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

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ABSTRACT

Objectives Clinical communication needs of teenagers and young adults with cancer (TYACs) 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? and (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 8480 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 TYACs' care is common, complex and dynamic. Due to the degree of challenge and nuances raised, healthcare professionals need further training on effective triadic communication.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ 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 UK teenagers and young adults with cancer (TYACs) age range and not the broader age used elsewhere, so the conclusions are applicable to younger adults, up to age 24 only and not necessarily the age of young adulthood used in some countries (between 29 and 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 2500 young people in the UK are diagnosed with cancer each year, which is the leading cause of non-traumatic death in young people in the USA 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 among 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 insights 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 TYACs' consultations.[11] As a commonly occurring form of communication in the care of TYACs, 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 communication and decision-making in adults[19] and one review of doctor–parent–child communication.[20] While 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?

Box 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, teenagers and young adults with cancer.

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 Improving Outcomes Guidance, the guidance document underpinning TYAC services in England.[2] The review protocol was prospectively registered with PROSPERO. 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 (IK). Keywords were generated across five strands detailed in box 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 (online supplemental file 1).

Database searches were compiled and de-duplicated in Mendeley, abstracts were screened in Rayyan by two researchers (DJC and LAMS), and 172 full articles were read by three researchers (LAMS, DJC and RMT) 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 (EC and DJC) 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. DJC and EC explored heterogeneity across the studies. The integration of results from studies using different methods and epistemological positions was supported by LAMS and RMT, 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 8480 studies were identified in the search, of which 36 fulfilled the inclusion criteria (figure 1). The included articles are summarised in online supplemental table 2.

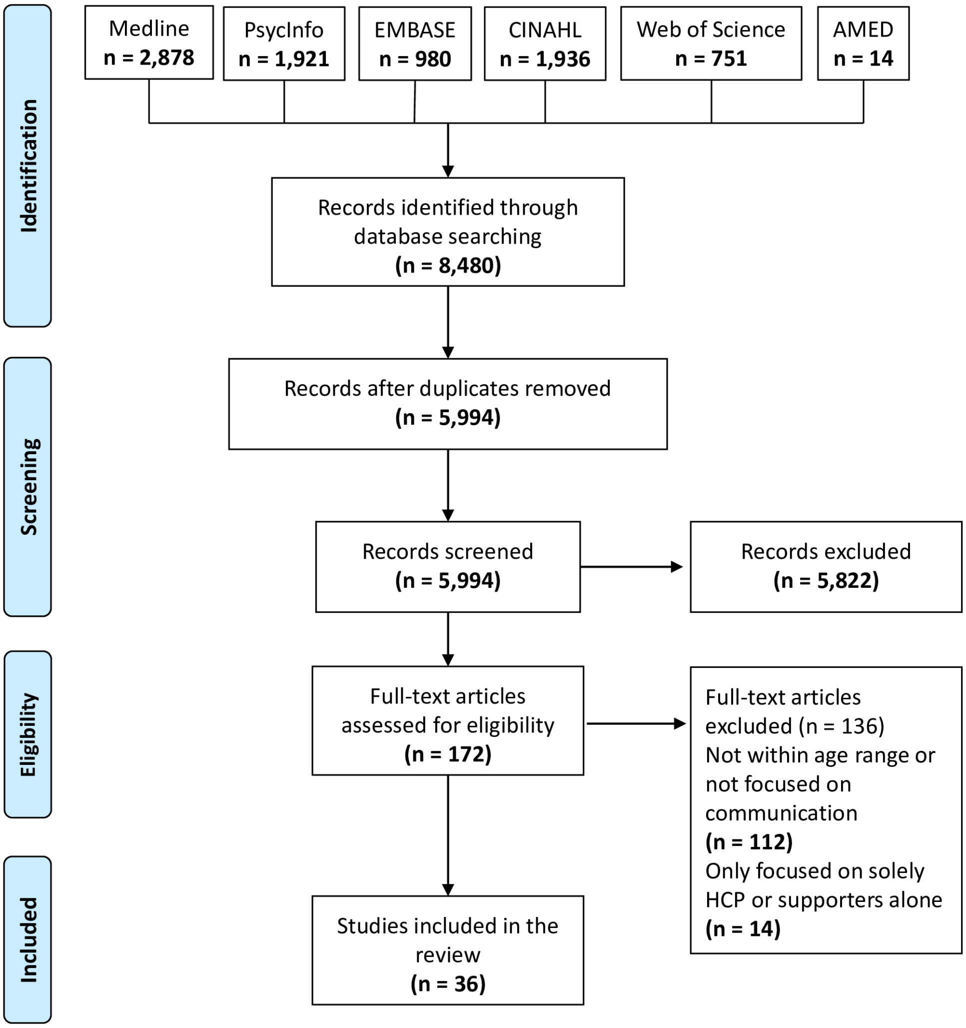

Figure 1 PRISMA flow diagram. HCP, healthcare professional; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

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 1 year) (n=2)[47,48]; survivorship (more than 1 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 USA[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 5 were high evidence,[24,31,35,45,56] 24 were medium[5,12,25,27–30,32–34,36,37,39–42,44,46,47,49–51,55,57] and 7 were low evidence.[26,38,43,48,52–54] We used Gough's review-specific criteria to weigh the quality of each paper.[23] To do this, we used three parameters:

1. The integrity of the evidence on its own terms.
2. The appropriateness of the method for answering the review questions.
3. 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 three 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 semistructured interviews to understand TYACs' experiences and speaking to the TYAC and supporter separately. The high-scoring papers included papers that focused on communication in the triad, but this only occurred in 10 papers. In nine 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 under one-third researched the triad (n=10) of TYACs, supporters and HCPs,[5,24,30–32,34–36,50,51] one-third TYACs only (n=12)[28,29,33,37,38,40–42,44–46,48] and just over one-third TYACs and supporters (n=14)[12,25–27,39,43,47,49,52–57] (see table 1).

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 2. 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]

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 TYACs, retained information from HCPs, acted as a conduit of information between the TYACs and HCPs, 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 TYACs 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' (p 533).[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 towards clinicians comprised a mean of

Table 1 Study population

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

Participants included in the study and the number of papers included for each of the three participant groups.
HCPs, healthcare professionals; TYACs, teenagers and young adults with cancer.

Table 2 Supporter demographics

Supporter type	Number of supporters	Percentage quoted to one 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 further specification	21	3.2	53 54
Other	3	0.5	55
Total	657	100.1	

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

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 TYACs 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 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[37]; several wanted collaboration with supporters and clinicians[26 27 44 57] and some completely relied on supporters and HCPs 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. While 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 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 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 TYACs and HCPs, 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 TYACs without their parents present.[31] While 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 women.[58] 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 burdens. 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 TYACs and has demonstrated that there is a paucity of evidence focused specifically on triadic communication with TYACs. Of the 36 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,[59] depict the interaction pathways between patients, families and HCPs and hypothesise the influence of family on interpersonal processes and outcomes of medical consultations.

The data clearly identified that parents are the predominating supporters 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 development of an internal value and belief system.[38 60–62] This has been phrased as 'retreating to family' and can negatively impact peer relationships by impeding the development and maintenance of a peer network.[40 63 64] 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.[61 65 66] Partners felt relegated to a non-participatory role by a parent, and mothers struggled to relinquish their existing role as primary supporter.[61 66] It is relevant to note that the participants in these three studies were in their early 20s.

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.[67–69] 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 is 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'.[70] HCPs have ethical and legal obligations outlined in the UK best practice guidance, statute and case law.[71] In the UK, parents can legally make decisions for children under 16 years unless the child disagrees and is deemed 'Gillick Competent'.[72] Moreover, studies have shown children aged 14 and older can approach the level of understanding of adults.[73 74] 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[75] 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 while 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 several 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 age 24 only and not necessarily the age of young adulthood used in some countries (between 29 and 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, for example, 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 policymakers

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.[5 76–78] Furthermore, HCPs can find it difficult to apply teaching in this area in clinical practice.[53 79] HCPs need education and training to navigate triadic communication to optimise the involvement of the young person while 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 practice and rehearsal of skills under observation with detailed and descriptive feedback. This is arguably warranted here.[80 81]

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).[82] The BoC is a UK document that helps shape and deliver developmentally appropriate care to TYACs. 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 while 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 supporter's 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-focused clinical communication training for HCPs to allow them to effectively facilitate and navigate triadic 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.

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Contributors All authors meet the criteria for authorship. DJC, LAMS and RMT were involved in developing the protocol. DJC, IK and LAMS coordinated the running of the study and were responsible for data acquisition. DJC, LAMS, RMT and EC contributed to the analysis. DJC 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. DJC is responsible for the overall content as guarantor.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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.

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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 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

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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

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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 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

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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

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PsycINFO (via Ebsco)

#	Query	Limiters/Expanders	Last Run Via	Results
S11	S1 AND S2 AND S7 AND S8	Limiters - Publication Date: 20221101-20241231 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search 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	
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	6,549
S8	(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	3,524,144
S7	(S5) or (S3)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,557
S6	S4 AND S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	62,384

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
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
S3	("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 ("teenage and 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

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 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	937,154

CINAHL (via Ebsco)

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#	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
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
S3	("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 ("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 ((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	(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	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* 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*)) 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

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

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 "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/ 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 ("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

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 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
S11	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	Interface - EBSCOhost Research Databases Search Screen - Basic 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
S8	(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
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 Narrow by SubjectAge: - adolescence (13-17 yrs) Narrow by SubjectAge: - young adulthood (18-29 yrs) Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - APA PsycInfo	13,275
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	58,767
S3	("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

	(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*))			
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	2,423,980
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 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	894,375

CINAHL (via Ebscohost)

Accessibility Information and Tips

Print 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

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
S3	("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	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	59,927

	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 ((MH “adolescence+” OR MH “young adult+”) AND (MH “neoplasms+”))			
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 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

Table 2. Summary of Articles

First author (year)	Title	Setting	Study Type - analysis method *Data collection*	Focus	Participant Characteristics	Key findings	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.	54 participants: **10 AYACs (age range: 17-23 years)** 25 parents (including 12 bereaved parents) 19 healthcare professionals	Important to have direct communication with the child or young person regarding decision-making. Interdisciplinary care with integrated teams is vital for high quality end of life care. Continuity of healthcare professionals was positive. AYACs would prefer to die at home but family and healthcare professionals may be hesitant.	Medium
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 excluded from information-sharing sessions between parents and healthcare professionals. 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 shield AYACs from bad news. Trust and honesty are the foundations of effective communication between AYACs and healthcare professionals. AYACs reacted negatively towards dishonesty.	Medium
Barakat (2014)	A Qualitative Study of Phase III Cancer Clinical Trial Enrollment Decision Making Perspectives from AYAC, Caregivers and Providers	USA Single centre	Qualitative - thematic analysis *Semi-structured interviews.*	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 charge of decision-making. Caregivers perceived AYAC to be in charge of decision making most of the time whereas the AYACs felt that "AYAC abdicates to carer" was the most common form of decision making. Distress and poor health limited AYAC involvement in the decision. Developmental and emotional maturity facilitated involvement.	High

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 with respect to oncofertility. A significant finding from this study suggests that health professional shy from discussing posthumous planning of cryopreserved materials with adolescent cancer patients and their parents. 5 out of 16 AYAs felt that the decision was not theirs and that it was instead the parents' or the pysicians' to make. Some parents felt that the decision was made by the clinician - explicit or implicit recommendations from the clinician strongly influence decision making. No decisional regret expressed by any members of the dyad.	Medium
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 identified 1. flow of information to inform decision making 2. disclosure of prognosis 3. decision maker and stakeholder involved in decision making 4. barriers and facilitators to decision making Differing values and agendas. The parents valued messages to "life the spirits" whereas the AYACs values honesty from the healthcare professionals Gatekeeping of information. Theme of "deference to authority"	Medium

Darabos (2021)	Cancer Related Decision Making Among AYAC, Care Givers and Oncology Providers	USA Single centre	Qualitative – <u>content analysis with hypothesis coding</u> *Semi-structured interviews.*	Decision-making and triadic communication	<u>30 Participants:</u> **11 AYACs (age range: 15-24 years)** 11 supporters 8 healthcare professionals	Four decision-making patterns were identified: 1. AYAC driven, 2. Collaborative, 3. Deferral to parents, 4. Provider-based, AYA/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 more likely to drive decisions regarding supportive care than treatment related decisions. AYACs and caregivers explained how cognitive and emotional processes influenced cancer related decisions. Emotional coping was more common than problem-based coping Direct and honest communication contributes to a stronger relationship. Individuality is key along with flexibility. Time alone is important.	High
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	<u>22 participants</u> **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 is high prior to diagnosis, decreases after diagnosis and is reclaimed after treatment.	Medium
Ellis (2016)	Fertility concerns among child and adolescent survivors and parents: a qualitative study	Australia single centre	Qualitative semi-structured telephone interviews	Fertility related themes with AYACs who are recently off treatment and with their parents	<u>97 participants from 45 families</u> **19 AYACs (age range 7-17 at diagnosis, mean age 13.3)** 44 mothers and 34 fathers	Both parents and AYACs are concerned about the potential impacts on fertility of treatment. Poor doctor-patient communication was 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

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 can cause conflict when adolescents are cognitively mature but legally lack the ability to make decisions. AYACs feel a loss of autonomy. Age-appropriate environments are important. Effective communication differs depending on the type of professional (i.e., doctor vs nurse) Adolescents negatively affect communication when: 1. They are indifferent. 2. There priorities conflict with treatment 3. They conflict with parents. Healthcare professionals negatively affect communication when: 1. They don't treat the adolescent in an age-appropriate way. 2. They don't take the adolescent seriously. 3. They give too much information or withhold important information	Medium
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 must be kept at the centre of interactions in recognition of their stated needs: 1. Engagement. 2. Individually tailored information. 3. Support unproxied by parents/family. AYACs did not want 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 dissatisfaction and irritation having to repeat their cancer story.	Medium

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 their child 10 out of 31 times - this was motivated by a compassionate goal of preparing the parents so they can better support the child when the bad news is broken) or close family member/sibling or boyfriend or girlfriend (n=2). Some parents withheld info and some AYACs preferred parents not to know their diagnosis Asymmetry in the triad discussed - but the key quality needed in the triad is mutual trust HCP found parental presence helpful in the study. HCPs should show empathy (no neutrality) and attention to detail	Medium
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.	75 participants: **11 AYACs (age range: 12.6-17.5 years)** 44 supporters 20 healthcare professionals	Adolescent patients' involvement in conversations about relapsed or refractory cancer is limited. Adolescents were accompanied by one (27%) two (64%) or more than two (18%) family members in the discussion. Adolescents spoke 3.5% of words compared to 66.9% clinicians and 30% parents. No conversations included instances in which the clinicians' asked adolescents for their communication preferences or desired role in decision-making.	High
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 participants: **126 parent-AYAC dyads AYACs (14-20 years, mean age 16.9**)	Young people wanted early information (86%) but only 39% 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	Low

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 identified: emotional care needs; parent-AYA dynamics including autonomy and agendcy; decision-making considerations including values and practicalities; and reflections on oncofertility and follow-up. Both AYAC and parents placed importanceon AYA autonomy in fertility decision-making but, but many AYAs appreciated the role of parents in providing support and guidance throughout the process. Healthcare professionals are encouraged to autonomously engage AYA’s around fertility decision making, while concurrently offering opportunities that promotes parental support.	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 – thematic analysis *Semi-structured interviews.*	Shared decision-making – primary treatment and trial participation – at diagnosis.	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/symptoms. For trial enrollment, many AYACs allowed themselves to be steered by the recommendation of the healthcare professional who recruited them, thinking they were acting in their best interests.	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	Participants faced challenges concerning: 1) Teens’ limited participation in their care 2) communicating emotionally sensitive information 3) managing physical and emotional responses Time alone with clinicians was important. Mutual protectionism or the need to “emotionally protect eachother” was prevalent.	Medium

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 themes 1) altruism - wanting to help future AYACs 2) trust in the clinicians 3) individuals perceptions of cure contra toxicity 4) adolescents as active participants in the decision making process 5) parental responsibility and authority 6) the difficulty of uncertainty	Low
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 cancer were comfortable discussing EOL, and the majority preferred to talk about EOL 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 not known by their families, reinforcing the importance of eliciting individual preferences and engaging dyads so parents can understand their children's wishes. 53% of AYACs had never spoken about their end of life preferences but 82% considered it important to let their loved ones know their wishes.	Low

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)	Four major themes of emotional concerns expressed by AYA patients 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", 3) fear 4) sadness AYA patients and family members expressed emotional concerns. HCPs typically responded by providing information, rather than affective aspects of the concerns In the sadness theme however, an explicit provide space affective response was the most common response (n=8) followed by an explicit provide space content response (n=7) To make patients 'feel known' HCP should pay attention to the affective aspect of the expressed concern.	Medium
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) increased congruence in the triad compared to the control standard of care group– so it is key. The family centres ACP AYACs reported feeling more informed that the control group	Low

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 share decision-making with oncologists. The remainder were split between the AYAC wanting primary responsibility in decision-making (20%) or wanting their oncologist to have primary responsibility (22%). A lower proportion of younger AYACs wanted sole responsibility but this did not achieve statistical significance (P = 0.07). The majority (90%) of AYACs who lived with a parent/guardian wanted some form of input from their parents (either collaborative or considering their opinion). Younger AYACs (15-17 years) were more likely to want greater involvement by their parents but were also more likely to be less involved than they wanted to be relative to their parents. Decisional regret was less likely among AYACs who trusted oncologists completely, and who reported that oncologists understood what was important to them when treatment started.	Medium
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 participants: **9 AYACs (age range 16-20)**	Consent encompassed the first discussion of CCT. Patients reflected positive and negative effects of timing, decisional role, 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

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) Reliance on health care team and social support networks to facilitate FP decisions (noted just by parents), (2) withholding parental opinion and deferring the decision to the adolescent, (3) ease of communication, (4) communication barriers and facilitators, (5) not being present or not remembering details of FP conversations. Four content themes: (1) preference for biological parenthood (or grandparenthood), (2) consideration of future partner of AYAC's desire for biological parenthood, (3) sperm banking whilst it is a viable option, (4) openness to alternative parenthood options	Medium

Patterson (2012)	The Unmet Needs of Emerging Adults With a Cancer Diagnosis	Australasia	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 Participants: **14 AYAC aged 20-25**, average age of 22	A cancer experience poses the potential for significant impact on the four requirements for achievement of adulthood. The needs of these emerging adults were grouped into six themes; information, healthcare provision, daily living, interpersonal support, identity renegotiation and emotional distress. These themes relate directly to the four requirements of adulthood. 1. The task of accepting responsibility for oneself emphasises the importance of empowering AYAC in their communication with HCP. 2. The task of deciding on personal beliefs and values highlights the importance of keeping the AYAC informed and encouraging them in decisions giving maximum opportunity to explore beliefs. 3. Establishing a relationship with parents as equals highlights the importance of maximising AYAC autonomy in relation to supporters. 4. The task of becoming financially independent highlights the importance of minimising disruption to daily life.	Low

Pennant (2020)	The Role of Social Support in Adolescent/Young Adults Coping with Cancer Treatment	USA	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, 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 contradictory. AYACs appear to want autonomy and independence, but appreciate help with daily tasks from their parents. They express the desire for privacy, but also value physical presence and communication Parents must oscillate between being involved in and catering to their AYAC child's needs during treatment while allowing space for independence and autonomy. The findings underscore the importance of maintaining open communication with AYAC patients about their preferences and needs throughout the course of treatment and asking them about both individual and social preferences, which may change frequently.	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	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 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 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 professionals/supporters) or passive (healthcare professionals/supporters as decision makers) role.	Medium

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.	16 Participants: **16 AYAC aged 15-20 (at time of interview - with an average of one year from diagnosis)**	Factors influence the involvement of AYAC in 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: mental mindset, self care practices, self-advocacy and negotiating relationships. Parents were often present and staying strong was a recurring theme across mental mindset and negotiating relationships. HCP are critical to facilitate AYAC participation in day to day decision making by encouraging autonomy and with effective communication.	Medium
Sawyer (2019)	Developmentally Appropriate Care for Adolescents and Young Adults with Cancer: How Well is Australia Doing?	Australasia Multicentre	Quantitative – Chi-squared and Fisher's exact test *Single time point survey.*	Explore quality of AYAC care in Australia.	196 participants: **196 AYACs (age range: 15-25 years)**	>90% of AYACs reported positive responses for 11 of the 14 experience of care items which related to the quality of communication and general interactions with the cancer care team. The most highly endorsed of these experiences of care items related to staff being friendly and respectful, communicating in ways that the AYAC understood, being supportive of AYACs asking questions and engaging families in discussion and decisions as the AYAC wished. Older AYAC (20-25 years) report more empowerment to make decisions than younger AYACs and were more likely to report that healthcare professionals included their family in discussions and decision-making the way they wanted them to be included.	Low

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.	<u>37 participants:</u> **37 AYACs (age range: 12-20 years; mean: 16 years)**	Building relationships: demonstrating clinical competence, reliability, empathy, and showing care and concern. When 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 AYACs' needs. These needs related to the amount, complexity, timing, and pacing of information, and balancing communication between parents and AYACs. AYACs think honesty and transparency is important. However, transparency could be burdensome. Exploring uncertainties and fears of the future mad AYACs feel better prepared and decreasing anxiety. There was variation between AYACs for exploring these unknowns. AYACs varied in their preferences in sharing distressing information and whether healthcare professionals should remain present and or give AYACs their privacy. AYACs often feel that treatment related decisions realistically only have one choice giving a sense of powerlessness. They played a greater role in decisions outside of treatment related areas. While some AYACs preferred very passive or active roles most described an interdependent process of communication involving them, their parents, and their 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

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	<u>37 Participants:</u> **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 logistics. Five factors that influence AYAC roles in communication were: AYAC agency Clinical encouragement Emotional and physical well-being Personality, preferences and values Insights and skills There are multiple benefits of engagement of the adolescent.	Medium
Son (2023)	Family Communication About Cancer in Korea: A Dyadic Analysis of Parent-Adolescent Conversation	Korea	Qualitative descriptive study	The aim was to understand communication experiences of Korean AYAC and their parents in the context of young adult cancer.	<u>14 participants:</u> **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, different views on communication challenges and limited sharing and progress in the conversation. This study offers insights 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.	Medium

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).	<u>78 participants:</u> 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 distress. Parents and adolescents reported similar moderate levels of cancer related communication problems. The most commonly endorsed cancer-related problem was "not talking about what to do if the AYAC got significantly worse'. Parents reported better problem solving ability and better dyadic functioning than their adolescent.	Low
Weaver (2016)	"Being a Good Patient" During Times of Illness as Defined by Adolescent Patients With Cancer	USA	Qualitative - <u>semantic content analysis</u> Semi-structured interviews		<u>40 participants</u> **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 interviewer (57.5%)	Medium
Weaver (2015)	Adolescents' Preferences for Treatment Decisional Involvement During Their Cancer	USA Multicentre	Qualitative – <u>semantic content analysis</u> *Semi-structured interviews.*	Investigate AYACs' decision-making preferences and how supports and healthcare professionals can support involvement.	<u>40 participants:</u> **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 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 medical decisions. Although adolescents wanted to be involved in decisions, they also expressed an appreciation of family insight, parental presence, and clinician guidance. AYACs can retrospectively identify their preferences for inclusion in medical decision-making, and even when preferring involvement, they value the input of trusted others.	Medium

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 decision making (SDM) during the treatment trajectory were found. Participants experienced the highest decisional conflict during diagnosis. Roles in healthcare communication varied from direct participation to indirect involvement. Overall, participants reported that doctors and parents decided their level of involvement, communication and or decision making.	Medium
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 52% of AYAC did not recall discussion regarding treatment 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 medical decisions.	Medium

[¥] Age range at diagnosis is given except where this was not provided in the article in which alternative metrics are presented and this is highlighted.
AYA(C) = adolescent and young adult (with cancer); NOS = not otherwise specified; RM-ANOVA = repeated measures analysis of variance.