Clinical Oncology Society of Australia

COSA guidelines for the psychosocial management of AYAs diagnosed with cancer

September 2024

These guidelines have been published by the Clinical Oncology Society of Australia (COSA) and replace the 2012 guidance for healthcare professionals titled *Psychosocial management of AYAs diagnosed with cancer.*

This work was undertaken by COSA in partnership with the Behavioural Sciences Unit at UNSW Sydney with funding facilitated by Canteen, as part of the Youth Cancer Services program funded by the Australian Government.

Guideline developer:

In partnership with:

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1. Abbreviations

AYA	Adolescent and young adult
CNS	Central nervous system
LGBTQI+	Lesbian, gay, bisexual, transgender, queer and/or questioning, intersex and other diverse sexual orientation and gender identities
PROs	patient-reported outcomes
PROMs	Patient-reported outcome measures
QoL	Quality of life

2. Introduction

2.1 Background

In 2012, COSA produced a guidance for healthcare professionals titled *Psychosocial management of AYAs diagnosed with cancer* as part of a national Youth Cancer Networks Program project funded by the Australian Government. The guidance was developed by a Working Group of multidisciplinary healthcare professionals with expert knowledge of the topic areas at a time when recognition of the distinct needs of this age-group were just emerging. As a result, the available evidence to inform the guidance was limited, mainly comprising opinion pieces, clinical commentary and case reports. Many resources used to inform the guidance lacked peer review and as such, the rigour desired for clinical practice recommendations.

The field of AYA oncology and associated evidence-base has significantly developed since this time, and dedicated AYA cancer services have been established in many countries, including Australia. While the best standard of care for young people with cancer is undoubtedly provided by clinicians who have been specifically trained to care for them, outside these services AYA patients represent a small part of the patient profile for most healthcare professionals. As a result, specialist training in adolescent medicine or cancer care may not be a priority for these clinicians. In Australia, around a quarter of AYAs requiring hospital-based cancer treatment are cared for outside of dedicated AYA cancer services.[1]

Optimal psychosocial care for AYAs with cancer requires the development of core competencies and skills including:

- understanding the developmental stages of normal adolescence
- an awareness of the rights of young people
- understanding issues around confidentiality and privacy
- acknowledging the needs of young people from diverse or minority populations
- recognising the needs of family members, partners and carers
- developing AYA focused communication and relationship building skills
- understanding and responding to non-compliance
- workforce boundaries and professional self-care
- working with educational institutions and workplaces, and
- facilitating the provision of financial information and support.

These areas are addressed in the guidelines and, when implemented appropriately, will improve the care provided to AYAs with cancer. In order to achieve best-practice care, further education and training for healthcare professionals is strongly recommended.

2.2 Intended users

These guidelines have been developed for all healthcare professionals involved in the clinical management of AYAs diagnosed with cancer.

These guidelines aim to:

- provide succinct information regarding the age-appropriate psychosocial needs of AYAs diagnosed with cancer
- provide information about how to meet these needs across different treatment settings
- make evidence-based recommendations regarding best-practice psychosocial care of AYAs diagnosed with cancer.

2.3 Target population

These guidelines are applicable to all AYAs – aged between 15 and 25 years of age – diagnosed with cancer of any type. The guidelines acknowledge the importance of personalised assessment and management plans, based on the patient's needs, preferences, life stage, level of maturity and independence, in the context of multidisciplinary health care.

2.4 Purpose and scope

These guidelines provide information to assist healthcare professionals working with AYAs with cancer to recognise and meet the particular psychosocial needs of young patients. They describe how the age and stage of life of AYAs may impact their distress levels, self-esteem, need for information and communication, family dynamics, peer relationships, self-identity, sexuality and sexual function, body image, perceptions of future, early survivorship, existential perspectives and other subjective components of the cancer experience.

Evidence-based recommendations and consensus-based good practice statements are provided across the following areas:

- delivering health care
- clinical management
- acute psychosocial care
- post-acute psychosocial care
- treatment and side effects
- enhancing well-being
- life outside cancer
- relationships
- progressive and incurable cancer.

Out of scope is the psychosocial care of AYAs diagnosed with cancer regarding long-term survivorship, alternative therapies (used in lieu of conventional cancer treatment) and support needs for children of AYA patients.

AYA optimal care pathway

These guidelines are intended to be both complementary and in alignment with the principles described within the Cancer Australia-endorsed *Optimal Care Pathway for Adolescents and Young Adults with Cancer*.[2]

These guidelines add in-depth, evidence-based recommendations for clinical practice that build on these principles, and provide concrete, actionable, age-appropriate ways in which to deliver optimal youth friendly care. The use of these guidelines in tandem with the overarching frameworks and timelines provided within the optimal care pathway will together support high-quality, best-practice AYA cancer care in Australia, with a focus on ensuring optimal psychosocial care for AYAs with cancer during active treatment and beyond.

2.5 Funding

This work was undertaken by COSA in partnership with the Behavioural Sciences Unit at UNSW Sydney with funding facilitated by Canteen, as part of the Youth Cancer Services program funded by the Australian Government.

2.6 Guideline development process

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Systematic reviews

A series of eighteen connected systematic reviews across four databases [MEDLINE, PsycINFO, CINAHL, Cochrane] were completed and meta-review methodology used to synthesise results into evidence summaries and key points in a "review of reviews" approach. Existing national and international guidelines were also reviewed for relevant content.

Where content from reviews was deemed to be insufficient or did not exist, a rapid review for individual studies was conducted on that topic. The only topic with insufficient review material was the support needs of siblings. [Link to *Support needs of families, partners, and carers*]

Two independent reviewers evaluated publications for importance, quality and potential clinical practice impact and screened articles for eligibility. Inclusion criteria included review articles focused on the psychosocial health and well-being of AYAs (age range 15-25 years) diagnosed with any type of cancer (primary, secondary or recurrent), published in English from 2005-2024.

Articles were excluded if they were exclusively paediatric (mean age <15 years), exclusively adult (mean age ≥40 years) or where AYAs were part of a broader study population and aggregated data was presented only. Childhood cancer survivors were outside the scope of these guidelines and articles excluded if cancer diagnosis was prior to 15 years of age.

A total of 251 review articles met the inclusion criteria for the guidelines across all topics, and seven individual studies were included for the content on siblings. A detailed description of the search method and results is published in Sansom-Daly et al. (XXXX).

Development of recommendations and good practice statements

The multidisciplinary Working Group of expert AYA clinicians (disciplines including psychology, neuropsychology, social work, nursing, medical oncology, exercise physiology, nutrition, AYA service management) and AYA patient representative synthesised the evidence and distilled evidence-based recommendations and consensus-based good practice statements.

- Recommendations were categorised as “strong” if the evidence was from at least one guideline or higher-level review (systematic, meta-analysis, integrative).
- Recommendations were categorised as “weak” if the evidence was from another type of review (narrative, rapid, scoping or review without specified method).
- Good practice statements were used where no evidence existed but there was consensus-based agreement based on clinical observation and/or judgement.

Citation

Clinical Oncology Society of Australia Psychosocial Guidelines Working Group (XXXX) COSA guidelines for the psychosocial management of AYAs diagnosed with cancer. Clinical Oncology Society of Australia; Sydney.

3. Recommendations for delivering health care

3.1 Communication and relationship building

Recommendations

Strong recommendations

- Healthcare professionals should have specialised communication and relationship building skills tailored to the young person's developmental stage to effectively support AYAs with cancer.
- Healthcare professionals should establish a private line of communication for the AYA with cancer, to increase their sense of personal agency and autonomy, especially when discussing personal or sensitive material.
- Healthcare professionals should not use medical jargon or euphemisms when speaking to AYAs with cancer, acknowledging the impact this can have on their understanding, and in turn, their willingness to ask questions.
- Healthcare professionals should provide information to AYAs with cancer that takes into account their level of health literacy, life stage, and level of cognitive and emotional development.
- Healthcare professionals should identify the amount and type of information the AYA with cancer prefers, before delivering information, noting the uniqueness of each AYA. By consulting the young person in this way, they will feel more involved and in control of their own health care.
- Healthcare professionals should provide information to AYAs with cancer in a number of different ways to maximise their understanding, such as verbal and written, alongside visual aids where possible. The information should be repeated throughout treatment to enhance their understanding. Healthcare professionals should listen with sensitivity and empathy throughout the information exchange with the young person.
- Healthcare professionals should support AYAs with cancer in navigating sources of information from the internet, by recommending websites that are relevant, reliable, safe and appropriate for them.
- Healthcare professionals should be empathic, respectful, open and honest when communicating with AYAs with cancer. Young people value healthcare professionals who they are able to confide in, and those who take the time to establish a relationship with them. We recommend healthcare professionals try and understand the AYA's world, outside of their cancer.

Weak recommendation

- AYAs with cancer are more likely to feel valued and heard when healthcare professionals develop a successful relationship with them, which can be pivotal to the way they experience their care within the health system.

Evidence summary

Tailoring communication

Specialised communication and relationship-building skills are essential for healthcare professionals who care for AYAs with cancer.[3] Young people engage very differently with healthcare teams than younger children or older adults do.[4] When communicating with young people, healthcare professionals need to respond to each patient's level of maturity and independence with an individualised approach, to ensure the basic rights of the patient are being met.[5]

Communicating effectively with AYAs may prove challenging for healthcare professionals who generally work with other adults who share the same views and expectations about healthcare, and those from the paediatric sector, who most commonly work with the parents of younger patients to achieve the best outcome.[4]

Key points

- Reinforce the collaborative nature of the relationship between the healthcare professional and AYA with cancer. Young people appreciate clinicians who treat them as a person and not just as a patient.[6]
- Ensure all young people are given time alone or a "private line" of communication to increase their sense of personal agency, whilst prompting a sense of autonomy.[3, 7-9] This is particularly important when discussing personal or sensitive material with a young person.[8, 9]
- Young people can find it challenging navigating the medical jargon and complexity of level of details,[10] and may become reluctant to ask questions for fear of seeming "stupid".[6] Assist the AYA by initiating common questions, rather than waiting for them to do so.[11]
- Avoid euphemisms when speaking to AYAs and use simple language, proper terminology, and check for understanding to ensure there isn't any confusion or misunderstanding.[12]
- Use gender-neutral language (for example partner instead of husband/wife or boyfriend/girlfriend) when speaking to AYAs.[12]
- Silence should not be interpreted as a lack of desire to understand what is going on or an indication that an AYA does not have any further questions.[11]
- Treat the young person's concerns with respect, and keep in mind that their priorities may be different to those of the healthcare professionals treating them, their family and/or carers.[13] Remain aware of potential communication challenges that may arise when negotiating the inclusion of family in discussions while simultaneously fostering the AYA's emerging independence.[14, 15]

Providing information

Information is important because it gives the young person a sense of control, reduces their confusion, anxiety and uncertainty about their illness,[16] and may assist them to plan for the future.[17, 18] Communicating information effectively to young people requires a tailored approach due to the intersection of cancer at an age associated with emotional reactivity and variable maturity.[7, 19] AYAs with cancer can be challenging in terms of individual differences in how much and what information they need, prefer and can handle emotionally.[20]

Health literacy is described as the degree to which an individual has the capacity to obtain, process and understand basic health information needed to make appropriate health decisions.[21, 22] It is crucial for healthcare professionals to provide information that is at the young person's level of health literacy.[21]

Key points

- When providing information to AYAs with cancer, select and tailor it to match the patient's life stage and level of cognitive and emotional development,[13, 19, 23] allowing them to play a larger role in their cancer care in conjunction with their family members or carers.[5, 13, 15]
- Establish the individual preferences of the young person for information, noting differences in the desired amount and type (e.g., do they want more general information or detailed information) prior

to delivering information to them,[23, 24] acknowledging that information can be distressing for some people and empowering for others.[20]

- Direct information to the AYA, not through their parents.[18] Sit at the patient's level and face the young person during conversations.[25] Ensure the AYA feels consulted and involved in treatment decisions by being honest and sharing all information that is available and/or requested by them.[6, 11]

- Complex information about treatment regimens for example, should be provided in a number of different ways to maximise the AYA's understanding.[6, 15, 16, 26, 27] Consider using verbal and written information, alongside visual aids (i.e., sharing the patient's scans) where possible, and contextualise the information to the young person's way of life in the here and now.[11, 26, 28]

- Young people are likely to require frequent repetition of information to assist understanding.[6, 15, 16] Information should be repeated at different stages of cancer treatment and during each interaction with the young person.[19, 25, 29] A simple approach is to start by eliciting what the patient already understands, find out what they wish to know, and check afterwards what they have understood.[17]

- Most AYAs are familiar with technology and regularly use the internet as a source of information and support, despite knowing the information is of variable quality.[8, 21, 22, 25] Given the limited number of websites available with information targeted directly to young patients, healthcare professionals should support them by recommending websites that are truly helpful, relevant, safe, and appropriate for their age.[8, 20, 22]

Engaging and building relationships

Developing a successful working relationship with AYAs with cancer is essential to best practice care as it enhances trust and communication, ensures the young person feels valued and heard, and can promote greater adherence to treatment.[30-32] [Link to *Adherence to treatment*] The way in which healthcare professionals treat young people is pivotal to the culture of the health care they experience.[4, 29]

Key points

- Be aware of where the AYA is in their physical, emotional and social stage of development and how these factors may impact upon their experience and responses during their cancer journey.[3, 13, 25]

- Be honest, open, professional, authentic and just be yourself. Young people with cancer want a trusted healthcare professional who interacts and cares about them.[6, 14, 15, 26]

- Young people value healthcare professionals they can confide in, and those who take the time to build a relationship with them.[3, 4, 6, 29] This established relationship is then more likely to enhance a young person's sense of control and autonomy during cancer treatment.[7]

- Build the AYA's trust by following through on commitments. Young people are often less forgiving when commitments are broken due to their stage of cognitive development and egocentrism.[25] If commitments need to change, explain the reasons why to the young person in a timely manner.[6] For instance, if you tell a young person that you will meet with them when they are having treatment, but you can't make it, make sure that you let them know, even if they seem like they aren't engaged.

- Establish rapport with the young person[3] and try to understand and interpret behaviours from their perspective,[25] by demonstrating genuine concern.[3]

- Nurture realistic expectations as this will create an opportunity for any goals to be met. This may mean discussing the same information repeatedly until the young person understands what is being discussed, what the goals are, and how these can be achieved. Listen with sensitivity and empathy throughout the information exchange with the AYA.[10, 33]

- Be empathic, respectful and non-judgemental. This is particularly important when having more sensitive discussions[8] with AYAs surrounding topics such as sexual identity formation, exploration of sexual preferences and practices, the development of romantic partnerships and family planning.[12]
- Bring curiosity to your practice with AYAs. Try to understand their world, what's important to them and make sure that you are getting to know about them outside of their cancer.[6, 28] This may mean that you need to become more comfortable with talking about particular topics that highlight your own discomforts.[27, 28]

3.2 Confidentiality and privacy

Recommendations

Strong recommendations

- Healthcare professionals should always assure and maintain confidentiality early when working with AYAs with cancer, noting the increased desire for privacy within this stage of development.
- Healthcare professionals should address confidentiality with AYAs with cancer at regular intervals throughout treatment, allowing opportunities for the AYA to report any care needs or concerns.

Evidence summary

Background

Assuring and maintaining confidentiality and privacy is an essential part of working with young people within health care.[32] AYAs have an increased desire for privacy within this crucial stage of development,[32] whereby some young people find themselves isolated and unable to speak openly and honestly to their family or partner, in order to not cause any further pain or anguish to their loved ones.[7, 17] Some young people will consider sacrificing their own preferences for those of their parents.[34]

Assure confidentiality in all clinical settings unless the AYA is at risk to themselves or others, or disclosure is required by law or in accordance with institutional or state-based policies. Young people who do not feel that their confidentiality will be respected are more likely to delay or forgo the use of important health services.[32] This may translate to missed appointments or poor compliance with treatment. The young person should feel comfortable coming back and enquiring with their healthcare team about the challenges they may have experienced throughout and after their cancer journey.[10]

Key points

- Confidentiality is best addressed in a transparent manner with both the AYA and their family members or carers at the initial consultation and at regular intervals throughout the cancer journey.[10]
- Assuring confidentiality with the young person will allow for more accurate reporting in relation to their health care needs and concerns.[32]
- Young people who attend appointments with family members or carers should be given the opportunity to speak alone with healthcare professionals and assured that information will not be shared with family members.[26] Healthcare professionals should always speak to the young person first, before highlighting any issues or concerns in front of parents or partners.[10]
- Opportunities for conversations in private with AYAs will alleviate any pressures the young person may experience with their family members or carers present in the room.[32] This includes giving the young person information surrounding their health care without family and carers present.[10]

3.3 Family involvement in health care

Recommendations

Strong recommendations

- Healthcare professionals should have an awareness of the role family networks play in the AYA's life, and how much family involvement the AYA would like throughout the course of their cancer experience.
- Healthcare professionals should explain that it is not about excluding family members or carers, but rather the AYA with cancer having the opportunity to speak to healthcare professionals first, noting some young people would prefer to have parents and partners included in discussions about their health care.

Evidence summary

Background

By this stage in their life, many AYAs have found independence. A cancer diagnosis can create challenges for young people when they need to become newly reliant on relationships, heavily associated with childhood and dependency.[17, 35] This new dependence on family members and/or carers may undermine the developmental shift toward a greater sense of independence and control, and lead to resentment of this change in the relationship.[35]

The involvement of parents can become problematic when the adolescent reaches young adulthood and wants to manage their own health care.[7, 17] However, complete independence is unlikely to be sustainable when the young person is under the stress imposed by cancer diagnosis and treatment.[17] Family networks play a pivotal role in the well-being of AYAs, providing necessary emotional and practical support.[17] Young people with cancer report a greater sense of belonging and a new appreciation for family who support them during this time.[35]

Key points

- Have an open and honest discussion with the AYA about the level of family or carer involvement they wish to have in their health care, and a clear understanding of what information will remain private between the patient and the healthcare team.[26] This should be re-negotiated with the AYA at regular stages during the cancer care continuum, including before, during and after treatment.[7, 26] Not allowing the young person to choose the level of family involvement can lead to distrust and resentment of both clinicians and family members, resulting in lower treatment adherence.[7, 24]
- Keeping the young person and their family well informed as a priority will reduce any unnecessary distress and uncertainty. AYAs who show the lowest distress also report the best patient-family communication.[17]
- Explain at the start to family members and carers that this is not about excluding them but rather giving the young person an opportunity to talk to their doctor or other healthcare professionals independently first. Many AYAs wish for their parents and/or partners to be included in discussions about their health care and so their presence may in fact be requested.[35] They can undertake several helpful roles and responsibilities including asking questions on behalf of the AYA, retaining and recalling information, and acting as a sounding board for the young person.[7]
- In order to provide holistic care, healthcare professionals still need to acknowledge and consider the concerns of the young person's family in the delivery of care and the support they require.[17] [Link to *Relationships*]

- Family structure should also be observed, noting how particular cultures and family structures play a role in the young person's health care.[32]

3.4 Active decision making in health care

Recommendations

Strong recommendation

- Healthcare professionals should ensure that AYAs with cancer are active participants in decision making regarding their own health care. This often is triadic in nature including the AYA, family and clinician. Whilst the desire and ability of a young person to participate in decision making may vary, healthcare professionals should still assess the AYA's preferences and respect differences that arise.

Evidence summary

Background

Young people are able to have views and make decisions regarding their own health care. There is increasing evidence to support involving AYAs with cancer in the decision-making process,[36] given decision making is considered a key element of patient and family-centred health care.[37]

A cancer diagnosis involves ongoing engagement in medical decision-making across the disease trajectory, between young people and their clinicians, rather than a single event.[25, 37] These interactions are often triadic in nature, including family members or carers in addition to the healthcare professional and patient.[25, 38] The essence of shared decision-making is to present choices, describe options and support decisions based upon the best available evidence, and that align with the AYA's individual values, preferences and treatment goals.[36]

Active decision making for AYAs supports greater independence and a sense of control over their own health care.[10, 32, 39] Young people with cancer should be encouraged to have an active role in making decisions about their health care, including having input into treatment regimes,[10, 30, 32] fertility preservation,[38] clinical trial participation, discontinuation of treatment and location of care and death when standard therapy has failed.[24] Although the desire and ability of a young person to participate in their own medical decision making can vary, healthcare professionals should always assess the AYA's preference and respect any differences that may arise.[30]

Young people can be more open to talking about difficult topics than parents might expect them to be, and parents may withhold information from them if they think it will be distressing[34] despite the AYA having a high desire to participate in the decision making process.[39] The need for advocacy and control can be immense for parents, and is often perceived as important to fulfill their parental role.[24] Mutual protection commonly occurs, particularly in the context of difficult information, where the young person will not disclose information to their parents as they want to protect them, and vice versa.[34]

If health care decisions are made for AYAs, there is likely to be greater incongruence between the preferences of the patient and their family, and the young person being less capable to reflect and adjust to their cancer diagnosis.[24, 34] Young people want to be taken seriously, have their voices heard and preferences respected.[11]

Key points

- Assess the developmental stage of the AYA in order to determine if decision making discussions should be conducted with the young person individually or together with parents.[26]
- Talk directly to young people, rather than to (or through) parents.[5]

- Strive for the highest possible level of patient dignity and autonomy, even when the AYA is not deemed competent to make decisions independently.[35]
- Honouring the AYA's decision can be challenging when it conflicts with the opinion of family members and the healthcare team. However, clinicians have a responsibility to support a model of shared decision-making that enables the young person to access information, freely voice their opinions, negotiate, and participate in the process.[30]
- Do not present the young person with a choice if they do not have a true choice, noting the impact this plays on their developing autonomy.[30]
- An AYA's reluctance or refusal for a particular intervention should carry considerable weight when the proposed intervention is not essential to their welfare. Gain a better understanding of their individual situation, including their fears or concerns regarding the proposed care/decision.[30]
- Be culturally respectful and explore patient/family/community values and practices that relate to health care.[38] Have cultural curiosity, and ask about the AYA's culture and what it means to them.[40]

4. Recommendations for clinical management

4.1 Inpatient environment and support services

Recommendations

Strong recommendations

- Hospitals should provide inpatient environments that are age-appropriate, where AYAs with cancer are cared for with other patients of a similar age, ideally with recreational facilities and spaces, and opportunities to connect with other young people.
- There should be flexibility around hospital routines and visiting policies for AYAs with cancer, and inpatient treatment should be planned to minimise waiting times and facilitate access to available age-appropriate support services.
- Healthcare professionals should provide AYAs with cancer information about expectations and conduct as an inpatient.
- Healthcare professionals should refer AYAs with cancer to community-based services, including possibly to palliative care for symptom management and support, and develop transition plans as early as possible, including when the AYA is an inpatient on active treatment.

Weak recommendation

- Orientation to the inpatient areas and early introduction to the hospital multidisciplinary healthcare team should occur prior to admission for AYAs with cancer. This can help to decrease feelings of anxiety and increase feelings of safety, trust and continuity of care.

Evidence summary

Background

Age-appropriate health care has a positive impact on an AYA's inpatient hospital stay.[16, 41, 42] For most AYAs with cancer, their cancer treatment will be their first experience of the acute health care system. Many will feel anxious, and unsure what to expect and do while an inpatient in hospital. Clinical inpatient care should correspond with the individual AYA's needs in order to be effective.[16]

Young people present treatment-related challenges not only due to the distinct biology of their cancers, but also the psychosocial needs[16] and physiological state of their bodies.[43] It is important to understand these unique differences to ensure the delivery of age-appropriate, high quality and flexible inpatient care.[16, 42] The complex needs of AYAs necessitates healthcare professionals to be educated and skilled in the treatment and management of young people while inpatients.[16, 43]

Age-appropriate and dedicated inpatient environments can increase AYA satisfaction with clinical care, bring young people together and give them a sense of community, connectedness and normalcy.[29] Hospitals can facilitate optimal AYA care through providing the patient with a sense of control, access to positive distractions, and access to social supports.[2] AYA inpatient settings can differ based on location, models of care and expertise of clinicians.[44] Where possible, consider whether a paediatric or adult hospital is most appropriate for the individual AYA.[33, 43, 45]

Key points

- AYAs prefer a hospital inpatient environment that is equipped for them, and to be cared for with other patients of a similar age.[16, 18, 42] Young people undergoing treatment value peer support and connecting with AYA cancer survivors.[16, 18, 46, 47]

- Ideally AYAs should have dedicated, multifunctional spaces within inpatient environments to suit their requirements.[16, 33, 48] This can provide opportunities for engaging with other AYAs, provide access to entertainment, distraction from clinical treatment and reduce isolation throughout inpatient stays.[16, 33, 49, 50]

- Offer young people a choice of hospital room wherever possible, either sharing with other AYAs or having a single room.[47] Provide support for privacy when needed, including bathroom and bedroom amenities, and ensure that private conversations can be undertaken when required.[2, 16]

- Offer young people with cancer a visit pre-admission to reduce anxiety. This could include orientation to the inpatient areas, overview of the treatment setting and introduction to the healthcare team before first admission.[51]

- Provide information to AYAs about what to expect as an inpatient.[18, 47] Try to avoid situations where the young person feels unprepared. Explain what tests and procedures may occur and provide a plan for the day. Having a whiteboard in the hospital room can help communication with the patient.

- Early introduction and familiarisation with an accessible hospital multidisciplinary healthcare team is essential to provide holistic and effective psychosocial and medical support while an inpatient.[16, 52]

- Young people have specific and often complex supportive care needs that require regular review throughout their cancer treatment. It is recommended that AYAs are booked in for treatment at times that facilitate greatest access to age-appropriate support services.[53]

- Implement strategies to reduce the amount of time the AYA spends in the treatment setting. For example, clinicians could suggest that the young person telephones the ward on the day of their admission to determine the best time to arrive to reduce unnecessary waiting times, have bloods taken the day before admission, and prepare and discuss discharge plans as soon as possible.

- Ensure the AYA is aware of what is acceptable behaviour inside the hospital. Discuss expectations about behaviour as early as possible, and provide clear ward-based conduct information.[54] For adolescents, it is often best to have parents present for this discussion so that everyone is aware of the expectations.[53]

- Consider developing flexible arrangements regarding the visiting policy for family and friends.[18, 33, 54] Opportunity to spend time with friends without parents or clinicians present is important, and designated time alone should be accommodated where possible.[4]

- Encourage AYAs to bring comforts from home that help provide a sense of familiarity and safety such as pillows, doonas, photographs, games, computers and music.[50]

- Paediatric and adult hospitals should be encouraged to have flexibility in age requirements to accommodate the individual needs of the AYA.[45]

- Referral to community-based services, including to palliative care for symptom management and support if required or appropriate, can occur at any time and should be considered when the AYA is an inpatient and undergoing active treatment.[50] [Link to *Primary care* and *Early access to palliative care*]

- When treating patients under the age of 18 in adult settings, it is important to be aware of local hospital policies, requirements for consent and child protection issues. All inpatient services for young people should demonstrate strong and up-to-date child protection arrangements.

4.2 Continuity of health care

Recommendations

Strong recommendations

- Health services should allocate resources for a dedicated AYA care coordinator with AYA expertise who is integrated within the wider health care network. Care coordination provides a comprehensive approach to achieving continuity of care for AYAs with cancer.
- Systems should be in place to ensure multidisciplinary communication and handover processes, collaboration, coordination and transition between paediatric and adult health care providers for AYAs with cancer.

Evidence summary

Background

Healthcare professionals are a source of support for AYAs with cancer, especially when there is continuity of health care and the clinician is perceived to be an expert.[18, 42] Continuity of care promotes a sense of safety and trust for AYAs and their family. Where possible, maintaining continuity of care should be prioritised when planning treatment and care for young people with cancer.

The simplest and most effective way to improve and maintain continuity of care for AYAs with cancer is to appoint a care navigator or key worker[2] from within the multidisciplinary healthcare team. These roles are highly valued by the young person, their family members or carers and the healthcare team.[45] AYA care coordination provides health information, emotional support, empowerment and patient advocacy, and can be an important physical presence at key time points. An AYA care coordinator provides continuity in what is often a fragmented and complex healthcare system for patients in this age group.[2]

Key points

- The role of the care navigator or key worker is pivotal, and best placed to assist the young person and their family navigate the healthcare system by providing continuity, consistency, advocacy, advice and support.
- Nurses primarily deliver daily care and are central to providing continuity of care for inpatient stays. They can act as a mediator and advocate for the AYA within the multidisciplinary healthcare team.[17] Having a therapeutic relationship with nursing staff is crucial to the young person's perception of a positive inpatient experience and assisting with continuity of care.[4]
- AYAs appreciate the involvement of clinicians who are adept at working with this age group,[33] therefore upskilling designated multidisciplinary healthcare team members to become regular members of the AYA team can add value with their expertise and increase continuity of care.[2, 45]
- Treating institutions should have a cross-institutional psychosocial handover procedure for AYAs with cancer.[2] While medical handover is regarded as standard practice and a legal duty, it is important to also ensure adequate handover of supportive care.[53]
- Systems should be in place to ensure multidisciplinary collaboration, coordination and transition between paediatric and adult health care providers[2] and to develop and promote linkages with relevant community-based providers.[55] Where an AYA requires transition from paediatric inpatient to adult inpatient setting, the transition should be planned and coordinated prior to the time of transition. [Link to *Primary care* and *Post-acute psychosocial care*]

4.3 Adherence to treatment

Recommendations

Strong recommendations

- Healthcare professionals should communicate openly with AYAs with cancer to promote treatment adherence and build trust, including being truthful and transparent in discussions.
- Healthcare professionals should identify risk factors early that may impact the AYA's adherence to cancer treatment. Risk factors for poor adherence in this cohort include lack of parental involvement and support, logistical issues such as access to treatment, financial concerns, and side effects of treatment that impact the young person's daily living and QoL such as changes in physical appearance and greater symptom burden.
- Healthcare professionals should routinely assess and monitor treatment adherence in AYAs with cancer to promote compliance and identify non-adherence.

Evidence summary

Background

Adherence to treatment protocols leads to optimal outcomes for people with cancer. AYAs have an increased risk of non-adherence to medical regimens.[56-58] Non-adherence to oral medication in young people with cancer has been reported to range from 21-60%,[59] although there is no consistent definition of adherence, and the degree to which an individual adheres to treatment is difficult to measure.[43, 60, 61]

Barriers to treatment adherence among AYAs with cancer may include developmental factors such as risk-taking behaviours and the underappreciation of the future consequences of decision making during a period of growth in self-identity and separation from the family unit.[35, 56, 62, 63] Parental involvement in AYA health care might be greater for younger adolescents who are dependent on parents/guardians for consent to treatment, whereas young adults may have already experienced a level of independence, whether that be social, financial or housing, and have full authority to consent to treatment. [Link to *Family involvement in health care*]

During this life stage there can be a shift in health care management from parent to child, and disagreement or confusion may arise regarding the cancer treatment protocol and/or the person responsible for administering medication.[35] Encouraging the young person to be actively involved in making decisions and managing their own health care can improve treatment adherence, with positive family relationships and open communication important factors that support compliance.[64] [Link to *Active decision making*]

In addition to parental involvement and support, other psychosocial factors may impact treatment adherence in AYAs with cancer. Psychosocial supports, through friendships and peer groups, may support AYA development and self-management skills and enhance adherence rates.[56, 65] On the contrary, socioeconomic status may negatively impact treatment adherence with both longer and more complex treatment regimens associated with non-adherence in this cohort.[64] Logistical issues such as accessing cancer treatment and financial stress including out-of-pocket expenses may be contributing factors.[59, 61]

Adherence may also be affected by the side effects of cancer treatment and their impact on AYA daily living and QoL.[59, 64] Concerns such as changes in physical appearance, managing symptoms such as pain, nausea and fatigue, and missing out on "normal" activities have been linked to poor adherence in young people.[59, 61] Amongst AYAs with cancer, racial and ethnic minorities have been reported to be more likely to have low self-efficacy for health care management[66] which can directly impact symptom management.[67]

Poor relationships and communication with healthcare professionals may be another barrier to treatment adherence for AYAs with cancer.[6] Developing a successful working relationship with the young person can promote treatment adherence and open communication can encourage AYAs to be more cooperative.[6] Truthfulness and transparency from clinicians builds trust with young people.[6] Taking the time to explain medication regimes and developing adherence strategies with the AYA soon after cancer diagnosis may help prevent non-adherence later on. AYAs from culturally and linguistically diverse backgrounds may have poor adherence to treatment if there are barriers to communication.[35] [Link to *Communication and relationship building*]

Key points

- Open communication promotes treatment adherence in AYAs with cancer and builds trust. Healthcare professionals working with AYAs should provide regular opportunities for clarification of the treatment protocol and provide appropriate education about the purpose of treatment and long-term importance of adhering to treatment.

- Identify risk factors early that may impact the young person's adherence to treatment,[35, 62] including logistical issues, financial concerns, and side effects of treatment that may impact their daily living and QoL such as changes in physical appearance and greater symptom burden.[59, 61]

- Suggest adherence strategies such as having a routine for taking medication, using reminder tools (e.g., alarm on mobile phone), using organisation tools (e.g., dosette, or keeping medication in a visible location) or having a back-up plan (e.g., carrying an extra dose of medication in bag).

- Evaluate family relationships, psychosocial support and history of psychological difficulties in AYAs with cancer. Poor adherence is very frequently an expression of distress. Ensure multidisciplinary healthcare team members are involved where appropriate, including clinical psychologists and social workers.[62]

- Continually assess adherence to treatment in AYAs with cancer.[56, 59] There are numerous assessment tools for treatment adherence, each with strengths and limitations.[63] Direct measures include bioassays of serum and urine, but these are unable to detect all drugs and can be costly and invasive (in the case of blood tests).[63] Indirect measures of adherence that are easy to implement and administer include pill counts, patient self-report, family report, or medication diaries; however these are subject to recall bias and/or can be manipulated.[63] When assessing adherence, clinicians should consider the accuracy of information required and the individual AYAs situation.[63]

- Regularly monitor and discuss treatment adherence to promote compliance.[63, 64] Encourage the young person to bring their medications or a medication diary to each appointment to review the dose, purpose of treatment and any adverse effects.[63, 64] AYAs may need time before they are comfortable reporting non-adherence,[63] so developing a successful working relationship with clinicians is important.

If poor adherence is recognised or suspected:

- Re-evaluate whether adequate treatment education and adherence promotion have been provided. Communicating information clearly, honestly and collaboratively is often more effective than resorting to threats or authoritarian approaches.

- Enquire about the young person's fears or unanswered questions regarding their disease, its treatment, or late effects.

- Explore barriers to adherence with the AYA, and whether strategies to promote adherence have lapsed or alternative strategies should be considered. If possible, modify the medication regimen[62] such as simplify the dosing schedule, or alter the time and/or frequency of administration. Discuss strategies to deal with adherence at times of important social events (e.g., parties and weekend activities).[64]

4.4 Workforce boundaries

Recommendations

Weak recommendations

- Regular opportunities for reflection and supervision are suggested for healthcare professionals working with AYAs with cancer.
- Institutions treating AYAs with cancer should create policy and clear guidelines for conduct regarding relationships between healthcare professionals and AYA patients.
- Institutions treating AYAs with cancer should develop clear policy around the use of social media by staff.

Good practice statement

- Healthcare professionals should be mindful of the personal information they share with AYA patients and interact safely in a relationship that is developed for therapeutic purposes.

Evidence summary

Background

Maintaining professional boundaries is essential for the establishment of therapeutic relationships between AYAs with cancer and healthcare professionals.[29] Getting to know a young person and their family is a natural part of the process, especially when long inpatient stays occur. Professional boundaries can become uncertain when the healthcare professional feels the AYA has become a friend and may experience pressure to maintain this friendship.[68] It is the responsibility of the healthcare professional to provide the same level of care to all patients and protect them from inappropriate influence or relationships.

The age of an AYA patient and their inexperience of the health system can create dynamics with healthcare professionals and ward staff that may not occur with other age groups. In some instances, nurses may be a similar age or only a little older than the AYA with cancer[54] and older staff may respond to a young person as if they were their own child.

Social contact and recreational networking outside of the health care setting crosses professional boundaries between clinicians and AYA patients. Maintaining a caring but professional demeanour and containing involvement with patients to the hospital or clinic setting promotes healthy, independent, autonomous development of young people.

Many AYAs are active users of social media. Social media contact between AYAs with cancer and healthcare professionals has the potential to complicate the professional relationship and is not recommended. Healthcare professionals should be aware of local policy and guidelines regarding social media use.[45]

Key points

- Professional boundaries are important as they allow healthcare professionals and AYAs with cancer to interact safely in a relationship that is developed for therapeutic purposes.[29]
- Healthcare professionals must ensure that all aspects of the relationship with the AYA focuses exclusively on the needs of the young person.[68]

- Institutions treating AYAs with cancer should highlight the vulnerabilities of their staff when dealing with patients in this age group, and explicitly state institutional policy regarding such relationships and create clear guidelines for conduct.[54]

- Opportunities for professional education, preceptorship, training and clinical supervision can be extremely useful in this context as they enable reflection and learning in a positive and constructive manner. These should be offered to healthcare professionals working with AYAs with cancer on a regular basis.[29]

- Clinical staff should be mindful of the personal information they share with young patients. Strong relationships can be built over lengthy inpatient admissions and treatment plans. Central to a successful working relationship with AYAs is good listening[3] and building trust through supportive, open and honest communication.[29]

- Healthcare professionals should encourage AYAs with cancer to strengthen their existing friendships and should be wary of filling a social void that may create greater problems for the patient when treatment ends or during complex and confronting times during the course of their cancer experience.

- Institutions treating AYAs with cancer should develop clear policy around the use of social media by staff.[45] It is recommended that staff and patients do not interact on social media platforms.

4.5 Professional self-care

Recommendations

Strong recommendation

- Suitable training in professional self-care should be available to healthcare professionals working with AYAs with cancer.

Weak recommendation

- Clinical supervision or other institutional approaches that build resilience and enhance workplace culture should be available to healthcare professionals working with AYAs with cancer.

Good practice statement

- Healthcare professionals caring for AYAs with cancer should incorporate self-care into their regular routines.

Evidence summary

Background

Professional self-care is an essential component of providing best practice clinical care to AYAs with cancer. Caring for AYA patients and the needs of their family can be stressful. There is a risk of burnout and secondary traumatic stress[45] or sub-optimal patterns of work if healthcare professionals involved in AYA cancer care are not mindful of the potential for over-identification with young patients or family members, violations to professional boundaries, past or present personal grief/loss feelings that may be triggered, and splitting across teams.

Self-care includes ways of coping with stress, grief, burnout, compassion fatigue, promotion of health and maintenance of well-being. It is important to not underestimate the possible burden of the sensitive, dynamic, and often intimate work performed by healthcare professionals on their own psychosocial health.[69]

Key points

- Regular and timely support is essential for healthcare professionals caring for AYAs with cancer. This may include staff training in self-care, education, clinical supervision or other organisational approaches that build resilience and enhance the workplace culture.[45, 69]
- Regular peer consultation in a validating, empathic and professional team environment that has governing boundaries and agreed limits of confidentiality may provide an avenue for regular case consultation, form a mode of debriefing for staff, and provide an opportunity for regular peer review.
- Collegial support and validation may assist in not only ensuring the healthcare professional's mental health but also of the young patient in their charge.
- A particular awareness of vulnerable times, and ways to access appropriate self-care strategies, modes of assistance, and emotional support, is important in maintaining the well-being of individuals and teams working with these patients.
- Healthcare professionals should incorporate self-care into their regular routines.

4.6 Multidisciplinary workforce capacity

Recommendations

Strong recommendations

- AYA cancer workforce capacity should be built through education and training in order to maintain a capable and future focused AYA cancer workforce that is responsive, well-equipped, and well-supported in providing care for young people with cancer.
- Accredited AYA health and oncology training courses should be available and accessible to the Australian healthcare workforce in order to enable a strong knowledge base that can be further developed with ongoing education and experience.

Good practice statements

- Flexible professional development, education and training opportunities or tools including practice guidelines/standards, simulation, digital health solutions (telehealth, eLearning) and accredited post graduate programs are critical to building AYA workforce capacity.
- Interdisciplinary training among healthcare workers can foster teamwork and holistic care practices.
- Connecting less experienced healthcare professionals with experienced clinicians who specialise in AYA cancer care though mentoring, coaching and preceptorship will allow for guided learning, sharing of experiences, and professional development.
- Collaboration among multidisciplinary healthcare professionals administering psychosocial care to AYAs with cancer, such as oncologists, nurses, social workers, psychologists and allied health providers, through combined training sessions is required to improve teamwork and provide continuity of care.
- Professional competency standards and endorsed position statements should inform institutional AYA cancer professional development pathways and connection to state and national networks of AYA expertise.

Evidence summary

Background

Building and maintaining staff capacity in AYA cancer care is crucial[43, 45, 49] to ensure that healthcare professionals are well equipped to provide safe, high-quality care to young people, their families and carers.[2, 70, 71] Developing a competent AYA cancer workforce requires not only advancing the practice-based knowledge, comprehension and abilities of those caring for young people, but also optimising the well-being of those who choose to work in the field.[43, 72] [LINK to *Professional self-care*]

Providing psychosocial care to AYAs requires a multidisciplinary workforce with the right capabilities, capacity and experience across various settings.[26, 45, 52, 73] Nurses, social workers, youth workers, Aboriginal health workers, primary care physicians, clinical and other psychologists, psychiatrists, occupational therapists, and school and education advisers are among the professionals who work with young people with cancer.[2, 45, 71] In addition to strengthening sufficient workforce capacity to care for the current and future AYA cohort, developing expertise across diverse hospital and community settings including primary care is essential, as not all young people with cancer will receive care through the age-specific expertise of an AYA multidisciplinary healthcare team.[2, 49, 52]

The complex needs of young patients require healthcare professionals providing psychosocial care to be educated and skilled in understanding AYA cancer, its treatment and the unique implications for psychosocial functioning and QoL across the life span.[2] Some evidence suggests that a lack of knowledge and experience is seen as a barrier to the delivery of developmentally-appropriate care[41, 74] and a need for continued education is now widely accepted.[26, 43, 52, 71, 73, 75]

In recent years, position statements outlining education requirements for healthcare professionals[76] have been refined to delineate skills, knowledge, attitudes and communication competency requirements. Important topics in AYA cancer professional development, education and training programs have been articulated,[5, 29, 41, 48, 49, 76] most recently in the *Optimal Care Pathway for Adolescents and Young Adults with Cancer*[2] and include:

- AYA cancer epidemiology, biology and treatment
- foundations in general AYA health and the impact of cancer on normal biopsychosocial development
- AYA-specific assessment tools and their application
- legal and ethical issues in AYA cancer care
- providing effective age and culturally appropriate communication
- understanding professional boundary issues in the context of AYA cancer care
- late effects of cancer for AYAs, including fertility and mental health considerations.

Key points

- Young people place importance on being cared for by staff that are knowledgeable and experienced about AYA cancer, its treatment and their psychosocial needs.[29, 33, 49]

- Providing safe, high quality psychosocial care for AYAs with cancer requires an engaged, capable, and future-focused multidisciplinary workforce that is responsive, well-equipped and well-supported.[2, 29, 70]

- AYA specific education and training for healthcare professionals should include a range of modes and modalities including formally accredited programs developed in collaboration with professional bodies.[43, 45, 76]

- Greater access to developmentally-targeted psychosocial care can be facilitated by leveraging the current capacity of the community and primary care workforce to collaboratively and sustainably support the needs of AYAs with cancer.[2, 70]

- Providing adequate staff support in AYA oncology is essential for ensuring high quality patient care, reducing burnout, and fostering a collaborative work environment. Implementing comprehensive support strategies can help create a positive work environment, improve job satisfaction and lead to better outcomes for clinicians and AYAs in the oncology setting.[69]

5. Recommendations for acute psychosocial care

Recommendations

Strong recommendations

- All young people with cancer should have access to psychosocial screening as well as routine review by a member of the psychosocial care team both during treatment and into the survivorship period.
- Psychosocial care for AYAs with cancer should be provided within a holistic framework. Healthcare professionals should understand and respect the external pressures and stressors for young patients with cancer, and these should be addressed as part of supportive care planning.
- PROMs can assist healthcare professionals to identify, manage and treat symptoms that impact the young person's QoL and should be used to facilitate appropriate clinical care and referral.

Weak recommendation

- Healthcare professionals should invite AYAs with cancer to explore their spiritual needs in the context of their individual situation, and access support as required.

Evidence summary

Background

Adolescence and young adulthood are a time of inherent stress and vulnerability. To best support AYA patients across the course of their cancer experience, a preventative approach to their psychosocial management is recommended. An essential component of this is the administration of a structured, age-appropriate psychosocial assessment at regular intervals throughout the cancer care continuum, which can be completed by any member of the healthcare team. These assessments should address the needs of the AYA and any significant others, such as family members or carers.

To complement this approach, all young people with cancer should have access to social work and specialist psychological support if required. Psychosocial professionals working with AYAs should be aware of their developmental needs and be up to date with evidence-based treatment approaches recommended for AYA care. Where age-appropriate psycho-oncology support is not readily accessible, referrals could be made to community supports and private mental health professionals.

It is important to note that cancer treatment generally involves an accumulation of stress over time. This means that a young patient who exhibited good coping during the early stages of the cancer care continuum may require additional support and guidance to manage the changing stress levels as their cancer experience progresses. The preventative approach, which involves both regular assessments and informal "catch-ups" with the AYA and their family, can safeguard patients from falling through the gaps by identifying the support they need, even as their needs change.

Psychosocial screening and care planning

Age-based screening tools and assessment measures are crucial to the provision of best practice care for AYAs with cancer.[2, 77-84] The use of appropriate psychosocial tools will assist healthcare professionals working with this cohort to support psychosocial coping during active treatment and promote optimal post-treatment survivorship. A preventative approach, comprising regular psychosocial screening and care planning, enables healthcare teams to identify those patients at risk of a negative psychosocial outcome, monitor the progressive coping of the patient, and identify areas of need requiring additional care and support.

Key points

- There is significant evidence for the role of PROMs and screening tools in this population to identify, manage and treat symptoms that impact on the young person's QoL across the domains of physical, emotional, psychological and practical aspects of being diagnosed and treated for cancer.[77, 79, 85-88] The use of PROMs can assist healthcare professionals to deliver care that is consistent with what AYAs need and want.

- Resources permitting, a full psychosocial assessment is also recommended during the early care-planning phase and at regular intervals throughout the cancer care continuum, especially if pre-existing mental health or psychological disorders are noted at referral. Regular reviews can enhance the therapeutic relationship between clinicians and AYAs, and should be seen as an expected part of care rather than a problem/issue-based relationship when a concern arises.[55, 89]

- At diagnosis and during treatment, Australian healthcare teams should use the *Adolescent and Young Adult Oncology Psychosocial Care Manual*[50] – a three step psychosocial care pathway that integrates an AYA specific Screening Tool (AYA-POST), Care Plan and Assessment Measure. The *Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process*[90] is used at the end of treatment and beyond. These manuals support the young person throughout the course of their cancer experience by addressing their supportive care needs during treatment, and takes into consideration their needs for optimal post-treatment survivorship.

- At a minimum, it is recommended that administration of the Screening Tool (AYA-POST)[50] occurs at:
    - diagnosis
    - early treatment
    - six months post-diagnosis, and
    - up to 24 months post-treatment completion.[52, 86, 91-94]

- The Survivorship Screening Tool (AYA-S-POST) should first be administered at approximately six weeks post-treatment completion in AYA cancer survivors.[90]

- To support the outcomes of the tools, all young people with cancer should have access to specialist age-appropriate psychological support.[16, 18, 95, 96]

- Institutions without ready access to such services are encouraged to develop a referral directory of appropriately trained community-based mental health professionals.

- A list of support services and resources should be provided to all AYAs with cancer at the time of diagnosis, and at appropriate intervals during treatment. The list should include services provided at the treating institution, within the community and online, and highlight those that are AYA-specific, and any that are disease-specific.

Psychosocial care within a holistic framework

Life does not stop for cancer. AYAs may continue to feel pressure from other aspects of their life throughout the course of their cancer experience and these pressures may build to create additional stress for the young person. In order to provide holistic psychosocial supportive care, it is important for the healthcare team to understand, and respect, the external pressures and stressors in the life of the AYA as well as developmental and socioeconomic factors which may influence how the young person copes with their diagnosis.[97] These should be addressed as part of supportive care planning.[16, 52, 79, 91]

Key points

- Provide reassurance to the AYA that being diagnosed with cancer, undergoing treatment and managing uncertainty are all expected to have an impact on their emotional health and well-being. In conjunction with this, healthcare professionals should identify ways in which the young person is being supported both within the cancer context, and externally.[16, 18, 20]
- Identify areas outside of the cancer that might be causing additional pressure on the young person.
- Provide education on the benefits of reducing external stressors during this period and discuss ways to alleviate these stressors. Help the young person to understand the stressors which are present in their lives and support the AYA to develop strategies to manage these. For instance, support the young person to make decisions about study, work, and communicating with the people in their lives about their situation.[20, 98, 99] [Link to *Life outside cancer*]
- Work with the AYA to identify their strengths. Explain how their personal strengths can support and sustain them throughout their cancer experience. Foster and encourage ongoing connection to peers during treatment and into the survivorship period.[93, 100] [Link to *Relationships*]
- Take the time to ascertain the people who are close to the young person and who they identify as their main supports. It is important to not assume who this might be, as developmentally AYAs will often connect with people outside of their families, peer groups and others as their main supports.[100]
- If there is a concern about a young person, it is important to discuss the options for additional support if not already connected.

Identify and manage psychological distress

While many AYAs with psychological distress will present in similar ways to adult patients, it is important to note that some young people may display distress in different ways to adults.[94, 101] Healthcare professionals working with AYAs with cancer need to be vigilant to signs and symptoms of distress in young people and take appropriate action. The interventions to manage and respond to AYA distress should not be assumed to be the same as those used with older patients. Healthcare professionals working with AYAs should be aware of developmental differences and best practice care for managing distress in young people.[17, 41, 94, 101-103]

AYAs with cancer may experience significant psychological distress such as anxiety, depression, substance abuse and other mental illness.[35, 91, 101, 103] If there is a concern regarding the young person's mental health, the patient should be immediately referred to a psychiatrist, clinical psychologist, social worker or other specialist as appropriate.

Key points

- Be vigilant to age-typical expressions of distress and the concerns of significant others that the behaviours of the young person are "out of character".[41, 101, 104, 105]
- Young adolescents may have difficulty expressing distress and emotions and at times may display these feelings (e.g., refusal to talk or engage, repetitive behaviours, walking out of consults). These behaviours require sensitive and developmentally-appropriate management, such as promoting a sense of normalcy, being flexible and non-judgemental, and having open communication.[94, 101]
- Engagement with age-appropriate psychosocial support from the beginning of cancer treatment, and into the 24 months post-treatment completion is important for the management of psychosocial distress and sequalae in AYAs.[16, 17, 47, 94, 96, 102, 104, 106-108]

- Referral to a mental health professional, as per institutional protocol, is recommended if there are sudden or significant changes to the young person's sleep, appetite, energy, weight, or heart rate that do not appear to be directly related to physical and/or medical side effects of their cancer treatment.

- In AYAs with cancer, thinking patterns or thoughts can be a better indicator of the presence of low mood and depression than physical symptoms. For instance, AYAs expressing a sense of hopelessness, worthlessness and a desire for hastened death require review by a member of the psychosocial team, or appropriate referral.[94, 101, 104, 106]

- Uncontrolled pain and symptoms, including fatigue, will have a significant impact on the levels of anxiety, mood state and tolerance in AYAs with cancer.[104-106, 109]

- Be particularly mindful of young people who present with specific risk factors for depression or other psychological distress. These might include a history of depression or other mental health concerns in themselves or their immediate family, use of substances such as alcohol or other drugs, and complex psychosocial stressors.[103-105] [Link to *Alcohol, tobacco and other drugs*]

- AYAs are particularly sensitive to changes in sleep-wake disturbance and monitoring their sleep during treatment is important.[106, 110]

- Acknowledge and discuss body image, fertility and sexuality concerns, often created by physical changes or disfigurement due to cancer treatment [Link to *Treatment and side effects*]. Concern about body image can be a significant source of distress, social anxiety and/or social isolation for a young person.[10, 80, 89, 92, 111, 112]

- AYAs with cancer will likely experience disruption to their social functioning and connection to peers. It is important to address these concerns, but also discuss how to facilitate ongoing communication and connection whilst on treatment.[89] [Link to *Life outside cancer*]

- In high-risk situations such as suicide and/or self-harm, healthcare professionals should follow the policies and procedures of the treating institution.

Existential or spiritual beliefs and needs of patients

Adolescence and young adulthood can be a time of existential and spiritual development. A cancer diagnosis may lead to existential questioning that affects how the AYA makes sense of, and copes with, their cancer experience.[19, 20, 88, 94, 113-117]

Key points

- Healthcare professionals working with AYAs must be respectful and mindful of the existential needs of this age group.[117] It is important to screen for existential/spiritual distress.[8, 20, 88, 114, 118]

- Young people should have the opportunity to explore existential and spiritual issues in a trusting relationship.[93, 114, 115]

- While spiritual support may not always require specific pastoral care services, referral to such services should be considered if indicated.[35, 114, 119, 120]

6. Recommendations for post-acute psychosocial care

Recommendations

Strong recommendations

- Healthcare professionals should assess the psychosocial and educational needs of an AYA cancer survivor across the post-acute period. Unmet needs should be identified and subsequently addressed through appropriate interventions or supportive care.
- Healthcare professionals should assess the QoL and psychosocial well-being of an AYA cancer survivor across the post-acute period using appropriate measures, to understand the young person's current well-being state, as well as changes over time. Information from QoL and psychosocial measures should be used to guide appropriate psychosocial care.
- Collaborative, open communication should occur between the multidisciplinary healthcare team, the AYA and their family members or carers. Ongoing, open and sensitive communication, including record keeping, should be maintained between all parties.

Weak recommendations

- Healthcare professionals collaboratively plan the transition from acute care with the goal of minimising uncertainty and psychological distress for AYAs with cancer. A transition plan, collaboratively developed by the multidisciplinary healthcare team, as well as the AYA and their family members or carers, should be developed.
- Healthcare professionals should develop a survivorship care plan for AYAs with cancer in a collaborative process with the multidisciplinary healthcare team, the AYA and their family members or carers.
- Primary care should be integrated in an ongoing multidisciplinary healthcare team for AYAs with cancer. Primary care providers, through shared-care models, for instance, should be integrated with the multidisciplinary healthcare team to provide transitional and ongoing collaborative care to young people.

Evidence summary

Background

The post-acute period refers to the stage directly following the completion of active cancer treatment and before the commencement of long-term survivorship (i.e., 5+ years after the completion of active treatment). The post-acute period is characterised by a significant transition for the AYA, their family and their healthcare team from acute medical regimes to greater emphasis on current and longer-term QoL and psychosocial well-being. The focus of this period is to prepare and ready the young person for transition to the post-treatment stage, ensuring that best practice psychosocial care is in place so that common survivorship concerns or challenges that present within this period can be addressed.

Heightened anxiety and uncertainty commonly characterise the end of active cancer treatment in AYAs.[121, 122] Psychological distress often continues through early survivorship.[123] Fear of cancer recurrence can be a significant concern for young people,[124, 125] along with concerns around returning to employment and/or continuing education.[126] Educational needs regarding the transition are common during this period as well as focused psychosocial interventions.[33, 127, 128] Primary care may be utilised to facilitate the transition by working closely with the acute care team and providing ongoing supportive care between the stages.[129]

Like their peers, it may be relatively common for AYA cancer survivors to use drugs and/or alcohol, and this may further exacerbate the psychosocial and cognitive concerns commonly experienced during this period.[130, 131] [Link to *Alcohol, tobacco and other drugs*]

Effective, feasible and consistent measurement of QoL and psychosocial well-being in AYAs with cancer, using validated measures, is important within and during the transition between acute care and early survivorship.[78, 79, 112] This information is vital for healthcare professionals to identify and deliver appropriate education and psychosocial care to AYA cancer survivors.

Transition to the post-acute period

Transition-focused care is one of the five guiding principles of AYA cancer care in the Australian *AYA Vision 2033*.[132] International guidelines recommend that AYA-specific screening and subsequent reassessment take place, especially at times of transition, including the transition to the post-acute period.[69, 133] The empirical literature supports this need.[121, 134] The use of appropriate psychosocial tools will assist clinicians working with AYA cancer survivors to support psychosocial coping during the transition to the post-acute period. An active approach, comprising regular psychosocial assessment and subsequent care planning, enables healthcare professionals to monitor the progressive psychosocial well-being of the AYA, and identify areas of need requiring additional care and support.

AYAs with cancer commonly experience heightened distress, identity challenges and uncertainty at the end of active treatment.[41, 121, 135-137] Providing young people with appropriate information in the post-acute period is important for minimising uncertainty and psychosocial distress.[50] As many AYA cancer survivors may not have thought about life after treatment, or had access to appropriate resources, educational needs regarding the transition are common during this period.[33, 127, 128, 137] Due to the uncertainty and associated psychological distress of the transition for AYAs, the post-acute period should include:

- assessment of needs
- assessment of QoL and psychosocial well-being
- education regarding the transition and potential experiences
- development of a transition plan.[138]

There are a variety of needs assessment tools that healthcare professionals can utilise for AYAs with cancer in the post-acute period.[33] Validation of many psychosocial measures within AYA cancer survivor populations is limited,[92] and there is currently no one recommended tool. However, clinicians should adopt a needs assessment tool which includes domains of particular concern within this transition phase.[92, 98] Specifically, psychological/emotional needs, and informational needs should all be included.

Similarly, a variety of tools have been used in the assessment of QoL and psychosocial distress for AYA cancer survivors, with limited evidence regarding the utility of one tool over others.[92, 98] Ideally, clinicians should use a QoL and psychosocial distress measure which is valid and reliable,[139] but also fits the current patient and clinical context (e.g., capabilities, time availability) to facilitate effective and feasible assessment. In Australia, The *Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process*[90] is frequently utilised at the transition from active treatment to the post-acute period.

If psychosocial distress and unmet needs are demonstrated during the transition to post-acute care, the following themes are key to address: Education on cancer (including long-term effects); coping; sexual identity; maintaining normalcy; and AYA support (including peer and family support).[135] While there is inadequate data to make conclusions regarding any specific psychosocial interventions for AYA cancer survivors during this period, dynamic group therapy, cognitive behavioural therapy, online peer support and education have been utilised.[135] Problem-focused coping, emotion-focused coping, and secondary control coping have also all been found to be effective in reducing distress in AYA cancer survivors.[105]

AYA transition plans

Transition plans are commonly recommended in the transition between paediatric and adult healthcare services for cancer survivors, or from acutely managed to primarily self-managed care.[127, 137, 140, 141] However, transition plans are also recommended for the transition from acute to post-acute AYA cancer care, and may alleviate patient psychosocial distress and uncertainty[75, 138] and facilitate collaboration and a shared understanding between healthcare professionals.[75, 142] A post-acute period transition plan could be developed collaboratively between the AYA, their family members or carers, and the multidisciplinary healthcare team.

Although transition plan tools specifically for AYAs with cancer transitioning to post-acute care are sparse, other transition tools, such as those for the transition between paediatric and adult care, may be adopted. The transition plan may be developed using a tool such as the *Transition Rubric*,[140] which facilitates the collaborative development of a transition plan involving assessment, transition objective, and the process. The *Transition Rubric* includes multiple domains including on-going medical care, psychosocial health, cognitive health, behavioural health, and employment among other domains. The entire rubric, or a subset of domains, may be utilised in the early stages of transition planning depending on the context of the clinical case, facilitating ongoing documentation of assessment, goals and processes across survivorship domains.

Early survivorship period

The early survivorship period directly following the transition from acute care is a period of significant change for AYA cancer survivors. The needs, heightened psychosocial distress, and uncertainty which characterise the end of active treatment can often persist into early survivorship.[104, 107, 121, 123, 143] However, the severity and types of psychosocial needs may also change once acute care is complete.[96] Informed and collaborative planning, assessment, and supportive care and intervention provision is fundamental to facilitating a positive early survivorship experience for AYA cancer survivors and minimising short and long-term psychosocial distress and challenges.[2] To effectively assess and support the psychosocial well-being of AYA cancer survivors in the early survivorship period, clinicians should:

- understand the typical needs, challenges and concerns of AYAs during this phase[62]
- assess needs, psychosocial challenges and QoL of the AYA cancer survivor and deliver appropriate psychosocial care
- ensure collaborative and open communication between the AYA, their family and the multidisciplinary healthcare team
- develop a survivorship care plan.

AYA cancer survivors are also at an increased risk of anxiety and mood disorders, reflecting a greater likelihood of distress.[144] Distress and uncertainty in this period can be driven by factors such as change of service providers and service provisions, the fear of cancer recurrence, concerns around returning to employment and/or continuing education, identity concerns, fertility concerns, and body image concerns.[91, 92, 95, 103, 123-126] For AYAs some of these changes may be exacerbated by coinciding with the typical concerns and challenges relating to their stage of development. For example, concerns about increasing health care independence may be co-occurring with general concerns regarding transition to independent adulthood.[145] Similarly, developmental concerns regarding body image in this age group may be exacerbated by bodily changes relating to their cancer and/or cancer treatment.[145] Young adults may have heightened concerns about fertility issues and their ability to return and progress in employment and education given their developmental stage.[126, 145] Healthcare professionals should be aware of the common needs, challenges and concerns of AYAs with cancer during the early survivorship stage and understand how these may be exacerbated or functionally related to their developmental stage.

The assessment of needs, psychosocial challenges and QoL[146] should be informed by the individual and developmental stage and capabilities of the AYA cancer survivor. While there is no preferred measure for these assessments, the chosen assessment/s should include domains relative to AYAs such as educational needs, return-to-work concerns, body image difficulties, low mood, anxiety, and fertility concerns.[80] Some assessments have differing validity for different AYA cancer survivors, for example the *Perceived Barriers Scale* is recommended for CNS cancers, but there is no consistently preferred measure for non-CNS cancers.[82] Assessments should be valid and reliable for the particular AYA cancer survivor, whilst being practical and feasible to ensure consistent monitoring of current state, and any changes over time. Interventions utilised to address the psychosocial needs and challenges identified depend strongly on the individual characteristics of the AYA cancer survivor. Online psychosocial intervention during this stage, as the survivor moves away from acute care, has gained momentum.[86, 147] Healthcare professionals may consider web-based psychosocial interventions to facilitate the ongoing transition from acute care for AYA cancer survivors.

Collaborative and open communication between healthcare professionals, the AYA cancer survivor, and their family members or carers is fundamental for ensuring effective psychosocial care for the patient.[2] In order to facilitate this collaboration, a summary record of the AYA's cancer and treatment, as well as other essential information (i.e., particular concerns, preventative measures) could be developed.[55] A post-acute care AYA multidisciplinary team, with equal medical and psychological professional members, could also be established to work with the AYA cancer survivor and their family. [45] Social support from healthcare professionals and family members may also improve psychosocial QoL,[100] further emphasizing the importance of collaborative healthcare in early survivorship care for AYAs with cancer. While most AYAs want to be included in decision-making,[11] the desire and ability of a young person to participate in their own medical decision making can vary and clinicians should always assess the AYA's preference.[30] [Link to *Active decision making in health care*]

AYA survivorship plans

Survivorship plans for AYAs are recommended by a range of national and international guidelines including *AYA Vision 2033*,[132] *Adolescent and Young Adult Oncology Psychosocial Care Manual*,[50] *Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process*,[90] *Optimal Care Pathway for Adolescents and Young Adults with Cancer*,[2] *Canadian Framework for the Care and Support of Adolescents and Young Adults with Cancer*[72] and *NCCN Clinical Practice Guidelines in AYA Oncology*.[148] An interdisciplinary clinical team may collectively develop an early survivorship plan in collaboration with the AYA cancer survivor and their family members or carers. Survivorship plans may be broad and encompass not only psychosocial survivorship planning, but also holistic planning across other domains including financial, biomedical, health promotion, cognitive, and occupational/educational.

The psychosocial domain within a survivorship plan for AYAs may include screening recommendations, interventions, and prevention strategies.[84] The plan should align with holistic disease management strategies and recognise the interactions between activities across the plan's domains. Cancer survivorship plans facilitating and coordinating psychosocial care should be tailored to the individual AYA's personal (i.e., current age, age of diagnosis, developmental stage, personal context) and clinical (i.e., diagnosis characteristics, treatments, presenting challenges) situation.[2, 50, 72, 132] The development of survivorship plans can be time consuming, therefore clinicians should consider the timing and context of the survivorship plan prior to development.

Primary care

The role of primary care in supporting AYA cancer survivors through the transition to post-acute care and primarily self-managed or directed survivorship is emphasised in the *Adolescent and Young Adult Oncology Psychosocial Care Manual*.[50] International guidelines highlight that primary care may be used in follow-up or shared care approaches for AYAs in the post-acute period,[148] and suggest that shared care approaches incorporating both the primary oncology team and primary care are not only feasible but facilitate appropriate, accessible care for AYAs in the post-acute period. [148] The development of a successful working relationship between an AYA cancer survivor and primary care provider is encouraged[148] and may support appropriate assessment, management and referral for psychosocial care. Clinicians should:

- facilitate primary care physicians as part of the interdisciplinary healthcare team
- recognise the potential role of primary care in the psychosocial management of AYA cancer survivors.

The role of primary care in cancer survivorship has been growing. Contemporary models of cancer survivorship care typically emphasise the role of primary care.[128] Shared care, needs-stratified care, and community-based care all involve primary care within their approach.[128] In the early survivorship period, shared-care models have been shown to be feasible and facilitate appropriate accessible care for AYA cancer survivors, including for psychosocial challenges.[148] Within a shared-care model, a partnership is established between the oncology multidisciplinary team and a primary care physician, and expertise and service provision is collaboratively provided by both groups.[128] Ultimately, the integration of the primary care physician into the multidisciplinary team facilitates accessible and supportive care. As the early survivorship period progresses, a community-based care approach is often utilised.[127, 134] In this model, the majority of care is based in the primary care setting and offered by a provider who is willing and able to assume follow-up responsibilities for the patient.[127] In both models of care, primary care provides patient-centred, integrated, and comprehensive care over extended periods of time.[148, 149]

Primary care can provide psychosocial assessment, management, and referral for AYAs during the early survivorship period.[149] A key role of the primary care provider within this period is to ensure that the interdisciplinary healthcare team is informed of the AYA cancer survivor's psychosocial well-being.[129] A primary care physician may execute a survivorship plan and administer psychosocial assessment regularly.[142] A primary care physician should monitor the current state of psychosocial well-being of the AYA cancer survivor, as well as changes over time. The primary care physician plays an important role in ensuring the identification of psychosocial needs and challenges in AYA cancer survivors and the appropriate and timely referral to the required services.[75] Multiple studies have shown that primary care can be effectively utilised in the collaborative care effort to assess, manage and refer AYA cancer survivors with psychosocial challenges.[150]

7. Recommendations for treatment and side effects

7.1 Alcohol, tobacco and other drugs

Recommendations

Strong recommendations

- Healthcare professionals should assess substance use in AYAs with cancer at diagnosis, during and after treatment using appropriate tools. Questions about past and present alcohol, tobacco and/or e-cigarette and other drug use should be included when taking a full medical history and documented in the AYA's medical record.

- Healthcare professionals should address substance use in AYAs with cancer in the context of the AYA life stage and provide appropriate referrals or education if problematic substance use is discovered.

Evidence summary

Background

Alcohol use is commonplace in the social lives of Australian young people, and consuming alcohol at risky levels is not unusual with 42% of 18-24 year olds, and 5.5% of 14-17 year olds drinking at risky levels (more than ten standard drinks per week on average, or more than four standard drinks in a single day at least once a month).[151] Illicit drug use, while not as normalised as alcohol, is not unusual with 35% of people aged 18-24 and 13% of people aged 14-17 years having used an illicit drug within the past year.[151] While fewer young people are smoking tobacco daily than ever before, there has been a surge in the use of e-cigarettes (vapes), with 21% and 9.7% of people aged 18-24 and 14-17 years respectively using e-cigarettes in 2022-2023.[151]

Smoking rates in AYAs undergoing treatment for cancer may be slightly lower than the general AYA population.[152] While the majority of research does not find substance use or substance disorders to be significantly elevated within AYA cancer survivors compared to peers without a history of cancer,[144] it may be relatively common for AYA cancer survivors to use drugs and/or alcohol.[130, 131]

Substance use, including alcohol, tobacco and illicit drugs can lead to adverse psychosocial outcomes[153] that may impact AYAs with cancer both during and after treatment. For AYAs with cancer, alcohol use may lead to suboptimal adherence to treatment, possibly increasing symptom burden and clinic visits and/or hospital admissions.[154] AYAs undergoing treatment for cancer who smoke may be impacted by tobacco-related complications including poorer response to treatment, increased treatment-related toxicity and higher levels of severe side effects that negatively affect QoL and symptoms such as depression, fatigue and pain.[155, 156] For example, greater postoperative risks such as delayed wound healing and increased risk of infection linked to smoking can increase AYA symptom burden and directly impact daily functioning.[155, 156] Substance use can also lead to comorbidities, negatively impact physiological outcomes and further exacerbate psychosocial and cognitive challenges commonly experienced by AYA cancer survivors during this phase, including psychosocial distress and cognitive impairment.[130, 131, 152, 155, 157]

Clinicians should consider two main issues regarding the use of alcohol, tobacco and other drugs in AYAs during active cancer treatment:

- patient safety and addressing any complications or dangers that may arise when young people use alcohol and/or drugs when undergoing treatment

- educating the young person to make the best decisions for themselves regarding the use of alcohol and/or drugs during their treatment period.[158]

In AYA cancer survivors, it is important to recognise the impact on well-being that substance use may have and provide appropriate education and referrals after reassessing substance use at critical time points including upon completing treatment and in survivorship.[2]

Key points

- Healthcare professionals should assess substance use in AYAs with cancer at diagnosis and other critical time points using appropriate tools.[2] Questions concerning past and present alcohol, tobacco and/or e-cigarette and other drug use should be included when taking a full medical history and documented in the AYA's medical record. Be aware of institutional policy about discussing (and disclosing) drug and alcohol use with adolescents under the age of 18.

- All information should be provided in a clear and direct manner, using a non-judgmental approach, and in a confidential environment to encourage AYA disclosure on substance use.[2] Young people with issues that may impact upon the provision of medical treatment, or even those who may have simple questions about having "a beer or two on the weekend", may be reluctant to disclose information if confidentiality is not assured.[53]

- Particular consideration should be given to issues such as management of drug dependency, exposure to blood-borne illnesses, and interactions with medically prescribed drugs. Appropriate referrals or education should be undertaken if these issues are of concern.[53]

- Young people with cancer who smoke tobacco should have access to best practice smoking cessation care (brief advice model of care to promote quitting) during treatment and beyond, and referred to smoking cessation behavioural intervention services, such as Quitline.[156]

- It is important to be mindful of the significance that feeling "normal" and being "part of the crowd" plays in the AYA developmental stage – and the role that alcohol, tobacco and drugs may play in this.[154]

- It should not be assumed that AYA patients will avoid alcohol, tobacco or other drugs during their treatment. While it should not be condoned by treating teams, the use of alcohol and/or drugs should be recognised in the context of the AYA life stage when many experiment with using particular substances.[2, 154]

7.2 Fertility and reproductive function

Recommendations

Strong recommendations

- Healthcare professionals should discuss any risks to future fertility with AYAs diagnosed with cancer before the start of treatment.

- Healthcare professionals should refer, when required, AYAs diagnosed with cancer to fertility preservation specialists or reproductive health services promptly.

- AYAs diagnosed with cancer should be offered fertility counselling to assist with decision-making.

Evidence summary

Background

There is clear evidence that AYAs with cancer wish to be informed about the potential impact of their cancer diagnosis and treatment on their future fertility.[5] Many young patients are not adequately informed about the potential impact on fertility of their cancer treatment and options for preserving fertility.[38] It is important that AYAs are informed of their options for protecting or preserving their fertility as early as possible before treatment begins.[159]

In some centres, the practice of discussing the risk of infertility with AYAs diagnosed with cancer and referring them for assisted reproductive assessment is routine. However, many young people report feeling that:

- they were not, or were inadequately, advised of the risk to their fertility or options for preserving fertility[33, 73, 74, 91, 111, 160-162]
- the decision about whether to pursue fertility preservation or not was made for them[39]
- their healthcare provider was focused on treating the cancer and not the possible impact of cancer treatment on them[111]
- they felt rushed into making a decision and were not given enough time to discuss concerns[5]
- they did not consider parenthood to be important at the time of their cancer diagnosis but later felt their perspective had changed or they regretted earlier decisions[111, 163]
- they experienced psychological distress at the conclusion of cancer treatment regarding their future fertility status.[5, 73, 102, 111, 164]

Key points

- Risks to future fertility should be fully discussed with AYAs before the start of cancer treatment.[26, 165] Raising fertility issues early, at the time of cancer diagnosis, is strongly supported by AYA patients.[5, 39, 111]

- Younger adolescents may require more open and supportive discussions on any risks to future fertility than older AYAs.[35]

- Timely information and advice on fertility should be given by appropriately trained clinicians to minimise psychological distress[166] and allow AYAs to focus on their options for fertility preservation.[111]

- Information on fertility should be provided in a clear, honest, sensitive and empathetic manner,[5, 33, 159] and tailored to the AYA's developmental stage, relationship status, gender and sexual orientation.[33, 71, 167] LGBTQI+ young people have unique reproductive health priorities and concerns that should be addressed.[167]

- AYAs diagnosed with cancer that are interested in fertility preservation should be referred promptly to fertility preservation specialists or reproductive health services.[111, 165]

- Discussions on fertility should be supported by age-appropriate written or online information, and a summary included in the AYA's medical record.[26, 33]

- AYAs should be offered fertility counselling, ideally by a reproductive specialist and/or trained counsellor, to assist with decision-making and other psychological support.[73, 74 111, 165, 166]

COSA guidelines for fertility preservation for people with cancer

The *COSA guidelines for fertility preservation for people with cancer*[165] of reproductive age, including AYAs, include detailed advice about discussing fertility with patients to maximise their awareness and understanding of their options, and optimise future fertility outcomes. The guidelines[165] recommend:

Impact of cancer treatment on fertility

- Healthcare professionals should inform all people diagnosed with cancer (or their parents in the case of children) that there is potential for cancer treatment to impact their fertility.

- Healthcare professionals should advise patients prior to cancer treatment of the risk of:
  - a reduction in ovarian reserve after treatment
  - the loss of testicular hormone function and a reduction in sperm count after treatment.

- Patients of any age with a risk of infertility (or their families in the case of children) should be given the opportunity to discuss fertility preservation before cancer treatment.

Discussing risk

- All patients with cancer, regardless of age or relationship status, should receive age-appropriate information and support regarding the impact of specific cancer treatments on their future fertility.

Referral and service provision

- Healthcare professionals should consider, where appropriate, referral of patients to fertility preservation specialists. Patients with cancer should have an opportunity to meet with fertility counsellors to provide decision-making and psychological support.

Psychological support

- Fertility counselling should be offered to everyone with potentially curable cancer, ideally by a reproductive specialist and/or trained counsellor. Counselling should include education about fertility preservation options and support for patient decision-making.

- The use of decision support tools, such as fertility preservation decision aids, should be offered where available as they may assist people with cancer with the decision-making process.

7.3 Sexuality and sexual function

Recommendations

Strong recommendations

- Healthcare professionals should incorporate routine sexual health screening and assessment into clinical practice and the overall treatment plan, addressing psychosexual, physical, emotional and social aspects of well-being for AYAs with cancer. Topics for discussion should include sexual activity, orientation, gender identity and sexual health concerns of the patient.
- Healthcare professionals should provide non-judgemental and age-appropriate sexual health education tailored to the specific needs of AYAs with cancer, including LGBTQI+ individuals, which acknowledges their diverse, cultural, social and personal background. Information should be provided on safe sexual practices while on cancer treatment, potential changes to sexual function, contraception, sexually transmitted infections and healthy relationships.
- Psychosocial support services should be offered to AYAs with cancer, including counselling or referral to a sexual health specialist or family planning clinic for contraceptive options as required. Healthcare professionals should consider the age of the patient and any institutional policies when determining whether parental consent is required for referral.
- Healthcare professionals should provide support for intimate relationships to AYAs with cancer, including providing sexual health information to partners.
- Healthcare professionals should maintain confidentiality and conduct conversations in private to encourage open and honest discussions with AYAs with cancer about sexual health issues without fear of judgement or disclosure.

Weak recommendations

- Healthcare professionals use models like (EX) Plissit, BETTER, PLEASURE and ALARM to systematically assess and comprehensively address sexual health concerns in AYAs with cancer.
- Healthcare professionals engage family members of young people with cancer in discussions when appropriate and provide guidance on how parents can support their AYA-aged child's sexual health needs while respecting their privacy and autonomy.[10]

Evidence summary

Background

Addressing the physical issues that impact psychosocial well-being in AYAs with cancer is a crucial aspect of holistic health care.[10, 12, 27, 35, 52, 112, 168-171] During adolescence and young adulthood, body image, sexual well-being and reproductive functioning play pivotal roles in shaping a young person's self-esteem, sense of self, interpersonal relationships and overall QoL.[35, 161, 172, 173] Cancer and its treatments can negatively impact normal development, leading to significant psychosocial challenges.[27, 41, 170, 171]

A cancer diagnosis can drastically alter an AYA's body image.[41, 116, 172] Treatments like chemotherapy, surgery and radiation often result in visible changes such as hair loss, weight fluctuations and scars.[10, 52, 112] These changes can lead to feelings of inadequacy, anxiety and depression, which can hinder social interactions and intimate relationships, further impacting mental health.[52, 106, 116, 170] [Link to *Physical appearance and body image*]

Sexual health is a vital aspect of QoL among AYA cancer survivors.[10, 171, 174, 175] Sexual well-being, encompassing sexual health, function and satisfaction is intricately connected to physical health.[112, 172] The cancer itself and associated treatments can affect sexual well-being leading to issues such as decreased libido, loss of desire, arousal disorders, pain during intercourse (e.g., due to vaginal dryness), loss of pleasurable sensation and erectile dysfunction.[12, 27, 52, 168-172, 174-178] These challenges can create emotional distress and strain romantic partnerships making it difficult for young people to maintain healthy intimate relationships. Many AYAs fear losing a partner or the termination of a relationship if they cannot perform sexually.[12, 27, 169]

Healthcare professionals can mitigate these effects and enhance QoL for young people by facilitating appropriate interventions and that manage sexual health concerns.

Key points

AYAs with cancer have been shown to have more sexual related concerns that their peers, and this is heightened among sexual and gender minorities, who experience more unmet cancer related needs. Exacerbating this is a paucity in the literature of how to meet these needs.[98, 167, 179] Normal adolescent activities often focus on sexual awareness, finding a partner and sexual activity,[10, 17] yet discussions about these topics between parents and young people can be difficult and embarrassing.[17, 27, 42] Many parents are unaware of their adolescents' sexual activities and parental presence can act as a barrier to sexual health discussions between young people and healthcare professionals.[27, 42, 167, 175] Compounding this issue, healthcare professionals often do not initiate conversations around sexual health concerns with this cohort citing lack of training, experience, their own embarrassment and time constraints.[17, 167, 168]

While this may also be a topic that the young person is reluctant to initiate,[10, 17, 52, 168, 171, 172, 177] most will appreciate an open and frank discussion about how their cancer treatment could affect their sexuality and their sexual behaviours.[161, 177]

Healthcare professionals involved in the care of AYAs with cancer should provide appropriate sexual and reproductive health information, support and resources throughout treatment and beyond.[10, 12, 27, 42, 52, 106, 168, 170, 172, 174, 175, 177, 180] This should be specific to cancer type, age, gender and sexuality (including LGBTQI+ young people), and take into account cultural and spiritual influences.[98, 167, 168, 176, 177, 179]

Although there are complexities to addressing sexual health with AYAs, and the need for comprehensive training in this area, there are significant recommendations and supports that healthcare professionals can use to enable improved outcomes for AYAs in this context. These centre around a structured, sensitive and integrated approach to sexual health care for AYAs with cancer, ensuring comprehensive support that addresses their diverse needs and challenges.

- Incorporate sexual health screening and assessment into routine clinical practice and the overall treatment plan for AYAs with cancer, addressing psychosexual, physical, emotional and social aspects of the young person's well-being. Healthcare professionals working with AYAs with cancer should include discussions about sexual activity, orientation, gender identity and sexual health concerns of the patient.[10, 12, 17, 27, 52, 98, 106, 135, 170, 171, 175-178]
- Models such as (EX) Plissit, BETTER, PLEASURE and ALARM should be used by healthcare professionals to systematically assess and comprehensively address sexual health concerns in AYAs with cancer.[10, 12, 27, 172, 175]
  - **(EX) Plissit** (Permission, Limited Information, Specific Suggestions, Intensive therapy).[181] The 'EX' (Extended) in this framework allows for explicit permission giving at any stage through the PLISSIT framework.[182]
  - **BETTER** (Bring up the topic, Explain, Tell, Timing, Educate, Record).[183]

  - **PLEASURE** (Partner, lovemaking, emotions, attitudes, symptoms, understanding, reproduction, energy.[12, 183, 184]
  - **ALARM** (Activity, Libido, Arousal, Resolution, Medical).[12, 183, 185]

- Provide comprehensive sexual health education to AYAs with cancer. Sexual health education should be non-judgemental, age-appropriate and tailored to the specific needs of AYAs, including LGBTQI+ individuals, which acknowledges their diverse, cultural, social and personal backgrounds. Healthcare professionals should provide information on safe sexual practices while on treatment, potential changes to sexual function, contraception, sexually transmitted infections and healthy relationships during clinical appointments.[12, 17, 27, 98, 135, 161, 170-172, 177]

  Healthcare professionals should take into account that young people are likely to feel extremely uncomfortable and embarrassed discussing their sexual behaviours. Ensure the AYA understands why this topic is being raised and the possible impact of cancer treatment on their sexual health and function.

- Offer psychosocial support services, including counselling or referral to a sexual health specialist or family planning clinic for contraceptive options as required, to AYAs with cancer. Consider the age of the patient and any institutional policies when determining whether parental consent is required for referral.[12, 27, 135, 168, 175, 177]

- Integrate reproductive health services and options for fertility preservation by referring AYAs with cancer to fertility preservation specialists or reproductive health services if treatment may affect their reproductive capabilities.[111, 165] [Link to *Fertility and reproductive function*]

- Incorporate partners by providing them with sexual health information and support for intimate relationships.[12, 52, 161, 175, 177] [Link to *Support needs for intimate relationships*]

- Maintain strict confidentiality and conduct consultations in private settings to encourage open and honest discussions with AYAs with cancer about sexual health issues without fear of judgement or disclosure.[175, 177]

- When appropriate, engage family members of the young person in discussions and provide guidance on how parents can support their AYA-aged child's sexual health needs while respecting their privacy and autonomy.[10]

7.4 Physical appearance and body image

Recommendations

Strong recommendations

- Healthcare professionals should incorporate body image into routine psychosocial screening for AYAs with cancer, in order to assess AYA needs and identify concerns as they arise.
- Healthcare professionals should provide early psychoeducation on body image to all AYAs with cancer, including how body image may be impacted during treatment. Information should include common practical coping strategies utilised by AYA patients.
- Healthcare professionals should offer psychosocial support for body image to AYAs with cancer as a preventative measure and in response to identified needs. Interventions offered could include regular opportunities for the young person to connect with other AYA cancer patients and existing social and family networks, referral to a psychologist or counsellor for age-appropriate therapeutic intervention, and exercise and nutrition modifications in accordance with the patient's medical needs or physical restrictions.
- Healthcare professionals should adopt a biopsychosocial approach to addressing physical function and body image concerns as this is likely to result in more positive outcomes for AYAs with cancer than focussing on physical surgeries or techniques alone.

Evidence summary

Background

Adolescence and young adulthood is a unique life stage marked by psychosexual development, establishment of one's self-concept and the strengthening of peer and romantic relationships.[27, 35, 178] A cancer diagnosis commonly disrupts these processes for AYAs.[10, 12, 27, 35, 106] The physical changes and side effects resulting from the cancer and treatment regime can impact an AYA's relationship with their own body.[10, 12, 17, 35, 168, 174, 176-178] While differing definitions exist, body image is generally understood as one's own subjective thoughts, feelings and behaviours towards their own body, and this subjective relationship can be influenced by objective physical changes to the body.[186-188]

Cancer related physical changes commonly reported as distressing by AYAs include weight gain/loss, muscle loss, changes in facial features, loss of or decreased functioning of sexual organs, decreased general physical functioning and hair loss.[52, 112, 178, 186, 187] These specific aspects of physical appearance and functioning are strongly associated with identity during this life stage, and many AYAs report a sense of alienation from their own bodies and concerns about negative evaluation or subsequent rejection or judgement from peers.[52, 186, 187, 189] Social avoidance is a common strategy for managing these concerns,[187, 189] and poorer body image is associated with other negative psychosocial outcomes such as depression,[186, 187] disruption to psychosexual development,[172, 176] difficulty establishing and maintaining intimate relationships[35, 172, 176] and disconnection from peers.[187, 189] Poor body image is most commonly reported during cancer treatment, when physical changes are often most pronounced.[106, 187] However, AYA cancer survivors also report ongoing difficulties with body image after treatment is completed.[12, 178]

AYAs with cancer may engage in adaptive cognitive and behavioural strategies to manage the potentially harmful effects of physical changes on their body image.[186, 189] Such strategies include the use of clothing, cosmetics and wigs to restore a sense of "normality" with one's self and one's peers,[187, 189] as well as cognitive strategies, such as reconceptualising their sense of self and rejecting the notion of oneself as "weak" or "different".[189] Appropriate engagement in exercise may lead to improved body image in AYAs with cancer.[12, 186, 189] Some AYAs even report positive body image or improved body image compared to peers without cancer, particularly after treatment is completed.[172, 186] Positive experiences with peers during and after cancer treatment can help to restore a sense of belonging and mitigate the effects of physical changes on body image and identity for young people.[186, 187, 189] Therefore, providing psychoeducation and opportunities for connection with peers with shared experiences can have positive impacts on body image.[12, 186, 187, 189]

Body image is heavily influenced by one's own psychological resilience or vulnerabilities[187] and should be addressed holistically in AYAs with cancer to account for individual biopsychosocial factors.[106, 176, 187] Greater clinical attention is often given to addressing physical components of body image such as reconstructive surgery, whilst AYAs report a desire to also discuss the psychosocial components of body image with their healthcare providers.[52, 186]

Key points

- Include body image in regular psychosocial screening practices for AYAs with cancer, to promote early identification of patient needs and concerns as they arise.[12, 106, 168] Ideally, provide screening measures and discussions that encourage subjective expression of body image concerns, to assist in an accurate conceptualisation of body image issues and promote open discussion with clinicians.[12, 106, 176]

- At an early stage of treatment, provide psychoeducation to all AYAs about how cancer can impact their body image (not simply anticipated physical changes), and how this may change through the course of their cancer treatment.[12, 186, 189] AYAs can be better equipped to cope with body image related psychosocial changes if they receive information about common practical coping strategies utilised by young people (e.g., accessing wigs and hats, social skills strategies). If required, refer the AYA to a social worker or psychologist to assist with this.[186, 189]

- Offer psychosocial support for body image to AYAs with cancer as a preventative measure and in response to identified needs. AYAs have been found to benefit from a combination of various types and formats of body image interventions.[186] The following interventions could be offered by the healthcare team:

    - Regular opportunities for the AYA to connect with other peers going through cancer treatment.[12, 186, 187, 189] Referrals to hospital-based or external programs that facilitate peer connections may assist with this.[186] Similarly, interactions to maintain and develop connections with the AYAs existing social and family networks.[189] AYAs with cancer may benefit from the support of a social worker in navigating and entering changing social landscapes, and problem-solving barriers to connection that may arise. [LINK to *Relationships*]

    - Referral to a psychologist or counsellor for age-appropriate therapeutic intervention, particularly where negative self-perceptions or social avoidance has been identified.[27, 171, 177, 187, 189] Re-evaluate the need for counselling support with AYAs at key points in the cancer care continuum, especially post-treatment.[52]

    - Discuss appropriate modifications for exercise with the AYA in accordance with their medical needs or physical restrictions, recognising the importance of physical activity at all stages of cancer treatment.[12, 189, 190] Consider referrals to exercise physiology and/or physiotherapy to assist with this.[12] Referral to a dietitian may assist in guiding appropriate nutrition patterns that account for an AYAs individual needs (both physical and emotional). [LINK to *Psychosocial well-being*]

- Maintain a biopsychosocial lens during discussions of medical interventions to address the physical impacts of cancer on AYAs. Physical therapies and surgeries can positively influence body image particularly when the cancer or associated treatment has resulted in limb or organ loss.[112, 161] However, such interventions should not be discussed to the exclusion of psychosocial factors. Adopting a biopsychosocial approach to addressing physical function and body image concerns is likely to result in more positive outcomes than focussing on physical surgeries or techniques alone.[176] Input from the multidisciplinary healthcare team including psychology and social work may assist in building a thorough understanding of needs and treatment plan to address body image concerns.

8. Recommendations for enhancing well-being

8.1 Physical activity

Recommendations

Strong recommendations

- AYAs with cancer should avoid inactivity and return to normal daily activities as soon as possible following diagnosis (i.e. be as physically active as current abilities and conditions allow).
- Healthcare professionals should promote physical activity during and after treatment to improve psychosocial well-being and QoL in AYAs with cancer.
- Healthcare professionals should develop individualised physical activity programs for AYAs with cancer, tailored to the specific needs and preferences of the young person to increase motivation and adherence.
- Healthcare professionals should incorporate physical activity interventions for AYAs with cancer that are easily accessible and sustainable for long-term engagement. Flexible scheduling and remote participation options could be designed for AYAs with cancer.
- Group-based physical activity should be facilitated to provide opportunities for social support and peer connections in AYAs with cancer.
- Accredited exercise physiologists and physiotherapists are the most appropriate healthcare professionals to prescribe and deliver physical activity programs to AYAs with cancer.

Evidence summary

Background

Cancer treatment in AYAs is associated with impairments in cardiovascular fitness, functional deficits and psychosocial well-being.[191-194] Impairments may persist into survivorship and are associated with fatigue, sleep disturbance, reduced QoL, increased risk of cardiovascular disease and late mortality.[191] Associated morbidity and mortality are likely to be a result of the direct toxic effects of anticancer therapy as well as the indirect consequences of treatment, such as increased sedentary behaviours.[191]

While physical inactivity rates in AYAs with cancer are similar to those in AYAs without a history of cancer, the majority of AYAs with cancer do not meet current physical activity guidelines.[195, 196] Cancer treatment exacerbates the negative impacts of inactivity, affecting both physical and psychological health.[196] This impact is evident in PROs such as decreased QoL, increased anxiety and depression, social isolation, and disruptions to their sense of normalcy and autonomy. Integrating physical activity into the care of AYAs with cancer not only addresses physical health issues but also offers crucial psychosocial benefits, enhancing their overall well-being and QoL.

Over the past decade, research and clinical interest in exercise training for people with cancer has significantly increased. Studies involving children, AYAs, and older adults with cancer have shown that structured exercise is safe both during and after cancer treatment and is well tolerated, with adherence rates exceeding 80%.[192, 197]

Participation in physical activity programs, especially those that are group-based, can lead to improved coping and psychological resilience for young people, significantly enhancing overall mental well-being.[8, 197, 198] Furthermore, regular physical activity has been linked to better mental health, lower stress and fewer depressive symptoms in AYAs with cancer, with patients who engage in higher levels of physical activity consistently reporting better scores in depression and self-concept.[157, 191] There have been mixed findings related to the potential long-term effects of QoL, sleep quality and anxiety.[191, 192, 197, 199]

Implementing personalised physical activity plans that cater to the specific needs and preferences of young individuals is essential. Offering programs that are accessible, flexible, and continuous is vital for long-term engagement.[91, 196] Health apps and wearable devices can enhance these programs by tracking progress and boosting motivation.[199, 200] It may also be necessary to explore remote and home-based exercise options for AYAs with cancer. This approach acknowledges the challenges posed by distance and the geographical spread of patients and treatment centres which can make group-based physical activity less feasible. It might also be the preference of the individual AYA to choose a remote or home-based option. Therefore, tailored, individualised remote or home-based programs are needed to help AYAs develop autonomous self-management skills.[195]

AYAs express a desire to achieve and maintain sufficient physical activity levels both during and after cancer treatment, but they often require guidance and support to do this.[194, 195] All healthcare professionals involved in the care of AYAs with cancer play a crucial role in promoting physical activity. Healthcare professionals should educate AYAs on the benefits of physical activity related to health, both in typical development and in relation to their cancer experience and adopt targeted, evidence-based strategies aimed at promoting increased physical activity.[201] Consideration should be given to the AYA's physical strengths and weaknesses, exercise preferences, and individual goals and/or motivations in order to maximise compliance.[196, 201] Accredited exercise physiologists and physiotherapists are particularly well-suited to prescribe and deliver physical activity programs for AYAs utilising the strategies mentioned.[194]

While the benefit of physical activity on physical capacity is well documented[192, 197, 200] there is less evidence on the effect on psychosocial well-being and QoL.[198] There is a strong need for more rigorous research in AYAs with cancer to better determine the essential attributes of exercise (i.e., mode, duration, intensity) for maximising positive effects on QoL. This might include adopting more sensitive QoL measures such as the PedsQL-Cancer Module Scales to capture exercise interventions for cancer specific QoL.[192, 196, 198, 200] Considerations for young people from diverse and marginalised groups should be integrated into program design and implementation.[157]

Key points

- The majority of AYAs with cancer do not meet current physical activity guidelines.[195, 196] Integrating physical activity into the care of AYAs with cancer not only addresses physical health issues but also offers crucial psychosocial benefits, enhancing their overall well-being and QoL. Patients with higher physical activity levels consistently report better depression and self-concept scores.[157, 191]

- AYAs express a desire to achieve and maintain sufficient physical activity levels both during and after cancer treatment, but often need guidance and support to do this.[194, 195]

- To maximise safety and therapeutic effect, exercise should be prescribed and delivered to AYAs with cancer under the direction of an accredited exercise physiologist or physiotherapist with a focus on transitioning to ongoing self-managed exercise.[193, 194]

- Individualised physical activity programs should be developed for AYAs with cancer, tailored to the specific needs and preferences of the young person and utilising technology to track progress and increase motivation.[199, 200]

- Physical activity interventions should be designed to be easily accessible and sustainable, especially for AYAs experiencing geographical location and scheduling barriers, with flexible scheduling and remote participation options.[91]

- Facilitating group-based physical activities for AYAs with cancer can provide significant psychosocial benefits, including improved social support and mental health.[8, 157] [Link to *Coping strategies and social support*]

- It is prudent for exercise professionals to remain cognisant of potential harm through exercise, to educate patients about, and monitor presence of, contraindications, which largely relate to the presence of new or unusual changes to existing signs and symptoms.[193]

8.2 Fatigue and sleep

Recommendations

Strong recommendations

- Healthcare professionals should be aware of the significant impact of symptom clusters, such as the combination of fatigue and sleep disturbances, on psychosocial well-being in AYAs with cancer.
- Healthcare professionals should implement interventions to manage fatigue in AYAs with cancer, such as regular physical activity and aerobic and strength training.
- Healthcare professionals should implement effective interventions to measure and manage sleep disturbances in AYAs with cancer.

Evidence summary

Background

Symptom clusters, such as the combination of fatigue and sleep disturbances, are prominent and interrelated symptoms in AYAs with cancer, significantly impacting their psychosocial outcomes.[106, 110, 123] AYAs undergoing chemotherapy report considerably more sleep problems and higher levels of fatigue compared to their same-age peers and their pre-diagnosis state.[116, 202-204] These issues encompass difficulties in falling asleep, staying asleep, and maintaining daytime alertness,[106, 116] contributing to a profound disruption in their daily lives and psychosocial well-being.[106, 116, 204, 205]

The interplay between fatigue and sleep disturbances exacerbates the psychological and emotional burden on AYAs with cancer.[205] Persistent fatigue and poor sleep quality are associated with increased anxiety, depression and social withdrawal,[18, 205] which in turn further disrupt sleep patterns and contribute to a vicious cycle of symptom exacerbation. The hospital environment, treatment side effects, and the psychological stress of a cancer diagnosis compound these issues, leading to significant challenges in maintaining normal activities, academic performance, and social relationships for young people.[110, 202]

The impact of these symptom clusters extends beyond the immediate treatment period,[109, 116] affecting long-term psychosocial outcomes for AYAs with cancer.[203] Chronic fatigue and sleep disturbances hinder emotional regulation, cognitive functioning, and physical coordination, thereby impairing the ability to engage in social interactions and enjoy daily activities.[206] Effective management of fatigue and sleep through interventions such as physical activity,[197, 200] aerobic and strength training in combination,[207] sleep hygiene, social activities and peer connection and comprehensive symptom management is crucial for improving the QoL and overall psychosocial health of AYAs with cancer.[106, 204, 206]

Healthcare professionals should prioritise the assessment and management of sleep and fatigue in AYAs with cancer and encourage a collaborative approach involving patients, families, and clinicians to address these symptoms effectively.

Further research is needed to develop tailored interventions and standardised measurement tools to better address the fatigue and sleep related needs of AYAs with cancer.[110, 208]

Key points

- Healthcare professionals should acknowledge the significant impact of sleep and fatigue on QoL for AYAs with cancer. Openly discuss fatigue and sleep issues during clinical encounters to validate patients' experiences and provide support. Clinicians should educate patients about the potential impacts of insufficient sleep on their overall well-being and daily functioning.

- Routinely assess sleep quality and habits in AYAs with cancer. Investigate and manage causes of nocturnal awakenings such as medication side effects, hydration protocols, pain, nausea, nightmares, and anxiety.
- Routinely evaluate fatigue levels in AYAs with cancer, acknowledging that fatigue can persist up to two years post-treatment (or longer in those with significant late effects of treatment such as chronic graft versus host disease). Address fatigue as a multidimensional symptom with physical, psychological, and emotional impacts.
- Strive to improve the young person's ability to engage in normal activities and social interactions through comprehensive symptom management.
- Use a symptom cluster approach to manage related symptoms like fatigue, sleep disturbances and depression in AYAs with cancer. Educate the young person about the interplay between these symptoms and the importance of holistic management strategies.
- Implement interventions to manage fatigue in AYAs with cancer, such as regular physical activity, aerobic and strength training, which has shown to improve fatigue levels and overall QoL.
- Promote social and mental activities that can help the young person manage fatigue, such as spending time with friends and family, and engaging in enjoyable hobbies.
- Recommend strategies for improving sleep, including creating a restful sleep environment and establishing a consistent sleep routine.
- Facilitate referrals for psychological support when necessary to help manage emotional and mood disturbances related to sleep and fatigue issues in AYAs with cancer.

8.3 Nutrition

Recommendations

Strong recommendation

- Healthcare professionals providing dietary interventions to AYAs during cancer survivorship, should incorporate principles of behaviour change and positive self-efficacy to improve dietary intake.

Weak recommendations

- Healthcare professionals should address the link between weight changes, body image and psychosocial outcomes, as well as address food insecurity, when providing dietary interventions to AYAs with cancer.
- Healthcare professionals should promote dietary interventions to AYAs during cancer survivorship to improve psychosocial outcomes.

Good practice statement

- Healthcare professionals should use sensitive communication and supportive dialogue when addressing concerns raised by AYAs with cancer related to physical appearance and body image.

Evidence summary

Background

Nutritional concerns during cancer treatment for AYAs have been well documented with treatment side effects such as nausea, vomiting, diarrhoea and taste changes leading to inadequate dietary intake malnutrition.[116] Malnutrition during cancer treatment has shown to lead to decreased chemotherapy tolerance, increased infection rates and reduced overall survival[9, 209] as well as impacting patient well-being.[18] Weight loss, particularly due to cancer cachexia, presents additional challenges, including reduced functionality, psychosocial impacts, and decreased survival rates.

For AYAs with cancer there is a complex interplay of weight issues, body image disruptions, and adverse psychosocial outcomes.[116] The loss of lean muscle mass and the visible nature of cachexia can significantly affect the young person's body-image and social interactions, requiring sensitive communication and supportive dialogue from healthcare professionals and family members.[9] These factors can significantly impact overall well-being and QoL in AYAs. [Link to *Physical appearance and body image*]

Psychological functioning is composed of multiple domains with health behaviours including dietary intake being a key domain of functioning.[157] With less than half of AYA cancer survivors meeting dietary guidelines, inadequate nutrient intake[209] and emerging evidence about correlations between dietary patterns and psychosocial concerns (such as anxiety and depression) suggests that interventions to improve dietary intake, behaviour change and self-efficacy may improve psychological functioning.[67, 157, 210] Cancer-related financial burden[18] potentially leading to food insecurity may increase the risk of depression, anxiety, and lower health-related QoL in AYAs, further complicating nutritional challenges.[209]

Further research and evidence-based interventions are needed on the links between nutrition and psychosocial outcomes for AYAs with cancer to enhance holistic care for young people. There is a lack of evidence around dietary interventions for AYAs that focus on psychological well-being and QoL as outcome measures.[210] Developing and implementing tailored dietary interventions and educational support programs can enhance AYA cancer survivors' awareness of existing food support programs and improve their dietary habits. The next steps for optimizing the psychological health of AYA cancer survivors should include developing or refining interventions that target modifiable factors such as diet.

Key points

- Healthcare professionals should recognise the emerging link between nutrition and psychological outcomes in AYAs with cancer, as highlighted by the *National Institute for Health and Clinical Excellence Guidance on Cancer Services*,[211] which acknowledges the role of nutrition in improving well-being for AYAs undergoing cancer treatment.
- Routine screening for food insecurity, nutrition security and malnutrition should be implemented as part of AYA cancer survivorship plans, starting at diagnosis and continuing through clinical follow-up visits.
- Provide professional nutritional support services to AYA cancer survivors to improve their nutritional and psychosocial outcomes, addressing poor dietary intake, dietary patterns, and nutrient deficiencies.
- When offering dietary advice to AYAs during cancer survivorship, incorporate principles of behaviour change and positive self-efficacy to enhance adherence and outcomes.
- During nutritional counselling, consider the financial toxicity associated with cancer treatment for AYAs with cancer, which can lead to financial insecurity and the inability to purchase adequate nutrition. Routine screening and support programs should address food and nutrition insecurity to mitigate these adverse effects.
- Address concerns related to physical appearance and self-image in AYAs through supportive dialogue and counselling. Be mindful of the language used around under and over-nutrition when discussing nutritional concerns with AYAs during and after cancer treatment.
- Provide holistic psychosocial support that addresses self-esteem, body image, and coping strategies to support the overall well-being of AYA cancer survivors.
- Accredited practicing dietitians are particularly well-suited to prescribe and deliver dietary interventions to AYAs with cancer.

8.4 Integrative therapies

Recommendations

Weak recommendation

- AYAs with cancer could consider yoga and mindfulness-based interventions to improve QoL and support psychological and social well-being during and after cancer treatment. These interventions should be personalised based on individual preferences to improve effectiveness.

Evidence summary

Background

Integrative therapies are part of a holistic approach to cancer care where complementary therapies are used as an adjunct to conventional cancer treatments. The integrative approach is evidence-informed and patient-centred, focusing on personalised care to improve QoL, manage symptoms, and enhance the effectiveness of conventional cancer treatments. It includes interventions such as mind and body practices, natural products, and/or lifestyle modifications.[212]

While the literature on integrative therapies is growing and use has been shown to be effective for cancer care, research on the psychosocial impact for AYAs is limited.[91] Mindfulness-based interventions have been shown to effectively manage anxiety, depression and stress in young people with cancer.[213] Yoga has been used by AYAs with cancer for relaxation[91] and may help to improve QoL and decrease anxiety in various stages of the cancer trajectory.[214] Both interventions are feasible in the inpatient/outpatient and community settings and are often well received. However, evidence suggests that there may be challenges enrolling young people in mindfulness-based interventions, suggesting that there is a cohort of patients that may be disinterested or bored with the intervention and drop out.[214]

More high-quality randomised controlled trials are needed to understand the psychosocial impact of integrative therapies on AYAs with cancer.[213-215] There is a need to develop standardised measurement tools specific to integrative therapies.[32, 91, 214]

Key points

- Consider yoga and mindfulness-based interventions to help improve QoL, reduce anxiety, and enhance emotional and social well-being in AYAs with cancer. Interventions should be personalised based on individual patient preferences to improve effectiveness.[215]

- Healthcare professionals working with AYAs with cancer should promote integrative therapies that enhance social support and peer connections. [Link to *Coping strategies and social support*]

- Encourage legacy-making activities and meaning-centred programs to improve resilience, self-esteem, and overall psychological well-being.[91] Although the evidence for these benefits is predominantly qualitative, they are consistently reported.[91] However, more research is needed to fully establish their effectiveness.[214]

8.5 Creative therapies

Recommendations

Strong recommendations

- Healthcare professionals could consider integrating music therapy into routine care for AYAs with cancer, personalised to their individual needs rather than a one-size fits all approach.
- AYAs with cancer should receive music therapy from a trained music therapist to enhance QoL and psychological well-being. Music therapy interventions can assist young people to reduce anxiety and stress, improve coping and enhance social support.

Weak recommendation

- We suggest that creative therapies such as art therapy can be a useful tool for AYAs with cancer to express themselves, manage stress and enhance social support.

Evidence summary

Background

Creative therapies are useful tools in the holistic care of cancer patients. These therapies, which include modalities such as music therapy, art therapy, group and technology-based interventions aim to enhance physical, emotional, and mental well-being. They can help AYAs with cancer express their feelings, manage stress, and enhance their QoL, particularly during treatment and into the survivorship period.[91, 216]

Additional reliable data on the efficacy of creative therapies for the psychosocial care of AYAs with cancer is needed.[8] More high-quality randomised controlled trials and standardised measurement tools specific to creative therapies would strengthen the evidence base.[91, 217, 218]

Music therapy

Music in cancer care can extend from patients listening to self-selected music, music interventions by medical clinicians (music medicine) such as pre-recorded music for passive listening, to music psychotherapy interventions offered by trained music therapists (music therapy).[218] Music therapists implement a music intervention to cancer patients using a therapeutic process and the use of personally tailored music experiences such as receptive music listening, singing or playing musical instruments, song-writing and musical improvisation.[218] Music therapy interventions can be more effective than music medicine interventions because they are based on patient preferences and the therapist can individualise them to address identified needs from ongoing assessments.[218]

In AYAs with cancer, music therapy delivered by a qualified music therapist has been associated with reduced anxiety and stress, enhanced coping and resilience and improvements in overall well-being and QoL, including improvements in social support and the family environment.[218-220]

Art therapy and other interventions

Art therapy delivered by a trained art therapist uses visual art materials and creative processes (drawing, painting, sculpting) to help cancer patients communicate their thoughts and feelings. AYAs with cancer may find art therapy subjectively helpful and qualitative analysis indicates it may help young people to express themselves, feel relaxed and enhance social support.[8]

While art therapy, semi-structured social weekends, group therapies and technology-based interventions are all documented in the literature, these lack methodological rigour and/or sufficient data to draw conclusions in regard to their psychosocial efficacy specifically for AYAs with cancer.[15, 221]

Key points

- Healthcare professionals should consider integrating music therapy into routine care for AYAs with cancer,[8, 217-219] according to individual needs rather than a one-size fits all approach.

- Social support for AYAs with cancer can be increased through creative therapy activities such as music therapy, art therapy and structured peer interactions.[8, 216] [Link to *Coping strategies and social support*]

9. Recommendations for life outside cancer

9.1 Developmental needs and support

Recommendations

Strong recommendations

- Healthcare professionals should encourage and facilitate opportunities for peer involvement and group support during and after treatment to help AYAs with cancer regain a sense of normalcy.
- Services should be provided to support AYAs with cancer to return to education and/or employment in order to help AYAs integrate back to "normal" life.

Weak recommendations

- The normal developmental needs of AYAs with cancer should be prioritised and respected by the healthcare team and family members or carers in order to improve treatment adherence, cooperation, and approaches to care.
- Healthcare professionals should be cautious when setting treatment and survivorship goals for AYAs with cancer that reflect a traditional linear developmental trajectory. Instead, healthcare professionals should work with AYAs to develop goals that are in line with the young person's own personal values.

Evidence summary

Background

Adolescence and young adulthood are developmental periods typically associated with increased autonomy, independence, and identity formation. However, a cancer diagnosis and treatment can threaten these developmental processes as AYAs often feel different to their peers without a history of cancer.[47] Therefore, the provision of age-specific and developmentally appropriate psychosocial support is essential in preventing or reducing disruptions to the young person's development and minimising the negative impact on their physical health and QoL.[128]

To support QoL throughout treatment and beyond it is important that AYAs with cancer continue to live as normal a life as possible, achieve developmental tasks, and participate in the many milestones that occur during this stage of life.[47] Living with cancer and maintaining connection to their education, employment, family and peer relationships are essential parts of a young person's life (and QoL) and should be addressed and supported throughout treatment.

Key points

- AYAs have neurodevelopmental differences to adults which can bring up issues that impact their illness outcomes and QoL.[63] The normal developmental needs of AYAs with cancer should be prioritised and respected by the healthcare team and family members or carers. Doing so can help to improve treatment adherence, cooperation, and approaches to care.
- There is no universal approach to supporting AYAs as each individual's developmental trajectory is unique. Therefore, it is important that the healthcare team continue to engage with the AYA with cancer and assess for changes to their psychosocial needs throughout treatment and into survivorship.[222] Clinicians should work with AYAs to develop treatment and survivorship goals that are in line with the young person's own personal values.

- Opportunities for peer involvement and group support during and after cancer treatment can help AYAs regain a sense of normalcy as cancer treatment often results in an inevitable increased reliance on parents or carers and a disconnect from peers.[47] Promoting social re-integration after treatment can be important and beneficial for AYAs.[47]
- Providing services that aim to support AYAs with cancer to return to education and/or employment are important help AYAs integrate back to "normal" life.[47] Many AYAs identify their cancer experience to be a major disruption on their control over life and their future life plans.
- Healthcare professionals can help AYAs to regain a sense of normalcy in their cancer experience by establishing trust, understanding and open communication with them.[35]

9.2 Coping strategies and social support

Recommendations

Strong recommendations

- Healthcare professionals should help AYAs with cancer identify new and existing coping strategies that they may have based on past life experiences and assess these strategies for past potential efficacy. Identified coping strategies may be emotion or problem focused.
- Healthcare professionals should be mindful of times across an AYA's cancer experience that can be associated with a high level of distress and prioritise support to help young people find coping strategies that work during these times.
- While long-term use of avoidant coping strategies may be associated with distress, it can be helpful in the short-term and should not necessarily be discouraged if it assists AYAs with cancer adjust.
- AYAs with cancer who need, or desire support should have access to regular one-on-one psychotherapy. Psychotherapeutic and psychoeducation interventions that may be effective in this cohort include targeting positive emotions, depression anxiety and stress management, goal setting, cognitive reframing and meaning making.
- Healthcare professionals should support AYAs to discuss their cancer diagnosis with peers who do not have a history of cancer in order to facilitate understanding and social support. The social-ecological model may provide a useful framework for supporting cancer disclosure to peers by AYAs with cancer.
- Healthcare professionals should encourage AYAs with cancer to connect with peers as a means of increasing coping by reducing isolation and maintaining social and emotional well-being. Specific AYA cancer support groups can offer opportunities for social support, and some AYAs may find social media and apps facilitating social connections useful for seeking wider support.

Weak recommendations

- Healthcare professionals should support AYAs to identify coping strategies that address different domains of functioning and QoL through the cancer care continuum.
- Healthcare professionals should address the unmet information needs of AYAs with cancer as a means of supporting coping using open and direct communication to foster trust with the young person. Individual patient preferences regarding the amount and type of information should be assessed over different stages of the cancer care continuum as these preferences can change.

Evidence summary

Background

The cancer experience for AYAs can be viewed as a journey with AYAs requiring different levels of information, support, autonomy, and coping skills across the trajectory from diagnosis to beyond.[47] There is not a single set of coping skills or strategies that can be seen as better or more adaptive than other coping skills universally.[223] Rather it is important to acknowledge that young people may use different coping strategies at different stages of their cancer experience,[223, 224] and that the developmental age of AYAs can influence the number of different coping strategies available to any one individual based on past life experiences.[97, 105, 224] Cancer has the potential to impact all aspects of an AYA's QoL and functioning.[97, 116]

Key points

- Healthcare professionals can provide support to AYAs with cancer by helping them identify new and existing coping strategies that they may have based on past life experiences,[97, 105] and assess these for past potential efficacy.[97] Coping strategies may be emotion focused (change the way you think or feel about the problem) or problem focused (change the environment and seek more information). Patients who are younger at diagnosis may have had fewer opportunities to learn and use coping strategies.[97, 105, 224]

- It is important to be mindful of times across an AYA's cancer experience that can be associated with a high level of distress. This may include during diagnosis, challenges with treatment toxicities, changes in functional capacity, changes in prognosis and at the end-of-life. Supporting AYAs to find coping strategies that work during these times should be prioritised.[105, 225]

- While long-term use of avoidant coping strategies may be associated with distress, in the short-term it can be helpful and healthcare professionals should not necessarily discourage use if it helps the AYA adjust.[105, 223, 224]

- When it is needed and desired by an AYA with cancer, healthcare professionals should support access to one-on-one psychotherapy that is delivered through manualised interventions, and in combination with online self-guided activities. Psychotherapeutic and psychoeducation interventions such as targeting positive emotions, depression, anxiety and stress management, goal setting, cognitive reframing and meaning making have shown feasibility and efficacy among AYAs with cancer.[157] One-on-one sessions between an AYA and psychosocial clinician are preferred where sensitive topics may be discussed to prevent and protect against the potential discomfort of discussing these issues with other AYAs.[135] One-off sessions have shown less efficacy than sustained engagement with psychotherapeutic and psychoeducational interventions.[99, 108]

- Healthcare professionals should support AYAs to identify coping strategies that address different domains of functioning and QoL through the cancer care continuum.[97, 116] These include physical (pain, fatigue and sleep, nutrition, physical appearance and body image), social, emotional and spiritual.[116]

- Addressing the unmet information needs of AYAs with cancer can be a useful way to support coping.[116] Healthcare professionals should use open and direct communication to foster trust with the young person and assess the amount and type of information the AYA prefers over different stages of the cancer care continuum as these can change.

- AYAs should be supported to discuss their cancer diagnosis with peers who do not have a history of cancer as this can facilitate understanding and social support.[226] Psychosocial clinicians can help role-play with AYAs so that they can rehearse what they want to say, anticipate possible reactions from peers, and address any fears they may have about disclosing their cancer experience.[226] The social-ecological model may provide a useful framework for supporting cancer disclosure to peers by AYAs with cancer.[227]

- Healthcare professionals should support AYAs with cancer to connect with peers as a means of increasing coping by reducing isolation and maintaining psychological health and social well-being through the cancer care continuum.[93, 97, 116, 135, 157, 227, 228] Specific AYA cancer support groups may be helpful avenues for social support. [Link to *Support needs for relationships with peers, friends and colleagues*]

- Social media and apps facilitating social connections and social skills may be useful for some AYAs with cancer, though evidence is still emerging.[157, 227, 228] AYAs have reported benefits to using online forums for seeking support and managing uncertainty, especially in the case of not wanting to burden immediate family, friends and loved ones.[226]

9.3 Education and employment support

Recommendations

Strong recommendations

- Healthcare professionals should recognise that re-entry to education or employment is a challenging time for AYAs with cancer and provide support to navigate the system and involve key persons. In educational institutions, a key contact person should be identified within the school, university or TAFE campus to act a designated education coordinator for the young person.
- Healthcare professionals should address education and employment issues with AYAs during cancer treatment. Discuss goals for return to school or work with the young person and provide support that is individualised, takes into account their personal strengths and weaknesses/impairments, and considers potential new directions for study or employment.
- Healthcare professionals should advocate for AYAs at their place of work, if desired by them, to establish flexible working conditions, which can help AYA cancer survivors stay in the work force long-term.
- Healthcare professionals should support AYAs in identifying and accessing services available at their place of work such as Employee Assistance Programs.

Weak recommendations

- Remotely-delivered lessons can be effective for ensuring continued learning and engagement and we suggest that they should be considered in instances where the AYA with cancer cannot participate in learning in person.
- Healthcare professionals should liaise with educational institutions so that education staff are explicitly informed around the impact of fatigue from cancer and treatment on AYAs' learning.
- Educational interventions for AYAs should be adapted and modified as the young person progresses along the cancer trajectory and should include planning for transition to adult health care as well as a focus on developing self-advocacy skills.
- Healthcare professionals should provide AYAs with information and resources that aid transition from cancer treatment to work.
- Healthcare professionals should consider referral to career counselling as needed for AYAs with cancer returning to work.

Good practice statement

- Healthcare professionals could consider writing letters of support to the AYA's educational institution to help them obtain additional support through school and exam provisions where it is indicated, due to the impacts of their cancer diagnosis and/or treatment on their physical, psychological or neurocognitive function.

Evidence summary

Background

Education and employment are important to help AYAs develop a sense of identity, self-esteem, social networks and income.[52, 94, 229] A cancer diagnosis can cause significant disruptions to the trajectory and timing of these milestones, and young people require support to participate in educational and employment opportunities with as little interference as possible.[62, 230]

A successful return to school can be beneficial to psychological well-being,[229] and tailored re-entry programs can help to improve knowledge and confidence in both patients and teachers.[35, 229] Conversely, cancer-related disruption to school or work is associated with increased psychological distress.[91] Key concerns of AYAs with cancer include school absence, inability to complete assignments or exams, the feeling of being left behind and difficulties with reintegration such as being accepted back into friendship groups, being bullied over appearance, and catching up on school curriculum.[52, 229, 231-234]

Young people with cancer that are employed may need to take extended time off from work, or change their duties, during treatment. Many AYAs report difficulty in returning to work, and experience reduced productivity at work (due cognitive and/or physical issues such as fatigue), and the need to adjust work goals accordingly in the long-term (such as careers involving physical abilities).[52, 62, 94, 232-235] The lasting impact of cancer on an AYA's career and employment is not clear, and most research to date has been conducted in countries other than Australia.[234] Some studies report an increased risk of unemployment among AYAs with cancer, or older age at time of their first job.[20, 233, 235]

Key points

- Re-entry to education or employment is a challenging time for AYAs with cancer.[229] AYAs in their last year of high school or first year/s of working may need particular support.[230] Young people should be supported to navigate the system and involve key persons (classmates, teachers, employers) in the process, who should also receive information and support.[41, 230, 234] [Link to *Support needs for relationships with peers, friends, and colleagues*]

- A key contact person should be identified within the school, university or TAFE campus to act as a designated education coordinator for the AYA while undergoing treatment.[231] Increased knowledge of the AYA's condition helps education staff to support them better, and facilitates peer understanding.[226] A specialist coordinator can facilitate more effective communication between education staff and the AYA and/or their parents, and relieve the pressure to organise education and re-integration arrangements for the young person. Effective collaboration between the patient, family, hospital and educational institution is important to ensure the patient can continue to engage effectively.[229] Planning also offers hope and sends the implicit message that the future remains important.[231]

- Education and employment issues should be addressed with AYAs during cancer treatment.[231] Supporting continued school or work participation, where the AYA feels capable, can support transition to life after cancer and maintains a sense of normalcy through treatment.[234] Engagement with school or work should be encouraged where possible and be consistent with the AYAs preferences and capacity.[126] Remotely-delivered lessons can be effective for ensuring continued learning and engagement[23] and should be considered in instances where the AYA cannot participate in learning in person.

- Good survivorship preparation and appropriate education/occupation support to help plan goals are important needs for AYAs, but are often unmet.[91] Healthcare professionals should discuss goals for return to school or work with the AYA and provide support that is individualised, takes into account their personal strengths and weaknesses/impairments, and considers new directions for study or alternative employment opportunities if needed.[235]

- Healthcare professionals should liaise with educational institutions so that education staff are explicitly informed around the impact of fatigue from cancer and treatment on AYA learning.[23]

- Educational interventions for AYAs need to be adapted and modified as the young person progresses along the cancer trajectory, and should include planning for transition to adult healthcare as well as a focus on developing self-advocacy skills.[126]
- Employment support from healthcare professionals should include the provision of information and resources that aid the transition from cancer treatment to work for AYAs.[52]
- If desired by the AYA, healthcare professionals should advocate for them at their place of work to establish flexible working conditions, which can help AYA cancer survivors stay in the work force long-term.[230]
- AYAs with cancer should be supported to identify and access services available at their place of work such as Employee Assistance Programs.[235]
- Healthcare professionals should strongly consider referring AYAs with cancer to career counselling as needed.[135]

9.4 Financial information and support

Recommendations

Strong recommendation

- Healthcare professionals should provide education, resources and emotional support to AYAs with cancer and their family members or carers to address financial toxicity and the uncertainties around returning to work, career changes and employment benefits to enhance financial security.

Weak recommendations

- Social workers play a pivotal role in navigating the financial burden on AYAs with cancer by completing financial screening tools to identify the financial impact of cancer treatment, and to link AYAs with appropriate financial assistance, counselling and relief.
- Healthcare professionals should ensure that AYAs with cancer who must travel longer distances for treatment are educated to ensure they can access further financial assistance and support.

Good practice statement

- Refer the AYA and/or their family members or carers to a social worker for assistance in navigating the Centrelink system, to be referred to not-for-profit organisations such as Cancer Council, or information on early access to superannuation.

Evidence summary

Background

The financial impact of cancer and its treatment is significant for many young people and their families, relationships, and social groups.[91] Due to healthcare costs and needing significant time off work, AYAs can become financially dependent on their parents whilst on treatment and into survivorship,[91, 94, 222, 236] and unsurprisingly AYAs with cancer report a high level of financial toxicity.[18, 62, 98, 102, 230, 233, 236]

This impact is felt not only whilst on treatment but in survivorship.[234] Research has confirmed that AYA cancer survivors are significantly more likely to experience financial hardship compared to other adults with no history of cancer.[230] Ongoing difficulties to achieve financial independence from parents impedes AYAs establishing autonomy,[232, 236] and parents can experience financial hardship (toxicity) as they are financially supporting their young adult child.[234] The issue of reduced income and increased expenses can impact on opportunities for young people to participate in "normal" life. Financial hardship and toxicity have further consequences of increased depression, anxiety and psychological distress which can continue to extended family members and carers.[62, 92, 236]

Key points

- The support of an advocate within the multidisciplinary healthcare team may be crucial in ensuring that the patient's rights are met.[222]
- Financial security can be enhanced by providing education, resources and emotional support to AYAs with cancer and their family members or carers to address financial toxicity and the uncertainties around returning to work, career changes and employment benefits.
- Social workers may play a pivotal role in navigating the financial burden on AYAs with cancer by completing financial screening tools to identify the financial impact of cancer treatment, and to link AYAs with appropriate financial assistance, counselling and relief.[98]
- AYAs with cancer travelling longer distances for treatment should be educated to ensure they can access further financial assistance and support.[98]

9.5 Cognitive function

Recommendations

Strong recommendations

- Healthcare professionals should be aware of the potential impacts of cancer and its treatments on cognitive function in AYAs and how these impacts can affect many aspects of functioning and emotional health.
- Healthcare professionals should consider referring AYAs with cancer for assessment of cognitive function with a suitably trained psychosocial clinician where self-reported cognitive difficulties are causing significant distress and/or impact on daily function, particularly regarding their education, employment or establishing independence.

Weak recommendations

- Healthcare professionals should assess AYAs with cancer for presence and contribution of other psychosocial and functional difficulties such as anxiety, depression, sleep disturbance and fatigue, and help the young person resolve these challenges in the first instance when cognitive difficulties have been reported.
- Healthcare professionals should consider the unmet information needs of AYAs in relation to cognitive impacts of cancer and its treatments, and discuss the potential of cognitive difficulties and impacts on daily life with the young person.
- Interventions and cognitive rehabilitation focusing on teaching memory skills, task management, attention training and psychological well-being may benefit AYAs with cancer that are experiencing cognitive difficulties.
- Structured social skills training may be useful for AYAs with cancer experiencing cognitive difficulties. This should be tailored to the young person's developmental stage and address age-relevant social support and challenges.

Evidence summary

Background

AYAs can experience cognitive impacts through treatment and beyond that are due to the cancer and/or the treatment they have received.[157, 235] While the scientific literature is still emerging, commonly reported cognitive impacts include difficulty paying attention, remembering things, and keeping up with school or work.[235]

Cancer-related cognitive impairment can be particularly distressing at times when AYAs are utilising their cognitive skills such as returning to school, establishing a career, developing social and romantic relationships, or establishing financial independence.[157] Cancer-related cognitive impairment may also be present with other psychosocial concerns such as fatigue, sleep disturbance and mental health concerns such as depression and anxiety, and unmet information needs are often reported with regard to cancer related cognitive impairment in young people.[237]

AYAs that report difficulties with cognitive function in later survivorship are more likely to report negative impacts on QoL across social emotional domains including: school/study attainment, employment and career, financial toxicity and interpersonal relationships.[157, 237]

Key points

- It is important to be aware of the potential impacts of cancer and its treatments on cognitive function and how these impacts can affect many aspects of functioning and emotional health in AYAs.[157, 235, 237] Clinicians should consider the developmental stage of the young person and challenges they may be facing when understanding the likely impacts of cognitive difficulties.[126, 140, 238]

- When AYAs with cancer report cognitive difficulties, healthcare professionals should assess for presence and contribution of other psychosocial and functional difficulties, particularly anxiety, depression, sleep disturbance and fatigue, and help the young person resolve these challenges in the first instance.[126, 237]

- Healthcare professionals are encouraged to consider the unmet information needs of AYAs in relation to cognitive impacts of cancer and its treatments. Discussion around the potential of cognitive difficulties and impacts on daily life is encouraged with young people, particularly after treatment completion.[122, 126, 237]

- Referral for assessment of cognitive function with a suitably trained psychosocial clinician should be considered for AYAs with cancer where self-reported cognitive difficulties are causing significant distress and/or impact on daily function, particularly with regard to education (school/study), employment (work/career) or establishing independence.[122, 126, 140, 157, 235, 237, 238] AYAs who have been diagnosed with a CNS cancer or received CNS directed therapy may be at particular risk of developing cognitive difficulties.[126]

- AYAs with cancer experiencing cognitive difficulties may benefit from interventions and cognitive rehabilitation focusing on teaching memory skills, task management (goal setting, prioritisation and time management), attention training and psychological well-being.[126, 157] Interventions may be delivered in group format or through individual and tailored sessions with psychosocial clinicians.[126]

- Structured social skills training may be useful for AYAs with cancer experiencing cognitive difficulties (especially those with neurocognitive deficits as a result of diagnosis or treatment), and healthcare professionals should ensure this is developmentally appropriate and addresses social support and challenges relevant to the age and life stage of the AYA.[97]

- Evidence for risk factors associated with cognitive function in cancer patients is emerging. While young people diagnosed with CNS cancers and/or receiving CNS directed treatment (including radiation therapy or intrathecal chemotherapy) are at higher risk of cognitive impacts,[122] consideration of AYAs diagnosed at a younger age, of female sex, diagnosed with leukaemia, Hodgkins lymphoma, breast and gynaecological cancers, and those treated with chemotherapy alone is warranted.[126, 237]

- AYAs with cancer should be encouraged to maintain a healthy lifestyle including regular physical activity, eating a balanced diet, avoiding smoking/alcohol/drugs, ensuring adequate sleep and maintaining social connections. While no evidence exists for the efficacy of these factors in improving cancer related cognitive impairment among AYAs with cancer, they are known contributors to brain health and cognitive function among the general population and are likely to be beneficial for young people.

- Mixed evidence exists for the value of online brain training in AYAs,[157] but studies in other age groups living with and beyond cancer have reported benefits especially regarding self-reported cognitive function and QoL. However, these online programs can be costly, so these programs should be discussed with young people in a balanced way with consideration of likely benefits and costs.

10. Recommendations for relationships

10.1 Support needs of families, partners, and carers

Recommendations

Strong recommendations

- Healthcare professionals working with AYAs with cancer should be aware of the impact of treatment on the young person's family or carers and the additional stressors inherent within the family environment that may increase parental distress. These areas should be canvassed with relevant family members at diagnosis, at regular intervals throughout treatment, and at times of significant change in the treatment of the patient.
- Healthcare professionals should address the information needs of family members, partners and carers of AYAs with cancer by providing honest, accurate and easily understood information in both verbal and written format, at key points in the cancer care continuum. Topics to cover include the impact of the cancer, treatment and side effects, coping strategies and available support services.
- Healthcare professionals should be mindful of the negative impacts on siblings of AYAs with cancer and consider the sibling's specific needs.

Weak recommendations

- When addressing the information needs of family members, partners or carers of AYAs with cancer, information and support could be provided on practical, financial, psychological, social, physical health and self-care impacts. Healthcare professionals should provide information and support to family members on how to talk to their AYA-aged child about the emotional impact of cancer and other sensitive or distressing topics.
- If the AYA with cancer identifies stress associated with how their family members or carers are coping and responding, the provision of additional support and information is suggested for all relevant family members. Healthcare professionals may be able to formally or informally assess the needs of family members directly and make appropriate referrals.
- The multidisciplinary healthcare team should take collective responsibility to link siblings with appropriate services and/or resources to address their needs whilst the AYA is undergoing cancer treatment, in any setting.
- Healthcare professionals could consider ways to ensure the needs of siblings of AYAs with cancer are routinely assessed, with formal assessment processes inclusive of siblings.
- During hospital admissions, healthcare professionals could consider ways to support communication between the AYA in hospital and their siblings at home, provided that such communication is manageable and desirable for both parties. Consider providing youth-friendly spaces on wards for AYAs and siblings to interact and providing siblings with a tour of the hospital environment for familiarisation.
- Practical support should be provided to siblings of AYAs with cancer, such as communication with education providers, provision of information and resources and referrals to counselling and community-based organisations such as Canteen for ongoing support.

- Healthcare professionals should consider and discuss the needs of siblings when an AYA with cancer is receiving end-of-life care, as concern for siblings can influence AYA decision making.

Good practice statements

- Healthcare professionals should complete a thorough psychosocial assessment to identify what significant others are in the life of the AYA with cancer and what specific support they will require.
- Understanding who makes up the patient's family, what their family relationships are like, who is available to support them and any family stressors will help the healthcare team to develop a supportive care plan. Ask them to draw a family tree to understand family composition and dynamics and prompt discussions about these issues.
- During care planning, all AYAs with cancer and their families or carers should be given or referred to information about their rights to Government benefits and assistance from not-for-profit organisations and community agencies.
- Family members and partners of AYAs with cancer should be given information about accessing psychosocial supports so that they can continue to support the young person.
- Healthcare professionals are encouraged to have age-appropriate discussions with siblings of AYAs with cancer where possible, and may wish to provide resources such as picture books for younger siblings.
- Healthcare professionals are encouraged to take opportunities with the AYA with cancer and their siblings to complete memory-making tasks such as photos, letter writing, videos etc.

Evidence summary

Background

Family, peers, partners and significant others all play a role in supporting a young person through their cancer experience. In particular, family support can help AYAs to successfully cope during treatment and into the survivorship period, hence providing support and guidance to family members is critical for supporting the patient. All of these relationships should be addressed as part of the psychosocial assessment of an AYA with cancer and incorporated into the management approach of the healthcare team.[50]

The AYA and their family members should be encouraged and supported to maintain their existing friendship and support networks, and also given information about peer support programs and groups so they can make connections with other AYAs, siblings or parents who have a lived experience of cancer.

Family members

The majority of AYA patients will be reliant on family to some extent during their treatment. Of those who had previously left the family home, some will return home for a period, if not the entirety, of their treatment. The cancer care continuum through diagnosis, treatment and beyond will inevitably have an impact on the whole family,[14, 17, 121, 239, 240] and how AYAs cope with their cancer will also have an impact on family member coping and adjustment.[41, 240, 241]

How the family copes with the cancer diagnosis and treatment will have a direct impact on how the young person copes.[14, 121, 239, 240] As a result, the practical and support needs of the patient are very much intertwined with the needs of the family and each family should be viewed as part of an interactive system.[17, 41, 239-241] Providing family-focused care requires an awareness of community supports and services and referral as required.

Key practical impacts for parents and partners of AYAs with cancer include shifts to regular routines and schedules,[240] maintaining working or other caring responsibilities or school attendance for siblings,[240, 241] and additional financial burden including medical expenses and costs of attending care (e.g., parking, moving house).[240] Psychological impacts are common and include both positive (e.g., increased closeness to the AYA with cancer)[41, 239] and negative outcomes (e.g., high rates of depression, anxiety, fear or worry, distress, intrusive thoughts, and suicidal thoughts).[121, 239, 240] Roles of family members and carers can also change with the need to assist the AYA with medications and treatment regimens at home, and can lead family members to feel socially isolated.[240] Physical impacts such as parents neglecting their own health in favour of caring for their AYA-aged child with cancer, sleep difficulties and fatigue are common.[240] Many family members report high unmet information needs in relation to all aspects of the AYA's cancer experience.[5, 240]

Keeping family members, including siblings, adequately informed can assist family members to feel empowered when dealing with a life-threatening illness.[5, 14, 121, 239, 240] It is important that the correct amount of information is given to family members at the right time, particularly when the young person has just been diagnosed with cancer, and at each stage throughout the cancer experience including into survivorship or during end-of-life.[121, 240, 241] When providing information to siblings, the content and format should be tailored to their cognitive and developmental needs.[240]

When the AYA with cancer has a poor prognosis, factors related to how, when, and what is discussed during end-of-life discussions have the potential to influence parent, partner and sibling outcomes and well-being after the AYA has died.[14, 241] Having the opportunity to plan the young person's location of death is associated with better parent outcomes, including lower decisional regret and feeling more prepared and comfortable with the location of death.[241] Structured AYA-specific communication tools, such as *Voicing My CHOiCES*™, can be utilised to generate family-centred advance care planning conversations and help family members better understand the preferences of the AYA.[14, 242]

See [*Progressive and incurable cancer*] for recommendations related to end-of-life support for families, partners and carers.

Key points

- Be aware of the impact of cancer diagnosis and treatment on the young person's family or carers and the additional stressors inherent within the family environment. For example, the financial impact of reduced work hours and/or paying for childcare, accommodation and transport can cause significant worry for family members as they focus on supporting the young person.[240, 241] The presence of these external stressors can impact parent distress.[239] These areas should be canvassed with relevant family members at diagnosis, at regular intervals throughout treatment, and at times of significant change in the treatment of the patient.

- Identify factors of resiliency and risk within the family of AYAs with cancer. Factors that enhance resiliency include having close family and extended family ties, cohesion and mutual respect of family members, parent's encouragement and respect of AYA children's developmental challenges, and clear communication.[121] Risk factors include preexisting mental health issues, sociodemographic difficulties and unemployment (either prior to or resulting from cancer diagnosis), issues of abuse, conflict and separation, enmeshed relations, and drug and alcohol issues.[239]

- Address the information needs of family members and partners of AYAs with cancer through the provision of information in both verbal and written format[239, 240] and at key points in the cancer care continuum covering diagnosis, prognosis, treatment and effects of treatment. Specific information and support could be provided on practical, financial, psychological, social, physical health and self-care impacts.[240] Provide information and support to family members on how to talk to their AYA-aged child about the emotional impact of cancer and other sensitive or distressing topics.[240]

- Be mindful of the cultural and spiritual beliefs of family members and partners of AYAs with cancer, especially with sensitive topics such as fertility, as this may influence the way family members and partners receive or want information.[5]
- Family members and partners of AYAs with cancer should be provided with honest, accurate and easily understood information about the impact of the cancer, including treatment and side effects, coping mechanisms, support services available, self-care/family care activities and the changes to family routines, relationships and daily living.[121, 239-241]
- Provide additional support and information for all relevant family members if the AYA with cancer identifies stress associated with how their family members or carers are coping and responding.[239] Healthcare professionals may be able to formally or informally assess the needs of family members directly and make appropriate referrals.

Siblings

It is important for healthcare professionals working with AYAs with cancer to identify and support the needs of their siblings.[243] Siblings may feel left out or “invisible” to the healthcare team,[243] and that their needs are under-recognised within their family, as their parents are strongly focused on the needs of their ill brother or sister.[244] Whilst the focus of healthcare professionals is primarily on the patient, it is acknowledged that siblings need support too.[243] However, given that siblings are rarely seen by the healthcare team, any difficulties that the sibling is experiencing may only come to the attention of clinicians if reported by a parent or the AYA themselves.[243]

Siblings may experience a range of complex emotions such as guilt, anger, and distress, as well as changes in family dynamics and social relationships.[244] Siblings may be distressed by separation from their unwell brother or sister during hospital admissions, especially if they cannot visit.[245] The AYA with cancer and their sibling may be protective of each other and both may moderate their language and behaviour in attempts to reduce the distress of the other.[246, 247]

When an AYA with cancer dies, it is often the most significant loss that the sibling has ever experienced and it can have a profound impact on them, but few talk regularly about their loss.[248] Siblings can experience psychological issues such as unresolved grief, many years after their brother or sister has died.[249]

10.2 Support needs for relationships with peers, friends, and colleagues

Recommendations

Strong recommendations

- Healthcare professionals should encourage and facilitate young people with cancer to interact with other AYA cancer patients to reduce feelings of isolation and normalise common experiences. This could be through seeing patients in waiting rooms, on the ward or in cancer support groups, online platforms, or camps.
- Healthcare professionals should encourage and facilitate where possible connections with peers, groups and organisations that the AYA was involved with prior to their cancer diagnosis in order to help them cope during treatment and beyond.
- Healthcare professionals should provide AYAs with cancer information to assist them to manage and maintain their peer relationships. This may include information on how to talk to friends about their cancer experience and tips on maintaining friendships during active treatment.
- Healthcare professionals should support AYAs with cancer to remain at school where possible in order to improve their well-being, self-worth, social interaction and allow for normality.
- Healthcare professionals should provide information and support to the young person's classmates, teachers or employer about the AYA's cancer diagnosis.

Evidence summary

Background

The support of friends and peers can help the young person through their cancer experience and assist them to manage treatment and beyond. Therefore, direct support and guidance offered to friends and peers can also assist with supporting the patient.

Peer relationships are central to the world of the developing young person. Encouraging AYAs to interact with existing friends as well as other AYAs going through cancer treatment can improve connection and social interaction.[8, 29, 35] Peers who are also receiving cancer treatment, or in later survivorship, can play an important role in normalising common feelings and experiences and creating a sense of inclusion.[19]

Separation from peers due to cancer treatment can have long-term negative implications for healthy peer relationships if not managed appropriately. The healthcare team has an obligation to assist the AYA patient to manage these relationships.[35, 226]

Key points

- Provide young people with information to assist them to manage and maintain their peer relationships.[226] This may include information on how to talk to friends about their cancer experience and tips on maintaining friendships during active treatment.[33]
- Encourage peer interactions when the AYA is an inpatient. For example, make sure the ward is a welcoming place to visit, provide a private place for young people to get together, and offer some education to friends to alleviate their concerns.[33, 41]
- Foster interactions with other AYA cancer patients when the young person is interested in this. Friendships with other patients normalise these common experiences.[18, 19, 231] Specific AYA cancer support groups may help the young person to address common feelings of being misunderstood and feeling left behind from other peers.[228] Healthcare professionals should provide information about

cancer support groups, online platforms, retreats and camps to AYAs with cancer[20, 46, 62, 228] and are encouraged to refer young people to local AYA cancer support networks through community-based organisations like Canteen.

- Be aware of the importance of education and/or employment for AYAs with cancer to remain connected to friendships and have social interactions with their peers and colleagues, which is vital in this developmental period.[20, 41, 230] Remaining at school in particular allows for a sense of normality, self-worth, reduces feelings of isolation and improves overall QoL.[62, 231] Healthcare professionals should provide information and support to the young person's classmates, teachers or employer about the AYAs cancer diagnosis.[41, 230] [Link to *Education and employment support*]
- Be aware of key social events in the life of the young person and promote flexibility where possible around treatment dates, planned hospital admissions, consultation times, and procedures to reduce feelings of disconnection.[17, 47]
- Encourage the AYA's family to be respectful of the essential role that friends play in healthy AYA development and support the continued involvement of friends in the daily life of the young person.

10.3 Support needs for intimate relationships

Recommendations

Strong recommendations

- Healthcare professionals should provide support to both the AYA with cancer and their partner to help them navigate communication and intimacy in their relationship during treatment and beyond.
- Healthcare professionals should be aware that AYAs with cancer may have different priorities compared to their peers, which may change the way they go about developing and sustaining romantic relationships.
- Healthcare professionals should offer written information to AYAs with cancer, and the young person should be supported to seek information to address any sexuality or intimacy concerns.

Weak recommendation

- We suggest that healthcare professionals should avoid assumptions about sexual activity, behaviours or attractions in AYAs with cancer.

Evidence summary

Background

Intimate relationships during adolescence and young adulthood may be newer and not fully developed, with less resilient foundations for the sort of challenges presented by a cancer diagnosis. However, they should not be regarded as any less significant or important to the young person.

The impact of cancer diagnosis and treatment on a young person's psychosexual development can be significant. Issues such as body image, social and peer isolation, tenuous and interrupted relationships, and physical changes due to treatment such as such has hair loss, weight fluctuations and scars can create emotional distress and impact intimate relationships.[10, 52, 112, 180] Some AYAs may end relationships to protect their partner, while others may cling tightly to a new partner who may or may not have the resources to cope with the challenges of the situation.

AYAs that are in existing romantic relationships at the time of diagnosis may adjust better to their cancer experience and have greater social support compared to those who are unpartnered.[161] However, existing relationships may also bring pre-existing conflicts to the situation or the cancer diagnosis may create new conflicts that impact the patient.[161]

Key points

- Provide support to the AYA with cancer and their partner to help them navigate communication and intimacy in their relationship during treatment and beyond.[85, 112] Partners should be included in psychosocial monitoring and support for AYA cancer survivors.[112]
- Young people with cancer may have different priorities compared to their peers, which may change the way they go about developing and sustaining romantic relationships.[52, 232]
- Written information should be offered, and the young person supported to seek information to address any sexuality or intimacy concerns. AYAs are keen to receive information about the impact of cancer on dating, sexuality and reproductive function.[10, 20]
- Issues around intimate and sexual relationships can be difficult matters to address. Healthcare professionals should create opportunities for discussion and models such as (EX) Plissit, BETTER,

PLEASURE and ALARM can be used to assess and address sexual health concerns in AYAs with cancer and their partners.[10, 12, 27, 172, 175] Partners should also receive sexual health information to support intimate relationships. [Link to *Sexuality and sexual function*]

- Avoid making assumptions about sexual activity, behaviours or attractions in AYAs with cancer.[173] Healthcare professionals should tailor support to the specific needs of AYAs, including LGBTQI+ individuals, which acknowledges their diverse, cultural, social and personal backgrounds. More research is needed that is inclusive of young people's perceptions and experiences of all romantic relationships.[173]

11. Recommendations for progressive and incurable cancer

Recommendations

Strong recommendations

- Oncologists and primary care physicians should provide patient and family-centred supportive and palliative care to AYAs with cancer and their families, based on their needs. The early introduction of such care may be especially helpful to AYAs with progressive cancer and/or greater symptom burden.
- The timely integration of appropriate palliative care teams ahead of symptom crises or cessation of curative cancer treatment should be considered for AYAs. Local guidelines should be developed and followed to assist the primary oncology team and specialist palliative care team to deliver holistic concurrent care.
- Healthcare professionals should have individualised and family-centred advance care planning conversations with AYAs and their families. AYAs should be offered opportunities to be involved in decisions about their care, including end-of-life planning. Clinicians may find structured AYA-specific communication tools such as *Voicing My CHOiCES™* helpful to support these conversations.
- Healthcare professionals should assess and develop a tailored grief support plan for families and carers, both before and after the death of an AYA with cancer.
- Healthcare professionals caring for AYAs with advanced cancer and palliative care needs should receive education and communication skills training, as well as supervision and debriefing opportunities.

Evidence summary

Background

Whilst cancer in Australian young people is rare, it remains the second leading cause of death in AYAs and the impact on those affected is substantial.[250] Supportive and palliative care is crucial and beneficial to all patients, and not just for those who do not survive. It is a challenge for healthcare professionals to integrate timely and needs-based supportive and palliative care for AYAs with cancer.

The burden of cancer extends beyond mortality. AYAs living with cancer endure physical and psycho-existential symptoms[225, 251-254] at a time of critical development across physical, psychological, cognitive and social domains[255] and cancer is a life-changing diagnosis that can affect these milestones. However, AYA development may also affect the experience of cancer and of any palliative care input for patients, families, and clinicians.

Early and timely access

Palliative care has historically been synonymous with end-of-life care, a potential barrier to early integration for AYAs with cancer.[256] However, integration of palliative care into the interdisciplinary management of young people is crucial with barriers existing at patient, family, clinician, and system levels.[257] For example, healthcare professionals may fear appearing to take away hope or think that AYAs are unlikely to be interested in discussing end-of-life issues.[251] AYAs are often open to engaging in palliative care.[217] Furthermore, there is no evidence that inclusion of palliative care affects hope or distress, and when introduced early, the integration of an appropriate palliative approach can help with adjustment to a cancer diagnosis, improve symptom control and existential distress, understand patient and family wishes, and facilitate discussion of end-of-life issues.[251, 258] An early and timely introduction of palliative care concepts allows time for the AYA and their family members or carers to build trusting relationships in hospital and community settings. Formal palliative care involvement may be associated with less invasive medical treatments in the last month of life and fewer deaths in the intensive care setting.[259]

Palliative care input

Palliative care is a philosophy of care that seeks to prevent and relieve physical, psychosocial and spiritual suffering for individuals with a life-limiting or life-threatening illness such as cancer, and their families.[260] This holistic care is best provided by a multidisciplinary team of healthcare professionals with different skills.[261] Oncologists and primary care providers, in addition to a specialist palliative care team if appropriate, may deliver aspects of palliative care. Interventions are both pharmacological and non-pharmacological; for example, medications may be used to alleviate pain or nausea, physiotherapy and occupational therapy services can help young people maintain control and independence, and psychological support[254] can help with existential distress, low mood, anticipatory grief and anxiety. Opportunities for AYAs with cancer to develop positive psychological coping skills can enhance their QoL, hope and mental health.[254]

Models of palliative care and service delivery for AYAs with cancer vary internationally. For example, care might be provided within the paediatric or adult healthcare system or both, sometimes by dedicated AYA specialists.[43, 262] Paediatric settings typically favour a family-centred approach, at times at the expense of AYA autonomy, whereas in the adult setting, opportunities to assess and support age-appropriate psychosocial needs may be missed.[43] Transitioning from the paediatric to the adult setting is a critical time point in AYA care,[251] and careful attention is needed as transition can be complex and risks being poorly managed.[263]

Provision of a holistic palliative approach by clinicians alongside cancer treatment and ahead of symptom crises or cessation of curative treatments may help therapeutic relationships, relieve physical and psychosocial distress, increase QoL, and identify patients' goals of care at different points in the disease trajectory.[242, 251, 261] Early introduction of palliative concepts may be especially helpful in the setting of progressive cancer[264] and/or poor symptom control.[258] Comprehensive guidelines for AYAs with cancer should incorporate provision of individualised appropriate palliative care.[251] Screening tools such as the *Supportive & Palliative Care Indicators Tool (SPICT™)*[265] can assist with assessing unmet supportive or palliative care needs, but AYA-specific tools are needed.[55] Oncologists are trained and able to provide supportive and palliative care. However, the decision to refer young people to a specific palliative care team may include, among other things, phase 1 trials[251] or refractory symptoms.[254] It is vital to reinforce to clinicians, AYAs and their families that cancer-directed treatment and palliative care support can be provided concurrently as the two not mutually exclusive.[251] Local guidelines can assist the primary oncology team and specialist palliative care team deliver concurrent care when necessary.[148] If palliative care teams become involved, contact with the primary oncology team, including at the end-of-life, should be maintained to prevent feelings of abandonment for AYAs and their families or carers.

AYAs with terminal cancer should have access to age-appropriate community-based palliative care, respite care and palliative care beds.[266] Ideally, inpatient environments should be age-appropriate and tailored to meet the needs of the AYA while receiving supportive and palliative care, including space to spend time with other patients of a similar age.[43] [Link to *Inpatient environment and support services*] Enabling young people to remain safe and comfortable in their home environment is often important. Young people may appreciate care in their own environment, either in-person or via video-conferencing from community palliative care or hospital-in-the-home services.[267] Some AYAs have clear preferences about remaining at home, versus admission to a hospital or a hospice unit, at the end of their life. Supporting AYAs' preferences requires hospital teams to liaise and collaborate with community-based palliative care services[266] and primary care physicians through timely referrals[254] and updates. The role of the primary care physician may become increasingly important during the palliative phase when time out of the hospital may be a priority for the young person, particularly in rural areas with limited access to specialist palliative care. In many cases, the primary care physician will continue to see family members during the bereavement phase and for many years to come.

Patient and family-centred care

Adolescence and young adulthood can bring unique challenges, including exploring independence and autonomy, individuating from parents and family, and establishing intimate and meaningful peer relationships. How parents cope with the diagnosis and treatment will have a direct impact on how the young person copes.[14, 121, 239, 240] Parents may struggle to balance involvement in their child's care while respecting their autonomy and other meaningful relationships, and AYAs may desire independence but need to become newly reliant on their parents for care and support.[17, 35, 102] Support from friends and peers plays an important role in helping the young person to cope with cancer and try to normalise common feelings and experiences. Unfortunately, limited research exists to guide how healthcare professionals might support parents of AYAs with incurable cancer. Clinicians must adeptly identify and navigate the complex dynamics involved to provide patient-centred and family-inclusive care and balance the competing needs of the young person and their family.

AYAs with cancer commonly receive cancer treatments in the last weeks of life[268] and die in hospital rather than at home.[148] This is despite many young people whose wish to die at home is known although notably not all prefer to die at home.[269, 270] Importantly, the opportunity for choice may be as important as the decision itself.[241] End-of-life conversations typically occur late, leading to limited time for preparation and planning for what to expect in the end-of-life period and what support can be provided. Late conversations may reflect speed of disease progression or prognostic uncertainty that results when more treatment options are available (i.e., Phase I studies), leading to later transitions away from disease-targeted treatments.[242]

Most young people with cancer desire information about their prognosis,[271] want to be involved in end-of-life decision making[272] and find advance care planning helpful.[258, 273] Parents may underestimate the readiness of their AYA-aged child to talk about end-of-life decisions[270, 274] and their preferences for a "natural death" over intensive care interventions when dying.[274] Importantly, AYAs may have varying needs around the timing of advance care planning conversations, whilst some may decline to engage altogether.[275] Decisions differ and many AYAs enter their last month of life wanting life-prolonging measures, including up to the end of their life.[276] The timing and content of these conversations are challenging, with AYA decision-making influenced by myriad factors, including family, friends, cultural background, social media, healthcare professionals, experience with the healthcare system, financial considerations and confidentiality.[255]

The opportunity for open, honest communication and for AYAs to be involved in decisions about their life and treatment is vital.[266] The timing and content of conversations must be individualised. They should utilise a family-centred approach to bridge gaps in knowledge of preferences and wishes between AYAs and their families, which may, in turn, facilitate congruence in decision-making.[34, 270, 274] Limited confidence and training in communication, prognostic uncertainty, and a desire to shield AYA patients from distress may delay clinicians' initiation of end-of-life discussions.[242] Importantly, AYAs who do not have the opportunity to discuss their prognosis honestly require more pain relief, display more anxiety, and may be less likely to have their end-of-life goals met.[242]

End-of-life conversations may be best held with a clinician who has a strong rapport with the young person and feels comfortable with confronting and emotional discussions, regardless of their area of specialisation.[242] These conversations can be supported by structured AYA-specific communication tools such as *Voicing My CHOiCES*^{TM},[242, 256] which has been adapted for Australian AYAs,[277, 278] and particular phrases and language may help clinicians to navigate advance care planning and end-of-life conversations.[279] Opportunities for legacy formation and meaning-making should be offered.[256] Surrogate decision-makers should be identified for AYAs who cannot provide input into their own decisions.[256] This may be particularly relevant and needed earlier when disease-related neurocognitive deterioration can be predicted, such as for those diagnosed with a brain tumour.[23, 122]

Providing support, fostering independent thinking, and ensuring that the young person is not alone in their decision-making, while reinforcing autonomy may assist AYAs in sitting with prognostic uncertainty and adhering to treatment plans.[256] Notably, some young people may never engage in advance care planning or end-of-life conversations, even if they are aware of the incurable nature of their cancer and impending death. In these situations, it can be helpful to have conversations about likely deterioration and death with parents or carers so that they are prepared for changes that may occur and appropriate care options as their loved one deteriorates.

Grief and bereavement care

The *Victorian Bereavement Support Standards for Specialist Palliative Care Services* emphasise screening to identify needs, focusing on individual resilience, and providing support from pre-death to beyond as required, without time limitations.[280] While best practice might be for open-ended access to bereavement support because support needs change over time, this is often not feasible within existing resources and frameworks.

A bereavement care plan should be developed prior to the death of an AYA patient, including how the important people in the young person's life, such as parents, partner and peer groups, will be supported.[266] Strategies to support other young people who have had treatment at the same time and potentially formed friendships with the AYA who has died should also be considered and implemented.

It is worth noting that regret may complicate grief for parents who have not had honest and open conversations about death with their AYA-aged child, particularly if they sensed that their child was aware of their impending death.[281] As outlined, advance care planning conversations may allow families to understand and honour the AYA's wishes[282] and have a role in mitigating parental regret. Some families may be comforted by ongoing contact with their young person's healthcare teams, and others may prefer support outside the hospital. Bereavement follow-up can be variable and inconsistent which might be mitigated with the development of local guidelines.[86]

Support for healthcare professionals

Healthcare professionals should receive proper training and psychological support when caring for AYA patients at the end-of-life.[266] The *Victorian Bereavement Support Standards for Specialist Palliative Care Services* also stress the crucial role of supporting staff through procedures such as conducting death reviews, investing in their professional development, and providing supervision.[280] Depending on the context, bereavement support may be provided by community palliative care services, hospital-based social workers or community bereavement services.

Education and training deficiencies exist in both adolescent medicine and end-of-life interactions,[283] and the need for palliative care education was rated highly by doctors and nurses in an Australian-based AYA-learning-needs survey across cancer networks.[284] Various modalities for education in palliative care for AYAs with cancer include experiential learning, group didactic opportunities, shared learning among care disciplines, end-of-life training programs, online learning and hearing from bereaved family members as educators.[283] Simulation-based education can be a valuable and feasible tool to increase cancer clinicians' understanding and confidence with advance care planning.[285]

12. Uncertainties and future research

Diverse and minority AYA populations

There is a distinct lack of literature regarding best practice care for AYAs with cancer who are First Nations Australians and those from culturally and linguistically diverse background or minority populations including those with recent migrant or refugee status in Australia and LGBTQI+ people. Furthermore, most research conducted to date, particularly regarding socioeconomic impacts, has been conducted in countries other than Australia. As such, special consideration of these priority populations and adhering to the principals of delivering culturally safe psychosocial care is needed to improve outcomes. Further research in the Australian setting is warranted.

AYA clinical trials and participation

Currently, there is limited literature on participation in clinical trials for AYAs with cancer including psychosocial care throughout domains.[92, 98, 145, 286, 287] This hampers understanding and confidence in specific intervention and supportive care strategies, as well as models of care, that may enhance psychosocial care for AYAs.[287] Research within the psychosocial domain for AYAs with cancer commonly has small sample sizes, no comparison or control groups, and self-report limitations relating to diagnosis and treatment history.[91] Low clinical trial participation for AYAs with cancer is common not for just psychosocial domains, but also biomedical domains.[98] One key factor causing low clinical trial participation may be the preference of young people for flexibility and convenience in health care services received.[98] Participation may also be impacted by age eligibility criteria (e.g., restricted to over or under age 18 years), and a lack of clinical trials in the types of cancer that occur commonly in the AYA age group. Other reasons may be attributed to structural limitations, including limited provider awareness of available trials, poor eligibility screening processes, and poor communication within the healthcare team.[92] Ultimately, the engagement of AYAs with cancer in clinical trial psychosocial domains is low and additional, larger, clinical trials are needed.[86]

Conceptualisation of mental health

In recent years there has been an increasing acknowledgement of the significant limitations of the diagnostic approach to mental health across populations.[288, 289] The diagnostic approach, utilising tools such as the *Diagnostic and Statistical Manual of Mental Disorders*, is the primary conceptualisation of mental health in cancer.[290] The diagnostic approach has significant general limitations including high levels of comorbidity, and within-disorder symptom heterogeneity.[288] Diagnostic tools such as the *Diagnostic and Statistical Manual of Mental Disorders*, allow for two people to be diagnosed with the same disorder but share few common symptoms.[288, 290] The diagnostic approach has additional specific considerations in people with cancer, such as the inclusion of numerous physical and neurocognitive symptoms, such as fatigue, weight gain/loss, and concentration difficulties, which are common in cancer survivorship and not necessary characteristic of their psychological state, but rather of their cancer and treatment history.[291] This coupled with the allure of "tickbox" formulation using diagnostic tools such as the *Diagnostic and Statistical Manual of Mental Disorders* may lead to under and overdiagnosis of common disorders within cancer survivorship, such as Major Depressive Disorder and Post-Traumatic Stress Disorder.[290] Overall, these limitations may greatly impact the validity and applicability of research, including clinical trials, which assess interventions and models of care for particular diagnostic groups.[288] To mitigate these issues in cancer patients there have been calls to examine the potential relevance of alternative conceptualisations of mental health, such as the *Hierarchical Taxonomy of Psychopathology*, which take a dimensional rather than categorical approach by viewing mental health "symptoms" along a continuum.[290, 291] However, additional research is required, particularly within AYAs living with and beyond cancer groups.[291]

Directions for future research

Additional research in the Australian setting

- Future research should specifically investigate the impact of AYA cancer in Australia's First Nations People, those from culturally and linguistically diverse background or minority populations, and LGBTQI+ young people.
- Future research should include socioeconomic impacts relevant to AYAs with cancer in Australia.

Enhance clinical trial development and participation

- Future research should emphasise the focus on clinical trials for psychosocial care in AYAs with cancer.
- Future research should develop and assess strategies aimed at enhancing the participation of AYAs with cancer in psychosocial clinical trials.

Assess alternate conceptualisations of mental health

- Future research should continue to assess and bring awareness to the limitations and considerations of the diagnostic approach to mental health in AYAs with cancer.
- Future research should further develop, and assess the applicability and utility, of modern dimensional conceptualisations of mental health in AYA cancer survivors, across research and clinical settings.

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