

Listening through narratives: using a narrative approach when discussing fertility preservation options with young cancer patients

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ABSTRACT

Despite clinical practice guideline recommendations mandating that fertility preservation be discussed with young cancer patients, many providers fail to initiate such discussions with adolescents. Researchers and clinicians often focus on system-level changes to improve access to fertility preservation for adolescents and young adults in Canada. However, little of the available information considers the *way* in which health care providers approach those discussions.

Research has shown that, even when fertility preservation options are broached with adolescents, survivors often report dissatisfaction with those conversations, thus raising additional concerns about their content and quality. Here, we consider how a narrative approach—and the Frank narrative typology in particular—could improve the quality of such conversations by helping providers to more accurately and thoughtfully respond to the needs of adolescent patients when discussing the possibility of fertility preservation. Based on findings from a qualitative research project, we provide concrete suggestions for how to more sensitively approach fertility preservation conversations with male adolescent cancer patients and survivors.

Key Words Fertility preservation, adolescent and young adult oncology, narrative medicine, patient-centred care

Curr Oncol. 2017 Feb;24(1):10-15

www.current-oncology.com

PREAMBLE

In 2014, Gupta *et al.* from The Hospital for Sick Children conducted a study in which they interviewed 14- to 18-year-old male survivors of childhood cancer ($n = 15$) about their perceptions of fertility preservation¹. In 2016, as part of a master's thesis in Health Services Research and Bioethics, the same interview transcripts were reanalyzed to examine how the narrative types developed by Arthur Frank could be used to help health care providers improve the quality of fertility preservation discussions with adolescent patients². The present work resulted from the findings of the master's thesis. Research ethics boards at the University of Toronto and The Hospital for Sick Children approved the Master of Science research.

DISCUSSION

What Is the Current Gap in Practice Related to Fertility Preservation Discussions with Youth?

Cancer therapy, including chemotherapy and radiation treatments, can increase the likelihood of infertility for

survivors^{3,4}, and being offered the choice of fertility preservation (FP) via tissue banking before undergoing treatment has been shown to be important to quality of life for cancer survivors⁵⁻⁷. Despite clinical practice guidelines recommending that FP options be discussed with all cancer patients^{8,9}, many health care providers (HCPs) fail to initiate those discussions with adolescents¹⁰⁻¹⁶. As a result, adolescents are less likely to have access to FP services and supports. Moreover, even when FP options are raised with adolescents, survivors often report dissatisfaction with those conversations, citing a lack of adequate information and insufficient time and importance given to FP discussions^{17,18}. Those findings raise additional concerns about the content and quality of such discussions.

In their four-part oncofertility series in *Current Oncology*, Ronn and Holzer summarized a number of key barriers to FP services access for adolescents and young adults in Canada and offered recommendations for improvement. Those recommendations include the development of a coordinating body and the creation and circulation of comprehensive FP education materials¹⁶. Similarly, other researchers note that FP discussions should be initiated by

HCPs, should include comprehensive reproductive health counselling, should be supplemented with education materials, and should be routinely repeated with patients during follow-up care^{19–23}. Although such tactics are important, specific strategies that could be used while having one-on-one FP discussions with adolescents are not considered. An alternative approach is needed to fill that quality gap. We propose that the use of narrative approaches in FP discussions with adolescents might address the disparity.

What Might a Narrative Approach in Clinical Discussions Offer?

Rita Charon, a physician and literary academic, draws upon the work of prominent narrative scholars to describe “narrative medicine”^{24–28}. According to Charon, narrative medicine is medicine practiced with “narrative competence”—the ability to “acknowledge, absorb, interpret, and act on the stories and plight of others”²⁸. Narrative medicine fosters empathy and trust between patients and providers, improves communication, and has a therapeutic effect for patients^{29,30}. Medical students are taught skills in narrative analysis^{31,32}, and narrative-based workshops are now being offered to HCPs to “enhance reflective practice in inter-professional clinical and/or teaching settings” and “creatively champion patient-centred care” by shifting the story back to the patient experience^a. Through reflective writing, mindfulness exercises, and narrative techniques, HCPs are encouraged to reflect on patient illness narratives and their personal journeys through medicine²⁸.

Arthur Frank, a sociologist and narrative researcher, developed a typology of three different illness narratives (restitution, quest, and chaos narratives) based on extensive interviews that he conducted with cancer survivors and on his personal experience with cancer^{33–35}. Table 1 outlines the Frank narrative types. According to Frank, when HCPs listen to the illness narratives of their patients, they enter into a relationship with those patients. Frank asserts that, together with cultural and personal preferences, those relationships can play an important role in guiding individuals toward particular narrative types. By using the Frank narrative typology as a listening tool, HCPs, patients, and caregivers can become more aware of the kinds of stories being told and created in those interactions^{33,34}.

The Frank narrative types have been used in studies of adult experiences with cancer, HIV/AIDS, stroke, and chronic illness^{35,37–44}. Those studies expose the complex ways in which social and cultural narratives shape the meaning of illness for patients. Some studies describe patterns between the narrative types and offer modifications to the typology based on their findings^{35,43}. Although participant comments usually align with a predominant narrative type, a single individual might draw on various elements of each narrative concurrently or over time.

Because of the valuable role that the Frank narratives played in studies with adults, we used the Frank narrative typology as a theoretical framework in our research study

to analyze 16 interviews with male adolescents who had experienced childhood cancer. We examined how those young men make sense of infertility as a potential long-term effect of cancer treatment. We found that the restitution narrative was the most dominant narrative type in the participant stories, followed by the quest and chaos narratives. Participants expressed each of the narrative types at different points, and no single interview “fit” perfectly with any one narrative form. Indeed, Frank notes that the narrative typology is not intended to capture people’s stories and constrain them within specific narrative forms. Rather, the narrative types can be useful in identifying narrative direction and emphasis and can act as a supportive listening tool to better understand people’s experiences.

Although the Frank narrative types have previously been used to examine adult cancer narratives, our study is the first to use this typology with an adolescent sample. The Frank narrative approach surfaced novel findings about the adolescent experience of serious illness, perspectives on FP and future parenthood, and the evolving sense of self². For instance, although adults who tell restitution narratives often hope for a return to their pre-illness self, the adolescents in our study wanted to achieve restitution to the “normal” self they believe they would have been had they not had cancer. Instead of hoping to be restored to a former self, these participants saw FP as an opportunity to achieve an imagined version of who they thought they might be.

Families also play an important role in young people’s illness stories. In Frank’s descriptions of the narrative types, he concentrates on people’s individual narratives and neglects to consider the embeddedness of close family, friends, and support systems within illness stories. Although family could be important to individuals of all ages, our study echoes assertions made by others^{45,46} that family is of particular significance to young people.

Ultimately, we found the Frank typology to be a useful listening tool. It provides a means of engaging with adolescent stories and a way of understanding experiences that might otherwise be difficult to connect to. For those reasons, we believe that the Frank narrative typology might improve the quality of FP conversations with adolescents^b.

How Might the Frank Narrative Typology Serve to Improve the Quality of FP Discussions for Young Cancer Patients?

Frank³⁶ emphasizes that a key strength of the narrative types is how they can serve to enhance provider understanding and to assist HCPs in building stronger relationships with their patients. The clinician’s role is to listen openly to patients and to show them that their stories are valuable³⁶. The HCP cannot outwardly change the stories relayed by patients, but through the act of listening and joining in a trusting relationship with patients, HCPs might help to create a space for new stories to be told³⁶.

^a See <https://www.mountsinai.on.ca/care/psych/staff-education-programs/mspi/narrative-atelier-2015/na-program-feb3-2015.pdf>, for example.

^b Although our research was conducted with male adolescents, a narrative approach might also improve the quality of FP conversations with female adolescent patients. Further research is needed to better understand how to implement and evaluate the effectiveness of the narrative approach in clinical practice.

TABLE I The Frank narrative types

Key characteristics of narrative type		
Restitution	Quest	Chaos
<ul style="list-style-type: none"> ■ Frequently told in Western medicine. 	<ul style="list-style-type: none"> ■ The narrator portrays him- or herself as embarking on a journey of transformation after an illness diagnosis. 	<ul style="list-style-type: none"> ■ Often disjointed and without structure.
<ul style="list-style-type: none"> ■ Usually follows this storyline: “Yesterday I was healthy; today I am sick, but tomorrow I will be healthy again”¹³. 	<ul style="list-style-type: none"> ■ The narrator describes learning something from the illness experience¹³ and shares the resulting wisdom with others. 	<ul style="list-style-type: none"> ■ Emphasize human vulnerability and helplessness.
<ul style="list-style-type: none"> ■ Individuals who tell restitution narratives want their health to be restored to “normal.” 	<ul style="list-style-type: none"> ■ Wellness is not defined in relation to the narrator’s understanding of “normal.” Rather, it represents a newer, wiser state that the narrator has claimed. 	<ul style="list-style-type: none"> ■ According to Frank¹³, chaos narratives emerge with hindsight, when a person is outside of and thinking back on the chaos.
<ul style="list-style-type: none"> ■ Individuals often look to an external source, such as the treatment or the providers, to return them to “normal.” 		<ul style="list-style-type: none"> ■ The storyteller imagines his or her body and life as never improving.
<ul style="list-style-type: none"> ■ In studies with adults, “normal” often means a return to a former pre-illness self³⁶. 		
<ul style="list-style-type: none"> ■ In our study with adolescents, “normal” meant restoring them to the self that they feel they would have been had they not had cancer². 		

In the context of a busy oncology practice, it is possible that HCPs might not have enough time to use a narrative approach. Nevertheless, the benefits of the Frank narrative typology speak more to a provider’s attitude toward FP conversations than to the total amount of time invested. For example, by approaching FP conversations with a willingness to actively reflect on personal biases and to listen openly, a provider has the opportunity to validate the patient’s story and to build a relationship, leaving room for future discussions.

Frank explicitly details three aspects of narrative listening that HCPs should be aware of when using the narrative typology in clinical practice. Based on the interviews we conducted with young male survivors (described in the Preamble), we present, in the three subsections that follow, an outline of aspects of narrative listening, a consideration of the ways in which the Frank typology could improve the quality of FP discussions with adolescents, and concrete examples of how to use the narrative types in practice.

Just Listening

According to Frank, “just listening” is a specific kind of listening without the intention of changing a person’s attitude, perspective, or situation. Rather than listening to prescribe or diagnose, when HCPs “just listen,” they actively try to appreciate how a person understands their situation at that moment. In this way, “just listening” can promote empathy on the part of HCPs. It can help providers to identify and relate to how tellers might feel about their illness at that moment. As Frank asserts, HCPs who “just listen” “hold the utterly sincere belief that the story [they] are hearing *needs no change*”³⁶ and recognize that people have to tell certain narratives before they can move on³⁶. By listening without the intention of sharing personal opinions, HCPs can diminish the influence of professional power on how the ill person constructs their story.

Frank’s description of “just listening” is similar to DasGupta’s depiction of “narrative humility,” which acknowledges that “patients’ stories are not objects that we can master, but rather [are] dynamic entities that we can approach and engage with”⁴⁷. Health care providers who listen with narrative humility recognize that larger forces enable the telling of certain kinds of stories and restrict others, that narratives are unique to the individual, and that the assumptions of listeners influence the way that a person’s story is interpreted. When utilizing the Frank narrative types, there is a risk that stories will be put into static boxes and individuals will be labelled with one narrative type. Listening openly and with narrative humility can leave space for a patient’s story to change, not only within a given interaction, but also between visits along the illness trajectory. Listening with narrative humility can also help to ensure that the narrative types are not being used as diagnostic tools, but instead to cultivate relationships⁴⁷.

Rather than simply providing the required FP information to patients and asking if the patient has any follow-up questions, HCPs who practice “just listening” could approach the FP conversation with a focus on active listening. In that case, the emphasis shifts from relaying information to understanding what is meaningful to the particular patient. Providers can ask open-ended questions and give patients sufficient time to respond. For instance, instead of asking a pointed question such as “Have you thought about having children,” HCPs might ask, “How do you see yourself in the future? How do you visualize your life when you are older?”

Additionally, the Frank narrative typology could play a unique role in helping HCPs to remain open to listening to various kinds of narratives. Frank notes that “listeners will have distinct *preferences* for one type of story over another”³⁶. Having the narrative types as a framework can

help HCPS to remain flexible and receptive when listening to a variety of stories. As HCPS actively listen to patients, they might ask themselves, “Do the adolescents see the FP technology as a movement towards normalization or perhaps as a reminder of the nightmare of cancer? Do they feel that they play a prominent role in their future lives, or do they leave their hope up to an external source?”

When used in conjunction with self-awareness practices, such as reflective journaling, and mindfulness exercises⁴⁸⁻⁵⁰, the narrative types can also encourage HCPS to reflect on their attitudes toward health and parenthood and to pay attention to the types of stories that they bring to interactions with patients. Health care providers could ask themselves, “Are there certain narrative types that I prefer to listen to?” and “How do the stories that I bring to this discussion influence, enhance, and hinder the patient’s story?” When HCPS acknowledge their biases, they open up space to listen more freely to varying perspectives^{33,36}. Therefore, through the process of “just listening,” HCPS work toward establishing greater intention and awareness in their medical practice.

illuminating to the Ill Person the Narrative Being Told

Once HCPS are comfortable “just listening” to their patient’s story, they can “help the ill person *hear exactly what story* he or she is telling”³⁶ by reflecting the story back. According to Frank, although the three narrative types can be particularly helpful as listening tools, every illness story includes elements of all three narratives types. The goal is not to direct people away from some narratives and toward others; rather, it is to show the ill person that their story “*already* contains different immanent narrative directions”³⁶. In Tables II and III, we share expressions used by the participants in our study to demonstrate how

an adolescent might express certain narrative types, and we describe how providers can illuminate the narratives they hear. By drawing awareness to the types of stories being told, HCPS can encourage patients to reflect on their personal experiences and beliefs.

When HCPS reflect back to a patient the story they are hearing, they focus on the patient’s individual values and think about how the information that they share about FP fits within and relates to the young person’s beliefs. Instead of conveying information, HCPS ensure that the patient fully understands what FP entails and can better offer meaningful information².

Highlighting to the Ill Person That Their Story Is Valuable

Finally, HCPS should make clear to their patients that “they are living a story that is theirs to tell”³⁶. Frank argues that when individuals are ill and other people share stories about them, ill people begin to doubt their own perceptions. It is critical to emphasize to patients that no one knows their stories better than they themselves do. That affirmation can come in small gestures. As Frank writes, “Noting a change between what is said one day and the next, without interpreting that change, affirms to the ill person that it’s *his* or *her* story, to tell as he or she will”³⁶. By giving power to the individual’s values, a space is created for them to see their situation differently.

Frank asserts that when other people share stories about an ill person, that person starts to doubt their own opinions and experiences—a situation that can be particularly true for adolescents, who might ground their stories in family narratives. It might be difficult for adolescents to discriminate their own values about potential parenthood and FP from those of their family members. By validating a person’s narrative as worthy of being told, HCPS can assist

TABLE II Male adolescent narratives^a about fertility preservation

Narrative type		
Restitution	Quest	Chaos
I want to live a more normal life. I don’t want to miss out on any experiences because of cancer. If fertility preservation offers a chance to not be held back, then let’s go for it.	I appreciate my family so much. If I have the opportunity, I will seize it, and I will use it to the best of my ability. That’s why I [do do not] want to preserve my fertility.	Fertility preservation is awesome because it’s awesome, and it’s not good because of the chance that something bad might happen.... Well, it’s cool but it’s, again, the risks there are probably high for parents and even the kid if they know what they’re talking about so ...

^a How an adolescent might represent the Frank narrative types in clinical practice when speaking about fertility preservation and potential infertility.

TABLE III Using narrative techniques in clinical care^a

Narrative type		
Restitution	Quest	Chaos
I am hearing that you want to live a normal life. What does “normal” look like to you?”	It sounds as if you see yourself playing an active role in your life and that you are thinking about what is valuable and meaningful to you personally. Would you say that’s true?	It sounds as if you might be unsure right now about whether fertility preservation was the right choice for you. It is okay to feel unsure.

^a How a clinician might illuminate to the ill person the narrative being told.

adolescents in making a decision that is informed both by the risks and benefits of the procedure and by their own personal values.

SUMMARY

Here, we explored the effects that narrative medicine—and the Frank narrative typology in particular—can have in clinical practice, and we offered concrete suggestions for how HCPs can more sensitively approach FP conversations with adolescent cancer patients and survivors. When used as a framework for thinking about FP and parenthood, the Frank narrative typology can help HCPs to become more aware of their personal preferences, values, and beliefs, and to better understand an adolescent's perception of infertility and the meaning ascribed by them to FP options. The Frank narrative typology provides HCPs with a way of joining in a relationship with their adolescent patients so that they can move together to a place of shared understanding and trust, creating space for new stories to be told.

ACKNOWLEDGMENTS

We thank everyone who took the time to participate in this study. The 2014 study from the Hospital for Sick Children, which provided the original data for the Master's research project, was supported by the C¹⁷ Council and the Kids with Cancer Society, the Childhood Cancer Canada Foundation, and the Coast to Coast Against Cancer Foundation. SIGR was supported by a Canadian Institutes of Health Research Canadian Graduate Scholarships Master's Award.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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