).(84) The BoC is a UK document that helps shape and deliver developmentally appropriate care to TYAC. However, it is recognised that age is poorly correlated with developmental maturity and therefore any communication framework needs to be specific to TYACs, recognising the transitional nature of adolescence meaning a one size fits all approach is likely inadequate.

Unanswered questions and future research

Future research is warranted to triangulate triadic perspectives and understand more about the interactional dynamics of these complex communication encounters. A key research need is investigating how best to support decision-making whilst engaging supporters, understanding their priorities and information needs may conflict.(31,36,37,40) Conflict management must also be understood in the emotional context of young adult oncology. How to effectively educate HCPs to communicate within the triad, to ensure the young person and the supporters needs are met is a priority. This needs to include how best we facilitate time

 alone between young patients and HCPs. Continued development and utilisation of comprehensive triadic theoretical frameworks may provide guidance and direction for future research, allowing for greater integration and progress with this diverse research area and commonly occurring form of healthcare communication.

Conclusion

Triadic communication is a pivotal component of communicating with TYACs and the presence of supporters impacts clinical communication both positively and negatively. Young people desire a sense of personal agency, autonomy and control related to information flow and decision making. This includes private lines of communication with HCPs without the presence of supporters. HCPs recognise the importance of time alone with young people; however this does not translate to clinical practice. Therefore, further research on communication dynamics is needed to allow for the development of bespoke, TYAC focussed clinical communication. This then needs to be formally embedded in national guidance and postgraduate training for HCPs working in TYAC care to allow equitable access for TYACs.

Author Contributions:

DC, LS and RT were involved in developing the protocol; DC, IK and LS coordinated the running of the study and were responsible for data acquisition; DC, LS, RT and EC contributed to the analysis; DC drafted the manuscript. All authors have critically reviewed the manuscript for important intellectual content and have read and agreed to the published version of the manuscript. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest:

The authors declare no conflict of interest.

Ethics Approval:

This was a systematic review and therefore ethics approval was not required.

Funding:

This paper presents work supported by the Wellcome Trust, (grant number G115288) under its Programme PhD for healthcare professionals course awarded to the first author Deborah Critoph, University of Cambridge. R.M.T. is partially funded through UCLH Charity. The views expressed are those of the author (s) and not necessarily those of the Wellcome Trust or UCLH Charity.

Data availability statement:

All data relevant to the study are included in the article or uploaded as supplementary information. No previously unpublished primary data are included in the paper. All data

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

relevant to the systematic review are included in the paper or uploaded as supplementary information.

Figure Legends:

Figure 1: PRISMA Flow diagram

Table 1: Search terms

Table 2: Summary of articles

Table 3: Study Population

Participants included in the study and numbers of papers included for each of the three participant groups

Table 4: Supporter DemographicsDetails of the supporter demographics and percentages of within the included publications

References:

- 1. Cancer Research UK. Young peoples' cancers incidence statistics [Internet]. 2016 [cited 2019 Jul 10]. Available from: https://www.cancerresearchuk.org/healthprofessional/cancer-statistics/young-people-cancers/incidence
- 2. National Institute of Health and Clinical Excellence. Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer National Institute for Health and Clinical Excellence [Internet]. Nice. 2005. 198 p. Available from: https://www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-childrenand-young-people-with-cancer-update-pdf-773378893
- 3. Care Quality Commission., NHS Patient Survey Programme. 2018 Children and Young People's patient experience survey. Statistical Release. 2019;(November).
- 4. White B, Viner RM. Improving communication with adolescents. Arch Dis Child Educ Pract Ed. 2012;97(3):93–7.
- Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer [Internet]. 2016;63(8):1423–30. Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017
- 6. Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and Shaped by Health Care Professionals Caring for Adolescents and Young Adults with Cancer? J Adolesc Young Adult Oncol. 2021;10(5):503–11.
- Gibson F, Aldiss S, Fern LA, Phillips B, Gravestock H, Malik S, et al. Reporting the whole story: Analysis of the "out-of-scope" questions from the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership Survey. Health Expect. 2021;

8.	Smith LAM, Critoph DJ, Hatcher HM. How Can Health Care Professionals
	Communicate Effectively with Adolescent and Young Adults Who Have Completed
	Cancer Treatment? A Systematic Review. J Adolesc Young Adult Oncol [Internet].
	2020 Jan 14; Available from: https://doi.org/10.1089/jayao.2019.0133
9.	Reid J, McKeaveney C, Martin P. Communicating with Adolescents and Young Adult
	about Cancer-Associated Weight Loss. Curr Oncol Rep. 2019;21(2):6.
10.	Phillips CR, Haase JE. A Connectedness Primer for Healthcare Providers:
	Adolescents/Young Adult Cancer Survivors' Perspectives on Behaviors That Foster
	Connectedness during Cancer Treatment and the Resulting Positive Outcomes. J
	Adolesc Young Adult Oncol [Internet]. 2018;7(2):174–80. Available from:
	http://www.liebertpub.com/products/product.aspx?pid=387
11.	Mellblom A V, Finset A, Korsvold L, Loge JH, Ruud E, Lie HC. Emotional concerns in
	follow-up consultations between paediatric oncologists and adolescent survivors: a
	video-based observational study. Psychooncology [Internet]. 2014 Dec;23(12):1365
	72. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20
10	AN=109768272&site=ehost-live
12.	Korsvold L, Mellblom AV, Finset A, Ruud E, Lie HC. A content analysis of emotional
	concerns expressed at the time of receiving a cancer diagnosis: An observational
	study of consultations with adolescent and young adult patients and their family members. European Journal of Oncology Nursing [Internet]. 2017;26:1–8. Available
	from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=cin20&A
	120589318&site=ehost-live&custid=ns123475
13.	Ward A, Critoph D, Westacott R, Williams R, Dogra N. A collaboration on teaching a
10.	assessing triadic consultation skills. PEC Innovation [Internet].
	2022;1(October):100091. Available from:
	https://doi.org/10.1016/j.pecinn.2022.100091
14.	van Staa AL. Unraveling triadic communication in hospital consultations with
	adolescents with chronic conditions: The added value of mixed methods research.
	Patient Educ Couns. 2011;82(3):455–64.
15.	Cahill P, Papageorgiou A. Triadic communication in the primary care paediatric
	consultation: A review of the literature. British Journal of General Practice.
	2007;57(544):904–11.
16.	Maras M. Hidden in plain sight. Int J Psychiatry Med. 2022;57(6):481–5.
17.	Young B, Dixon-woods M, Windridge KC, Heney D. Study of Patients and Parents. B
	Med J. 2003;326(7384):305.
18.	Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical revie
	Soc Sci Med [Internet]. 2011;72(6):823–31. Available from:
	http://dx.doi.org/10.1016/j.socscimed.2011.01.015
19.	Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, et al. Physician-
	patient-companion communication and decision-making: A systematic review of
	triadic medical consultations. Patient Educ Couns. 2013;91(1):3–13.
20.	Tates K, Meeuwesen L. Doctor-parent-child communication. A (re)view of the
	literature. Soc Sci Med. 2001;52(6):839–51.
21.	Popay J, Roberts, H SA et al. Guidance on the Conduct of Narrative Synthesis in
	Systematic Reviews.

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

- 22. Petticrew M RH. Systematic Reviews in the social sciences. In: Systematic reviews in the social sciences [Internet]. Available from: https://onlinelibrary.wiley.com/doi/book/10.1002/9780470754887
 - 23. Gough D. Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. 2007 [cited 2023 Jul 2]; Available from: https://www.tandfonline.com/action/journalInformation?journalCode=rred20
 - Barakat LP, Schwartz LA, Reilly A, Deatrick JA, Balis F. A Qualitative Study of Phase III Cancer Clinical Trial Enrollment Decision-Making: Perspectives from Adolescents, Young Adults, Caregivers, and Providers. J Adolesc Young Adult Oncol. 2014;3(1):3– 11.
 - 25. Hart RI, Cameron DA, Cowie FJ, Harden J, Heaney NB, Rankin D, et al. The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: a qualitative study involving adolescents and young adults with cancer and their caregivers. BMC Health Serv Res. 2020;20(1).
 - 26. Ingersgaard MV, Tulstrup M, Larsen HB, Schmiegelow Kjeld AO Ingersgaard MVO http://orcid. org/0000 0002 7037 2104. A qualitative study of decision-making on Phase III randomized clinical trial participation in paediatric oncology: Adolescents' and parents' perspectives and preferences. J Adv Nurs. 2018;74(1):110–8.
 - 27. Olsavsky AL, Theroux CI, Dattilo TM, Klosky JL, O'Brien SH, Quinn GP, et al. Family communication about fertility preservation in adolescent males newly diagnosed with cancer. Pediatr Blood Cancer. 2021;68(7).
 - Weaver MS, Baker JN, Gibson D V, Gattuso JS, Hinds PS, Gibson D V, et al. "Being a good patient" during times of illness as defined by adolescent patients with cancer. Cancer [Internet]. 2016 Jul 15;122(14):2224–33. Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142
- 29. Mobley EM, Thomas SM, Brailsford J, Ochoa CY, Miller K, Applebaum A, et al. Clinical Trial Participation: A Qualitative Study of Adolescents and Younger Adults Recently Diagnosed with Cancer. J Adolesc Young Adult Oncol. 2023 Jun 1;12(3):303–13.
- Bahrami M, Namnabati M, Mokarian F, Oujian P, Arbon P. Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study. Supportive Care in Cancer [Internet]. 2017;25(5):1587–96. Available from:

https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=122279626&site=ehost-live

- 31. Darabos K, Berger AJ, Barakat LP, Schwartz LA. Cancer-Related Decision-Making Among Adolescents, Young Adults, Caregivers, and Oncology Providers. Qual Health Res. 2021 Nov 1;31(13):2355–63.
- 32. Davies J, Kelly D, Hannigan B. "Life then", "life interrupted", "life reclaimed": The fluctuation of agency in teenagers and young adults with cancer. Eur J Oncol Nurs. 2018;36(100885136):48–55.
- Fern LA, Taylor RM, Whelan J, Pearce S, Grew T, Brooman K, et al. The Art of Age-Appropriate Care. Cancer Nurs [Internet]. 2013;36(5):E27–38. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=110243702&site=ehost-live
- Fourneret E. Breaking Bad News about Cancer to Adolescents and Young Adults: The French Experience. J Law Med [Internet]. 2018 [cited 2021 Nov 22];25(2):530–7.
 Available from: https://pubmed.ncbi.nlm.nih.gov/29978652/

35.	Frederick NN, Mack JW. Adolescent patient involvement in discussions about
	relapsed or refractory cancer with oncology clinicians. Pediatr Blood Cancer
	[Internet]. 2018;65(4):1. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin2 AN=128132562&site=ehost-live
36.	Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care Partnerships: Towa
	Technology to Support Teens' Participation in Their Health Care. Proc SIGCHI Conf
	Hum Factor Comput Syst [Internet]. 2016 May 7 [cited 2018 Jun 2];2016:5337–49.
	Available from: http://www.ncbi.nlm.nih.gov/pubmed/28164178
37.	Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients'
	Experiences With Treatment Decision-making. Pediatrics. 2019;143(5).
38.	Patterson P, Millar B, Desille N, McDonald F. The Unmet Needs of Emerging Adults
	With a Cancer Diagnosis A Qualitative Study. Cancer Nurs. 2012;35(3):E32–40.
39.	Pennant S, Lee SC, Holm S, Triplett KN, Howe-Martin L, Campbell R, et al. The Role
	Social Support in Adolescent/Young Adults Coping with Cancer Treatment. Childre
	[Internet]. 2020;7(1):1–25. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin2
	AN=142468088&site=ehost-live
40.	Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. 3 Dimensions
	Treatment Decision Making in Adolescents and Young Adults With Cancer. Cancer
	Nurs [Internet]. 2020 Nov;43(6):436–45. Available from:
	https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin2
	AN=146822019&site=ehost-live
41.	Pyke-Grimm KA, Franck LS, Halpern-Felsher B, Goldsby RE, Rehm RS. Day-to-Day
	Decision Making by Adolescents and Young Adults with Cancer. Journal of Pediatr
	Hematology/Oncology Nursing [Internet]. 2022;39(5):290–303. Available from:
	https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fullte
	D=medl&AN=35538622 https://cambridge- primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVI
	edline&id=pmid:35538622&id=doi:10.1177%2F27527530211068718&issn=
42.	Zarnegar S, Gosiengfiao Y, Rademaker A, Casey R, Albritton KH. Recall of Fertility
	Discussion by Adolescent Female Cancer Patients: A Survey-Based Pilot Study. J
	Adolesc Young Adult Oncol [Internet]. 2018 Apr;7(2):249–53. Available from:
	http://www.liebertpub.com/products/product.aspx?pid=387
43.	Viola A, Taggi-Pinto A, Sahler OJZ, Alderfer MA, Devine KA, Ed M, et al. Problem-
	solving skills, parent-adolescent communication, dyadic functioning, and distress
	among adolescents with cancer. Pediatr Blood Cancer. 2018;65(5).
44.	Weaver MS, Baker JN, Gibson D V, Gattuso JS, Sykes AD, Hinds PS. Adolescents'
	preferences for treatment decisional involvement during their cancer. Cancer
	[Internet]. 2015;121(24):4416–24. Available from:
45	http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142
45.	Sisk BA, Keenan M, Kaye EC, Baker JN, Mack JW, DuBois JM. Co-management of communication and care in adolescent and young adult oncology. Pediatr Blood
	Cancer [Internet]. 2022;69(10):e29813. Available from:
	https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fullte
	The second s

46.	primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m edline&id=pmid:35719025&id=doi:10.1002%2Fpbc.29813&issn=1545-500 Sisk BA, Keenan M, Schulz GL, Kaye E, Baker JN, Mack JW, et al. Interdependent
	functions of communication with adolescents and young adults in oncology. Pediatr Blood Cancer [Internet]. 2022; Available from: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1545-5017
47.	Barlevy D, Wangmo T, Ash S, Elger BS, Ravitsky V. Oncofertility decision making: Findings from Israeli adolescents and parents. J Adolesc Young Adult Oncol [Internet]. 2019;8(1):74–83. Available from: https://www.proquest.com/scholarly- journals/oncofertility-decision-making-findings-israeli/docview/2426222863/se- 2?accountid=47868
48.	Sawyer SM, McNeil R, Thompson K, Orme LM, McCarthy MAOSSM; O http://orcid. org/0000 0002 9095 358X, Sawyer SM, et al. Developmentally appropriate care for adolescents and young adults with cancer: how well is Australia doing? Supportive Care in Cancer [Internet]. 2019;27(5):1783–92. Available from: http://link.springer.de/link/service/journals/00520/index.htm
49.	Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among child and adolescent cancer survivors and their parents: A qualitative analysis. J Psychosoc Oncol. 2016;34(5):347–62.
50.	Ananth P, Mun S, Reffat N, Li R, Sedghi T, Avery M, et al. A Stakeholder-Driven Qualitative Study to Define High Quality End-of-Life Care for Children With Cancer. J Pain Symptom Manage [Internet]. 2021;62(3):492–502. Available from: https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=med19&AN=33556497 https://cambridge- primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:m edline&id=pmid:33556497&id=doi:10.1016%2Fj.jpainsymman.2021.01.
51.	Cicero-Oneto CE, Valdez-Martinez E, Bedolla M. Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study. BMC Med Ethics [Internet]. 2017;18:74. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=127010047&site=ehost-live
52.	Friebert S, Grossoehme DH, Baker JN, Needle J, Thompkins JD, Cheng YI, et al. Congruence Gaps Between Adolescents With Cancer and Their Families Regarding Values, Goals, and Beliefs About End-of-Life Care. JAMA Netw Open [Internet]. 2020 May 19;e205424–e205424. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=143389091&site=ehost-live
53.	Jacobs S, Perez J, Cheng YI, Sill A, Wang J, Lyon ME. Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. Pediatr Blood Cancer [Internet]. 2015;62(4):710–4. Available from: https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20& AN=109777063&site=ehost-live
54.	Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-centered advance care planning for teens with cancer. JAMA Pediatr. 2013;167(5):460–7.
55.	Wu LM, Chiou SS, Lin PC, Liao YM, Su HL. Decisional conflicts, anxiety, and perceptions of shared decision-making in cancer treatment trajectory among

1 2		
3		adelessents with cancer. A lengitudinal study, lowrnal of Nursing Scholarship
4		adolescents with cancer: A longitudinal study. Journal of Nursing Scholarship.
5	50	2022;54(5):589–97.
6	56.	Son H, Miller LE. Family Communication About Cancer in Korea: A Dyadic Analysis of
7		Parent-Adolescent Conversation. Glob Qual Nurs Res. 2023 Jan 1;10.
8 9	57.	Glackin A, Marino JL, Peate M, McNeil R, Orme LM, McCarthy MC, et al. Experiences
9 10		of Oncofertility Decision-Making and Care in a National Sample of Adolescent and
11		Young Adult Cancer Patients and Parents. J Adolesc Young Adult Oncol. 2023;
12	58.	Mack JW, Fasciano KM, Block SD. Adolescent and Young Adult Cancer Patients'
13		Experiences With Treatment Decision-making. Pediatrics. 2019;143(5).
14	59.	Martins A, Alvarez-Galvez J, Fern LA, Vindrola-Padros C, Barber JA, Gibson F, et al. The
15 16		BRIGHTLIGHT National Survey of the Impact of Specialist Teenage and Young Adult
16 17		Cancer Care on Caregivers' Information and Support Needs. Cancer Nurs.
18		2021;44(3):235–43.
19	60.	Dalton JM. Development and testing of the theory of collaborative decision-making in
20	00.	nursing practice for triads. J Adv Nurs. 2003;41(1):22–33.
21	61.	Grinyer A. Young people living with cancer: implications for policy and practice. Open
22	01.	
23 24	62	University Press; 2007. 182 p.
24 25	62.	Moules NJ, Laing CM, Estefan A, Schulte F, Guilcher GMT. "Family Is Who They Say
26		They Are"(a): Examining the Effects of Cancer on the Romantic Partners of
27		Adolescents and Young Adults. J Fam Nurs. 2018;24(3):374–404.
28	63.	Silva M, Barretta F, Luksch R, Terenziani M, Casanova M, Spreafico F, et al.
29		Adolescents with cancer on privacy: Fact-finding survey on the need for
30 21		confidentiality and space. Tumori. 2021 Oct 1;107(5):452–7.
31 32	64.	KM B, Smith A, Schmidt S, TH K, Zebrack B, CF L, et al. Positive and negative
33		psychosocial impact of being diagnosed with cancer as an adolescent or young adult.
34		Cancer (0008543X) [Internet]. 2012 Oct 15;118(20):5155–62. Available from:
35		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
36		AN=104372613&site=ehost-live
37	65.	Pyke-Grimm KA, Franck LS, Patterson Kelly K, Halpern-Felsher B, Goldsby RE, Kleiman
38 39		A, et al. Treatment Decision-Making Involvement in Adolescents and Young Adults
40		With Cancer. Oncol Nurs Forum [Internet]. 2019;46(1):E22–37. Available from:
41		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
42		AN=133553348&site=ehost-live
43	66.	Davies J. The experience and role of partners in helping to meet the support needs of
44	00.	
45 46		adolescents and young adults with cancer. Journal of Advanced Nursing (John Wiley &
40 47		Sons, Inc) [Internet]. 2019 May;75(5):1119–25. Available from:
48		https://search.ebscohost.com/login.aspx?direct=true&AuthType=athens&db=cin20&
49		AN=135934208&site=ehost-live
50	67.	lannarino NT. "It's My Job Now, I Guess": Biographical disruption and communication
51		work in supporters of young adult cancer survivors. Commun Monogr [Internet].
52		2018;85(4):491–514. Available from:
53 54		https://doi.org/10.1080/03637751.2018.1468916
55	68.	Coyne I, Amory A, Gibson F, Kiernan G. Information-sharing between healthcare
56		professionals, parents and children with cancer: More than a matter of information
57		exchange. Eur J Cancer Care (Engl). 2016;25(1):141–56.
58		
59		
60		

4

5

6 7

8

9

10

11

12 13

14

15

16

17 18

19

20

21

22

23 24

25

26

27

28 29

30

31

32

33

34 35

36

37

38

39

40 41

42

43

44

45 46

47

48

49

50

51 52

53

54

55

56 57

58

59

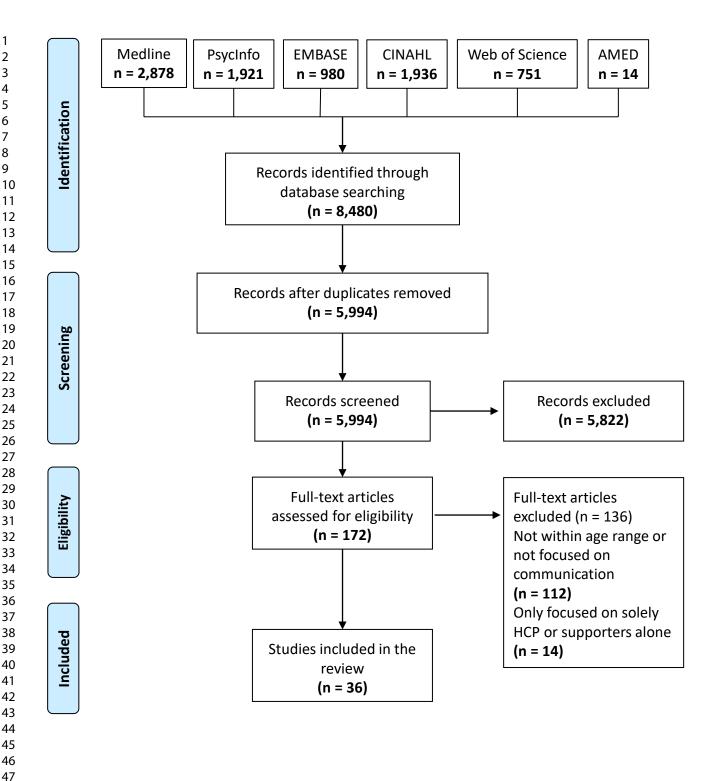
60

69. de Vries MC, Wit JM, Engberts DP, Kaspers GJL, van Leeuwen E. Pediatric Oncologists' Attitudes Towards Involving Adolescents in Decision-Making Concerning Research Participation. Pediatr Blood Cancer. 2010;55(1):123-8. 70. Frederick NN, Bingen K, Bober SL, Cherven B, Xu X, Quinn GP, et al. Pediatric oncology clinician communication about sexual health with adolescents and young adults: A report from the children's oncology group. Cancer Med [Internet]. 2021;10(15):5110-9. Available from: https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext& D=med20&AN=34128352 https://cambridgeprimo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM services page?sid=OVID:m edline&id=pmid:34128352&id=doi:10.1002%2Fcam4.4077&issn=2045-76 71. General Medical Council. Guidance for All Doctors. 0-18 Years: Guidance for All Doctors [Internet]. 2018;11. Available from: https://www.gmc-uk.org/ethicalguidance/ethical-guidance-for-doctors/0-18-years/making-decisions#paragraph-29 72. British Medical Association. Children and young people toolkit A toolkit for doctors. BMA.org.uk [Internet]. 2021; Available from: https://www.bma.org.uk Gillick T. Gillick competence What is Gillick Here's what you need to know about 73. capacity and The Gillick case. 2022; 74. Joffe S, Fernandez C V., Pentz RD, Ungar DR, Mathew NA, Turner CW, et al. Involving children with cancer in decision-making about research participation. Journal of Pediatrics. 2006;149(6). 75. Mårtenson EK, Fägerskiöld AM. A review of children's decision-making competence in health care. J Clin Nurs. 2008;17(23):3131-41. 76. Department for Constitutional Affairs. Mental Capactity Act 2005: Code of Practice. Mental Capactity Act 2005: Code of Practice. 2007;1–301. 77. Lea S, Gibson F, Taylor RM. Holistic Competence": How Is it Developed, Shared, and Shaped by Health Care Professionals Caring for Adolescents and Young Adults with Cancer? J Adolesc Young Adult Oncol. 2021;10(5):503-11. 78. Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer. 2016;63(8):1423-30. 79. Essig S, Steiner C, Kühne T, Kremens B, Langewitz W, Kiss A. Communication Skills Training for Professionals Working with Adolescent Patients with Cancer Based on Participants' Needs: A Pilot. https://home.liebertpub.com/jayao. 2019 Jun 4;8(3):354-62. 80. Coad J, Smith J, Pontin D, Gibson F. Consult, Negotiate, and Involve: Evaluation of an Advanced Communication Skills Program for Health Care Professionals. Journal of Pediatric Oncology Nursing. 2018 Jul 1;35(4):296–307. 81. Ruhe KM, Badarau DO, Brazzola P, Hengartner H, Elger BS, Wangmo T, et al. Participation in pediatric oncology: views of child and adolescent patients. Psychooncology. 2016;25(9):1036-42. 82. Blackmore A, Kasfiki EV, Purva M. Simulation-based education to improve communication skills: A systematic review and identification of current best practice. BMJ Simul Technol Enhanc Learn. 2018;4(4):159-64. 83. Mahoney P, Macfarlane S, Ajjawi R. A qualitative synthesis of video feedback in higher education. Teaching in Higher Education [Internet]. 2019;24(2):157-79. Available from: https://doi.org/10.1080/13562517.2018.1471457

2	
2	
3	
4	
5	
6	
-	
3 4 5 6 7 8 9	
8	
9	
10	
11	
12	
13	
14	
15	
13 14 15 16	
16	
17	
18	
19	
20	
20	
21	
22	
23	
24	
27	
25	
26	
27	
28	
20	
29	
20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38	
31	
32	
22	
24	
34	
35	
36	
37	
20	
39	
40	
41	
42	
43	
44	
45	
46	
47	
48	
49	
50	
E 1	
51	
52	
53	
54	
55	
55	
56	
57	
58	
59	
60	
7 W J	

84. Smith S, Mooney S, Cable M, Taylor RM. THE BLUEPRINT OF CARE for teenagers and young adults with cancer Second edition. 2016; Available from: https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition. pdf

to beet terms only



For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Pag	e 25 of 60				E	BMJ Open	6/bmjopen-2023-08 octed by copyright,	
1 2 3	First author			Study Type - analysis method	Table 2. S	ummary of Articles	cted by copyright, inc Key findings	
4	(year)	Title	Setting	Data collection	Focus	Participant Characteristics	Key findings	WoE Score
5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25	Ananth (2021)	A Stakeholder- Driven Qualitative Study to Define High Quality End- Of-Life Care for Children with Cancer	USA Multicentre	Qualitative - <u>thematic analysis</u> Semi-structured interviews and focus groups.	To explore end of life care (EOLC) priorities for children with cancer and their families.	 54 participants: 10 AYACs (age range: 17-23 years) 25 parents (including 12 bereaved parents) 19 healthcare professionals 	Important to have firegt communication v child or young person regarding do making. Interdisciplinary correction of the teams for high quality for the teams of the team of team o	ecision- s is vital nuity of nily and
	Bahrami (2017)	Information Sharing Challenges Between Adolescents with Cancer, their Parents and Health Care Providers: A Qualitative Study	Iran Single centre	Qualitative descriptive- exploratory study - grounded theory analysis Semi-structured interviews.	Information sharing between AYACs, parents and health professionals.	33 participants: 12 AYACs (age range at interview: 15-20 years, within 1 year of diagnosis) 6 supporters 6 healthcare professionals	AYACs feel they are scluded from infor sharing sessions of seen parents and her professionals. The second second second second inferior' sources. Parents were often the second s	althcare iliation, on from rmation atrolling ats may ffective althcare
26 27 28 29 30 31 32 33 34 35 36 37 38 39	Barakat (2014)	A Qualitative Study of Phase III Cancer Clinical Trial Enrollment Decision Making Perspectives from AYAC, Caregivers and Providers		Qualitative - <u>thematic analysis</u> Semi-structured interviews.	Clinical trial enrollment.	40 participants: 13 AYACs (age range: 15- 21 years) 16 supporters 11 healthcare professionals	Four patterns of tecision-making identified: 1. AYAC abdicates to caregiver, 2. Caregiver based and AYAC approved, 3. Collaborative, 4. AYAC in charge of tecision-making. Caregivers perceited AYAC to be in ch decision making to be abdicates to care the most common form of decision making Distress and poor chealth limited involvement in the decision. Developmental and emotional maturity face	eas the er" was s. AYAC
40 41 42 43 44 45 46 47				For peer review	/ only - http://bmjc	pen.bmj.com/site/about/gui	delines.xhtml	1

					I	3MJ Open	6/bmjopen-2	Page 26 of 60
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	Barlevy (2019)	Oncofertility decision making: findings from Israeli adolescents and parents	Israel Single centre	Qualitative- thematic analysis semi-structured interviews	To understand adolescent oncofertilty decision making in Israel, from perspectives of parents and adolescents	35 participants 16 AYACs (age range 12- 16 years) 19 parents	As in other cultural contexts, Israeli adolescents and parents demonstrate multifaceted decision making, will respect to oncofertility. A significant and g from this study suggests that health professional shy from discussing gosthumous planning of cryopreserved of materials with adolescent cancer patients and heir parents. 5 out of 16 AYAs felt that the decision was not theirs and that it was insteaded parents' or the pysicians' to make. Some gost felt that the decision was made by the ging an - explicit or implicit recommendation of the decisional regret expressed by an bers of the dyad.	Medium
16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42	Cicero- Oneto (2017)	Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study	Mexico Multicentre	Qualitative - <u>thematic analysis</u> Semi-structured interviews	futility	32 Participants 13 paediatric oncologists 13 parents or primary carers 6 AYACs (age range 13-18 years)	Four themes were Bioma fied 1. flow of Forma fied 1. flow of Forma fied 2. disclosure Forma fied 3. decision Forma forgnosis 3. decision Forma forgnosis 5. decision Forma forgnosis 5. decision Forma forgnosis 5. decision Forma forgnosis 6. decision Forma forgnosis 7. decision Forma fo	Medium
43 44 45 46 47				For peer review	v only - http://bmjc	open.bmj.com/site/about/gui	delines.xhtml de	2

Pag	e 27 of 60	BMJ Open by company co								
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	Darabos (2021)	Cancer Related Decision Making Among AYAC, Care Givers and Oncology Providers	USA Single centre	Qualitative – content analysis with hypothesis coding Semi-structured interviews.	Decision-making and triadic communication	30 Participants: 11 AYACs (age range: 15- 24 years) 11 supporters 8 healthcare professionals	 Four decision-making batterns were identified: AYAC driven Collaborative Deferral to participate Provider-based A&A/Caregiver-approved. Collaborative decision-making and AYAC-driven decisions were most commonly described. There was recognition that some decision-making was day context dependent. AYACs were make are than treatment related decisions. AYACs and care that treatment related decisions were most common that reatment related decisions. AYACs and care that treatment related decisions. AYACs and care that treatment related decisions. Direct and honest common that problem-based comparison that some common that problem the section of the sectio	High		
21 22 23 24 25 26 27 28 29 30	Davies (2019)	'Life then', 'life interrupted', 'life reclaimed': the fluctuation of agency in teenagers and young adults with cancer	UK single centre	qualitative - thematic analysis case studies - multiple interviews	Fluctuation of agency across time and between cases	22 participants 5 AYACs (16-24 years) 5 parents carers (2 fathers, 3 mothers, 1 couple), 5 healthcare professionals (4 nurses and 1 oncology consultant) 5 other supporters (1 boyfriend, 1 girlfriend, 1 aunt, 2 friends)	Agency fluctuates vor time within cases and between cases. Agency can fluctuate between personal, proxy and collective perspectives. Personal agency is nigh prior to diagnosis, decreases after diagnosis and is reclaimed after treatment.	Medium		
31 32 33 34 35 36 37 38 39	Ellis (2016)	Fertility concerns among child and adolescent survivors and parents: a qualitative study	Australia single centre	Qualitative semi-structured telephone interviews	recently off treatment and	97 participants from 45 families 19 AYACs (age range 7-17 at diagnosis, mean age 13.3) 44 mothers and 34 fathers	reported and conversations about fertility were frequently interrupted to discuss illness and treatment. These fertility discussions were not then continues once the AYAC was off treatment	Medium		
40 41 42 43 44 45 46 47				For peer review	r only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml de	3		

					E	3MJ Open	6/bmjopen	Page 28 of 6
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	Essig (2016)	Improving Communication in Adolescent Cancer Care: A Multiperspective Study	Germany, Austria, Switzerland Number of centres not stated	Qualitative – inductive thematic analysis Focus groups.	Explore effective communication with AYACs for communication skills training.	54 participants: 16 AYACs (age range: 13- 19 years) 8 parents 30 healthcare professionals	 Decision-making ycarb cause conflict when adolescents are pognitively mature but legally lack the ability in more decisions. AYACs feel a loss of autonomy. Age-appropriate environments are important. Effective communication differs depending on the type of professional tie., doctor vs nurse) Adolescents negative affect communication when: They are indifferent. There prioring on the type on flict with treatment They conflict with treatment They conflict with treatment They conflict with treatment They don't take the adolescent in an age-appropriate with a dolescent seriously. They give to professional tien. 	Medium
20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42	Fern (2013)	The Art of Age- Appropriate Care	UK Number of centres not stated	Qualitative – <u>thematic analysis</u> Peer-to-peer interviews, field notes and spider diagrams from focus groups.	Review a conceptual model of AYACs' cancer care experiences.	11 participants: 11 AYACs (age range: 13- 25 years)	Young people messive kept at the centre of interactions in recognition of their stated needs: 1. Engagemen ≥ 2. Individually aileged information. 3. Support unprovided by parents/family. AYACs did not went information to be directed at parents but at them. AYACs found it embarrassing when sensitive information was revealed in the presence of their parents. Lack of continuity of healthcare professionals leads to AYACs dussatisfaction and irritation having to repeat their cancer story. gies at Agence Bibliographique delines.xhtml	Medium
43 44 45 46				For peer review	v only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml e	4

Page	29	of	60
------	----	----	----

Pag	je 29 of 60	BMJ Open d by cop									
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	Fourneret (2018)	Breaking bad news about cancer to adolescents and young adults: the french experience	France Multicentre	qualitative semi- structured interviews	Explore the effectiveness and implementation of the French announcement protocol in 7 french paediatric oncology centres	90 participants 27 AYACs (21 were 14-17 and 6 were 18-22) 30 parents (16 mothers, 5 fathers, 9 parents together at the appointment) 33 healthcare professionals	 Parents and AYACs has e different needs - both of which need to be accounted for when breaking bad news. Awkwild and premature announcements were noted The announcement consultation – young patients were never algine when informed of their disease; either with parents (n=31) (parents were informed before the child 10 out of 31 times - this was motivated by a compassionate goal of preparing the parents (n=31) (parents were informed before the child 10 out of 31 times - this was motivated by a compassionate goal of preparing the parents is broken) or close family member of the parents is broken) or close family member of the parent is broken or girlfriend (n=2). Some parents with the parent of and some AYACs preferred parent for the discussed - but the key quality needed in the parent of the	Medium			
21 22 23 24 25 26 27 28 29 30 31	Frederick (2018)	Adolescent Patient Involvement in Discussions About Relapsed or Refractory Cancer with Oncology Clinicians.	USA Single centre	Qualitative – <u>content analysis</u> Audiotaped conversations.	Breaking bad news of relapsed or refractory cancer.	75 participants: 11 AYACs (age range: 12.6-17.5 years) 44 supporters 20 healthcare professionals	Adolescent patiens "involvement in conversations about relapsed refeactory cancer is limited. Adolescents were accompanied by one (27%) two (64%) or more and wo (18%) family members in the discussion Adolescents spoke 3.2% of words compared to 66.9% clinicians and 30% parents. No conversations included instances in which the clinicians' as feed of adolescents for their communication preferences or desired role in decision-making	High			
31 32 33 34 35 36 37 38 39 40 41	Friebert (2020)	Congruence gaps between adolescents with cancer and their families regarding values, goals and beliefs about end- of-life care	USA multicentre	Qualitative cross- sectional study	End of life care	<u>126 participants:</u> 126 parent-AYAC dyads AYACs (14-20 years, mean age 16.9)	Young people warked cirly information (86%) but only 39% fanglies, knew this. Families understanding of where was important to their adolescents when dealing with their own dying was excellent for wanting bonest answers from their physician and under anding treatment choices but poor for dying on natural death and being off machines that extend life, if dying. Parents do not know what AYACs want at the end of life	Low			
42 43 44 45 46 47				For peer review	only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml de	5			

					В	MJ Open	cted by c	ied: emotional care needs;	Page 30 of 6
$1 \\ 2 \\ 3 \\ 4 \\ 5 \\ 6 \\ 7 \\ 8 \\ 9 \\ 10 \\ 11 \\ 12 \\ 13 \\ 14 \\ 15 \\ 16 \\ 17 \\ 18 \\ 19 \\ 20 \\ 21 \\ 23 \\ 24 \\ 25 \\ 26 \\ 27 \\ 28 \\ 29 \\ 30 \\ 31 \\ 32 \\ 33 \\ 34 \\ 35 \\ 36 \\ 37 \\ 38 \\ 39 \\ 39 \\ 30 \\ 31 \\ 31 \\ 31 \\ 31 \\ 31 \\ 31 \\ 31$	Glackin (2023)	Experiences of Oncofertility Decision-Making and Care in a National Sample of Adolescent and Young Adult Cancer Patients and Parents	Australasia multicentre	Qualitative – cross sectional survey. Reflexive thematic analysis	Oncofertility decision making	210 participants: 99 AYACs (age range 15- 25 years) 111 parents 41 AYAC parent dyads from the same family	parent-AYA dypami agendcy; decision including values reflections on one of Both AYAC and pare AYA autonomyon fe but many AYA app in providing support the process. Healthcare profession autonomously decision making, we	s including autonomy and making considerations and practicalities; and	Low
	Hart (2020)	The Challenges of Making Informed Decisions About Treatment and Trial Participation Following Cancer: A Qualitative Study with Adolescent and Young Adults with Cancer and Care Givers	UK Multicentre	Qualitative – <u>thematic analysis</u> Semi-structured interviews.	Shared decision- making – primary treatment and trial participation – at diagnosis.	33 participants: 18 AYACs (age range: 16- 24 years) 15 supporters	diagnosis, exact and emotions, and the fact some AYACs discrete topics which we for There are limited of making at diagfosis this when they avere emotions/symptoms For trial enrollment, themselves to be stee of the healthcage	ons for 'real' decision- However, many preferred already overwhelmed by	Medium
	Hong (2016)	Care Partnerships: toward technology to support teen's participation in their health care	US multicentre	Qualitative semi-structured interviews and observations	To investigate how technology can support the partnerships between AYACs, parents and clinicians when the AYAC is experiencing complex chronic illness	33 interviews. 15 with AYACs (13 of whom had cancer. age range 13-17) 15 parents (10 mothers, 1 fathers, 1 aunt and 2 fathers and mothers together) 8 clinician caregivers	 communigating information managing responses Time alone with clinical protectionism or the ne eachother" was preval 	participation in their care emotionally sensitive ysical and emotional ans was important. Mutual d to "emotionally protect it.	Medium
40 41 42 43 44 45 46 47				For peer review	only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml e		6

Pag	Page 31 of 60 BMJ Ope					BMJ Open	cted by	6/bmjop	
1 2 3 4 5 6 7 8 9 10 11	Ingersgaard (2018)	A qualitative study on decision-making on Phase III randomized clinical trial participation in paediatric oncology: adolescents' and parents' perspectives and preferences	Denmark	qualitative exploratory study - in-depth semi- structured interviews with thematic analysis	To explore patients' and AYACs' motivs for accepting/ declining participation in the AL2008 trial and adolescents' involvement in decision making	 <u>16 participants</u> 5 AYACs (age range 12-16) 6 parents of AYACs 5 parents of children aged 3-10 years with cancer 	 and the second se	p erceptions of cure contra 9 as <u>a</u> active participants in the	Low
12 13 14 15 16 17 18 19 20 21 22 23 24	Jacobs (2015)	Adolescent end of life preferences and congruence with their parents' preferences: results of a survey of adolescents with cancer	Norway	Qualitative three sessions of dyadic interviews	To explore AYACs' end of life preferences and to assess the congruence of these preferences with the parents' beliefs	17 adolescent/ family dyads 17 AYACs (age range 14- 21, 71% under 18)	discussing EOL talk about EOL EOL. There were between adoles important facet were not know the important preferences and understand the AYACs had never	concer were comfortable the majority preferred to the majority preferr	Low
25 26 27 28 29 30 31 32 33 34 35 36 37 38						<i>h</i>	ng, and similar technologies.	n.bmj.com/ on June 13, 2025 at	
 39 40 41 42 43 44 45 46 47 				For peer review	only - http://bmjo	pen.bmj.com/site/about/guic	delines.xhtml	Agence Bibliographique de l	7

					E	SMJ Open		Sof emotional concerns	Page 32 of 6
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	Korsvold (2017)	A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members	Norway	exploratory mixed methods study audio recorded consultations	To investigate the emotional concerns of AYACs at the time of diagnosis and how to quantify how healthcare professionals respond	18 participants 9 AYACs (age range 13-23) Present with mother (n=9), father (n=1), sister (n=1) or mother and father (n=2)	 expressed by A members durin diagnosis: 1) side effect 2) "what hap aspects", 3) fear 4) sadness AYA patients an emotional concept by providing in aspects of the however, an exponse was the followed by an response (n=7) To make patients attention to the approximation of the patients attention to the patients attention attention attention at the patients at the patients attention at the patients attention at the patients attention at the patients attention at the patients at the pa	A patients and their family consultations for a cancer s/late effects or infertility, bens in the near future/practical	
21 22 23 24 25 26 27 28 29 30 31 32 33	Lyon (2013)	Family-Centered Advance Care Planning for Teens With Cancer	USA single centre	Qualitative a randomised control pilot study	To examine the efficacy of family-centres ACP	30 dyads mean age of AYACs 16 17 were randomised to intervention and 13 were randomised to control 87% of surrogates were biological parents and were female	The model (ACP) compared to the so it is key. Th	creased congruence in the triad control standard of care group- family centres ACP AYACs note informed that the control	Low
34 35 36 37 38 39 40 41 42 43 44 45 46 47				For peer review	/ only - http://bmjo	pen.bmj.com/site/about/guid		25 at Agence Bibliographique de l	8

Pag	je 33 of 60				E	BMJ Open	6/bmjopen-; cted by cop	
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	Mack (2019)	Adolescent and Young Adult Cancer Patients' Experiences with Treatment Decision-Making	USA Single Centre	Quantitative – multivariate analysis, logistic regression Surveys at diagnosis, 4 and 12 months.	Treatment decision-making	203 participants: 203 AYACs (age range: 15- 29 years)	A majority of $AYABCS (58\%)$ want to share	Medium
21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40	Mobley (2023)	Clinical Trial Participation: A qualitative study of Adolescents and Younger Adults Recently Diagnosed with Cancer	USA	Qualitative Grounded theory analysis of semi- structured interviews	Clinical trial participation	<u>9 participants:</u> 9 AYACs (age range 16-20)	Consent encompasted the first discussion of CCT. Patients reflected positive and negative effects of timing, decisional ole, and emotional impact. Informing participation involved decision-making processes, specific knowledge, understanding and external influence. Participant relationships emphasized the importance of communication and relationships with providers and parents. Patient determinants centered on motives from different perspectives, pre-conceived attitudes, and understanding of CCTs.	Medium
40 41 42 43 44 45 46 47				For peer review	r only - http://bmjc	open.bmj.com/site/about/gui	Agence Bibliographique de I	9

					E	3MJ Open	Greed by copyress themes 202	Page 34 of 6
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	Olsavsky (2021)	Family communication about fertility preservation in adolescent males newly diagnosed with cancer	USA	Qualitative	To explore fertility preservation communication among mothers, fathers and their male adolescents newly diagnosed with cancer.	87 participants: 33 AYAC aged 12-25 32 mothers 22 fathers Representing 37 families in total.	 Reliance of health care team and social support network to facilitate FP decisions (noted just be parents), withholding parental opinion and deferring the decision to the adolescent, ease of computing attain, communication for iters and facilitators, not being provide the parental opinion of the decision of FP conversations. not being provide the parenthold (or grandparent parents). consideration of the parenthold, sperm banking the parenthold, sperm banking the parenthold options. 	5 5 7
20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 46 47 47 47 47 47 47 47 47 47 47						open.bmj.com/site/about/guide	13, 2025 at Agence Bibliographique nologies.	10

Page 35 of 6	0		BMJ Open	A cancer experience by copyes the potential for Low	
1 Patters 2 (2012) 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26	n The Unmet Needs Australasia of Emerging Adults With a Cancer Diagnosis	to the limited research base a inform our understanding the needs of emerging adult with a diagnosi of cancer from developmental perspective tha appreciates the key transitiona tasks of emerging adulthood	s s a t	 A cancer experience of the second of the four requirements for achievement of adulthood. The needs of the second of the second of the four requirements of adulthood. The needs of the second of the se	
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47		For peer review only - http://br		Le	11

					BMJ Open	Themes of Support included; presence,	Page 36
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	Pennant (2020)	The Role of Social USA Support in Adolescent/Young Adults Coping with Cancer Treatment	Qualitative	To explore specific actions that help AYAC and what behaviours they want from their social supports	20 Participants: 10 AYAC ages 15-26, mean age 18.9 years 10 parents	 Themes of yuppert included; presence, distraction, positive attitude, maintaining AYAC autonomy, communication and advocacy. Mothers were the most noted family support. AYAC patients can differ in their preferences throughout treatment and this can, at times, appear contradicery. AYACs appear contradicery. They express the days for privacy, but also value physical presence and communication Parents must oscillate between being involved in and catering the autonomy. The findings interaction with and catering the presence and communication with AYAC patients appear contradicery appear contradicery. The findings interaction communication with AYAC patients appear contradicery appear contradicery. 	
24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40	Pyke- Grimm (2020)	3 Dimensions of USA Treatment Decision Multicentre Making in Adolescents and Young Adults with Cancer.	Qualitative – ethnographic Semi-structured interviews, field notes.	Explore the preferences of AYACs for involvement in healthcare decisions	<u>16 participants:</u> 16 AYACs (age range: 14.7-20 years)	Emotions around idia nosis inhibit information receptiveness and ability to engage in treatment decisions (especially important decisions). Initially AYACs struggle with the jargon and plethora of medical terms which are being used. They have limited knowledge which limits their questions, this increases over time. The importance of decisions differs from one AYACs to the next Also, some decisions are seen as having only one 'real' option. AYACs engaged on moor decisions much earlier in their treatment, and some began engaging in more important decisions later in treatment. AYACs could adopte an active (sole decision maker), collaborative (with healthcare professionals/supporters) or passive (healthcare professionals/supporters as decision makers) role.	
41 42 43 44 45 46			For peer reviev	v only - http://bmjo	open.bmj.com/site/about/gui	delines.xhtml d	12

Pag	e 37 of 60				E	SMJ Open	6/bmjopen-ź	
1 2 3 4 5 6 7 8 9 10 11 12 13 14	Pyke- Grimm (2022)	Day-to-Day Decision Making by Adolescents and Young Adults with Cancer	USA	Qualitative Interpretive focused ethnography within the socio- logic tradition, informed by symbolic interactionism	To explore involvement of AYAs with cancer in day-to- day decisions affected by their cancer and treatment.	<u>16 Participants:</u> 16 AYAC aged 15-20 (at time of interview - with an average of one year from diagnosis)	 Factors influence the providement of AYAC in decision making such as the type of decision, the point in the cancer bourney. They want to be involved. Four day to day decision making categories were identified: mendiating relationships. Parents were often present and staying strong was a recurring the second se	Medium
15 16 17 18 19 20 21 22 23 24 25 26 27 28 29	Sawyer (2019)	Developmentally Appropriate Care for Adolescents and Young Adults with Cancer: How Well is Australia Doing?	Australasia Multicentre	Quantitative – <u>Chi-squared and</u> <u>Fisher's exact test</u> Single time point survey.	Australia.	196 participants: 196 AYACs (age range: 15- 25 years)	>90% of AYACs degree ted positive responses for	Low
30 31 32 33 34 35 36 37 38 39 40 41 42							delines.xhtml de lided.	13
43 44 45 46 47				For peer review	only - http://bmjo	pen.bmj.com/site/about/guid	delines.xhtml de	13

						BMJ Open	Building relation	Page 3
$\begin{array}{c}1\\2\\3\\4\\5\\6\\7\\8\\9\\10\\11\\12\\13\\14\\15\\16\\17\\18\\19\\20\\21\\22\\23\\24\\25\\26\\27\\28\\29\\30\\31\\32\\33\\4\\35\end{array}$	Sisk (2022)	Interdependent Functions of Communication with Adolescents and Young Adults in Oncology	USA Multicentre	Qualitative – <u>content analysis</u> Semi-structured interviews.	Define communication functions from perspective of AYACs.	37 participants: 37 AYACs (age range: 12- 20 years; mean: 16 years)	competence, remaining, empathy, and showing care and concern. Ween clinicians demonstrated these attributes AYACs described feelings of trust in the clinicians ability and intent to care for them. Exchanging information: providing accurate and transparent information that was adapted to	High
36 37 38 39 40 41 42 43 44 45 46 47				For peer review	v only - http://bmjo	open.bmj.com/site/about/gui	Agence Bibliographique delines.xhtml	14

¹ Sisk (2022) Co-management of USA	Qualitative				
 communication and care in adolescent and young adult oncology 	Semi-structured interviews	Study aimed to learn how AYAs and parents shared and delegated roles in communication and care during and after treatment for cancer	37 Participants: 37 AYAC aged 12-24 Mean age 16 years	There are 6 roles that AYAC co-manage with parents; managing information, managing social and emotional needs, managing health, advocacy and empowerment, making decisions and managing legisters. Five factors that influence AYAC roles in communication overe. AYAC agency Clinical encouragement Emotional and physical well-being Personality, prefer the and values Insights and skills encourage. There are multiple bore fits of engagement of the adolescent.	Medium
16Son (2023)FamilyKorea17Communication18About Cancer19in Korea: A Dyadic20Analysis of21Parent-Adolescent22Conversation232425262728	Qualitative descriptive study	The aim was to understand communication experiences of Korean AYAC and their parents in the context of young adult cancer.	14 participants: 7 AYAC (ages 14-19 years) and 7 parent pairs	The main theme was experience the same thing but see it differently" along with three subthemes. Different expectations for parent-adolescent communication challenges and limited sharing and progress in the conversation. This study offers insights into different communication expectations and preferences between Korean acolescents and parents, and reasons for communication challenges, while explasizing the individualized assessment of parent-adolescent communication between them.	Medium
30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46	For peer review	only - http://bmjo	pen.bmj.com/site/about/guio	r technologies. delines.xhtml	15

					В	MJ Open	6/bmjopen	Page 40 of 6
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	Viola (2018)	Problem-solving skills, parent– adolescent communication, dyadic functioning, and distress among adolescents with cancer	USA	Mixed methods study	The aim was to describe and assess how intrapersonal (i.e., problem-solving ability) and social–ecological factors (i.e., cancer- related communication with parents and parent–adolescent dyadic relationship quality) are associated with adolescent adjustment (i.e., distress).	78 participants: 39 AYAC and 39 parent pairs AYAC 14-20 mean age 16.1 39 Parents - 79.5 % mothers	Better adolescent problem solving skills and better parent problem solving skills were associated with lower adolescent reported similar moderate levels of cancer related communication problems. The most commonly endorsed cancer-related problem was "net taking about what to do if the AYAC got signated to the solving ability and better dyadic function to the solving ability and better dyadic fu	Low
20 21 22 23 24 25	Weaver (2016)	"Being a Good Patient" During Times of Illness as Defined by Adolescent Patients With Cancer	USA	Qualitative - semantic content analysis Semi-structured interviews		40 participants AYAC ages 12-19 Mean age of 15.5 years	The concepts of a second compliance were the primary phases used to describe the good patient role, but always within the context of a relationship. Of note A total of 23 adolescents requested to be interviewed alone with the interviewer (57,6%)	Medium
26 27 28 29 30 31 32 33 34 35 36 37 38 39 40	Weaver (2015)	Adolescents' Preferences for Treatment Decisional Involvement During Their Cancer	USA Multicentre	Qualitative – <u>semantic content</u> <u>analysis</u> Semi-structured interviews.	Investigate AYACs' decision-making preferences and how supports and healthcare professionals can support involvement.	40 participants: 40 AYACs (age range at interview: 12-18.9 years; 0.5-6 months from diagnosis/relapse) NB: 34 AYACs primary diagnosis, 6 AYACs relapse.	AYACs indicate a spectrum of preferred decisional roles with the most common being an actively involved role (65%), although a shared decision-making approach was still valued. AYACs recognized that situational and social contexts might shift their preferred level of involvement in bedical decisions. Although adolescents wanted to be involved in decisions, they also expressed an appreciation of family insight, parena al presence, and clinician guidance. AYACs can retrospectively identify their preferences for inclosion in medical decision- making, and even when preferring involvement, they value the input of trusted others.	Medium
41 42 43 44 45 46				For peer review	v only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml de	16

Pag	Page 41 of 60		B	BMJ Open	cted by co	6/bm joper			
1 2 3 4 5 6 7 8 9 10 11 12	Wu (2021)	Decisional conflicts, anxiety, and perceptions of shared decision- making in cancer treatment trajectory among adolescents with cancer: A longitudinal study	Taiwan	Qualitative. An explanatory mixed method was used, incorporating questionnaires and individual interviews.	To describe the perception on levels of decision-making during cancer treatment for adolescents with cancer and examine the trajectory of their decisional conflict	44 participants: 22 AYAC 11 male and 11 female mean age 15.39 22 Supporters: father n=1 mothers n=12 both n=6 other n=3	Different levels of a making (SDM) were found. Participants experience conflict during a Roles in healthcase direct participants parents decide	rtigipation in shared decision ring the treatment trajectory rock the highest decisional grossis. communication varied from to indirect involvement. ported that doctors and the involvement, ported that doctors and the involvement, reported that doctors and reported that doctors and reported that doctors and reported the involvement, reported the involvement, reported the involvement, reported the involvement and reported the invol	Medium
 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 	al (2018) ¥Age ra				To assess: recall of a fertility discussion, satisfaction with fertility knowledge, and identify factors that may influence recall.	<u>19 participants:</u> 19 AYAC aged 13-18 years and a mean age of 15.6 n which alternative metrics ar ed; RM-ANOVA = repeated r	42% and 52% of AY regarding treating preservation during 63% of AYAC report most of the decision Key Finding - A get reported making recalled 71% of fe who reported and medical decisions.	did not recall discussion elated infertility or fertility ditial treatment planning. that parents made all or whereas 30.8% reported in parents. percentage of AYAC who perint decision with parents reality discussions than those reality made most or all of highlighted.	Medium
44 45 46 47				For peer review	/ only - http://bmjo	pen.bmj.com/site/about/gui	delines.xhtml	que de l	±,

Update – December 2023 Medline

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to December 19, 2023>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or parents/ or fathers/ or mothers/ or spouses/ or caregivers/ or siblings/ or friends/ or legal guardians/ 1148168

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp adolescent/ or exp young adult/) and exp neoplasms/) 337284

3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp communication/ or exp disclosure/ or exp information dissemination/ or exp physician-patient relations/ 6147070

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 13278879

- 5 1 and 2 and 3 and 4 3519
- 6 limit 5 to english language 3399

7 (202211* or 202212* or 2023* or 2024*).dp. or (202211* or 202212* or 2023* or 2024*).ez. or (202211* or 202212* or 2023* or 2024*).ed. or (202211* or 202212* or 2023* or 2024*).ep. 1958643

8 6 and 7 163

Embase

Embase <1974 to 2023 December 19>

1 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp *adolescent/ or exp *young adult/) and exp *neoplasm/) 10359

2 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp *interpersonal communication/ or exp *professional-patient relationship/ or exp *information dissemination/ or exp *conversation/ 7565603

3 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or *parent/ or *father/ or *mother/ or *spouse/ or *caregiver/ or *social worker/ or *sibling/ or *friend/ or *legal guardian/ 1440315

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 16593794

- 5 1 and 2 and 3 and 4 1032
- 6 limit 5 to english language 1010

7 (202211* or 202212* or 2023* or 2024*).dc. or (202211* or 202212* or 2023* or 2024*).dd. or (202211* or 202212* or 2023* or 2024*).dp.2647560

- 8 6 and 7 107
- PsycINFO (via Ebsco)

			Last Run	
#	Query	Limiters/Expanders	Via	Results
		Limiters - Publication Date:	Interface - EBSCOhost Research Databases Search	
S11	S1 AND S2 AND S7 AND S8	20221101- 20241231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Screen - Basic Search Database - APA PsycInfo	238
S10	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Narrow by	Interface - EBSCOhost Research	6,315

		Language: - english Search modes - Boolean/Phrase	Databases Search Screen - Basic Search Database - APA PsycInfo	
		Expanders - Apply equivalent subjects Search modes -	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA	
S9	S1 AND S2 AND S7 AND S8	Boolean/Phrase	PsycInfo Interface - EBSCOhost	6,549
			Research Databases Search Screen -	
	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go	Expanders - Apply equivalent subjects Search modes -	Basic Search Database - APA	
S8	through" or experienc*)	Boolean/Phrase	PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic	3,524,144
		Expanders - Apply equivalent subjects Search modes -	Search Database - APA	
S7	(S5) or (S3)	Boolean/Phrase	PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic Soarch	62,557
S6	S4 AND S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Search Database - APA PsycInfo	62,384

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

S5	((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,384
54	((DE "neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,384
53	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or ("teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 lymphom*) or (teenage* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,072
52	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or DE "communication" OR DE "information dissemination" OR DE "conversation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	2,545,968

	(Parent* or guardian* or mother* or father* or		Interface -	
	partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend*		EBSCOhost Research	
	or teacher* or social worker* or carer* or "third		Databases	
	person" or caregiver* or "care-giver*" or		Search	
	spouse* or chaperone*) OR DE "parents" OR DE		Screen -	
	"mothers" OR DE "fathers" OR DE "spouses" OR		Basic	
	DE "wives" OR DE "husbands" OR DE "siblings"	Expanders - Apply	Search	
	OR DE "significant others" OR DE "social	equivalent subjects	Database -	
	workers" OR DE "guardianship" OR DE	Search modes -	APA	
S1	"caregivers"	Boolean/Phrase	PsycInfo	937,154

CINAHL (via Ebsco)

Wednesday, December 20, 2023 4:07:56 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S3 AND S4	Limiters - Publication Date: 20221101- 20241231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	99
S6	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,152
\$5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,189

S4	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,149,468
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("young people" n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*)) OR ((MH "adolescence+" OR MH "young adult+") AND (MH "neoplasms+"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	61,263
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or MH "communication+" OR MH "discussion" OR MH "conversation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	2,080,061

	OR (MH "Professional-Patient Relations+")		Search Database - CINAHL	
S1	worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR MH "parents" OR	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	567,768

Web of Science Core Collection

Web of Science Search Strategy (v0.1)

Database: Web of Science Core Collection

Entitlements:

- WOS.IC: 1993 to 2023
- WOS.CCR: 1985 to 2023
- WOS.SCI: 1900 to 2023
- WOS.AHCI: 1975 to 2023
- WOS.BHCI: 2008 to 2023
- WOS.BSCI: 2008 to 2023
- WOS.ESCI: 2018 to 2023
- WOS.ISTP: 1990 to 2023
- WOS.SSCI: 1956 to 2023
- WOS.ISSHP: 1990 to 2023

Searches:

1: TS=(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) Date Run: Wed Dec 20 2023 16:03:59 GMT+0000 (Greenwich Mean Time) Results: 2283955

2: TS=("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" near/3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" near/3 cancer) or ("teenage and young adult" near/3 oncology) or (teenage*

2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
14	
15	
16	
17	
18	
19	
20	
12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29	
22	
23 74	
25	
26	
27	
28	
29	
30 21	
31 32	
33	
34	
35	
36	
37	
38 39	
39 40	
41	
42	
43	
44	
45 46	
40 47	
48	
49	
50	
51	
52	
53 54	
55	
56	
57	
58	
59	
60	

near/3 oncology) or (" ("teenage and young a (adolescen* near/3 le near/3 leuk?emia*) or h?ematol*) or (adoles ("young adult" near/3	young people" near, adult" near/3 leuk?e uk?emia*) or ("youn r ("teenage and your cen* near/3 h?emat h?ematol*) or ("tee phom*) or (adolesce	/3 cancer) or ("young p mia*) or (teenage* nea g people" near/3 leuk? ng adult" near/3 h?ema col*) or ("young people nage and young adult" n* near/3 lymphom*)	Pemia*) or ("young adult" htol*) or (teenage* near/3 " near/3 h?ematol*) or
Dec 20 2023 16:04:06			Results: 8540
Dec 20 2025 10.04.00			Results. 8540
or Dialogue* or triad*	or Interview* or cor d Dec 20 2023 16:04:	n* or Interact* or relati nsult* or "decision mak 13 GMT+0000 (Greenv	• •
•	erence or opinion or *)	involvement or occura	perception* or perspective* ance* or feel or "go ed Dec 20 2023 16:04:19
5: #4 AND #3 AND #2	AND #1	Data Pup: W	ed Dec 20 2023 16:04:26
GMT+0000 (Greenwic		Results: 764	eu Det 20 2023 10.04.20
6: #4 AND #3 AND #2	AND #1 and English	(Languages)	Date Run:
Wed Dec 20 2023 16:0	-		Results: 737
7: #4 AND #3 AND #2	-		or 2023 (Publication Years) 39 GMT+0000 (Greenwich
Mean Time)	Results: 132		, ·

AMED via Ovid

AMED (Allied and Complementary Medicine) <1985 to October 2023>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. 14291

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies

BMJ Open

lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. 120

3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. 60609

4 (affect* or effect* or influenc* or resultant or impact* or perception* or

perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 143225

to beet teriew only

5 1 and 2 and 3 and 4 19

6 limit 5 to yr="2005 -Current" 14

First run – November 2022 Medline (via Ovid)

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to November 23, 2022>

1 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "caregiver*" or spouse* or supporter* or support network*).ti,ab. or parents/ or fathers/ or mothers/ or spouses/ or caregivers/ or siblings/ or friends/ or legal guardians/ 1074121

2 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or (young adult adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or (young adult adj3 h?ematol*) or (young adult" adj3 lymphom*) or (young people adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young adult adj3 lymphom*) or (exp adolescent/ or exp young adult/) and exp neoplasms/) 333070

3 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp communication/ or exp disclosure/ or exp information dissemination/ or exp physician-patient relations/ 5715959

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 12406352

- 5 1 and 2 and 3 and 4 3380
- 6 limit 5 to (english language and yr="2005 -Current") 2715

Embase (via Ovid)

Embase <1974 to 2022 November 23>

1 (TYA cancer or TYA oncology or AYA cancer or AYA oncology or (young adult adj3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" adj3 cancer) or ("teenage and young adult" adj3 oncology) or (teenage* adj3 cancer) or (teenage* adj3 oncology) or (adolescen* adj3 cancer) or (adolescen* adj3 oncology) or (young people adj3 cancer) or (young people adj3 oncology) or ("teenage and young adult" adj3 leuk?emia*) or (teenage* adj3 leuk?emia*) or (adolescen* adj3 leuk?emia*) or (young people adj3 leuk?emia*) or (young adult adj3 leuk?emia*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 h?ematol*) or (teenage* adj3 h?ematol*) or (adolescen* adj3 h?ematol*) or (young people adj3 h?ematol*) or (young adult adj3 h?ematol*) or ("teenage and young adult" adj3 lymphom*) or (teenage* adj3 lymphom*) or (adolescen* adj3 lymphom*) or (young people adj3 lymphom*) or (young adult adj3 lymphom*)).ti,ab. or ((exp *adolescent/ or exp *young adult/) and exp *neoplasm/) 9638

2 (Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or decision making).ti,ab. or exp *interpersonal communication/ or exp *professional-patient relationship/ or exp *information dissemination/ or exp *conversation/ 6997005

3 (Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or supporter* or support network*).ti,ab. or *parent/ or *father/ or *mother/ or *spouse/ or *caregiver/ or *social worker/ or *sibling/ or *friend/ or *legal guardian/ 1339977

4 (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*).ti,ab. 15453173

5 1 and 2 and 3 and 4 939

6 limit 5 to (english language and yr="2005 -Current") 873

PsycInfo (via Ebscohost)

#	Query	Limiters/Expanders	Last Run Via	Results
		Limiters - Publication Year: 2005-2022 Expanders - Apply equivalent subjects	Interface - EBSCOhost Research Databases	
S11	S1 AND S2 AND S7 AND S8	Narrow by Language: - english Search modes - Boolean/Phrase	Search Screen - Basic Search Database - APA PsycInfo	1,683
S10	S1 AND S2 AND S7 AND S8	Expanders - Apply equivalent subjects Narrow by Language: - english	Interface - EBSCOhost Research Databases Search Screen - Basic Search	1,981

1					
2					
3			Search modes -	Database - APA	
4			Boolean/Phrase	PsycInfo	
5 6			Dooleany i made	i syenne	
0 7				Interface - EBSCOhost	
8				Research Databases	
9			Expanders - Apply equivalent subjects	Search Screen - Basic Search	
10			Search modes -	Database - APA	
11	S9	S1 AND S2 AND S7 AND S8	Boolean/Phrase	PsycInfo	2,017
12 13			·		·
14				Interface - EBSCOhost	
15		(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or	Expanders - Apply	Research Databases Search Screen - Basic	
16		encounter* or preference or opinion or	equivalent subjects	Search	
17		involvement or occurance* or feel or "go through"	Search modes -	Database - APA	
18	S8	or experienc*)	Boolean/Phrase	PsycInfo	3,366,619
19 20				Interface EDCCOhest	
20				Interface - EBSCOhost Research Databases	
22			Expanders - Apply	Search Screen - Basic	
23			equivalent subjects	Search	
24			Search modes -	Database - APA	
25 26	S7	(S5) or (S3)	Boolean/Phrase	PsycInfo	13,719
20				Interface - EBSCOhost	
28				Research Databases	
29			Expanders - Apply	Search Screen - Basic	
30			equivalent subjects	Search	
31		\sim	Search modes -	Database - APA	
32 33	S6	S4 AND S5	Boolean/Phrase	PsycInfo	13,275
34			Expanders - Apply		
35			equivalent subjects		
36			Narrow by		
37			SubjectAge: -		
38 39			adolescence (13-17 yrs)		
40			Narrow by	Interface - EBSCOhost	
41		((DE "neoplasms" OR DE "Benign Neoplasms" OR	SubjectAge: - young	Research Databases	
42		DE "Breast Neoplasms" OR DE "Endocrine	adulthood (18-29	Search Screen - Basic	
43		Neoplasms" OR DE "Leukemias" OR DE	yrs)	Search	
44	C.L.	"Melanoma" OR DE "Metastasis" OR DE "Nervous	Search modes -	Database - APA	12 275
45 46	S5	System Neoplasms" OR DE "Terminal Cancer"))	Boolean/Phrase	PsycInfo	13,275
47				Interface - EBSCOhost	
48		((DE "neoplasms" OR DE "Benign Neoplasms" OR	_	Research Databases	
49		DE "Breast Neoplasms" OR DE "Endocrine	Expanders - Apply	Search Screen - Basic	
49 50		DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE	equivalent subjects	Search Screen - Basic Search	
49 50 51	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous	equivalent subjects Search modes -	Search Screen - Basic Search Database - APA	58,767
49 50 51 52	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"))	equivalent subjects	Search Screen - Basic Search	58,767
49 50 51	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer"	equivalent subjects Search modes -	Search Screen - Basic Search Database - APA PsycInfo	58,767
49 50 51 52 53 54 55	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or	equivalent subjects Search modes -	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost	58,767
49 50 51 52 53 54 55 56	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or	equivalent subjects Search modes - Boolean/Phrase	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost Research Databases	58,767
49 50 51 52 53 54 55 56 57	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or	equivalent subjects Search modes -	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost	58,767
49 50 51 52 53 54 55 56 57 58	S4	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3	equivalent subjects Search modes - Boolean/Phrase Expanders - Apply	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic	58,767
49 50 51 52 53 54 55 56 57	S4 S3	DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3	equivalent subjects Search modes - Boolean/Phrase Expanders - Apply equivalent subjects	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic Search	58,767 1,864
49 50 51 52 53 54 55 56 57 58 59		DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer")) ("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3	equivalent subjects Search modes - Boolean/Phrase Expanders - Apply equivalent subjects Search modes -	Search Screen - Basic Search Database - APA PsycInfo Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA	

S2

S1

1

(adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3 leuk?emia*) or ("young people" n3 leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("teenage and young adult" n3 lymphom*) or (teenage* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*))

(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or DE "communication" OR DE "information dissemination" OR DE "conversation"

(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR DE "parents" OR DE "mothers" OR DE "fathers" OR DE "spouses" OR DE "wives" OR DE "husbands" OR DE "siblings" OR DE "significant others" OR DE "social workers" OR DE "guardianship" OR DE "caregivers"

	Re
Expanders - Apply	Sea
equivalent subjects	Sea
Search modes -	Da
Boolean/Phrase	Psy

Expanders - Apply

Search modes -

Boolean/Phrase

Interface - EBSCOhost esearch Databases arch Screen - Basic arch atabase - APA ycInfo

Interface - EBSCOhost **Research Databases** Search Screen - Basic equivalent subjects Search Database - APA PsycInfo

2,423,980

894,375

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

CINAHL (via Ebscohost) Accessibility Information and Tips

Print Search History

<u>Acc</u>	IAHL (via Ebscohost) <u>essibility Information and Tips</u> nt Search History Thursday, November 24, 2022 6:21:27	PM		
#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,837

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	
21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44	
45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	

S6	S1 AND S2 AND S3 AND S4	Limiters - Published Date: 20050101- 20221231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,866
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,106
S4	(affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,016,184
\$3	("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" n3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" n3 cancer) or ("teenage and young adult" n3 oncology) or (teenage* n3 cancer) or (teenage* n3 oncology) or (adolescen* n3 cancer) or (adolescen* n3 oncology) or ("young people" n3 cancer) or ("young people" n3 oncology) or ("teenage and young adult" n3 leuk?emia*) or (teenage* n3 leuk?emia*) or (adolescen* n3	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	59,927

	<pre>leuk?emia*) or ("young adult" n3 leuk?emia*) or ("teenage and young adult" n3 h?ematol*) or (teenage* n3 h?ematol*) or (adolescen* n3 h?ematol*) or ("young people" n3 h?ematol*) or ("young adult" n3 h?ematol*) or ("teenage and young adult" n3 lymphom*) or (teenage* n3 lymphom*) or (adolescen* n3 lymphom*) or ("young people" n3 lymphom*) or ("young adult" n3 lymphom*) or ("young adult" n3 lymphom*)) OR ((MH "adolescence+" OR MH "young adult+") AND (MH "neoplasms+"))</pre>			
S2	(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") or MH "communication+" OR MH "discussion" OR MH "conversation" OR (MH "Professional- Patient Relations+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	2,016,086
S1	(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*) OR MH "parents" OR MH "mothers" OR MH "fathers" OR MH "spouses" OR MH "siblings" OR MH "teachers" OR MH "social workers" OR MH "caregivers"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	544,991

Web of Science Core Collection

Web of Science Search Strategy (v0.1)

Database: Web of Science Core Collection

Entitlements:

 - WOS.IC: 1993 to 2022

- WOS.CCR: 1985 to 2022

- WOS.SCI: 1900 to 2022 - WOS.AHCI: 1975 to 2022 - WOS.BHCI: 2008 to 2022 - WOS.BSCI: 2008 to 2022 - WOS.ESCI: 2017 to 2022
- WOS.ISTP: 1990 to 2022
- WOS.SSCI: 1956 to 2022
- WOS.ISSHP: 1990 to 2022

Searches:

1: TS=(Parent* or guardian* or mother* or father* or partner or wife or wives or husband* or boyfriend* or girlfriend* or sibling* or friend* or teacher* or social worker* or carer* or "third person" or caregiver* or "care-giver*" or spouse* or chaperone*)

Results: 2129759

2: TS=("TYA cancer" or "TYA oncology" or "AYA cancer" or "AYA oncology" or ("young adult" near/3 (cancer or oncology or leuk?em* or lymphom* or h?ematol*)) or ("teenage and young adult" near/3 cancer) or ("teenage and young adult" near/3 oncology) or (teenage* near/3 cancer) or (teenage* near/3 oncology) or (adolescen* near/3 cancer) or (adolescen* near/3 cancer) or ("young people" near/3 cancer) or ("young people" near/3 cancer) or ("young people" near/3 oncology) or ("teenage and young adult" near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or (adolescen* near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or ("young adult" near/3 leuk?emia*) or (teenage* near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (teenage* near/3 h?ematol*) or (teenage* near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("young adult" near/3 h?ematol*) or ("young adult" near/3 lymphom*) or (teenage* near/3 lymphom*) or ("young adult" near/3 lymphom*))

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

3: TS=(Communicat* or Disclos* or inform* or Interact* or relationship* or Conversation* or Dialogue* or triad* or Interview* or consult* or "decision making") Results: 11889093

4: TS= (affect* or effect* or influenc* or resultant or impact* or perception* or perspective* or encounter* or preference or opinion or involvement or occurance* or feel or "go through" or experienc*) Results: 24306121

5: #4 AND #3 AND #2 AND #1	Results: 684

6: #4 AND #3 AND #2 AND #1

7: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) Results: 644

Results: 684

Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

8: #4 AND #3 AND #2 AND #1 and 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) and English (Languages) Results: 619

to occurrence of the occurrenc

Page 59 of 60

PRISMA 2020 Checklist

Pag	ge 59 of 60		BMJ Open BMJ Open by op	
1 2	PRISM	MA 20)20 Checklist	
3 4 5	Section and Topic	ltem #	Checklist item	Location where item is reported
б	TITLE			
7	Title	1	Identify the report as a systematic review.	Page 1
8 9	ABSTRACT	1		
9 10	Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
11	INTRODUCTION	1		
12 13	Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pages 3 and 4
14	Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 4
15	METHODS	1		
16	Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 5
17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36	Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to the date when each source was last searched or consulted.	Page 4 and supplemental file
	Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases, registers and websites, including any filters and limits use of the full search strategies for all databases and the full search strategies for all databases	Page 4, Table 1 and supplemental file 1
	Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many regiewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation gois used in the process.	Page 5
	Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each eport, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, detate of automation tools used in the process.	Pages 4 and 5
	Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with act outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which set to collect.	Page 5
		10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, unding sources). Describe any assumptions made about any missing or unclear information.	Page 5
	Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
37	Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 5
38 39	Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 5
40 41		13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing sum	Page 5
42		13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 5
43 44 45		13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 5
45 46				



PRISMA 2020 Checklist

4 Section and Topic Ifen (a) Checklist item Where it is report 13 Describe any methods used to explore possible causes of heterogenelly among study results (e.g. subgroup galays, meta-regression). Pages 5 13 Describe any methods used to explore possible causes of heterogenelly among study results (e.g. subgroup galays, meta-regression). Pages 5 13 Describe any methods used to explore possible causes of the synthesized results. Study results (a) Pages 5 13 Describe any methods used to assess relatintly (or confidence) in the body of evidence for an outcome. Offer any page 5 Not applicat 14 Describe any methods used to assess certaintly (or confidence) in the body of evidence for an outcome. Offer any page 5 Not applicat 15 Describe any methods used to assess certaintly (or confidence) in the body of evidence for an outcome. Offer any page 5 Study assessment Figure 1 In the review, ideally using a flow diagram. Figure 1 Figure 1 Figure 1 In the review, ideally using a flow diagram. Figure 1			BMJ Open de joint	Page 60 of 6
Section and Topic Item # Checklist item Location is room 13e Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup, and study is meta-regression). Pages 5 6 Reporting bias 14 Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup, and study is in the analysis is meta-regression). Not applicat assessment Reporting bias 14 Describe any methods used to assess robustness of the synthesis (arising from reporting assessment Not applicat assessment Certainly assessment 15 Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. Not applicat assessment Study selection 16a Describe the results of the search and selection process, from the number of records identified in the search to in the review, ideally using a flow diagram. Figure 1 page 6 Study selection 16a Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were assumat articles Figure 1 page 6 Study selection 117 Cite each included study and present its characteristics. Table 2 page 6 16 Core studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were astudise Figure 1 pages 6	PRISM	MA 20)20 Checklist	
Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robustness of the synthesized results. Image: Provide a general sensitivity analyses conducted to assess robus				Location where item is reported
Reporting bias assessment 14 Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bias assessment) Not applicat Certainty assessment 15 Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. Status sessment Image: Status sessment Not applicat RESULTS 16a Describe the results of the search and selection process, from the number of records identified in the search difference of the search dif		13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup adalysis, meta-regression).	Pages 5 and 6
Reporting bias assessment 14 Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bias assessment) Not applicat assessment applicat Certainty assessment 15 Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. Image: Control of the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search to the search and selection process, from the number of records identified in the search of the search and selection process, from the number of records identified in the search and selection. Figure 1 Study 17 Cite each included study and present its characteristics. Figure 1 Table 2 summary statistics for each group (where appropriate) and (b) affect estimate and its precision (e.g. onfidence/credible interval), ideally using structured tables or plots. Not Results of (e.g. c		13f		Not applicable
assessment Not applicat Results of individual studies 18 Present assessments of risk of bias for each included study. assessment of each group (where appropriate) and (b) affer applicat Not applicat Results of individual studies 19 For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. 19 For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. 10 Not applicat Results of syntheses 20a For each sult of all investigations of possible causes of heterogeneity. If confidence/credible interval) and measures of taising the theorem (e.g. confidence/credible interval) and measures of taising the theorem (e.g. confidence/credible interval) and measures of taising the theorem (e.g. confidence/credible interval) and measures of theterogeneity. If comparing groups, describe the direction of the effect. Not applicat 20a Present results of all sensitivity analyses conducted to assess the robustness of the synthesis assessed. Not applicat 20b Present results of all investigations of possible causes of heterogeneity. If comparing groups, describe the direction of the effect. Not applicat 20c Present results of all investigations of possible causes of heterogeneity. If comparing groups, describe the direction of the effect. Not applicat 20b Present results of all investigations of possible causes the robustness of the synthesized results.		14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bias b).	Not applicable
RESULTS Results <t< td=""><td></td><td>15</td><td></td><td>Not applicable</td></t<>		15		Not applicable
Study selection 16a Describe the results of the search and selection process, from the number of records identified in the search tight summer of studies included in the review, ideally using a flow diagram. Figure 1 page 6 Study 16b Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were second and explain and the second the summaries the characteristics. Table 2 Risk of bias in 18 Present assessments of risk of bias for each included study. Not applicat applicat applicat and its precision (e.g. applicat applicat and its precision (e.g. applicat appl	RESULTS			
16b Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria, but which were excluded, and explain why they with appear to meet the inclusion criteria. 8 Study characteristics 17 Cite each included study and present its characteristics. Not report appear to meet the inclusion criteria, but which were expropriate) and (b) appeding the estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. Not report applicate 8 Results of synthesis of all statistical syntheses conducted. If meta-analysis was done, present for each the summaring estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. Not applicate applicate applicate applicate applicate applicate applicate applicate	Study selection	16a		
Study characteristics 17 Cite each included study and present its characteristics. 17 Table 2 summar articles pages Risk of bias in studies 18 Present assessments of risk of bias for each included study. Not report pages Results of individual studies 19 For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) agefficit estimate and its precision syntheses Not applicat 20a For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. Not applicat 20b Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summarial estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. Not applicat 20b Present results of all investigations of possible causes of heterogeneity among study results. Of confidence/credible interval) and measures of statistical heterogeneity among study results. Of confidence/credible interval) Not applicat 20d Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. Not applicat 20d Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. Not applicat 20c Present assessments of certainty (or confidence) in t		16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they was been cluded.	Figure 1 page 6
Risk of bias in studies18Present assessments of risk of bias for each included study.Not repoResults of individual studies19For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) agetficit estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.Not applicatResults of syntheses20aFor each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.Image: structured tables or plots.Not applicat20bPresent results of all statistical syntheses conducted. If meta-analysis was done, present for each the summarg estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.Not applicat20cPresent results of all investigations of possible causes of heterogeneity among study results.Image: structure of statistical estimate and its precision (e.g. applicatNot applicat20dPresent results of all sensitivity analyses conducted to assess the robustness of the synthesized results.Image: structure of str	· · · ·	17	Cite each included study and present its characteristics.	
Results of individual studies 19 For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) affective stimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. Not applicat Results of syntheses 20a For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. intervent of the effect. Not applicat 20b Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summarg estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. Not applicat 20c Present results of all investigations of possible causes of heterogeneity among study results. or confidence/credible interval of all sensitivity analyses conducted to assess the robustness of the synthesized results. or confidence/credible interval of all sensitivity analyses conducted to assess the robustness of the synthesized results. or confidence/credible interval of all sensitivity analyses conducted to assess the robustness of the synthesis assessed. Not applicat Reporting biases 21 Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. meta-applicat Discussion 23a Provide a general interpretation of the results in the context of other evidence. or or Discussion 23a		18	Present assessments of risk of bias for each included study.	Not reported
Results of syntheses 20a For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. Image: Sintheses Not applicate of		19		Not applicable
LosLo		20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Not applicable
Interview		20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summare estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Not applicable
Zod Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. application Reporting biases 21 Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. Not application Certainty of evidence 22 Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. Bio DISCUSSION 23a Provide a general interpretation of the results in the context of other evidence. Bio Pages 1		20c	Present results of all investigations of possible causes of heterogeneity among study results.	Not applicable
Reporting blases 21 Present assessments of risk of blas due to missing results (ansing nom reporting blases) for each synthesis assessed. application Certainty of evidence 22 Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. B Not application DISCUSSION 23a Provide a general interpretation of the results in the context of other evidence. B Pages 1		20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable
Certainty of evidence 22 Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. Image: Certainty of evidence <	Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis asses	Not applicable
DISCUSSION Discussion 23a Provide a general interpretation of the results in the context of other evidence. 원 Pages 1		22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not applicable
Discussion 23a Provide a general interpretation of the results in the context of other evidence.	DISCUSSION			
3 and 11		23a	Provide a general interpretation of the results in the context of other evidence.	Pages 10 and 11
23b Discuss any limitations of the evidence included in the review. For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml For peer review only - http://bmjopen.bmjopeer review only - http://bmjopen.bmj.com/site/about/guidelines.xh		23b		Pages 11 and 12

PRISMA 2020 Checklist

Pag	ge 61 of 60		BMJ Open By op	
1 2				
3 4 5	Section and Topic	ltem #	Checklist item	Location where item is reported
6 7		23c	Discuss any limitations of the review processes used.	Pages 11 and 12
8		23d	Discuss implications of the results for practice, policy, and future research.	Page 12
9 10	OTHER INFORMA	TION		
10	Registration and	24a	Provide registration information for the review, including register name and registration number, or state that the second was not register	red. Page 3
12 13	protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Supplemental file
14		24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not appliable
15	Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the eview.	Page 13
16 17 18	Competing interests	26	Declare any competing interests of review authors.	Page 13
19 20 21	Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms are a extracted from in studies; data used for all analyses; analytic code; any other materials used in the review.	cluded Page 13
23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	From: Page MJ, McKe	nzie JE, E	Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic operation of the provide statement or grant similar technologies. For more information, visit: http://www.prisma-statement.org/	:n71. doi: 10.1136/bmj.n71