

# The Emerging Adult Population with FA: Challenges, Coping, and Quality of Life

## Summary of Results

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# Presentation Outline.

- Introduction
- Study Overview:
  - Background & framework
  - Research questions & methods
    - Semi-structured interviews
    - Surveys
  - Results
    - Interview themes
    - Survey results
- Final thoughts
- Questions?

# This project...

- Really began in 2008.
  - 10 adult patients at camp
  - Struck by themes in conversation:
    - *Substance use*
    - *Control*
    - *Relationships/intimacy*
    - *Body image*
    - *Parental support*
    - *The future*
    - *Undeserved admiration*
- Led to my research questions...

QuickTime™ and a decompressor are needed to see this picture.

# Research Questions

What are typical psychosocial challenges faced by the emerging adult population with FA?

What strategies do people adopt to cope?

How do these strategies correlate with quality of life?

# Importance of psychosocial research in adults with FA

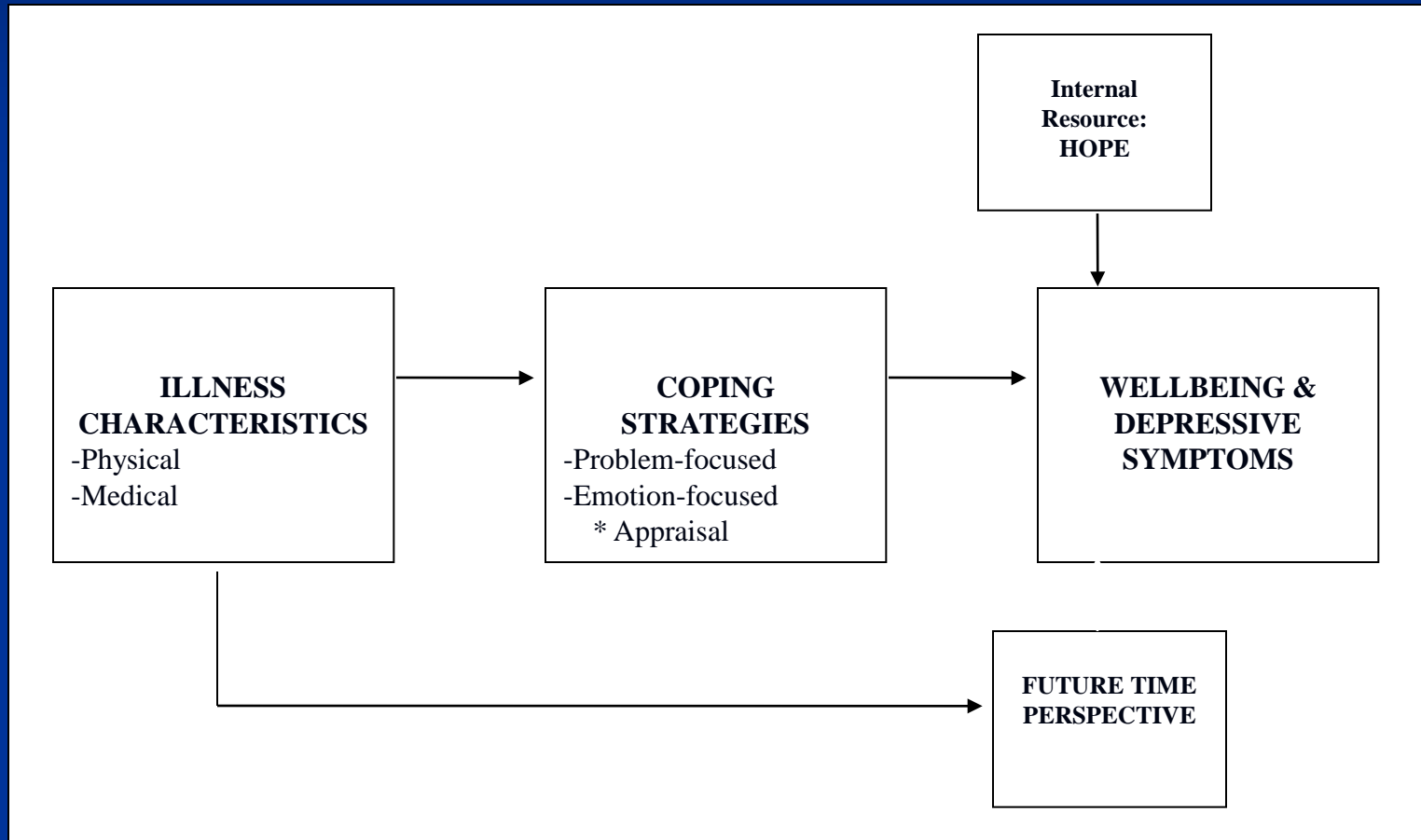
- Probably don't have to justify to this group! **But:**
  - We haven't done it yet.
    - No previously published psychosocial research in FA adult population
  - A growing adult population
    - Impact of continuing medical advances
    - Time perspective & illness demands
  - Relevance to other patient populations

# Study Framework (Brief Promise.)

- Lazarus/ Folkman Model of Stress & Coping
- Coping Strategies
  - Problem-Focused
  - Emotion-Focused
  - Appraisal

QuickTime™ and a  
decompressor  
are needed to see this picture.

# Conceptual Framework.



# Study Methods

How this project happened...

- Semi-structured interviews (n=18)
  - Adults from support group meetings
- Survey (n=96)
  - Adults contacted with help of FA Research Fund
  - Web-based & paper questionnaire:
    - Coping strategies
    - Wellbeing
    - Hope
    - Future time perspective
    - Questions based on preliminary interview data



# Results

- Disclaimer...

# Qualitative Results:

## *Participant Characteristics*

<b>Interview Participants</b>		
<i>Social Characteristics</i>		
		N=18
Age Range	18-55	
Student		6 (33.3%)
Employed		8 (44.4%)
Married		6 (33.3%)
Children (3 adopted)		4 (22.2%)
<i>Medical Characteristics</i>		
		N=18
BMT		9 (50%)
<input type="checkbox"/> 1 Cancer Diagnosis		6 (33.3%)
Infertility		4 (22.2%)
Diabetes		3 (16.7%)
Osteoporosis		2 (11.1%)
Other Complications		4 (22.2%)
<i>Familial FA Characteristics</i>		
		N=18
Sibling born with FA		6 (33.3%)
Loss of sibling to FA		4 (22.2%)

# Qualitative Results: *Challenges*

4 domains: Physical, Medical, Cognitive Perceptual, Social

- **Physical**
  - Anomalies
  
- **Medical**
  - Bone marrow transplant
    - 9/ 18 (50%)
  - Development of malignancies
    - 6/ 18 (33.3%)
    - Most common fear reported

# Qualitative Results: *Challenges*

4 domains: Physical, Medical, Cognitive Perceptual, Social

- **Cognitive perceptual**
  - Future
  - Self-perception
  - Relating with others
  - Growing older (adult roles/ milestones)
  
- **Social**
  - Loss of siblings
  - Loss of friends
  - Difficulty finding romantic relationships

# Survey Results:

## *Participant Characteristics*

Survey Participant Characteristics	
	n = 96
Median Age, y (range)	24 (18-58)
Female	54 (56.3%)
Male	39 (41.9%)
Married/partnered	30 (32.3%)
Children	11 (12%)
Biological	5 (5.6%)
<b>Education/Occupation</b>	
Full-time Student	35 (38%)
Works full-time	29 (31.5%)
Works part-time	16 (17.4%)
Indicated disability*	11 (12%)
Other	8 (8.7%)
Part-time Student	5 (5.4%)

\* This percentage reflects participants who wrote "On disability" in their surveys.

# Survey Results:

## *Illness Characteristics*

Illness Characteristics			
n = 96		n = 96	
Physical anomalies		Medical	
Short stature	67 (72.8%)	Bone marrow/stem cell transplant	49 (53.3%)
Small eyes	39 (42.4%)	Matched sibling donor	25 (51.0%)
Flat thumbs	16 (17.4%)	Unrelated donor	21 (42.8%)
Missing thumbs	15 (16.3%)	Other donor	3 (6.1%)
Missing radius bones	7 (7.6%)	<b>On Androgens</b>	10 (11%)
Three or more	34 (37%)	<b>Any cancer</b>	27 (30.3%)
Other	17 (18.5%)	Vulvar cancer/Cervical (F)	8 (9%) ; (14%F)
None	9 (9.8%)	Head and neck cancer	8 (9%)
<b>Social/Familial</b>		Skin cancer	6 (6.7%)
Other sibling(s) diagnosed	27 (29.7%)	Leukemia	4 (4.5%)
Loss of sibling(s) with FA	16 (17.6%)	Esophageal cancer	3 (3.4%)
Loss of friend(s) with FA	34 (37.8%)	Breast cancer	1 (1.1%)
Attended FA gathering	45 (50%)	Other cancer	4 (4.5%)

# Survey Results:

## *Prevalence of Coping Strategies*

High-Use  
Strategies

Moderate-Use  
Strategies

Low-Use  
Strategies

Coping Strategy	Range	Median
Acceptance	0-8	7
Active Coping	0-8	6
Use of Emotional Support	0-8	5
Positive Reframing	0-8	5
Self-Distraction	0-8	5
Planning	0-8	5
Use of Instrumental Support	0-8	4.5
Venting	0-8	4
Religion	0-8	4
Humor	0-8	4
Self-Blame	0-8	4
Behavioral Disengagement	0-8	3
Substance Use	0-8	2
Denial	0-8	2

# Survey Results:

## *Coping & Outcomes*

	Future Time Perspective	Hope	Wellbeing
Active Coping		.278** 0.007	
Positive Reframing	.208* 0.044	.331** 0.001	
Religion		.365** 0	.331** 0.001
Substance Use		-.360** 0	-.374** 0
Venting	-.369** 0	-.231* 0.025	-.291** 0.004
Behavioral Disengagement		-.362** 0	-.288** 0.005
Self-Blame	-.253* 0.014	-.305** 0.003	-.244* 0.018
Self-Distracton	-.232* 0.024	-.304* 0.003	-.244* 0.018
Denial	-.216* 0.036		



# Survey Results:

## *Coping & Outcomes*

	Future Time Perspective	Hope	Wellbeing
Active Coping		++	
Positive Reframing	+	++	
Religion		++	++
Substance Use		---	---
Venting	---	---	---
Behavioral Disengagement		---	---
Self-Blame	---	---	---
Self-Distracton	---	---	---
Denial	---		

# Okay...but what about diversity of illness experience?

- Physical
  - Anomalies
- Medical
  - BMT
  - Cancer
  - Chronic conditions
- Social
  - Losses due to FA
  - Difficulty forming relationships

# Significant Correlations: *Illness Experience, Coping Strategies, & Wellbeing*

	Physical Severity	Medical Severity	Social Severity	Total Severity
Coping Strategies	Venting (0.23*)	Planning (0.361**)	Use of Instrumental Support (0.318**)	Self-Distraction (0.239**)
	Self-Distraction (0.206*)	Active Coping (0.321**)	Self-Distraction (0.284**)	
		Self-Distraction (0.231*)	Use of Emotional Support (0.281**)	
			Religion (0.235*)	
Outcomes (-)		FTP Scale (-0.273*)	(FTP Scale (-0.236*))	FTP Scale (-0.349**)
				Hope (-0.232*)

# Significant Correlations:

## *Illness Experience, Coping Strategies, & Wellbeing*

	Physical Severity	Medical Severity	Social Severity	Total Severity
<b>Coping Strategies</b>	Venting (+)	Planning (++)	Use of Instrumental Support (++)	Self-Distraction (++)
	Self-Distraction (+)	Active Coping (++)	Self-Distraction (++)	
		Self-Distraction (+)	Use of Emotional Support (++)	
			Religion (+)	
<b>Outcomes (-)</b>		Future Time Perspective (-)	Future Time Perspective (-)	Future Time Perspective (- -)
				Hope (-)

# Tying it all together...

- Key Quantitative Findings:
  - Prevalence of Acceptance and Active Coping
  - Strategies that correlated positively with Hope & Wellbeing:
    - Religion
    - Positive Reframing
    - Active Coping
  - Strategies vary by illness experience.

Coping in Context: Returning to qualitative data...

# Qualitative Coping Themes

- Positive Reappraisal
- Internal Resources:
  - Perspective, Humor, Acceptance, Positive Thinking
- External Resources
- Connecting with the community
- Medical Management
- Lifestyle Management

# Positive Reappraisal of Living with FA

Personal Growth, Meaning, Self-Affirmation

- 17 (94.4%)
  - More compassion for others: 14 (77.8%)
  - Self Appreciation: 12 (66.6%)
  - Life Appreciation: 10 (55.6%)
  - Purpose: 7 (38.9%)
    - Helping others, specifically others with FA
- Emotion card sort

# Positive Reappraisal: Card Sort

Total Emotions in Card Sort	15
Total Negative	9
Total Positive	6
Total Emotions Chosen	97
Total Negative Chosen	49
Total Positive Chosen	51

Emotion	Number of People who Cited Emotion
Hope	13
Compassion	12
Love	12
Anxiety	9
Happiness	7
Sadness	7
Fear	7
Embarrassment	6
Anger	6
Guilt	5
Pride	4
Envy	3
Relief	3
Disgust	2
Jealousy	1



# Internal Resources

Medical Experiences, Future Illness, Self Concept III, Appreciation

- Positive thinking: 17 (94.4%)
  - Hope: 14 (77.8%)
  - Positive reappraisal of illness challenges: 11 (61.1%)
  - Mind/ body connection: 5 (27.8%)
    - Role of belief in God, preparedness, information
- Acceptance: 16 (88.9%)
  - Role of preparedness (8) (44.4%)
    - Time/ Incorporation (6) (33.3%)
  - Role of God (5) (27.8%)
- Perspective: 15 (83.3%)
  - Normalizing: 12 (66.7%)
  - Things could be worse: 9 (50%)
- Humor: 13 (72.2%)

# External Resources

- **Friends: 12 (66.7%)**
  - Emotional Support (10), Concrete Support (4), Self-Affirmation (4)
- **Physicians: 11 (61.1%)**
  - Medical Experience (5), Emotional Support (4), Concrete Support (1), Future Illness (4), Medical Management (4)
    - Trust in doctor: 8 (44.4%)
    - Shared care: 4 (22.2%)
- **Mom: 10 (55.6%)**
  - Emotional Support (9), Concrete Support (9), Medical Management (4)
- **Dad: 4 (22.2%)**
  - Concrete Support (4), Emotional Support (2)
- **Spouse: 6 (100%)**
  - Emotional Support (4), Concrete Support (2)

# Connecting with the Community

Isolation, Self Concept Different

- Advice
- Emotional Support
  - Sharing/ Connecting
  - Hope

# Medical Management

Control, Understanding, Life Stage, Self-Affirmation, Future Illness

- Taking on responsibility for medical care
  - Nearly 30% mention mom
- Research, information-seeking
- Coordinating appointments/ early detection
- Attending meetings
- Finding/ educating physicians
- Adherence to treatment and living healthy lifestyles
  - But not always following lifestyle recommendations...

# Lifestyle Management

Held Back in Life Stage, Held Back Socially, Compressed Time  
Perspective, Family Building

- Goals:
  - Life Benchmarks (Family, Occupation, etc.)
  - Life quality
- Risky Behaviors:
  - Engaging in known risky behaviors
  - Negotiation/ Moderation
    - Quality vs. Quantity
- Normalcy:
  - “FA is not your life.”

# What doesn't work so much...

## ■ Coping Strategies (n=18):

1. Substance use (4)
2. Passivity
  1. Doing little (4)
  2. Self-Sympathy, Dwelling (4)
3. Talking about FA... (4)
4. Avoidance of talking about FA... (3)

## ■ External Factors (n=18):

1. Social network that models risky behaviors (7)
2. Advice about restricting behavior (paternalism) (6)
3. Parents/ Spouse/ Partner that model(s) risky behaviors (5)
4. Providers who don't listen (5)
5. Parental overprotection (3)

# In their words...

- Get involved in your medical care - be proactive and informed.
- Reach out to the community for support and advice.
- Try to find something positive in it - look at it as an opportunity to grow.
- Find pride in it.
- Live your life - don't let it control your life.
- Always be hopeful.

*I would tell them not to let the diagnosis shatter their dreams. They're still attainable. And anything that you have set out to do for yourself? You can still do it. You're still independent. You still have a lot of potential in your life and you can really go for it. FA does not have to hold you back in everything you do. I would tell them to try to integrate it into their life and to carry it along with them in their back pocket, wherever they go, but to keep on keeping on, just like they would have before the diagnosis.*



# Thank you so much...

- Special thanks to the wonderful participants in this study - for your time, patience, and valuable insight.
- The Fanconi Anemia Research Fund for the incredible time and effort they spent helping me with this project
- Dr. Catherine Heaney & Dr. Jennifer Wolff
- Camp Sunshine

Questions?