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

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

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

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

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

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

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

Ella Clyne, Medical Student, University of Cambridge

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

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

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

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

## Abstract

## Background

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

## Aim

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

#### **Review questions:**

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

#### Methods

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

## Results

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

## Conclusion

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

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## PROSPERO registration CRD42022374528

## Strengths & limitations of this study

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

## Introduction

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

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

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

#### Aim

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

## **Review questions:**

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

## Methods

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

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## Table 1. Search Terms

|--|

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

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

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

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

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

## Results

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

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

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

Table 3 – Age range of patients at diagnosis

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

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## Who is present with TYACs in healthcare consultations and communication?

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

Table 4 – Table of supporters

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

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

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

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

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

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

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

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

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

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

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

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

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

#### Discussion

#### **Principal Findings**

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

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

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

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

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

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

#### Meaning of the study

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

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

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

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

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

## Strengths and weaknesses

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

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

## Implications for clinicians and policy makers

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

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

#### Unanswered questions and future research

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

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## Conclusion

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

## Author Contributions:

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

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

## Ethics Approval:

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

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## 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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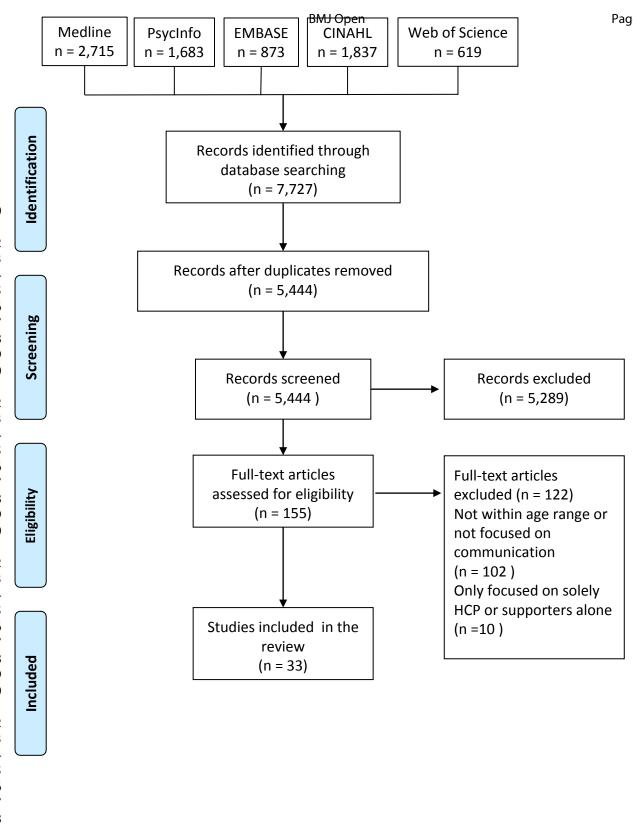
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| (year)            | Title   | Setting               | Data collection   | Focus   | Participant Characteristics <sup>¥</sup>   | Key find gs R   |
| Ananth<br>(2021)  | A Stakeholder-<br>Driven Qualitative<br>Study to Define<br>High Quality End-<br>Of-Life Care for<br>Children with<br>Cancer                             | USA<br>Multicentre    | Qualitative -<br><u>thematic analysis</u><br>Semi-structured<br>interviews and<br>focus groups.                                   | To explore end of<br>life care (EOLC)<br>priorities for<br>children with<br>cancer and their<br>families. | <ul> <li><u>54 participants:</u></li> <li><b>10 AYACs (age range: 17-23 years)</b></li> <li>25 parents (including 12 bereaved parents)</li> <li>19 healthcare professionals</li> </ul> | Important to gave direct communication with the<br>child or young person regarding decision-<br>making.<br>Interdisco line y care with integrated teams is vital<br>for high patient of life care. Continuity of<br>health of professionals was positive.<br>AYACs of the professionals may be hesitant.  |
| Bahrami<br>(2017) | Information<br>Sharing Challenges<br>Between<br>Adolescents with<br>Cancer, their<br>Parents and Health<br>Care Providers: A<br>Qualitative Study       | Iran<br>Single centre | Qualitative<br>descriptive-<br>exploratory study<br>- <u>grounded theory</u><br><u>analysis</u><br>Semi-structured<br>interviews. |   | 33 participants:<br>12 AYACs (age range at<br>interview: 15-20 years,<br>within 1 year of diagnosis)<br>6 supporters<br>6 healthcare professionals                                     | <ul> <li>AYACs feet they are excluded from information-<br/>sharing sections between parents and healthcare<br/>profession s. This leads to disaffiliation,<br/>confusion and AYACs seek information from<br/>'inferior' sources.</li> <li>Parents were often the first receivers of information<br/>allowing them to act as gatekeepers controlling<br/>information to flow to AYACs. Parents may<br/>want to sheld AYACs from bad news.</li> <li>Trust and homesty are the foundations of effective<br/>communication between AYACs and healthcare<br/>professionals. AYACs reacted negatively<br/>towards dianonesty.</li> </ul> |
| Barakat<br>(2014) | A Qualitative Study<br>of Phase III Cancer<br>Clinical Trial<br>Enrollment<br>Decision Making<br>Perspectives from<br>AYAC, Caregivers<br>and Providers |                       | Qualitative -<br><u>thematic analysis</u><br><i>Semi-structured</i><br><i>interviews</i> .  | Clinical trial<br>enrollment.   | 40 participants:<br><b>13 AYACs (age range: 15-<br/>21 years)</b><br>16 supporters<br>11 healthcare professionals  | <ul> <li>Four patterns of decision-making patterns identified:</li> <li>1. AYAC abdicates to caregiver,</li> <li>2. Caregiver based and AYAC approved,</li> <li>3. Collaborative,</li> <li>4. AYAC in marge of decision-making.</li> <li>Caregivers parceived AYAC to be in charge of decision making most of the time whereas the AYACs selt that "AYAC abdicates to carer" was the most common form of decision making.</li> <li>Distress and poor health limited AYAC involvement in the decision.</li> <li>Development and emotional maturity facilitated involvement.</li> </ul>   |
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| As in other Bultural contexts, Israeli adolesc<br>and parents demonstrate multifac<br>decision methics with respect to oncoferti | A significant finding from this st<br>suggests that health professional shy fi<br>discussing posthumous planning<br>cryoposerved materials with adolese<br>cancer patents and their parents. 5 out of<br>AYAS that the decision was not theirs<br>that it was instead the parents' or the pysici<br>to make the clinician - explicit or imp<br>recompositions from the clinician stror<br>influence clinician making. No decisional re-<br>expressing by any members of the dyad. |  |                              |
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| <u>35 participants</u><br>16 AYACs (age range 12-<br>16 years)   | 19 parents  | 13 paediatric oncologists<br>13 parents or primary carers<br>6 AYACs (age range 13-18<br>years)                | com/site/about/guidelines.xh |
| BMJ Open<br>To understand<br>adolescent<br>oncofertilty  | decision making<br>in Israel, from<br>perspectives of<br>parents and<br>adolescents   | on therapeutic futility  | :p://bmjopen.bmj.c           |
| Qualitative-<br>thematic analysis  | semi-structured<br>interviews   | Qualitative -<br>thematic analysis<br>Semi-structured<br>interviews  | er review only - htt         |
| Israel<br>Single centre  | л <sub>с</sub>  | Mexico<br>Multicentre  | For pe                       |
| Oncofertility<br>decision making:<br>findings from   | Israeli adolescents<br>and parents  | Decision-making<br>on therapeutic<br>futility in Mexican<br>adolescents with<br>cancer: a<br>qualitative study |                              |
| Barlevy<br>(2019)  |   | Cicero-<br>Oneto<br>(2017)   |                              |

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| 22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30  | Davies<br>(2019)  | 'Life then', 'life<br>interrupted', 'life<br>reclaimed': the<br>fluctuation of<br>agency in teenagers<br>and young adults<br>with cancer | UK<br>single centre        | qualitative -<br>thematic analysis<br>case studies -<br>multiple<br>interviews                   |   | 22 participants<br><b>5 AYACs (16-24 years)</b><br><b>5 parents carers</b> (2 fathers,<br>3 mothers, 1 couple),<br>5 healthcare professionals (4<br>nurses and 1 oncology<br>consultant)<br>5 other supporters (1<br>boyfriend, 1 girlfriend, 1<br>aunt, 2 friends) | Agency Luciates over time within cases and<br>between cases. Agency can fluctuate between<br>personal proxy and collective perspectives.<br>Personal agency is high prior to diagnosis,<br>decrease after diagnosis and is reclaimed after<br>treatments in on<br>treatments of the second sec |  |  |  |
| 31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41  | Ellis (2016)      | Fertility concerns<br>among child and<br>adolescent<br>survivors and<br>parents: a<br>qualitative study                                  | Australia<br>single centre | Qualitative<br>semi-structured<br>telephone<br>interviews  | recently off treatment and                      | 97 participants from 45<br>families<br>19 AYACs (age range 7-17<br>at diagnosis, mean age<br>13.3)<br>44 mothers and 34 fathers   | reported and conversations about fertility were<br>frequently interrupted to discuss illness and<br>treatment. These fertility discussions were not<br>then continues once the AYAC was off<br>treatment m   |  |  |  |
| 11<br>12<br>13<br>14<br>15<br>16<br>17  |                   |  | For pe                     | eer review only - ht   | tp://bmjopen.bmj.c                              | com/site/about/guidelines.xh  | bliographique 3<br>Itml de I   |  |  |  |

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| Essig<br>(2016) | Improving<br>Communication in<br>Adolescent Cancer<br>Care: A<br>Multiperspective<br>Study | Germany,<br>Austria,<br>Switzerland<br>Number of<br>centres not<br>stated | Qualitative –<br>inductive<br>thematic analysis<br>Focus groups.  | Explore effective<br>communication<br>with AYACs for<br>communication<br>skills training. | 54 participants:<br><b>16 AYACs (age range: 13-19 years)</b><br>8 parents<br>30 healthcare professionals | adolessents are cogniti<br>lack the abgity to make<br>AYACs teel closs of auto<br>Age-appenpinete environm<br>Effective communication<br>type of protessional (i.e<br>Adolescents enegatively<br>when:<br>1. They are indifferent<br>2. They point is cont<br>3. They will be professional<br>comments in when:<br>1. They are professional<br>comments in when:<br>1. They are professional<br>comments and the teat the<br>appropriate way.<br>2. They den't take the | nomy.<br>ents are important.<br>differs depending on the<br>., doctor vs nurse)<br>affect communication<br>flict with treatment<br>arents.<br>s negatively affect<br>e adolescent in an age-<br>adolescent seriously.<br>information or withhold |
| Fern (2013)     | The Art of Age-<br>Appropriate Care  | UK<br>Number of<br>centres not<br>stated                                  | Qualitative –<br><u>thematic analysis</u><br><i>Peer-to-peer</i><br><i>interviews, field</i><br><i>notes and spider</i><br><i>diagrams from</i><br><i>focus groups.</i> | Review a<br>conceptual model<br>of AYACs'<br>cancer care<br>experiences.                  | 11 participants:<br>11 AYACs (age range: 13-<br>25 years)  | <ol> <li>Engagement.</li> <li>Individually tailored.</li> <li>Support unproxied by AYACs and not want information was revealed by a service of continuity of hereits.</li> </ol>  | on of their stated needs:<br>l information.<br>by parents/family.<br>rmation to be directed at<br>rassing when sensitive<br>d in the presence of their<br>nealthcare professionals<br>tisfaction and irritation                                  |
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|             | Fourneret<br>(2018) | Breaking bad news<br>about cancer to<br>adolescents and<br>young adults: the<br>french experience   | Multicentre          | qualitative semi-<br>structured<br>interviews   | Explore the<br>effectiveness and<br>implementation<br>of the French<br>announcement<br>protocol in 7<br>french paediatric<br>oncology centres | 90 participants<br>27 AYACs (21 were 14-17<br>and 6 were 18-22)<br>30 parents (16 mothers, 5<br>fathers, 9 parents together at<br>the appointment)<br>33 healthcare professionals | Parents and AYACs have different needs - both of<br>which needs to be accounted for when breaking<br>bad newson Awkward and premature<br>announcements were noted<br>The anneuncement consultation – young patients<br>were dever alone when informed of their<br>disease either with parents (n=31) (parents were<br>informed thefore their child 10 out of 31 times -<br>this was in the parents so they can better support<br>the charge were the bad news is broken) or close<br>family method ber/sibling or boyfriend or girlfriend<br>(n=2).000000000000000000000000000000000000 |  |  |
|             | Frederick<br>(2018) | Adolescent Patient<br>Involvement in<br>Discussions About<br>Relapsed or<br>Refractory Cancer<br>with Oncology<br>Clinicians.                       | USA<br>Single centre | Qualitative –<br><u>content analysis</u><br><i>Audiotaped</i><br><i>conversations</i> . | Breaking bad<br>news of relapsed<br>or refractory<br>cancer.  | 75 participants:<br>11 AYACs (age range:<br>12.6-17.5 years)<br>44 supporters<br>20 healthcare professionals  | <ul> <li>Adolescent patients' involvement in conversations about alapsed or refractory cancer is limited.</li> <li>Adolescents were accompanied by one (27%) two (64%) in more than two (18%) family members in the discussion.</li> <li>Adolescents poke 3.5% of words compared to 66.9% elimitians and 30% parents.</li> <li>No conversations included instances in which the clinicians' g asked adolescents for their communication preferences or desired role in decision-making.</li> </ul>  |  |  |
|             | Friebert<br>(2020)  | Congruence gaps<br>between<br>adolescents with<br>cancer and their<br>families regarding<br>values, goals and<br>beliefs about end-<br>of-life care | USA<br>multicentre   | Qualitative cross-<br>sectional study   | End of life care  | 126 parent-AYAC dyads<br>AYACs (14-20 years, mean<br>age 16.9)  | Young people wanted early information (86%) but<br>only 32% families knew this. Families<br>understanding of what was important to their<br>adolescents when dealing with their own dying was<br>excellent for wanting honest answers from their<br>physician and understanding treatment choices<br>but poor for dying a natural death and being<br>off machines that extend life, if dying.<br>Parents do not know what AYACs want at the end<br>of life  |  |  |
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| Hart (2020)           | The Challenges of<br>Making Informed<br>Decisions About<br>Treatment and Trial<br>Participation<br>Following Cancer:<br>A Qualitative Study<br>with Adolescent<br>and Young Adults<br>with Cancer and<br>Care Givers | UK<br>Multicentre | Qualitative –<br>thematic analysis<br>Semi-structured<br>interviews.                                       | treatment and  | 33 participants:<br><b>18 AYACs (age range: 16-<br/>24 years)</b><br>15 supporters  | AYACs struggled to process information around<br>diagnosis, exacerbated by symptom burden,<br>emotions, and the fast pace of clinical activity.<br>Some AYACs disengaged from conversation<br>topics which were distressing.<br>There are limited options for 'real' decision-<br>making at diagnosis. However, many preferred<br>this when they were already overwhelmed by<br>emotions and the second by the recommendation<br>of the second by the recommendation   |
| Hong<br>(2016)        | Care Partnerships:<br>toward technology<br>to support teen's<br>participation in<br>their health care  | US<br>multicentre | Qualitative<br>semi-structured<br>interviews and<br>observations   | To investigate<br>how technology<br>can support the<br>partnerships<br>between AYACs,<br>parents and<br>clinicians when<br>the AYAC is<br>experiencing<br>complex chronic<br>illness | 33 interviews.<br>15 with AYACs (13 of<br>whom had cancer. age<br>range 13-17)<br>15 parents (10 mothers, 1<br>fathers, 1 aunt and 2 fathers<br>and mothers together)<br>8 clinician caregivers | interest of a<br>Participatity faced challenges concerning:<br>1) a structure of a sensitive<br>2) a some unicating emotionally sensitive<br>and a sen |
| Ingersgaard<br>(2018) | A qualitative study<br>on decision-making<br>on Phase III<br>randomized clinical<br>trial participation in<br>paediatric<br>oncology:<br>adolescents' and<br>parents'<br>perspectives and<br>preferences             | Denmark           | qualitative<br>exploratory study<br>- in-depth semi-<br>structured<br>interviews with<br>thematic analysis | To explore<br>patients' and<br>AYACs' motivs<br>for accepting/<br>declining<br>participation in<br>the AL2008 trial<br>and adolescents'<br>involvement in<br>decision making         | 16 participants<br><b>5 AYACs (age range 12-16)</b><br>6 parents of AYACs<br>5 parents of children aged 3-<br>10 years with cancer  | <ul> <li>Key there is in the clinicians</li> <li>in the clinicians</li> <li>in the clinicians</li> <li>in the clinicians</li> <li>in the generation of cure contrated of the clinicians</li> <li>in the generation of cure contrated of the clinicians</li> <li>in the generation of cure contrated of the clinicians</li> <li>in the generation of the clinicians</li> <li>in the generation of the clinicians</li> <li>in the clinicians</li></ul>   |
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| 47  |                                 |  | BMJ Open  |   | Adolesconts Swith cancer were comfortable  |
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| Jacobs Adolescent en<br>life preference<br>congruence w<br>their parents'<br>preferences: r<br>of a survey of<br>adolescents w<br>cancer  | and<br>n<br>ults                | Qualitative<br>three sessions of<br>dyadic interviews                    | To explore<br>AYACs' end of<br>life preferences<br>and to assess the<br>congruence of<br>these preferences<br>with the parents'<br>beliefs                  | 17 adolescent/ family dyads<br>17 AYACs (age range 14-<br>21, 71% under 18)   | Adolescents with cancer were comfortable<br>discussing FOL, and the majority preferred to<br>talk about FOL issues before they are facing<br>EOL. There were substantive areas of agreement<br>between adolescents and their surrogates, but<br>important facets of adolescents' EOL wishes<br>were for known by their families, reinforcing<br>the importance of eliciting individual<br>preference and engaging dyads so parents can<br>unders and their children's wishes. 53% of<br>AYAC framework spoken about their end of life<br>preference but 82% considered it important to<br>let their Byed ones know their wishes. |
| Korsvold A content ana<br>(2017) of emotional<br>concerns expr<br>at the time of<br>receiving a ca<br>diagnosis: An<br>observational<br>of consultation<br>with adolesce<br>young adult<br>patients and th<br>family member | ssed<br>cer<br>udy<br>and<br>ir | exploratory<br>mixed methods<br>study<br>audio recorded<br>consultations | To investigate the<br>emotional<br>concerns of<br>AYACs at the<br>time of diagnosis<br>and how to<br>quantify how<br>healthcare<br>professionals<br>respond | <u>18 participants</u><br><b>9 AYACs (age range 13-23</b><br>Present with mother (n=9),<br>father (n=1), sister (n=1) or<br>mother and father (n=2)                               | Four main themes of emotional concerns   |
| Lyon Family-Cente<br>(2013) Advance Care<br>Planning for T<br>With Cancer   | single centre                   | Qualitative<br>a randomised<br>control pilot<br>study                    | To examine the<br>efficacy of<br>family-centres<br>ACP  | 30 dyads<br>mean age of AYACs 16<br>17 were randomised to<br>intervention and 13 were<br>randomised to control<br>87% of surrogates were<br>biological parents and were<br>female | The model (AGP) increased congruence in the triad<br>compared in the control standard of care group-<br>so it is key. The family centres ACP AYACs<br>reported for ling more informed that the control<br>group  |
|   | For                             | peer review only - ht  | tp://bmjopen.bmj.   | com/site/about/guidelines.xl  | raphique 7   |

|                    |   |                      |  | BMJ Open   | L   | A majority of AYACs (58%) want to sha  |
|--------------------|---|----------------------|--|--|---|--|
| Mack<br>(2019)     | Adolescent and<br>Young Adult<br>Cancer Patients'<br>Experiences with<br>Treatment<br>Decision-Making               | USA<br>Single Centre | Quantitative –<br>multivariate<br>analysis, logistic<br>regression<br>Surveys at<br>diagnosis, 4 and<br>12 months. | Treatment<br>decision-making   | 203 participants:<br>203 AYACs (age range: 15-<br>29 years)   | A majority of AYACs (58%) want to sha<br>decision-making with oncologists. The<br>remainder overe split between the AYA<br>wanting pumary responsibility in decision<br>making (20%) or wanting their oncologist<br>have gimmery responsibility (22%).<br>A lower opportion of younger AYACs want<br>sole responsibility but this did not achie<br>statistic significance (P = 0.07).<br>The majority 90%) of AYACs who lived with<br>parent of 90%) of AYACs who lived with<br>parent of 90%) of AYACs who lived with<br>parent of 90% (either collaborative or considerin<br>their of 90%).<br>Younger of Cs (15-17 years) were more like<br>to want of the relative to their parents b<br>were and once likely to be less involved the<br>they wanted to be relative to their parents.<br>Decision of correct was less likely among AYAC<br>who the spon oncologists completely, and whe<br>report of the parent oncologists understood what w<br>important of them when treatment started. |
| Olsavsky<br>(2021) | Family<br>communication<br>about fertility<br>preservation in<br>adolescent males<br>newly diagnosed<br>with cancer | USA                  | Qualitative  | To explore<br>fertility<br>preservation<br>communication<br>among mothers,<br>fathers and their<br>male adolescents<br>newly diagnosed<br>with cancer. | 87 participants:<br>33 AYAC aged 12-25<br>32 mothers<br>22 fathers<br>Representing 37 families in<br>total. | <ul> <li>Five process themes:</li> <li>(1) Raiange on health care team and soci support networks to facilitate FP decision (need just by parents),</li> <li>(2) wighod ing parental opinion and deferring the decision to the adolescent,</li> <li>(3) easy of communication,</li> <li>(4) communication barriers and facilitators,</li> <li>(5) not being present or not remembering details of Conversations.</li> <li>Four content themes:</li> <li>(1) proference for biological parenthood (grad digreenthood),</li> <li>(2) consideration of future partner of AYAC desire for biological parenthood,</li> <li>(3) sperm wanking whilst it is a viable option,</li> <li>(4) openness to alternative parenthood options</li> </ul>  |
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| Page 31 of 47   |   |           |             | BMJ Open   |                          | cted by c   | experience poses the potential for   |
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| 1       Pattersor         2       (2012)         3       (2012)         4       5         6       7         7       8         9       10         11       12         13       14         15       16         17       18         19       20         21       22         23       24         25       26         27       — | The Unmet Needs<br>of Emerging Adults<br>With a Cancer<br>Diagnosis | Australia | Qualitative | Aim to contribute<br>to the limited<br>research base and<br>inform our<br>understanding of<br>the needs of<br>emerging adults<br>with a diagnosis<br>of cancer from a<br>developmental<br>perspective that<br>appreciates the<br>key transitional<br>tasks of emerging<br>adulthood<br>identified by<br>Arnett | 14 AYAC aged 20-25,      | achievemen<br>achievemen<br>The needing<br>into six the<br>daily light<br>renegotiation<br>These the<br>requirement<br>1. <b>b</b> into<br>a and<br>a and<br>3. <b>Al</b> taning<br>3. <b>Al</b> taning | interpersonal support, identity<br>on the four requirements for<br>adulthood.<br>of hese emerging adults were grouped<br>mess; information, healthcare provision,<br>ng interpersonal support, identity<br>on and emotional distress.<br>Set of adulthood.<br>The solution of adulthood.<br>The solution of a set of |
| 27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47  |   | For p     |             |  | :om/site/about/guideline | s.xhtml   | סיין on June 13, 2025 at Agence Bibliographique de I   |

|                                    |  |                    |   | BMJ Oper  | 1  | Themes of support included; presence,   |
|------------------------------------|--|--------------------|---|---|--|---|
| (2020) Supp<br>Adol<br>Adul        | Role of Social<br>oort in<br>lescent/Young<br>lts Coping with<br>eer Treatment |                    | Qualitative   | To explore<br>specific actions<br>that help AYAC<br>and what<br>behaviours they<br>want from their<br>social supports | 20 Participants:<br>10 AYAC ages 15-26, mean<br>age 18.9 years<br>10 parents | <ul> <li>Theme of support included; presence, distraction, positive attitude, maintaining AYACS autonomy, communication and advocated.</li> <li>Mothes were the most noted family support.</li> <li>AYAC patients can differ in their preferences throughout treatment and this can, at times, appear contradictory.</li> <li>AYAC patients can differ in their preferences throughout treatment and this can, at times, appear contradictory.</li> <li>AYAC patients of want autonomy and independence, but appreciate help with daily tasks from their parents.</li> <li>They express the desire for privacy, but also value poysical presence and communication Parents much oscillate between being involved in and starring to their AYAC child's needs during areatment while allowing space for independence and autonomy.</li> <li>The mode of the should be the preferences and needs throughout the course of treatment and asking them about both individual and social preferences, which may change frequently.</li> </ul> |
| Grimm Treat<br>(2020) Maki<br>Adol | tment Decision<br>ing in<br>lescents and<br>ng Adults with                     | USA<br>Multicentre | Qualitative –<br>ethnographic<br>Semi-structured<br>interviews, field<br>notes. | Explore the<br>preferences of<br>AYACs for<br>involvement in<br>healthcare<br>decisions                               | 16 participants:<br>16 AYACs (age range:<br>14.7-20 years)                   | Emotions around diagnosis inhibit information<br>receptiveness and ability to engage in treatment<br>decisions (especially important decisions).<br>Initially AYACs struggle with the jargon and<br>plethom of medical terms which are being used.<br>They have bimited knowledge which limits their<br>questions, this increases over time.<br>The importance of decisions differs from one<br>AYACs to the next. Also, some decisions are<br>seen abhaving only one 'real' option.<br>AYACs engaged in minor decisions much earlier<br>in their treatment, and some began engaging in<br>more important decisions later in treatment.<br>AYACs could adopt an active (sole decision<br>maker), collaborative (with healthcare<br>professional s/supporters) or passive (healthcare<br>professional s/supporters as decision makers)   |
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| Page 33 of 43  | 7                        |  |                            |   | BMJ Open   |  | Factors Figure the involvement of AYAC in   |
|--|--------------------------|--|----------------------------|---|--|--|---|
| 1<br>2<br>3<br>4<br>5<br>6<br>7<br>8<br>9<br>10<br>11<br>12<br>13<br>14                            | Pyke-<br>Grimm<br>(2022) | Day-to-Day<br>Decision Making<br>by Adolescents and<br>Young Adults with<br>Cancer   | USA                        | Qualitative<br>Interpretive<br>focused<br>ethnography<br>within the socio-<br>logic tradition,<br>informed by<br>symbolic<br>interactionism | To explore<br>involvement of<br>AYAs with<br>cancer in day-to-<br>day decisions<br>affected by their<br>cancer and<br>treatment. | <u>16 Participants:</u><br>16 AYAC aged 15-20 (at<br>time of interview - with an<br>average of one year from<br>diagnosis) | decision making such as the type of decision, the<br>point in the cancer journey. They want to be<br>involved.<br>Four day to day decision making categories were<br>identified: inental mindset, self care practices,<br>self-actionary and negotiating relationships.<br>Parents were offen present and staying strong was<br>a rector for the theme across mental mindset and<br>negotiating relationships.<br>HCP are offen the focus of the focus of the terms of the focus of the terms of the focus of the terms of terms of the terms of terms of the terms of terms of terms of terms of the terms of te |
| 15<br>16<br>17<br>18<br>19<br>20<br>21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31 | Sawyer<br>(2019)         | Developmentally<br>Appropriate Care<br>for Adolescents and<br>Young Adults with<br>Cancer: How Well<br>is Australia Doing? | Australasia<br>Multicentre | Quantitative –<br><u>Chi-squared and</u><br><u>Fisher's exact test</u><br>Single time point<br>survey.                                      |  | 196 participants:<br>196 AYACs (age range: 15<br>25 years)   | <ul> <li>&gt;90% of the action of the second state of the second</li></ul>                    |
| 31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47 |                          |  | For pe                     | eer review only - ht  | tp://bmjopen.bmj.  | com/site/about/guidelines.xł   | ne 13, 2025 at Agence Bibliographique de I<br>ntml 11   |

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

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

# Supplementary File – Search strategy and history

#### Searches run November 2022

Limited to 2005 onwards, and to English language only.

<text>

# Medline (via Ovid)

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

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

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

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# Embase (via Ovid)

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

#### BMJ Open

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

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

CINAHL (via Ebscohost)

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

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

Database - APA PsycInfo

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

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

# Web of Science Core Collection

# Web of Science Search Strategy (v0.1)

# Database: Web of Science Core Collection PLICZ

# Entitlements:

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

#### # Searches:

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

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

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

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

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

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

Results: 684

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

Results: 684

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

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



## PRISMA 2020 Checklist

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

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## PRISMA 2020

|              | BMJ Open |
|--------------|----------|
| 20 Checklist |          |
|              |          |

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

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# PRISMA 2020 Checklist

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

**BMJ** Open

# **BMJ Open**

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

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

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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"

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

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

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

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

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

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

Ella Clyne, Medical Student, University of Cambridge

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

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

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

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#### Abstract

#### Objectives

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

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

#### Design

Systematic review with narrative synthesis.

#### Data sources

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

#### Eligibility criteria for selecting studies

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

#### Data extraction and synthesis

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

#### Results

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

#### Conclusion

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

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#### Strengths & limitations of this study

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

#### Introduction

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

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

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

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

#### Aim

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

#### **Review questions:**

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

#### Methods

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

## Table 1. Search Terms

### Strand 1 – TYAC

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

TYAC: teenage and young adult with cancer

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

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

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

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

#### **Patient and Public Involvement Statement**

#### None

#### Results

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

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

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

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

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

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

Table 3 Study population

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

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

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

#### Who is present with TYACs in healthcare consultations and communication?

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

Table 4 Supporter Demographics

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

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

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

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

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

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

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

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

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

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

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

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

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

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

#### Discussion

#### **Principal Findings**

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

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

#### What are TYACs' s present?

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

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

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

#### Meaning of the study

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

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

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

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

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

#### Strengths and weaknesses

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

#### Implications for clinicians and policy makers

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

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

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

#### Unanswered questions and future research

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

#### Conclusion

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

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Ethics Approval:

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

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Data availability statement:

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

Figure Legends:

Figure 1: PRISMA Flow diagram

Table 1: Search terms

Table 2: Summary of articles

Table 3: Study Population

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

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

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|     | D=med20&AN=34128352 https://cambridge-   |
|     | primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM services page?sid=OVID:m  |
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# UNIVERSITY of York Centre for Reviews and Dissemination

# Systematic review

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

# 1. \* Review title.

**PROSPERO** 

Give the title of the review in English

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

supporters are present during healthcare consultations?

# 2. Original language title.

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

# 3. \* Anticipated or actual start date.

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

05/12/2022

# 4. \* Anticipated completion date.

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

07/08/2023

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

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

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

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

The review has not yet started: Yes

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

### 6. \* Named contact.

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

#### Deborah Critoph

**PROSPERO** 

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

Mrs Critoph

#### 7. \* Named contact email.

Give the electronic email address of the named contact.

dc625@medschl.cam.ac.uk

#### 8. Named contact address

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

Forvie Site

Addenbrookes Hospital

Department of Public Health and Primary Care

University of Cambridge

Cambridge

CB2 OPY

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## 9. Named contact phone number.

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

#### +44 (0)1223 330300

#### 10. \* Organisational affiliation of the review.

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

University of Cambridge

#### Organisation web address:

### 11. \* Review team members and their organisational affiliations.

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

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

### 12. \* Funding sources/sponsors.

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

Wellcome Trust

Grant number(s)

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

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#### 13. \* Conflicts of interest.

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

None

#### 14. Collaborators.

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

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# National Institute for Health Research

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

### 15. \* Review question.

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

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

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

**Research Questions:** 

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

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

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

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

# 16. \* Searches.

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

#### State Chersher With Druid in:

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

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

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

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

Articles focussing on any area of clinical communication

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

Papers published after 2005.

Exclusion criteria:

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Non-English language

Systematic reviews

Conference abstracts

Articles focusing on information needs rather than communication skills.

International prospective register of systematic reviews

Unpublished articles

Validation research methodology

Single case studies

Studies using retrospective documentation in clinical notes.

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

#### 17. URL to search strategy.

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

https://www.crd.york.ac.uk/PROSPEROFILES/374528\_STRATEGY\_20221205.pdf

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

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

#### 18. \* Condition or domain being studied.

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

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

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National Institute for Health Research

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

### 19. \* Participants/population.

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

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

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

Articles focussing on any area of clinical communication

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

Papers published after 2005.

Exclusion criteria:

Non-English language

Systematic reviews

Conference abstracts

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

Unpublished articles

Validation research methodology

Single case studies

Studies using retrospective documentation in clinical notes.

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

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

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

### 21. \* Comparator(s)/control.

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

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

Any relevant comparator.

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### 22. \* Types of study to be included.

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

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

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

International prospective register of systematic reviews

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

documentation in clinical notes.

#### 23. Context.

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

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

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

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

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

#### 24. \* Main outcome(s).

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

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

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

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### Measures of effect

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

Not applicable.

### 25. \* Additional outcome(s).

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

# PROSPERO International prospective register of systematic reviews

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None.

### Measures of effect

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

#### Not applicable.

### 26.chageeextraction (selection and coding).

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

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

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

1. Authors

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

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

7. Setting (treatment setting)

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

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

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

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# 27. \* Risk of bias (quality) assessment.

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

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

/01/12/bmjopen-2011-000138.DC1/BMJ\_Open\_IMG\_Physician\_Migration\_RATS\_Checklist.pdf).

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

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

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

# 28.chatrgedgy for data synthesis.

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

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

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

fo Explored and the statistic set of the set

• Developing a preliminary synthesis of findings of included studies

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

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

# National Institute for Health Research

#### PROSPERO International prospective register of systematic reviews

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

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

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

# 29. \* Analysis of subgroups or subsets.

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

Lower adolescence - 13-16

Middle adolescence - 16-19

Upper adolescent - 19-24

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

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

accessibility for the reader.

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#### 30. \* Type and method of review.

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

International prospective register of systematic reviews

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

NHS National Institute for Health Research

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

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

| NHS                    |
|------------------------|
| National Institute for |
| Health Research        |

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

### 31. Language.

**PROSPERO** 

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

There is not an English language summary

### 32. \* Country.

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

#### England

### 33. Other registration details.

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

# 34. Reference and/or URL for published protocol.

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

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Vancouver format)

Add web link to the published protocol.

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

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

# 35. Dissemination plans.

Do you intend to publish the review on completion?

#### Yes

Give brief details of plans for communicating review findings.?

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

# 36. Keywords.

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

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

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

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

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

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

DOI: 10.1089/jayao.2019.0133

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



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# **PROSPERO** International prospective register of systematic reviews

National Institute for Health Research

communicating with teenagers and young adults with cancer.

### 38. \* Current review status.

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

Please provide anticipated publication date

Review\_Ongoing

### 39. Anay gelditional information.

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

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

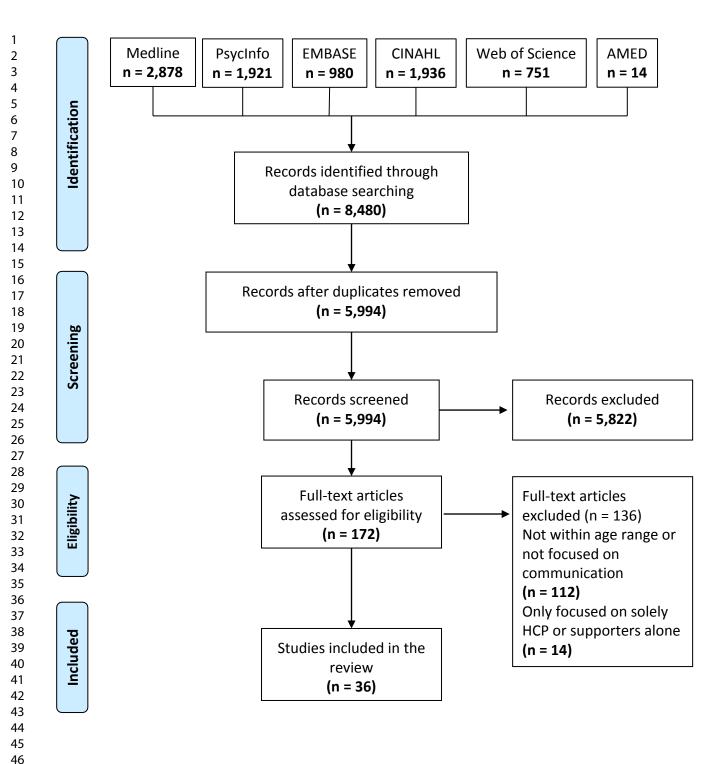
# 40. Details of final report/publication(s) or preprints if available.

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

Give the link to the published review or preprint.

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#### BMJ Open



#### **BMJ** Open

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

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

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| 22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30  | Davies<br>(2019)  | 'Life then', 'life<br>interrupted', 'life<br>reclaimed': the<br>fluctuation of<br>agency in teenagers<br>and young adults<br>with cancer | UK<br>single centre        | qualitative -<br>thematic analysis<br>case studies -<br>multiple<br>interviews                   | Fluctuation of<br>agency across<br>time and between<br>cases | 22 participants<br>5 AYACs (16-24 years)<br>5 parents carers (2 fathers,<br>3 mothers, 1 couple),<br>5 healthcare professionals (4<br>nurses and 1 oncology<br>consultant)<br>5 other supporters (1<br>boyfriend, 1 girlfriend, 1<br>aunt, 2 friends) | Agency fluctuates ≥ over time within cases and<br>between cases. Agency can fluctuate between<br>personal, proxy and collective perspectives.<br>Personal agency g is nigh prior to diagnosis,<br>decreases after diagnosis and is reclaimed after<br>treatment.   | Medium       |
| 31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40  | Ellis (2016)      | Fertility concerns<br>among child and<br>adolescent<br>survivors and<br>parents: a<br>qualitative study                                  | Australia<br>single centre | Qualitative<br>semi-structured<br>telephone<br>interviews  | recently off treatment and                                   | 97 participants from 45<br>families<br>19 AYACs (age range 7-17<br>at diagnosis, mean age<br>13.3)<br>44 mothers and 34 fathers   | reported and conversations about fertility were<br>frequently interrupted to discuss illness and<br>treatment. These fersility discussions were not<br>then continues once the AYAC was off<br>treatment   | Medium       |
| 41<br>42<br>43<br>44<br>45<br>46<br>47  |                   |  |                            | For peer review  | only - http://bmjo   | pen.bmj.com/site/about/gui  | delines.xhtml <b>B</b><br>delines.xhtml <b>C</b>   | 3            |

| Pag   | e 43 of 75      |  |   |   | E   | BMJ Open  | Decision-making ricar20 cause conflict when   |        |
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| 20<br>21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31<br>32                            | Fern (2013)     | The Art of Age-<br>Appropriate Care  | UK<br>Number of<br>centres not<br>stated                                  | Qualitative –<br>thematic analysis<br>Peer-to-peer<br>interviews, field<br>notes and spider<br>diagrams from<br>focus groups. | Review a<br>conceptual model<br>of AYACs'<br>cancer care<br>experiences.                  | 11 participants:<br>11 AYACs (age range: 13-<br>25 years)   | <ul> <li>Young people misse the kept at the centre of interactions in tecognition of their stated needs:</li> <li>1. Engagement and the stated information.</li> <li>2. Individually and the stated information.</li> <li>3. Support unprivated by parents/family.</li> <li>AYACs did not want information to be directed at parents but at them.</li> <li>AYACs found it emparrassing when sensitive information was revealed in the presence of their parents.</li> <li>Lack of continuity of healthcare professionals leads to AYACs dissatisfaction and irritation having to repeat their cancer story.</li> </ul>  | Medium |
| 33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47                |                 |  |   | For peer review   | v only - http://bmjo  | pen.bmj.com/site/about/gui  | logies.<br>idelines.xhtml   | 4      |

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

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

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| 12<br>13<br>14<br>15<br>16<br>17<br>18<br>19<br>20<br>21<br>22<br>23<br>24                         | Jacobs<br>(2015)      | Adolescent end of<br>life preferences and<br>congruence with<br>their parents'<br>preferences: results<br>of a survey of<br>adolescents with<br>cancer   | Norway  | Qualitative<br>three sessions of<br>dyadic interviews  | To explore<br>AYACs' end of<br>life preferences<br>and to assess the<br>congruence of<br>these preferences<br>with the parents'<br>beliefs                                   | 17 adolescent/ family dyads<br>17 AYACs (age range 14-<br>21, 71% under 18)   | Adolescents with the majority preferred to<br>talk about EOL in the majority preferences, but<br>important facets if adolescents' EOL wishes<br>were not known if adolescents' EOL wishes adolescents' EOL wishes<br>were not known if adolescents' EOL wishes adolescents' EOL wishes adolescents' EOL wishes adolescents' EOL wishes' adolescents' eol adolescents | Low        |
| 25<br>26<br>27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41 |                       |  |         |  |  | C A   | n.bmj.com/ on June 13, 2025 at Agence Bibliographique<br>ng, and similar technologies.   |            |
| 42<br>43<br>44<br>45<br>46   |                       |  |         | For peer review  | only - http://bmjo   | ppen.bmj.com/site/about/guid  |  | 7          |

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

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| 22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31<br>32  | Mobley<br>(2023) | Clinical Trial<br>Participation: A<br>qualitative study of<br>Adolescents and<br>Younger Adults<br>Recently<br>Diagnosed with<br>Cancer | USA                  | Qualitative<br>Grounded theory<br>analysis of semi-<br>structured<br>interviews   | Clinical trial<br>participation | 9 AYACs (age range 16-20)              | of timing, decisional jole, and emotional impact<br>Informing participation involved decision-making<br>processes, specific knowledge, understanding<br>and external infraence.<br>Participant relationships emphasized the<br>importance of communication and relationships<br>with providers and parents. Patient determinants<br>centered on motives from different perspectives<br>pre-conceived attitudes, and understanding of<br>CCTs |         |
| 33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47                            |                  |   |                      | For peer review   | / only - http://bmjc            | open.bmj.com/site/about/guid           | 2025 at Agence Bibliographique<br>gies.  | 9       |

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

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| 27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47                      |                     |   | For peer reviev |   | pen.bmj.com/site/about/g                                     | similar technologies.<br>uidelines.xhtml   | 11  |

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

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

| Pag   | e 53 of 75 |  |                    |   | l   | BMJ Open  | Building relation to the second secon |      |
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| 36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47  |            |  |                    | For peer reviev   | v only - http://bmjo  | open.bmj.com/site/about/gui   | delines.xhtml  | 14   |

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

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

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

# Update – December 2023 Medline

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

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

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

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

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

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

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

8 6 and 7 163

### Embase

Embase <1974 to 2023 December 19>

**BMJ** Open

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

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

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

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

5 1 and 2 and 3 and 4 1032

6 limit 5 to english language 1010

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

8 6 and 7 107

## PsycINFO (via Ebsco)

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

|    |  | Language: - english<br>Search modes -<br>Boolean/Phrase | Databases<br>Search<br>Screen -<br>Basic<br>Search<br>Database -<br>APA<br>PsycInfo          |           |
|----|--|---|--|-----------|
|    |  | Expanders - Apply                                       | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic<br>Search   |           |
|    |  | equivalent subjects<br>Search modes -                   | Database -<br>APA  |           |
| S9 | S1 AND S2 AND S7 AND S8  | Boolean/Phrase  | APA<br>PsycInfo  | 6,549     |
|    | (affect* or effect* or influenc* or resultant or                                   |   | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic             |           |
|    | impact* or perception* or perspective* or  | Expanders - Apply                                       | Search   |           |
|    | encounter* or preference or opinion or<br>involvement or occurance* or feel or "go | equivalent subjects<br>Search modes -                   | Database -<br>APA  |           |
| S8 | through" or experienc*)  | Boolean/Phrase  | PsycInfo<br>Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic | 3,524,144 |
|    |  | Expanders - Apply 🧹                                     | Search   |           |
|    |  | equivalent subjects                                     | Database -   |           |
| S7 | (S5) or (S3 )  | Search modes -<br>Boolean/Phrase                        | APA<br>PsycInfo  | 62,557    |
|    |  |   | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic             |           |
|    |  | Expanders - Apply                                       | Search   |           |
|    |  | equivalent subjects<br>Search modes -                   | Database -<br>APA  |           |
| S6 | S4 AND S5  | Boolean/Phrase  | APA<br>PsycInfo  | 62,384    |
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| \$5 | ( (DE "neoplasms" OR DE "Benign Neoplasms"<br>OR DE "Breast Neoplasms" OR DE "Endocrine<br>Neoplasms" OR DE "Leukemias" OR DE<br>"Melanoma" OR DE "Metastasis" OR DE<br>"Nervous System Neoplasms" OR DE "Terminal<br>Cancer"))   | Expanders - Apply<br>equivalent subjects<br>Search modes -<br>Boolean/Phrase | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic<br>Search<br>Database -<br>APA<br>PsycInfo | 62,384    |
|-----|---|--|---|-----------|
| S4  | ( (DE "neoplasms" OR DE "Benign Neoplasms"<br>OR DE "Breast Neoplasms" OR DE "Endocrine<br>Neoplasms" OR DE "Leukemias" OR DE<br>"Melanoma" OR DE "Metastasis" OR DE<br>"Nervous System Neoplasms" OR DE "Terminal<br>Cancer"))   | Expanders - Apply<br>equivalent subjects<br>Search modes -<br>Boolean/Phrase | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic<br>Search<br>Database -<br>APA<br>PsycInfo | 62,384    |
| 53  | ("TYA cancer" or "TYA oncology" or "AYA<br>cancer" or "AYA oncology" or ("young adult" n3<br>(cancer or oncology or leuk?em* or lymphom*<br>or h?ematol*)) or ("teenage and young adult"<br>n3 cancer) or ("teenage and young adult" n3<br>oncology) or (teenage* n3 cancer) or (teenage*<br>n3 oncology) or (adolescen* n3 cancer) or<br>(adolescen* n3 oncology) or ("young people"<br>n3 cancer) or ("young people" n3 oncology) or<br>("teenage and young adult" n3 leuk?emia*) or<br>(teenage* n3 leuk?emia*) or (adolescen* n3<br>leuk?emia*) or ("young people" n3 leuk?emia*)<br>or ("young adult" n3 leuk?emia*) or (teenage<br>and young adult" n3 h?ematol*) or ("teenage*<br>n3 h?ematol*) or (adolescen* n3 h?ematol*) or<br>("young people" n3 h?ematol*) or ("young<br>adult" n3 h?ematol*) or ("young<br>adult" n3 lymphom*) or (teenage* n3<br>lymphom*) or (adolescen* n3 lymphom*) or<br>("young people" n3 lymphom*) or ("young<br>adult" n3 lymphom*)) | Expanders - Apply<br>equivalent subjects<br>Search modes -<br>Boolean/Phrase | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic<br>Search<br>Database -<br>APA<br>PsycInfo | 2,072     |
| S2  | (Communicat* or Disclos* or inform* or<br>Interact* or relationship* or Conversation* or<br>Dialogue* or triad* or Interview* or consult* or<br>"decision making") or DE "communication" OR<br>DE "information dissemination" OR DE<br>"conversation"   | Expanders - Apply<br>equivalent subjects<br>Search modes -<br>Boolean/Phrase | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Basic<br>Search<br>Database -<br>APA<br>PsycInfo | 2,545,968 |

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

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

## CINAHL (via Ebsco)

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

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

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

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

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

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| near/3 oncology) or ("young people" near/3 cancer) or ("young people" near/3 oncology) or<br>("teenage and young adult" near/3 leuk?emia*) or (teenage* near/3 leuk?emia*) or<br>(adolescen* near/3 leuk?emia*) or ("young people" near/3 leuk?emia*) or ("young adult"<br>near/3 leuk?emia*) or ("teenage and young adult" near/3 h?ematol*) or (teenage* near/3<br>h?ematol*) or (adolescen* near/3 h?ematol*) or ("young people" near/3 h?ematol*) or<br>("young adult" near/3 h?ematol*) or ("young people" near/3 h?ematol*) or<br>("young adult" near/3 h?ematol*) or ("teenage and young adult" near/3 lymphom*) or<br>(teenage* near/3 lymphom*) or (adolescen* near/3 lymphom*) or ("young people" near/3<br>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*<br>or Dialogue* or triad* or Interview* or consult* or "decision making")<br>Date Run: Wed Dec 20 2023 16:04:13 GMT+0000 (Greenwich Mean Time)<br>Results: 12748181   |
| 4: TS= (affect* or effect* or influenc* or resultant or impact* or perception* or perspective*<br>or encounter* or preference or opinion or involvement or occurance* or feel or "go<br>through" or experienc*) Date Run: Wed Dec 20 2023 16:04:19<br>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)<br>Date Run: Wed Dec 20 2023 16:04:39 GMT+0000 (Greenwich   |
| Mean Time) Results: 132   |
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## 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

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|--|--|
| 15<br>16<br>17<br>18<br>19<br>20<br>21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40 |  |
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## First run – November 2022 Medline (via Ovid)

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

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

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

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

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

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

## Embase (via Ovid)

## Embase <1974 to 2022 November 23>

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

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

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

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

5 1 and 2 and 3 and 4 939

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

## PsycInfo (via Ebscohost)

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

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

S2

S1

2,423,980

894,375

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

## CINAHL (via Ebscohost) Accessibility Information and Tips

## Print Search History

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## Web of Science Core Collection

# Web of Science Search Strategy (v0.1)

# Database: Web of Science Core Collection

# Entitlements:

 - WOS.IC: 1993 to 2022

- WOS.CCR: 1985 to 2022

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

#### # Searches:

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

Results: 2129759

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

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

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

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

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

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

Results: 684

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

or



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# PRISMA 2020 Checklist

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

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## PRISMA 2020 Checklist

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



## PRISMA 2020 Checklist

|  |   |  | BMJ Open d by op   | Page 76 of 75                         |  |  |  |  |
|--|---|--|--|---------------------------------------|--|--|--|--|
| 1  | PRISM   | BMJ Open de by copyrigh Page 76 of Page 76 of Page 76 of Page 76 of Print Page 76 of Pag |  |                                       |  |  |  |  |
| 3<br>4<br>5  | Section and<br>Topic  | ltem<br>#  | Checklist item   | Location<br>where item<br>is reported |  |  |  |  |
| 6<br>7   |   | 23c  | Discuss any limitations of the review processes used.  | Pages 11<br>and 12                    |  |  |  |  |
| 8  |   | 23d  | Discuss implications of the results for practice, policy, and future research.   | Page 12                               |  |  |  |  |
| 9<br>10  | OTHER INFORMAT  | ION  | es s a   |                                       |  |  |  |  |
| 11   | Registration and  | 24a  | Provide registration information for the review, including register name and registration number, or state that the was not registered.  | Page 3                                |  |  |  |  |
| 12<br>13   | protocol  | 24b  | Indicate where the review protocol can be accessed, or state that a protocol was not prepared.   | Supplemental file                     |  |  |  |  |
| 14   |   | 24c  | Describe and explain any amendments to information provided at registration or in the protocol.  | Not appliable                         |  |  |  |  |
| 15   | Support   | 25   | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the eview.   | Page 13                               |  |  |  |  |
| 16<br>17<br>18   | Competing interests   | 26   | Declare any competing interests of review authors.   | Page 13                               |  |  |  |  |
| 19<br>20<br>21   | Availability of data, code and other materials  | 27   | Report which of the following are publicly available and where they can be found: template data collection forms are a extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | Page 13                               |  |  |  |  |
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**BMJ** Open

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

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

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

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

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

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

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

Ella Clyne, Medical Student, University of Cambridge

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

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

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

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

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

## Abstract

## Objectives

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

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

## Design

Systematic review with narrative synthesis.

## Data sources

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

## Eligibility criteria for selecting studies

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

## Data extraction and synthesis

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

## Results

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

## Conclusion

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

PROSPERO registration number CRD42022374528

## Strengths & limitations of this study

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

## Introduction

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

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

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

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

## Aim

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

## **Review questions:**

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

## Methods

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

## Table 1. Search Terms

## Strand 1 – TYAC

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

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

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

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

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

## **Patient and Public Involvement Statement**

## None

## Results

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

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

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

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

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

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

Table 3 Study population

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

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

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

## Who is present with TYACs in healthcare consultations and communication?

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



Table 4 Supporter Demographics

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

#### Discussion

#### **Principal Findings**

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

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

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

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

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

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

### Meaning of the study

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

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

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

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

## Strengths and weaknesses

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

### Implications for clinicians and policy makers

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

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

### Unanswered questions and future research

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

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

### Conclusion

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

## Author Contributions:

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

Conflicts of Interest:

The authors declare no conflict of interest.

Ethics Approval:

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

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## 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

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

Figure Legends:

Figure 1: PRISMA Flow diagram

Table 1: Search terms

Table 2: Summary of articles

Table 3: Study Population

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

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

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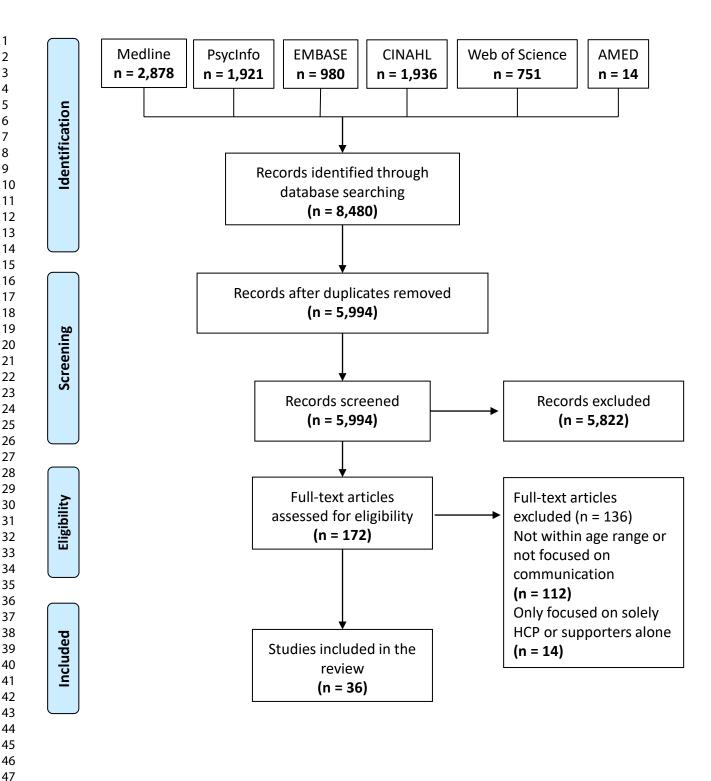
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|---|-------------------|---|-----------------------|---|---|--|--|---|
| 1<br>2<br>3   | First author      |   |                       | Study Type -<br>analysis method   | Table 2. S  | ummary of Articles   | cted by copyright, inc<br>Key findings   |   |
| 4   | (year)            | Title   | Setting               | Data collection   | Focus   | Participant Characteristics  | Key findings   | WoE Score   |
| 5<br>6<br>7<br>8<br>9<br>10<br>11<br>12<br>13<br>14<br>15<br>16<br>17<br>18<br>19<br>20<br>21<br>22<br>23<br>24<br>25 | Ananth<br>(2021)  | A Stakeholder-<br>Driven Qualitative<br>Study to Define<br>High Quality End-<br>Of-Life Care for<br>Children with<br>Cancer                             | USA<br>Multicentre    | Qualitative -<br><u>thematic analysis</u><br>Semi-structured<br>interviews and<br>focus groups.                     | To explore end of<br>life care (EOLC)<br>priorities for<br>children with<br>cancer and their<br>families. | <ul> <li>54 participants:</li> <li>10 AYACs (age range: 17-23 years)</li> <li>25 parents (including 12 bereaved parents)</li> <li>19 healthcare professionals</li> </ul> | Important to have firegt communication v<br>child or young person regarding do<br>making.<br>Interdisciplinary correction of the teams<br>for high quality for the teams of the team of team o | ecision-<br>s is vital<br>nuity of<br>nily and  |
|   | Bahrami<br>(2017) | Information<br>Sharing Challenges<br>Between<br>Adolescents with<br>Cancer, their<br>Parents and Health<br>Care Providers: A<br>Qualitative Study       | Iran<br>Single centre | Qualitative<br>descriptive-<br>exploratory study<br>- grounded theory<br>analysis<br>Semi-structured<br>interviews. | Information<br>sharing between<br>AYACs, parents<br>and health<br>professionals.                          | 33 participants:<br>12 AYACs (age range at<br>interview: 15-20 years,<br>within 1 year of diagnosis)<br>6 supporters<br>6 healthcare professionals                       | AYACs feel they are scluded from infor<br>sharing sessions of seen parents and her<br>professionals. The second second second second<br>inferior' sources.<br>Parents were often the second s | althcare<br>iliation,<br>on from<br>rmation<br>atrolling<br>ats may<br>ffective<br>althcare |
| 26<br>27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39                                      | Barakat<br>(2014) | A Qualitative Study<br>of Phase III Cancer<br>Clinical Trial<br>Enrollment<br>Decision Making<br>Perspectives from<br>AYAC, Caregivers<br>and Providers |                       | Qualitative -<br><u>thematic analysis</u><br>Semi-structured<br>interviews.   | Clinical trial<br>enrollment.   | 40 participants:<br><b>13 AYACs (age range: 15-<br/>21 years)</b><br>16 supporters<br>11 healthcare professionals  | Four patterns of tecision-making<br>identified:<br>1. AYAC abdicates to caregiver,<br>2. Caregiver based and AYAC approved,<br>3. Collaborative,<br>4. AYAC in charge of tecision-making.<br>Caregivers perceited AYAC to be in ch<br>decision making to be abdicates to care<br>the most common form of decision making<br>Distress and poor chealth limited<br>involvement in the decision.<br>Developmental and emotional maturity face   | eas the<br>er" was<br>s.<br>AYAC  |
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| 16<br>17<br>18<br>19<br>20<br>21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42 | Cicero-<br>Oneto<br>(2017) | Decision-making<br>on therapeutic<br>futility in Mexican<br>adolescents with<br>cancer: a<br>qualitative study | Mexico<br>Multicentre   | Qualitative -<br><u>thematic analysis</u><br>Semi-structured<br>interviews | futility   | 32 Participants<br>13 paediatric oncologists<br>13 parents or primary carers<br>6 AYACs (age range 13-18<br>years) | Four themes were <b>Bioma</b> fied<br>1. flow of <b>Forma</b> fied<br>1. flow of <b>Forma</b> fied<br>2. disclosure <b>Forma</b> fied<br>3. decision <b>Forma</b> forgnosis<br>3. decision <b>Forma</b> forgnosis<br>5. decision <b>Forma</b> forgnosis<br>5. decision <b>Forma</b> forgnosis<br>5. decision <b>Forma</b> forgnosis<br>6. decision <b>Forma</b> forgnosis<br>7. decision <b>Forma</b> fo | Medium        |
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| 21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30  | Davies<br>(2019)  | 'Life then', 'life<br>interrupted', 'life<br>reclaimed': the<br>fluctuation of<br>agency in teenagers<br>and young adults<br>with cancer   | UK<br>single centre        | qualitative -<br>thematic analysis<br>case studies -<br>multiple<br>interviews                   | Fluctuation of<br>agency across<br>time and between<br>cases | 22 participants<br>5 AYACs (16-24 years)<br>5 parents carers (2 fathers,<br>3 mothers, 1 couple),<br>5 healthcare professionals (4<br>nurses and 1 oncology<br>consultant)<br>5 other supporters (1<br>boyfriend, 1 girlfriend, 1<br>aunt, 2 friends) | Agency fluctuates vor time within cases and<br>between cases. Agency can fluctuate between<br>personal, proxy and collective perspectives.<br>Personal agency is nigh prior to diagnosis,<br>decreases after diagnosis and is reclaimed after<br>treatment.  | Medium |  |  |
| 31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39  | Ellis (2016)      | Fertility concerns<br>among child and<br>adolescent<br>survivors and<br>parents: a<br>qualitative study  | Australia<br>single centre | Qualitative<br>semi-structured<br>telephone<br>interviews  | recently off treatment and                                   | 97 participants from 45<br>families<br>19 AYACs (age range 7-17<br>at diagnosis, mean age<br>13.3)<br>44 mothers and 34 fathers   | reported and conversations about fertility were<br>frequently interrupted to discuss illness and<br>treatment. These fertility discussions were not<br>then continues once the AYAC was off<br>treatment   | Medium |  |  |
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| 43<br>44<br>45<br>46   |                 |  |   | For peer review  | v only - http://bmjo  | pen.bmj.com/site/about/gui  | delines.xhtml <b>e</b>   | 4            |

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

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

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

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

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

|  |                    |   |     |             | E  | 3MJ Open  | Greed by copyress themes 202   | Page 34 of 6 |
|--|--------------------|---|-----|-------------|--|---|--|--------------|
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| 20<br>21<br>22<br>23<br>24<br>25<br>26<br>27<br>28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39<br>40<br>41<br>42<br>43<br>44<br>45<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>46<br>47<br>47<br>47<br>47<br>47<br>47<br>47<br>47<br>47<br>47 |                    |   |     |             |  | open.bmj.com/site/about/guide   | 13, 2025 at Agence Bibliographique<br>nologies.  | 10           |

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

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

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

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

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

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

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

## Update – December 2023 Medline

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

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

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

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

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

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

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

8 6 and 7 163

#### Embase

Embase <1974 to 2023 December 19>

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

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

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

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

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

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

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

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

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

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

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

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

### CINAHL (via Ebsco)

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

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

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

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

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

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**BMJ** Open

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

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

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

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

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5 1 and 2 and 3 and 4 19

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

# First run – November 2022 Medline (via Ovid)

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

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

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

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

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

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

## Embase (via Ovid)

#### Embase <1974 to 2022 November 23>

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

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

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

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

5 1 and 2 and 3 and 4 939

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

### PsycInfo (via Ebscohost)

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

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

S2

S1

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

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

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

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

Expanders - Apply

Search modes -

**Boolean/Phrase** 

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

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

2,423,980

894,375

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# CINAHL (via Ebscohost) Accessibility Information and Tips

# Print Search History

| <u>Acc</u> | IAHL (via Ebscohost)<br><u>essibility Information and Tips</u><br>nt Search History<br>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<br>Date: 20050101-<br>20221231<br>Expanders - Apply<br>equivalent subjects<br>Narrow by Language:<br>- english<br>Search modes -<br>Boolean/Phrase | Interface -<br>EBSCOhost<br>Research<br>Databases<br>Search<br>Screen -<br>Advanced<br>Search<br>Database -<br>CINAHL | 1,837   |

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

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

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

## Web of Science Core Collection

# Web of Science Search Strategy (v0.1)

# Database: Web of Science Core Collection

# Entitlements:

 - WOS.IC: 1993 to 2022

- WOS.CCR: 1985 to 2022

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

#### # Searches:

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

Results: 2129759

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

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

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

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

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

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

Results: 684

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

to occurrence of the occurrenc

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|---------------|

# PRISMA 2020 Checklist

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



# PRISMA 2020 Checklist

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

# PRISMA 2020 Checklist

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