



**Adolescent Fertility Values
Clarification Tool**

**For Adolescent Females
12-18 Years Old**

Practitioner's Manual

Adolescent Fertility Values Clarification Tool

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❖ Introduction

Thank you for using the Adolescent Fertility Values Clarification Tool (AFVCT). Childhood cancer is a family disease. Families commonly respond to this crisis by focusing more on the immediate treatment needs, and not the potential consequences of late or long-term effects. Emerging research, however, is highlighting the prevalence of infertility among adolescent cancer survivors and the negative impact this has on future quality of life. This guide will help you prepare for and effectively administer the AFVCT to adolescent oncology patients, and to understand the value they place on being a parent in the future. As more practitioners begin to use this tool, more discussions about fertility will be initiated between the adolescent patient, their families, and the healthcare provider, with hopes to reduce the number of childhood cancer survivors who experience infertility-related distress.

This tool will also aid practitioners in developing an approach to discussing the impact of cancer treatment on future fertility, as well as preservation options that take into consideration the child's knowledge, desire, and value of parenthood. Since this is a tool, and not an instrument, there is no scoring guide. Using the AFVCT will help practitioners assess the patient's values and understanding of fertility in relation to the cancer diagnosis and treatment plan.

❖ What is the AFVCT?

The AFVCT is comprised of 10 items. These 10 items were originally adapted from standardized health related quality of life (HRQOL) instruments which were systematically reviewed by the research team. None of the HRQOL instruments that were reviewed asked about fertility, yet it is well known that adolescent patients are concerned with fertility. Furthermore, survivors who are subsequently faced with infertility express deep frustration over loss of reproductive capacity. For the few existing scales, a content analysis of the items was conducted. The first scale considered was Wenzel et al's (2005) Reproductive Concerns Scale. This 14-item scale queries respondents about their ability to have children, feelings toward decreased fertility, and ability to address fertility issues openly. However, this scale has not been validated and it was not created to be used with adolescents. A second scale was identified which measures HRQOL among patients experiencing polycystic ovary syndrome that was developed and validated for adult women. Yet, this scale only asks two items about reproductive concerns, and it was not validated for use with adolescents. Finally, a 21-item instrument by Schover et al. was reviewed. This instrument was created to survey male patients aged 14 to 40 years at diagnosis and recently treated in two cancer centers to determine their knowledge, attitudes, and experiences regarding cancer-related infertility and sperm banking. Schover's instrument has a variety of themes related to future concerns specific to one's ability to have children, options that patients would take if they could not have biological children, and feelings related to potential loss of fertility, but does not include female patients and is not specifically geared towards adolescents.

It was concluded that none of the existing scales were appropriate for adolescent-onset cancer patients. By incorporating information from the literature, and the associated findings of our content analysis, a ten item reproductive concerns scale was created and piloted

among adolescent cancer patients (aged 12-18 years) and their parents, as well as among four focus groups of healthy teens in the same age range. Adolescents and parents were interviewed separately, and each item statement was discussed. Participants were asked for their immediate reaction to each item; "was anything confusing about the statement? Are the feeling words like 'sad,' or 'frustrated' accurate to how you feel? How would you say it differently?" Based on these interviews and focus groups, adjustments were made to the statements and text which was not relevant, not accurate, or confusing was removed or changed. It was determined that due to the sensitive nature of the topic, this guidebook was necessary to assist practitioners in managing the variety of responses that they may encounter.

❖ Who is this guide for?

Practitioners from a variety of disciplines can use this tool. Social workers, nurses, child life specialists, oncologists, and other professionals are encouraged to use the AFVCT to help the patient clarify her own value of future parenthood. This tool will also aid practitioners in developing approaches for discussing fertility, its impact on future quality of life and preservation options based on the child's knowledge, desire for information, and value of parenthood. Responses are not scored or normed, but rather, should be assessed in the context of identifying what the patient may need to know when making a decision, what the patient is developmentally and emotionally capable of understanding, and how to engage the patient's patients in the information gathering process.

It should be noted that the practitioner administering the AFVCT should be prepared to assist, facilitate, and advocate for the desires of the patient. Though these desires may be difficult to predict, the AFVCT is intended to open the door to the discussion and guide the practitioner for future care.

Communication Centered on Values Clarification

The AFVCT allows the patient to respond open-endedly to statements they may or may not agree with. In this way, the patient may process the statement through dialogue with the person administering this tool. Traditionally, values clarification tools force the responder to make a decision based on a limited number of provided options in order to identify what truly matters to the respondent. However, the AFVCT relies on principles of dialectical behavior therapy, narrative therapy, and stream of consciousness discourse between practitioner and patient.

Many people working with children and teens know the challenges of creating an open dialogue, especially regarding sensitive or unfamiliar topics such as fertility and reproductive health. Responsibility falls on the practitioner to encourage discussion with active listening techniques such as:

- *What does that word, 'insert feeling word' mean to you?*
- *Have you ever thought about this before?*
- *Has this always been important/unimportant to you?*
- *I'd like to know more of your thoughts on this.*
- *Do you think this will still be important/unimportant to you in 5 years?*

Pre-evaluation

Prior to beginning the AFVCT, do your own pre-evaluation.

- *Does the patient know what the word, 'fertility' means? What about how treatment can impact fertility?*
- *Is the patient physically healthy enough to participate?*

- *Are the parents/caregivers and medical team aware that the patient will be discussing fertility issues?*
- *Are the parents/caregivers permissive of the patient discussing fertility issues?*
- *Does the patient have the cognitive faculties or maturity to process fertility issues?*
- *What does this patient already know about her treatment?*
- *Are there cultural or religious issues which must be considered when framing the delivered information/conversation?*
- *Are there any conflicts of interest (e.g. desires of the parents or medical team, timing of medical treatment) which must be considered when discussing this topic?*

It is also important to explain that the patient's responses are confidential, and to conduct the session in a private setting. The patient must be made aware that this is a one-time assessment wherein their responses will be kept private, and that they can speak to someone afterwards if they like (prepare them for termination to minimize emotional vulnerability after the assessment has concluded).

Response Types

This section will help you prepare for a variety of responses you may experience when using the AFVCT and interventions that may be useful. These are just a few of the many potential response styles that you may encounter from adolescents and their families.



Social Desirability Bias

Some of the statements in the AFVCT ask the patient to, in a sense, 'stir the pot.' Such as, 'if I cannot have a baby in the

future I would blame my doctor.' It would not be unreasonable for the patient to automatically answer 'no' to this statement for fear that their response may get back to their doctor, or that the interviewer would think negatively of them. It is important to explain that their responses are confidential, which may reduce the fear of the former. For the latter however, you can use these techniques to assist:

- *Do you think other patients like you would blame their doctor? What do you think of them?*
- *Do you think someone would have a right to blame their doctor?*
- *What would you think if someone else wanted to blame their doctor?*

Also validating the patient's opinion may encourage them to express further, thus clarifying their values for themselves and you.

- *You know, I've heard a lot of other patients say the same thing.*
- *It's OK to say you are frustrated if that is how you feel.*
- *A lot of other patients have wanted to come back to this question later, so we can do that too.*



Overly Positive Attitude

This is a layer of social desirability bias that deserves special attention. The practitioner administering this tool must be aware of the potential for patients to feel a tremendous amount of guilt in voicing their concerns. It is not uncommon for patients to repress their fears and dissatisfaction to avoid feeling like a burden on their treatment team and/or parents. Cues that a patient may be masking their true feelings include:

- *Immediate responses*
- *Over-emphasizing that everything is 'fine.'*
- *Reneging their first response*

It is up to the practitioner to determine if the patient is providing an overly positive response versus an honest response, as this could create mistrust between you and the patient if you show suspicion. Some ways to help determine this include:

- *That's interesting, could you tell me more about that?*
- *So you say that you are satisfied with the amount of information your doctor told you about fertility, and before you said you don't feel you have any control over your fertility. Could you explain those feelings a little more? (Offer some contradictory statement to allow them to process feelings)*
- *I know this is a big question to ask you to think about. Let's talk about what this statement is saying. What does this statement mean to you?*

A patient may be providing you with an overly positive response due to their desire to reduce feelings of burdening or could be practicing self-deception. If the latter is the case, follow-up contact in a counseling context may be warranted.



Tearful

Fertility and the potential loss of reproductive ability can be a sensitive subject for adults let alone adolescents. These patients are in the throws of an unexpected life transition when they're still developing their identities and testing their environments. Many worry about dying from cancer and discussing the possibility of not being able to have

children during survivorship could provoke a tearful response. Statements such as, 'If I cannot have a baby I will be sad,' and 'I am worried about having a baby in the future because my baby might get cancer' are the statements that would be most likely to trigger a tearful response. Some strategies to alleviate these types of responses:

- *Normalizing: it's normal for many patients to be a little caught off guard by this statement.*
- *Clarifying: what is it about being a parent in the future that appeals to you? (You can then talk about other ways to become a parent)*
- *Empathize: This statement makes me think of all sorts of feelings I would have. I can imagine you're probably feeling a lot right now. What are some other things you're feeling too? What's the difference between *feeling A and *feeling B?*
- *Reassure: Nowadays there are so many options that are available to lessen the risk that your baby would have cancer, think about what will be available when you're ready to have kids?*



Vague/Short

The classic short-response from adolescents can and should be expected. This may stem from a variety of sources including social desirability bias. It is important the patient understand the 'safety' of the environment. Feeling uncomfortable answering questions about fertility is normal and can result in a combination of both physical and mental closure. Separate the two by giving the patient something to occupy her hands with like a pen or small bouncy ball. Their mind can focus on the statements while feeling less vulnerable with a 'security blanket.'

Furthermore, invaluable attributes of the practitioner include consistent smiling and the use of humor. The

patient is providing unclear responses because they haven't processed this information before. Encourage them to continue and feel at ease through making a joke. In pilot testing this technique jump started a stalled response. Empathizing also works to encourage discussion: 'I know I am not in your shoes, but I have been confronted with having to make a lot of decisions all at once too. You and I have different routes of getting there, but I know the feeling of being overwhelmed.' Now you are helping the patient take a step back and look at the larger picture and you can assess whether the value the patient has on fertility is shutting down the conversation or something else.



Apathetic

It is quite possible the patient has never desired biological children or any children at all. In this case the patient will likely be apathetic and show little interest in discussing their worry about getting cancer again, or if they're satisfied with what they've been told about fertility. Here you can introduce the statements within the context of value choosing:

- *Which would you rather be: the only child, the youngest child, or the oldest child?*
- *What have you liked and changed your mind about after a short period of time: a brand of shoes, someone to be friends with, or what you want to do for a career?*
- *Which do you think is the worst: to become pregnant, to not get into the college you want, or to not have the same friends when you go back to school? (This one identifies the patient's values on the present vs. the future)*

The chaotic, uncertain time surrounding a cancer diagnosis can put concerns about fertility on the back burner. Their apathy can be an assessment cue towards developing an

approach for fertility and fertility preservation discussions. Accept their apathy otherwise it could lead to defiance.



Distressed

Though a distressed response was not witnessed during pilot-testing, the AFVCT administrator should be prepared to field these reactions. The statements were tested to ensure they weren't inherently distressing, therefore responses such as uncontrollable sobbing, trying to leave the room, or aggressive behavior towards the administrator most likely have root causes. You are not their therapist and do not have the responsibility of uncovering traumatic incidences. You are only assessing their values regarding fertility. Older adolescent patients (particularly those who are sexually active) are more likely to have already thought about having children in the future, or may even have school friends that have had children. Being diagnosed with cancer includes with it a loss of expectations for the future. When processing the statements and clarifying their own values from the AFVCT they may feel confronted to deal with not only the losses of their immediate plans, but also losses of what they value in the future after surviving cancer. You can de-escalate the patient with the following:

- *What are some other times you've been afraid/sad/unsure? How does this compare?*
- *What are some other things you've wanted when you get older? How does this compare?*
- *There are a lot of experts working on ways to reduce the risk of having problems getting pregnant and they have a lot of experience with girls like you.*

- *I can see it's not easy for you to talk about having kids in the future. Has this always been something you've wanted?*
- *We don't have to continue. This assessment is to see how concerned you are about fertility, and it seems like you're very concerned. I'd be happy to link you up with someone who can go over your options that may help you get pregnant when you're ready to have children.*

It is not necessary to complete all 10 items of the AFVCT if the patient is showing distress. The patient may have not been ready to answer the statements, have underlying issues that are emerging during the assessment, or deeply value fertility. In any case, after de-escalating you should refer for follow-up with a social worker or psychologist at your hospital.



Confident

Up until now we've been describing various responses to the AFVCT that are largely rooted in feelings of sadness, hostility, and fear. We have not yet described the confident adolescent—the adolescent that knows she places a high value on fertility. This confidence should not be confused with social desirability bias, however, as social desirability bias may be a false confidence elicited by the desire to please the clinician. True confidence in childbearing without signs of distress may seem like a response that the clinician would have the easiest time with as the appropriate referrals can be made for fertility preservation, but there are questions to consider. Because the patient values fertility does not mean she is necessarily prepared to hear about or undergo fertility preservation measures for a variety of reasons: concern about diagnosis, parental opposition, partner opposition, fear of procedures, etc. Furthermore, if the patient *does* value fertility and *does*

wish to pursue fertility preservation, additional barriers such as geography, financial, or the rush to start treatment may exist. It is important for the clinician to assess and be prepared for these barriers as the AFVCT is administered. You can sensitively assess these barriers by asking:

- *It seems that you are sure you want to be a parent in the future; Am I correct?*
- *Has anyone in your family gone to the doctor to have help getting pregnant? (If yes) What do you think about that? (If no) Have you heard of people going to the doctor to help them get pregnant?*
- *Let's make a list of what things you think people should think about. Have you thought of what it would be like if you went to the doctor to help get pregnant? Would any of these apply to you?*
- *If barriers identified: You know what's hard? When my favorite band is on tour and they never come to the city where I live/I can't afford to go see them/my mom didn't want me to go when I was younger/I had to go to a lot of appointments so I missed it. Sometimes I can watch their concert on TV though, so even though it's not same thing, I can still experience the concert in a different way. Has something like that ever happened to you?*

If the patient exhibits confidence in her desire for parenthood and there are barriers to fertility preservation, she still has options. Donor egg, surrogacy, and adoption are resources that can be considered. The clinician should also consider grief and loss counseling that can provide long-term support and make the appropriate referral.

❖ Analysis

How to Interpret Responses Assessing Their Understanding

Now that you have gone through the 10 items to clarify the patient's values on fertility, you should go back through any

inconsistencies. If the patient agrees with the statement, 'one day I would like to have a baby,' but in a later statement disagrees with, 'if I cannot have a baby in the future I will be sad' there is little clarity on the patient's values. Revisit any responses that conflict with each other, as this will help for your assessment as well as prompting the patient to assess and articulate their own feelings.

Through the AFVCT you are also helping the patient understand for themselves what their own needs are. By working with the patient and encouraging discussion for each item, the patient will be in an appropriate state to discuss any concerns with you. You are free to reframe your overall impression of their values and ask if this is correct. According to ASCO and AAP guidelines, all patients of reproductive age should be informed about risks to fertility. Here are a couple of scenarios that may help you introduce the idea of further discussion with a reproductive endocrinologist.

- *What I hear you saying is that having biological children in the future is very important to you, is that correct? There are experts working on technologies specifically for other teens in your situation, and they can go over all your options if you would like to speak to someone?*
- *It's very normal to be feeling a lot of emotions right now and hearing these statements I'm sure brings up questions. We have experts that would be able to go over your specific options, but you wouldn't have to do anything you're not comfortable with.*
- *Am I understanding correctly that you're saying future parenting is not your priority right now? I understand that this is just one more thing to deal with but it's important to think about life after cancer treatment. There are experts here that can talk to you about your specific options and things you can do now that give you more options later.*
- *It seems that you've never been interested in having biological children later on in life; did I understand*

correctly what you've been saying? A lot of people choose to not have children and are happy with that decision, but that was their choice. If you want, I can put you in touch with experts that can discuss the best options specifically for you, and they can help ensure that not having children in the future is still your choice.

The patient is now in a state of vulnerability. They have just spent the last 20 minutes discussing with you, a stranger, what their hopes and dreams are for a future family. To effectively close-out your assessment, ensure that the patient has alternative resources to utilize that can meet their emotional needs. It is important to ask the patient if they would like to speak to a social worker or counselor no matter their outward appearance, or reiterate their response to the statement, 'I feel like I can talk to my parents about fertility,' if they agreed.

Recap the purpose of the assessment. You wanted to better understand the patients own values on fertility because some people can have problems with fertility after their cancer treatment is over. This will help with termination and let the patient provide any closing remarks they think you should know about. Most likely they've been processing this information for the first time. Restate what the patient has self-actualized during the values clarification process as this can aid in the closure of your session. The patient can feel confident and empowered to bring specific fertility-related questions to the table.

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Appendix I AFVCT

1. I would like information about how my cancer treatment could affect my ability to have children.
2. I feel like I can talk to my parents about my ability to have a baby in the future.
3. One day I would like to have a baby.
4. If I cannot have a baby I will be _____.
5. I feel frustrated that I might not be able to have a baby in the future.
6. If I cannot have a baby I would blame my illness/cancer.
7. If I cannot have a baby I would blame my doctor.
8. I am worried about having a baby in the future because I might get sick/cancer again.
9. I am worried about having a baby in the future because my baby might get sick/cancer.
10. I feel like I have control over my ability to have a baby in the future.

Appendix II

Why do you need this guide?

The American Society of Clinical Oncology (ASCO) and the American Academy of Adolescents (AAP) have issued guidelines stating that all patients of reproductive age should be provided information and options about fertility preservation. This tool allows for adolescent patients to understand their own values of parenthood. Many different emotional responses and questions can be evoked secondary to tool administration. This guide will help you manage your expectations and preparedness for the variety of responses the patient may have. Also, the guide offers strategies and interventions based on the patient's self-reported values.

Appendix III

Assessment vs. Therapeutic Purposes

This tool has a dual purpose benefiting both the adolescent and administering practitioner. Options to reduce the patient's risk of being permanently infertile from their cancer and treatment are available in both experimental and established forms. It is difficult to assess the amenability of the patient to discuss fertility; many different responses can be elicited. The open-ended statements of the AFVCT encourage the patient and practitioner to begin a dialogue so that the patient may process the idea of having children in the future, if they were not able to have children in the future, and so on. This allows the practitioner to accurately assess the patient's concerns and develop approaches to educate the patient on her risk as well as risk-reducing options. An adolescent's initial reaction to the statement is not an accurate baseline for assessment due to many factors such as difficulty thinking about the future, fear of having 'one more thing wrong' that needs to be addressed, or disinterest in the topic.

This guidebook will help you not only assess the patient's responses, but prepare for the variety of responses that may emerge from therapeutic enlightenment. Though the AFVCT was not originally designed as a therapeutic tool, during the testing phase it was clear that allowing patients to process the concepts of infertility, their own values, their own desire for control, methods of engagement between interviewer and patient were enacted. You do not need to be a psychologist or counselor to use this tool. However you should be aware that many principles of therapy naturally emerge. You will experience pieces of dialectical behavior therapy wherein the patient will be asked to recognize and identify their own emotions. You will experience pieces of narrative therapy, wherein the assessment becomes more of a collaboration from the administrator and patient in

order to encourage identification of the patient's values through their own life experiences. You may also witness the patient recognizing values and fears they were not prepared for or expecting through stream of consciousness discourse. This guide will help you.

Appendix IV

Use of the AFVCT with other Instruments

You may be familiar with some quality of life instruments such as The Adolescent Cancer Quality of Life Inventory-32, Adolescent Pain Questionnaire, or the Adolescent Quality of Life Inventory TM. The AFVCT can be used in conjunction with these other instruments. However, it is highly recommended that the AFVCT statements are utilized at the end of the assessment for a variety of reasons.

First, it will maintain the internal validity of the other quality of life instruments. Reading the AFVCT statements first may create an environment of question-asking or distraction from future questions, thereby making the remaining questions which could be about physical health or social support not accurate depictions of the patient's feelings.

Secondly, the AFVCT is intended to clarify the patient's own values through a dialogue process. It would be difficult to assess the patient's values and offer interventions if the statements were in the beginning and the patient has mentally 'moved on' from the topic.

Lastly, due to the sensitive nature of fertility issues and the possibility of infertility caused by cancer treatment, going through surface-level quality of life questions may help you build rapport with the patient so that they feel safer disclosing fertility concerns. If they have not discussed fertility with their parents, or if other barriers exist such as religion or mistrust of authority, building rapport is paramount to accurately assessing their values. By keeping the AFVCT as the last evaluation when used with other instruments, you would not only be enhancing the comprehensiveness of the quality of life tool, but also afford the patient with a healthy way of organizing their thoughts on future fertility.

Appendix V FAQ's

1. How is the AFVCT different from other quality of life or values clarification tools?

Answer: The AFVCT has been designed and tested with adolescent oncology teens and their parents for reliability and validity. The statements presented are specific to cancer-related fertility concerns, the first of its kind. Many quality of life questionnaires rely on scoring systems and are not intended to facilitate discussion, while existing values clarification tools do not focus on the adolescent's desires for future fertility as it relates to their cancer treatment.

2. Why doesn't the AFVCT have a scoring system?

Answer: Quality of life instruments measure the perceptions of responder and many use the method of norm-based scoring; comparing the respondent's scores of items such as fatigue and pain to the average person in order to determine the 'normalcy' of the patient's issues. It would not be in the patient's best interest to score their concerns about fertility against the general population because 1) Adolescent cancer patients have unique concerns that the general population does not, and 2) there is currently no data on adolescents' concerns about fertility and reproduction.

3. Can the AFVCT be administered by a parent, friend, or relative?

Answer: It is highly recommended that the AFVCT be administered by a professional. Statements include values such as needing to blame someone for infertility, if the patient feels like they can talk with their parents about fertility, and if they're satisfied with the information they've been provided about fertility. The patient is likely to answer

in order to please the interviewer and true values on reproduction would not be captured.

4. What if the patient cannot understand English?

Answer: The AFVCT can be administered by an interpreter and since there is no scoring system the responses would remain valid.

5. Can the AFVCT be used for girls under age 12?

Answer: This is at the discretion of the practitioner and the patient's guardians. It is generally accepted that reproductive age begins at age 12; thereby it is assumed many adolescent girls would have a general understanding of reproduction. However we realize in some cases reproduction may have been discussed at an earlier age. It should be noted that this tool was not tested with any adolescent female under age 12.

6. Can the AFVCT be used for adolescent boys?

Answer: Fertility preservation options for males are medically less-invasive than options for females, therefore the reluctance behind fertility-related discussions with adolescent boys is lower. The fertility-preservation process for adolescent boys diagnosed with cancer many times does not involve surgery and anesthesia as it may for girls and boys are likely to feel more comfortable relaying their values to practitioners. Though the AFVCT was not tested with boys, the statements are not gender-specific. It would be preferable to develop a male version of the AFVCT and test it among adolescent boys diagnosed with cancer.

