

Transition Readiness Assessment for Young Adults with Special Healthcare Needs (YASHCN)

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Background

- Special health care needs – intellectual, developmental or physical disability
- Understudied field
- Transition Readiness Assessment Questionnaire (TRAQ)
- Looking at young adults with medical complexities
- Dissatisfaction among youth

1

Describe YASHCNs' perspectives on decision-making involvement during transfer from pediatric to adult care.

2

Compare perspectives on decision-making among YASHCNs with and without intellectual or developmental.

3

Explore YASHCN's perspectives on decision-making in healthcare and non-healthcare contexts.

Aims

Methods

- Recruitment
- Semi-structured phone interviews
 - TRAQ
- Content analysis
 - figure

Scenarios

1. Exciting internship in a different city
2. Doctor prescribes a new medication despite not finding anything wrong
3. Unusual symptom while at home

Interview script

PROBES

If participant needs an example:

“It’s an unpaid job in Pittsburgh, and it might lead to many more job opportunities”

Example pros and cons:

“Some pros include that it’s in the field of your choice, it has flexible hours, and many opportunities to make connections.”

“Some cons include that it’s unpaid, housing is not covered, and it is far from home.”

- What factors would you consider in making this decision?
- Who else would you involve in making this decision?

If participant does not bring up family, friends, or significant other, can prompt:

- How would you involve your family?
- How would you involve your friends or other people?
- How would you involve your significant other?
- How would you involve your healthcare team?
- How has your approach to making decisions like this changed since you were younger?
- What would make it difficult to handle this decision?
- What would make it easier?

Notes:

Thank you for sharing your thoughts about that situation. Now I’d like to talk about a different situation.

Categories

Autonomy

Knowledge

Goals

Self-management

Decision-making

Family/friends

Social support

Impact of school/work

Social determinants of health

Self-awareness

Healthcare interactions

Development/transition

Autonomy

- Forced autonomy
- Being vocal
- Coping with independence

Knowledge

- Healthcare logistics
- Setting parameters
- Knowledge gaps
- Problem-solving skills
- Engaging in appointments/inclusion

Goals

- Life goals
- Vocational decisions
- Balancing limitations with goals
- Shared life goals

Self-management

- Appointment preparation
- Prioritizing health
- Self-motivation

Decision-making

- Processes of making decisions
- Bad experiences shaping decisions
- Revisiting decisions
- Soliciting for opinions
- Different sources
- Learning from other's experiences
- Acute event/transformational experience

Family/friends

- Physical distance
- Emergency safety net
- Not involving friends
- Not involving family
- Negative aspects of family
- Familial coordination

Social support

- Role model
- Normalizing condition
- Emotional support
- Financial support
- Medical support

Impact of school/work

- Flexibility/accommodations
- Condition impacting school
- Condition impacting work
- Work impacting condition
- School impacting condition
- Disclosure

Social determinants of health

- Health insurance
- Financial barrier
- Continuity of care/access
- Built environment
- Transportation

Self-awareness

- Weighing ability to manage
- Awareness of limitations
- Awareness of consequences
- Being cautious
- Health as a barrier
- Emotional maturity

Healthcare interactions

- Health care provider coordination
- Disagreement/conflict with healthcare team
- Feeling unheard
- Frustration
- Power dynamic
- Ageism
- Developmentally appropriate interactions

Development/transition

- Not making changes
- Discounting future consequences
- Going through the motions
- Timing of transition
- Expectation vs reality

Feeling like a minor
character in their
own healthcare

Balancing support
with emerging
independence

Transformative
experiences shaping
how they navigate
life decisions

Themes

Findings

- 7 interviews completed so far

Balancing support with emerging independence

Interview #1

Physical distance

Setting parameters

Optimistic

Balancing

Sorry. I would ... Being unpaid would not be a deal breaker for me, because while it would be nice to have a paid internship, it's also good to be involved with things like that, to where it could open more doors to maybe more paid internships, or maybe career choices, especially in my field, psychology. If it was far from home, I would ... I like to explore. It wouldn't be a deal breaker for me. I would just wonder how far from home, and I would wonder how I would see people I care about, like family. I would weigh all that. I have a good support system, so I wouldn't let that ... It would all work out and that, but if it was unpaid and far from home, I would need to talk about it to everybody a little more, but that wouldn't be a deal breaker for me. As I said, not every ... If it was unpaid, that's still good, just to get your foot in the door, and they see what you can do. I'm very ... I work a lot, in school, or whatever I do, I'm ambitious, so I would want to do it, and see where life takes me.

Again, I like to explore. I don't like to feel like I'm stuck sitting somewhere, and not getting anywhere. If I can get in, even if it's an unpaid internship, I would like to go there and explore, and open new avenues for me in my field.

Transformative
experiences
shaping how they
navigate life
decisions

Interview #1

Self-awareness

Being cautious

Condition affecting school

Reflection

Transformative experience

Accommodations

Prioritizing health

Balancing limitations with
goals

Well, all my life I've been the one to think before I act, and have good role models in my life. I'd say as I got older, I've always been the one to always want to go to school. What the difference is now, when I was younger, I wouldn't know how to stop, and I would basically work myself, and I would get stressed and sick from that stress. As I got older, I learned to ... Having to take some time for me and my health, like last school year. I had to take off in the spring because I got pneumonia, and that happened this spring. When I was younger, I would have been worried about schoolwork in the hospital. I wouldn't have worried about getting well. I would have wanted to leave right away. When I got in the hospital, I wouldn't have taken time to further heal, I would have wanted to jump right back in to work and stuff, jump right back into school.

Now that I'm older, I learned to ... All my professors were always understanding and everything. They would give me passes and everything. Even then, I would still look to overwork myself. Now I'm listening to them and my parents, and I'm taking that time to make myself healthy again, and not worry about catching up on work that I can always push back later. If I'm not well, then that limits the chances of me performing well. I just learned that the work can always wait,

Balancing support with emerging independence

Interview #1

Prioritizing health

Social support

Emotional maturity

Weighing capacity

Accessibility

Being cautious

Mainly my mom and dad. My brother supports me in that, and my other family members too, but my mom and dad have been the biggest influences in that department. They raised me to be like this, so they know exactly what I'm going through, and they've always been with me through thick and everything. Hospitals, surgeries and all of that. They know that I get it from them, so they're able to talk to me and let me know that it's okay. They know I'm a workaholic, but they know what to say and how to help me, and maneuver my mindset to where it's not being angry at me, or taking my mind, but more so just giving me a knowledge that I could change my own mind. That helped me a lot.

To go back to the Pittsburgh internship example, what would make it more difficult to handle that decision?

More difficult would be, depending on the transportation I'd have to take to get there, if I would have to take ... I'm in a wheelchair, so if I have to take a longer route, it's how long of a ride it was. The time of year, because in the winter, and it's snowing outside, that's really harmful for me, and it takes me longer to get places in the snow. I have to take off from school some days when it snows too much, because I just physically can't go out in it. It depends on the time of year, the transportation I would have to take, and it would be where exactly it is located. Where, if it's really wheelchair friendly, but it's not.

Balancing support with emerging independence

Interview #2

Coping with independence

Going through the motions

That's okay. So let's, let's say that you're at home and you start having a new symptom that you've never had before. It's really bothering you. So what would happen? What would happen next?

I'll tell my mom.

And then what do you think would happen next?

She's gonna tell me to tell the doctor

and then can you tell me more how you think it'll play out?

Then I'll go to the doctors and see what they say.

when you say you go to the doctor, would you go to the emergency room where you go to the clinic?

No. Well, like my primary doc, either my primary doctor or one of my doctors that I see on a regular day basis.

Feeling like a
minor character
in their own
healthcare

Interview #2

Feeling unheard

Background character

Do you feel like they usually listen to you?

Yeah, some. It depends on the situation. Sometimes they don't. Other times, they do.

Could you give an example of when they didn't?

Um, I was telling them like I wasn't a particular part of my body wasn't feeling well and something was wrong and they thought there wasn't something wrong and come to find out there's actually something wrong.

And so how did that play out?

Yeah, something ended up was actually wrong and they had to treat it.

So you were right in the end.

Yes.

Feeling like a
minor character
in their own
healthcare

Interview #2

Developmentally appropriate
interactions

Power dynamic

Be a little like more sensitive cause I feel like sometimes they're insensitive because we're not children no more. Young adults still have feelings.

Could you give an example of how they could be more sensitive to that?

I mean, I just from this, this, this from, from like how doctors and nurses and the concerns are of a child. Child hospitals and adult. They don't see a lot of stuff there as much as children's hospitals does.

Um, and then is there anything else that you'd want to share about your opinions about decisions for young adults?

Nothing. No. I really just think they're insensitive.

Interview #3

SDOH

Distance

Self-awareness

Not including friends

Continuity of care

Access

I guess it would kind of look like how it looks when we were talking about me possibly moving to Florida for law school. One of the biggest things they came up was would my health insurance cover medical expenses if I went in Florida? If I had moved to Florida, would my health insurance cover it or what would happen if a medical emergency came up and I was not able to ... And I'm so far away, how would they be able to help? So obviously because Pittsburgh is in Pennsylvania, my health insurance would cover it. But also if a medical emergency was to occur, Pittsburgh is a really far drive and my family would want to be there if something was to happen, especially with my sickle cell.

And then how would you involve your friends or other people?

I'm going to say that I probably won't because ... Yeah, I guess probably no. It would probably just be my family and my boyfriend.

And how would you involve your healthcare team?

I would firstly figure out if they have a branch in Pittsburgh or somewhere that I could easily transfer to and just talk to them about how I could go about that and what they thought about it.

Limitations

- Population pool
- Selection bias
 - Email
- Telephone vs in-person
- Social desirability bias
- Recall bias

Implications

- Educate doctors and parents on perspective of youth
- Legal ramifications for legal decision-making
- Share information with employers/schools

Next Steps

- Continue the study until thematic saturation
- Compare TRAQ scores with responses



Lessons Learned

- Research requires a LOT of reading
- Perspective matters
- Checking myself



Interview #1

Physical distance

Setting parameters

Optimistic

Balancing

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