

An exploration of how male adolescents who had childhood cancer make sense of infertility

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Thank you to my committee

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Outline for today

- (1) Provide **background** for my thesis project
- (2) Present the **research objectives**
- (3) Outline **methods and theoretical framework**
- (4) Discuss **findings**
- (5) Delve into **discussion and implications**

Background

Infertility is a potential late-effect of cancer therapies

Adults who experienced childhood and adolescent cancers have identified fertility as a major factor for their quality of life

(Langeveld et al., 2002; Chapple et al. 2007; Knapp, Quinn, and Murphy 2011; Zebrack et al. 2004)

Fertility Preservation for Patients With Cancer: American Society of Clinical Oncology Clinical Practice Guideline Update

*Alison W. Loren, Pamela B. Mangu, Lindsay Nohr Beck, Lawrence Brennan, Anthony J. Magdalinski,
Ann H. Partridge, Gwendolyn Quinn, W. Hamish Wallace, and Kutluk Oktay*

Key Recommendations

- Discuss fertility preservation with all patients of reproductive age (and with parents or guardians of children and adolescents) if infertility is a potential risk of therapy
 - Refer patients who express an interest in fertility preservation (and patients who are ambivalent) to reproductive specialists
 - Address fertility preservation as early as possible, before treatment starts
 - Document fertility preservation discussions in the medical record
 - Answer basic questions about whether fertility preservation may have an impact on successful cancer treatment
 - Refer patients to psychosocial providers if they experience distress about potential infertility
 - Encourage patients to participate in registries and clinical studies

Discussions with male adolescents are limited

- Clinical practice
- Research

My MSc Research

My thesis explores male adolescents' perspectives about fertility preservation

I use a narrative analysis from an interpretivist lens to re-examine a collection of interviews with 14-18 year old males that were conducted in 2012

Research Objectives

I used Arthur Frank's three narrative typologies (the restitution, chaos, and quest narratives) as a theoretical framework in order to explore:

1) How male adolescent survivors of childhood cancer make sense of infertility as a long-term effect of cancer treatment

1) How their experiences of cancer shape their identities

Frank's narrative typologies

Frank's narrative typologies

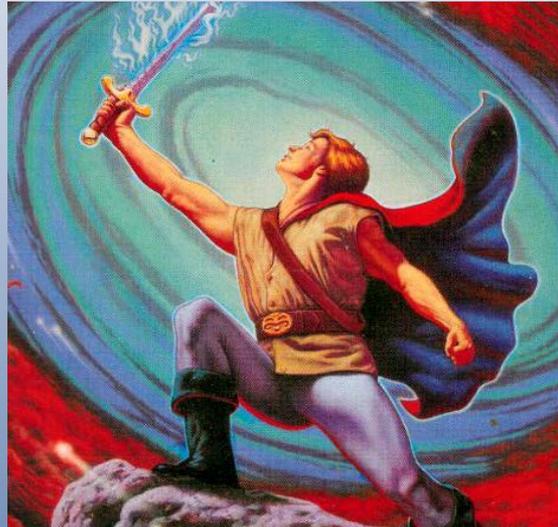


Restitution

Frank's narrative typologies



Restitution

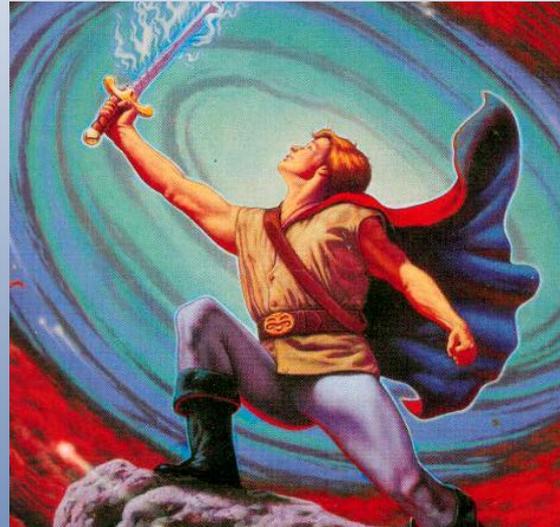


Quest

Frank's narrative typologies



Restitution



Quest



Chaos

Methods

In my narrative analysis I followed the following steps (Smith 2013; Caddick et al. 2015):

- 1) immersed myself in the data
- 2) identified initial themes that emerged from the data
- 3) listened to the recorded interviews and read the interview transcripts again with Frank's three narrative types in mind

Findings

- (1) the types of stories the participants told
- (2) the role of family in the participants' narratives
- (3) the importance placed on biological parenthood

(1) the types of stories the participants told

Restitution Narratives



Achieving restitution to a 'normal' self

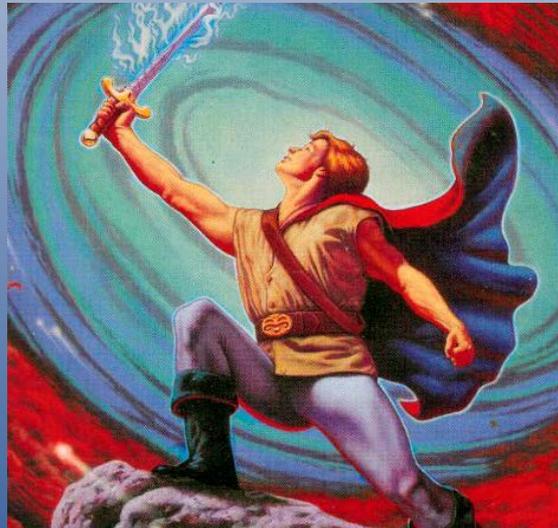
*“Yeah, cuz most definitely no one likes cancer and no one likes to think or feel that cancer is **holding them back** from a dream or something they want to do... I think if there's a chance of getting that [normal life], then let's go for it. Don't let anything hold you back if you can”*

*“that's probably the ultimate goal of this technology [fertility preservation]. That everyone gets a chance out of this misery of cancer. At the end of the day, we'll still have a **normal life afterwards**”*

-Andrew

(1) the types of stories the participants told

Quest Narratives



Quest Narratives

The cancer experience as valuable and transformative

“I just think about how grateful I am and I look back on how grateful I was to everybody that helped me and just because I went through that experience”

Resists the notion of an objective ‘normal’ life

Ben: I already live a normal life. Cause everyone has their own definition of normal, like either you’re in and out of the hospital for half your life or you sit at home in your basement and just watch TV your whole life or everyone—there’s no true definition of what a life is... It’s set in stone to what you do, and how you were raised and how you grew up as a kid

-Ben

(1) the types of stories the participants told

Chaos Narratives



Chaos Narratives

FP recalls painful experience of cancer

Geoff: *Yeah, been through enough pain so.*

Interviewer: *Yeah, so are you thinking about everything that you've been through?*

Geoff: *Yeah*

Interviewer: *Yeah*

Geoff: *Just another surgery on top of what I've been through, it's not—I won't do it so...*



(2) The role of family in the narratives

“It’s just – I came to appreciate my family so much more when I was in the hospital. I realised I took a lot of things for granted...people should have that option [of fertility preservation], should be able to experience that”

-Justin

*“...your family would already be paying a lot of money or **sacrificing money** to save you while you’re going through cancer, so I don’t know if giving them an extra cost would be a huge thing that I would want to lay on them”*

-Greg

*“wouldn’t want to cause any **tension** in my family because of what I chose to do”*

-Jason

(3) The importance placed on biological parenthood

Having biological children is normal

"I've always wanted a family and I've always wanted to have my own kids" -Jason

"one of those things in life that most people wanna see or wanna do" -Alex

"I'd rather have my own kids instead of adopting" -Shane

"It's hard to explain - it's not your child" -Tim

Greg values alternative methods of creating a family

“If I really wanted kids and I was infertile, I wouldn’t mind going to a sperm bank and using someone else’s genetics. I mean, it’s not the most important thing to me”

it *“sounds a bit bad, but I don’t think kids are, just the chance of having kids later on in life is worth putting all the extra money on my parents and my family”*

Summary of key findings

- 1) All three narrative types were evident in the interviews with a predominant emphasis on the restitution and quest narratives. Although the adolescents characterized their sense of selves differently in each of the three narrative types, this study demonstrates that questions about FP and potential parenthood may raise questions for adolescents about how they see themselves
- 1) The narratives highlighted the important role of family in the adolescents' understanding and experience of infertility
- 1) The narratives shed light on the importance of biological parenthood

Discussion and Implications

Reflections on Selfhood

This study demonstrates the complex relationship between illness and selfhood and shows that discussions about potential infertility and FP options may raise meaningful questions for male adolescents about how they see themselves

- **Restitution narrative:** participants wanted to be restituted to a 'normal' life and self
- **Chaos narrative:** participants depicted a loss of connection with and/or ambivalence towards their sense of selves
- **Quest narrative:** participants described a revised understanding of oneself through the cancer experience

Recommendations for policy

- (1) the ASCO guidelines should emphasize that HCPs be **aware and sensitive to the way they approach FP conversations**
- (2) the ASCO guidelines should highlight that **HCPs engage in critical reflection about their own perspective, prejudices, and assumptions about FP and potential parenthood**
- (3) the ASCO guidelines should indicate that FP discussions require HCPs to **listen closely to the patient's narrative** and respond to his **individual needs, views, and values**
- (4) Rather than suggest that referral *may* be necessary under certain circumstances, the guidelines should encourage **all patients in follow-up and survivorship support services to discuss the meaning of infertility risk, FP, and potential parenthood** with providers (psychosocial or otherwise)

Recommendations for policy

- (5) the ASCO guidelines should emphasize **that psychosocial providers be available at the time of diagnosis and in follow-up** appointments whether or not a person seems 'distressed' about potential infertility
- (6) the ASCO guidelines should indicate that it **may be important for patients to involve family members in the discussion** of FP
- (7) the ASCO guidelines should stress that oncologic HCPs offer patients a **variety of education materials** about infertility risk and FP options

Conclusions

It is critical to recognize that participants will have a diversity of reactions to FP discussions; participants' responses will likely evolve and change over time

Conversations about infertility and FP options can raise complex questions for male adolescents about how they understand and construct their sense of selves

Questions and further discussion

Thank you!