# Assessing and Supporting Adolescent Boys Having Fertility Preservation

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**Case Presentation**

A 12-year-old boy was diagnosed with relapsed acute lymphoblastic leukaemia 4 years after the completion of standard risk leukaemia treatment. Diagnostic and staging assessments confirmed that he had a combined bone marrow, central nervous system and left-sided testicular relapse.

He did not have fertility preservation at the commencement of his initial diagnosis due to his age and the low-fertility risk of his previous treatment, but the proposed curative treatment has a high gonadotoxic risk due to the dose of alkylating agents in the chemotherapy for bone marrow transplant conditioning and total body irradiation (TBI). As he had testicular disease, he also requires either testicular radiotherapy or consideration of an orchidectomy. if he does not respond to the proposed treatment, he could be offered other new novel agents or immune therapy as part of the clinical trial, and many of these treatments have an unknown fertility potential.

The paediatric oncologist asked specific reproductive questions and assessed his Tanner stage. He had sparse faintly pigmented pubic hair and a testicular volume of 8 ml. He has erections and 'wet dreams' but had not masturbated before. He became very embarrassed having this conversation, and his parents felt that it was not relevant to ask their son these questions.

The oncologist was unsure whether it was appropriate to refer this patient for sperm banking, and he seeks further advise from a fertility colleague.

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## 53.1 Assessment and Consultation

Puberty describes the transition from childhood to adulthood during which time adolescents become sexually mature and are capable of reproduction [1]. In males, this results in a number of physical changes which include the penis and testis getting bigger; hair developing on the face, armpits and pubic areas; the voice becoming deeper; muscles growing and becoming strong; and an increase in height velocity. These changes are coordinated by a complex neuroendocrine mechanism influenced by both genetic and environmental factors [2]. The Tanner scale or stage is a method of defining the stage of physical developments to document the timing and progression of pubertal development. In males, it assesses the development of penis and testicular volume and pubic hair development [3]. The testicular volume is measured using an orchidometer.

The onset of spermatogenesis is an early pubertal event with a wide variation in the onset and timing with the development of secondary sexual characteristics [4]. The median age of spermatogenesis is 13.4 years (range, 11.7–15.3 years) with a median testicular volume of 11.5 ml (range 4.7–19.6 ml) and a public hair distribution of Tanner 1–5 (median, 2.5 on a Tanner scale) [4]. Sperm cryopreservation is very successful in 12–18-year-olds with 88.4% of patients having spermatozoa in their ejaculate and of these 93.4% having motile spermatozoa which are a good enough quality for cryopreservation [5]. Age should not be a limiting factor for referring patients for fertility preservation consultation with fertility experts who can provide expertise in fertility risk and fertility preservation (FP) options as well as assessing a patient's suitability. Patients who are a Tanner 3 or above [6] or who have a testicular volume of greater than 5 ml [5] are ideal candidates, and hence accurate assessment of younger patients is important.

Despite 20 national and international fertility preservation guidelines recommending that fertility risk and options should be discussed with cancer patients, the rates of referral and consultations are still lower than expected. The reproductive needs of younger male patients are similar to older patients; however, there are a number of additional things to consider in the consultation and management of younger children and adolescent young adult (AYA) male patients:

1. *Consultation differences*: AYA patients are eager to receive verbal and written information about their fertility risk and options [7, 8], but both young patients and their parents feel that these discussions should be age appropriate and have support provided [8]. Consultations should also provide information in an honest and respectful manner. Younger adolescent male patients often find the fertility consultation embarrassing, but patients feel less stressed when staff are informal, friendly, not embarrassed, and speak clearly and directly to them [9]. Having

longer consultations which are not rushed and healthcare professionals (HCPs) with expertise and training [10] has been shown to improve the uptake for fertility services and is reported more favourably by patients and parents.

2. *Availability of resources:* Access to age-appropriate FP resources improves patient satisfaction [11]; however, FP educational materials are not consistently provided to patients [12].Although more resources are available about sperm banking, the quality of these resources is very variable, and the readability is often assessed as difficult or complex [13] for younger patients or patients with low health literacy. Paediatric decision aids have been shown to be important for younger patients, but parents and healthcare providers still have concerns about the content and readability [14] in younger patients.
3. *Health literacy of patient:* The reproductive health knowledge and understanding of patients is an important factor required for discussion and understanding about fertility preservation as well as comfort levels of patients. However, the health literacy of AYA will vary depending on access to sexual health education at home and school and family as well as cultural and religious values. The health literacy will also change dependent on the age and maturity of patients. It is very important that before HCPs start having a conversation about fertility preservation they determine patient's reproductive health literacy and adapt the consultations depending on the level of understanding a patient has.
4. *Parental role in sperm banking:* Parents have a very important role in fertility consultations. Many AYA rely on their parents to provide support during the consultations, to summarize the discussions and to take part in decision-making [15]. Parents are also generally involved in organisation of appointments and in some countries for the payment, and so AYA are dependent on them during this process [15]. Both mother and father recommendations and coordination have been showed to be statically significant with AYA men attempting to sperm bank. Patients who discuss the risks and benefits of sperm banking with their parents are also more likely to attempt sperm banking [15].
5. *Healthcare professional's role in oncofertility consultations*: HCPs also play an important role in discussions about fertility risk and fertility options, education of patients and supporting patients and parents through the process [16]. Paediatric oncologists receive little training about oncofertility care [17, 18], and this has an impact on the implementation of FP guidelines and the referral of patients to fertility services. HCPs communication has been shown to influence sperm banking, and when adolescent patients are referred to specialised fertility providers, they are five times more likely to bank sperm [5, 16]. However, HCPs take on different roles, and despite the expertise of nurses and allied health professionals, fertility conversations are still carried out more commonly by clinicians [5, 18, 19]. Many HCPs report a lack of training and comfort level [20] with reproductive consultations, and additional training is required to ensure the multidisciplinary team members in cancer and fertility centres have a good understanding about the reproductive needs of cancer patients and how to adapt oncofertility services for younger patients.
6. *Psychosocial impact of cancer:* The threat of temporary or permanent infertility has been shown to be associated with psychological distress, such as depression and anxiety, in both males and female cancer patients [21, 22]. For younger male patients, the consultation can be very embarrassing and cause additional distress or result in patients declining fertility consultations or not being fully invested in the consultations which may lead to regret at a later time. With age-appropriate support, patients experience less distress and decision regret [23] and feel more positive about the future. It is very important to have counsellors, social workers and psychologists who have expertise in the reproductive concerns of cancer treatment and who can provide psychological and practical support [22, 24, 25]. Psychological support is also required for parents who often experience psychological distress based on actual or potential infertility of their child or the distress of the fertility preservation process or later follow-up and

disclosure. Psychological support is associated with improved patient satisfaction, improvements in decision-making and improvements in patient quality of life.

7. *Who should be present at consultations?* Oncofertility consultations occur very early in the relationship between HCPs, patients and family members. It is unlikely that HCPs know enough about a family to understand individual family's relationships, religious and cultural narratives which influence consultations. Studies have shown that an equal amount of adolescents want parents to be present [26] or to have the consultations without parent's presence. Clinicians treating adolescent patients often want to provide care to adolescents without the parents present [27, 28]. This can lead to conflict with some parents who feel they should be present to provide support and guidance and ensure that they approve of the choices that are given and made. HCPs have to ensure that they give patients the choice about who is present at the start of the consultations and to ensure that patients can make choices without upsetting family members. It would be beneficial to give parents information about why patients may want consultations on their own or with a specific support person.
8. *Assent and consent:* The consent process for fertility preservation can be confronting, depending on national and local regulations and ethical guidelines. The risks and benefits of sperm banking will be discussed, leading to discussion of the use or disposal of semen in the event of a patient's death. This can obviously be very distressing for patients who are about to start initial or relapse treatment. For minors less than 18 years of age, it is standard practice to ensure that they are included in these consultations and understand and agree to the fertility procedures occurring and then assent. Parents will be required to sign the consent form after the assent has been signed, and although it is uncommon, it is possible to have situations when patients and parents have differences of opinions about fertility choices. Ethical situations are considered in a separate chapter.
9. *Legal parameters to consider:* It is a standard practice for clinics to provide pornographic material to assist with adult males producing semen in a very clinical environment. Although the practice may also be useful for underage children, there are a number of ethical, legal and parental issues in this practice which vary depending on the country, and clearer recommendations are required [29]. Clinics may invite patients to bring their own material.



## 53.2 Management

It is important that all cancer patients get an opportunity to discuss the reproductive risk of cancer treatment and possible fertility options even when fertility preservation is not possible or unlikely. This consultation provides additional patient satisfaction even when patients do not have fertility preservation as they have access to reproductive expertise support and follow up.

Despite consultation and assessment, younger male peri-pubertal patients may not be able to produce a sample collected by masturbation, and so other alternate methods can be considered such as testicular sperm extraction [30] (TESE) or electroejaculation [31].

Support during the fertility consultation and sperm banking is important, particularly for young male patients who may be very embarrassed about this process. It is very important for them to understand that their wishes will be respected, information is confidential and that they will be given the time and privacy to collect a sample. Sometimes, in our attempts to support patients, HCPs can make them more anxious by trying to organise a collection on a ward with limited privacy, having staff accompanying patients to the andrology clinic (patients may worry about the conversations they may have or if they will wait outside the room) or making jokes with the intention of reducing the tension but they can inadvertently make patients more anxious.

## 53.3 Outcome

After discussions between the oncologist and fertility provider, the patient and his parents agreed to be referred to a fertility specialist, and he attended this appointment with his father. The patient demonstrated Tanner stage III development, so semen cryopreservation was thought to be possible although other options of fertility preservation were also discussed.

After time to consider the consultation and age-appropriate resources, the patient and his father had a further consultation to ask further questions, complete the assent and consent forms and have blood taken for serology. On the day of the collection, the patient was overcome by anxiety and initially put off the collection; however after discussion with the AYA nurse practitioner and counsellor, he agreed to come to the fertility centre with his older brother. The patient was reminded that the specimen container did not need to be filled and was reassured that he would be left on his own with no interruptions from his brother or staff members.

A sample was successfully banked and the andrologist was able to confirm viable sperm motility and forms. The patient was given two other appointments so that further samples could be collected and stored.

### Clinical Pearls and Pitfalls

- Semen cryopreservation should be offered to all pubertal boys diagnosed with cancer.
- The onset of spermatogenesis is an early pubertal event with a wide variation in the age of onset and development of secondary sexual characteristics, and so male patients in early puberty with a testicular volume greater than 5 ml should be given an opportunity to undertake semen cryopreservation.
- Parents have a vital part to play in organisation of consultation, support and shared decision-making which increases the changes of AYA attempting to sperm bank.
- Clinicians with clear age-appropriate communication provide additional support to patients and improve the chance of cancer patients undertaking fertility preservation and patient satisfaction.
- Younger cancer patients require age-appropriate consultations and support which involves staff having expertise in communicating with younger patients, access to age-appropriate resources and support.

## Review Questions and Answers

Q1. How do you assess the suitability of younger boys and adolescents to undertake sperm cryopreservation?

A1. Patients who are a Tanner 3 or above [6] or who have a testicular volume of greater than 5 ml [5] are ideal candidates for sperm cryopreservation.

Q2. What are the components of age-appropriate care that need to be considered when providing fertility preservation consultations to children and adolescents?

A2. Younger cancer patients require age-appropriate consultations and support which involves staff having expertise in communicating with younger patients, access to age-appropriate resources and support. Parents have a vital part to play in organisation of consultation, support and shared decision-making which increases the changes of AYA attempting to sperm bank.

## References

1. Kail RV, Cavanaugh JC. Human development: a lifespan view (5th ed.). Wandsworth publishing: Cengage Learning. 2010. ISBN 0495600377. Retrieved March 8th 2018.
2. Choi JH, Yoo HW. Curr Opin Endocrinol Diabetes Obes. 2013;20(20):62–8.
3. Marshall WA, Tanner JM. Variations in the pattern of pubertal changes in boys. Arch Dis Child. 1970; 45(239):13–23. https://doi.org/10.1136/adc.45.239.13. PMC 2020414 . PMID 5440182.
4. Nielsen CT, Skakkebaek NE, Richardson DW, Darling JA, Hunter WM, Jørgensen M, Nielsen A, Ingerslev O, Keiding N, Müller J. Onset of the release of spermatozoa (spermarche) in boys in relation to age, testicular growth, pubic hair, and height. J Clin Endocrinol Metab. 1986;62(3):532–5.
5. Hagenäs I, Jørgensen N, Rechnitzer C, Sommer P, Holm M, Schmiegelow K, Daugaard G, Jacobsen N, Juul A. Clinical and biochemical correlates of successful semen collection for cryopreservation from 12-18-year-old patients: a single-center study of 86 adolescents. Hum Reprod. 2010;25(8):2031–8. https://doi.org/10.1093/humrep/deq147. Epub 2010 Jun 22.
6. Ogle SK, Hobbie WL, Carlson CA, Meadows AT, Reilly MM, Ginberg JP. Sperm banking for adolescents with cancer. J Pediatr Oncol Nurs. 2008;25(2):97–101.

7. Ussher JM, Parton C, Perz J. Need for information, honesty and respect: patient perspectives on health care professional's communication about cancer and fertility. Reprod Health. 2018;15(1):2. https://doi.org/10.1186/s12978-017-0441-z.
8. Stinson JN, Jibb LA, Greenberg M, Barrera M, Luca S, White ME, Gupta A. A qualitative study of the impact of cancer on romantic relationships, sexual relationships, and fertility: perspectives of Canadian adolescents and parents during and after treatment. J Adolesc Young Adult Oncol. 2015;4(2):84–90.
9. Crawshaw MA, Glaser AW, Hale JP, Sloper P. Young males' experiences of sperm banking following a cancer diagnosis–a qualitative study. Hum Fertil. 2008;11(4):238–45.
10. Wyns C, Collienne C, Shenfield F, Robert A, Laurent P, Roegiers L, Brichard B. Fertility preservation in the male pediatric population: factors influencing the decision of parents and children. Hum Reprod. 2015;30(9):2022–30. https://doi.org/10.1093/humrep/dev161. Epub 2015 Jul 3.
11. Kelvin JF, Thom B, Benedict C, Carter J, Corcoran S, Dickler MN, Goodman KA, Margolies A, Matasar MJ, ArielaNoy, Goldfarb SB. Cancer and fertility program improves patient satisfaction with information received. J Clin Oncol. 2016;34:1780–6.
12. Quinn GP, Vadaparampil ST, Malo T, Reinecke J, Bower B, Albrecht T, Clayman ML. Oncologists' use of patient educational materials about cancer and fertility preservation. Psycho-Oncology. 2012;21(11):1244–9.
13. Merrick H, Wright E, Pacey A, Eiser C. Finding out about sperm banking: what information is available on line for men diagnosed with cancer? Human Fertil. 2012; 15(3):121–8.
14. Murphy D, Sawczyn KK, Quinn GP. Using a patient-centered approach to develop a fertility preservation brochure for pediatric oncology patients: a pilot study. J Pediatr Adolesc Gynecol. 2012;25(2):114–21.
15. Klosky JL, Flynn JS, Lehmann V, Russell KM, Wang F, Hardin RN, Eddinger JR, Zhang H, Schenck LA, Schover LR. Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer. Fertil Steril. 2017;108(6):1043–9.
16. Klosky JL, Anderson E, Russel KM, Huang L, Schover L, Simmons JL, Kutteh WH. Provider influences on sperm banking outcomes among adolescent males newly diagnosed with cancer. J Adolesc Health. 2017; 60(3):277–83.
17. Fuchs A, Kashanian JA, Clayman ML, Gosiengfiao Y, Lockart B, Woodruff TK, Brannigan RE. Pediatric oncology Providers' attitudes and practice patterns regarding fertility preservation in adolescent male Cancer patients. J Pediatr Hematol Oncol. 2016;38(2):118–22.
18. King L, Quinn GP, Vadaparampil ST, Miree CA, Wilson C, Clayton H, Zebrack B. Oncology social workers' perceptions of barriers to discussing fertility preservation with cancer patients. Social Work Health Care. 2008;47(4):479–501.
19. Ussher JM, Cummings J, Dryden A, Perz J. Talking about fertility in the context of cancer: health care professional perspectives. Eur J Cancer Care. 2016;25(1):99–111.
20. Quinn GP, Vadaparampil ST, King L, Miree CA, Wilson C, Raj O, Watson J, Lopez A, Albrecht TL. Impact of physician's personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. Patient Educ Couns. 2009;77(3):338–43.
21. Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among child and adolescent cancer survivors and their parents: a qualitative analysis. J Psychosoc Oncol. 2016;34(5):347–62.
22. Lawson AK, Klock SC, Pavone ME, Hirshfeld-Cytron J, Smith KN, Kazer RR. Psychological counseling of female fertility preservation patients. J Psychosoc Oncol. 2015;33(4):333–53.
23. Li N, Jayasinghe Y, Kemertzis MA, Moore P, Peate M. Fertility preservation in pediatric and adolescent oncology patients: the decision-making process of parents. J Adolesc Young Adult Oncol. 2017;6(2):213–22. https://doi.org/10.1089/jayao.2016.0061. Epub 2016 Dec 1.
24. Logan S, Perz J, Ussher JM, Peate M, Anazodo A. Psycho oncology. A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. 2017. https://doi.org/10.1002/pon.4502. [Epub ahead of print] Review.
25. Skaczkowski G, White V, Thompson K, Bibby H, Coory M, Orme LM, Conyers R, Phillips MB, Osborn M, Harrup R, Anazodo A. Factors influencing the provision of fertility counselling and impact on quality of life in adolescents and young adults with cancer. J Psychosocial Oncol. 2018;36(4):484–502.
26. Ginsberg JP, Ogle SK, Tuchman LK, Carlson CA, Reilly MM, Hobbie WL, Rourke M, Zhao H, Meadows AT. Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. Pediatr Blood Cancer. 2008;50(3):594–8.
27. Bashore L. Semen preservation in male adolescents and young adults with cancer: one institution's experience. Clin J Oncol Nurs. 2007;11(3):381.
28. de Vries MC, Bresters D, Engberts DP, Wit JM, van Leeuwen E. Attitudes of physicians and parents towards discussing infertility risks and semen cryopreservation with male adolescents diagnosed with cancer. Pediatr Blood Cancer. 2009;53(3):386–91.
29. Crawshaw MA, Glaser AW, Pacey AA. The use of pornographic materials by adolescent male's cancer patients when banking sperm in the UK: legal and ethical dilemmas. Hum Fertil. 2007;10(3):159–63.
30. Schrader M, et al. "Onco-tese": testicular sperm extraction in azoospermic cancer patients before chemotherapy—new guidelines? Urology. 2003;61(2):421–5.
31. Adank MC, van Dorp W, Smit M, et al. Electro ejaculation as a method of fertility preservation in boys diagnosed with cancer: a single –center experience and review of the literature. Fertil Steril. 2014;102:199–205.