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Conflict Disclosure Information:

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Title of Presentation: Removing Oneself from the Shadows in Epilepsy

I have no financial or personal relationships to disclose

Removing Oneself from the

Master's Thesis
Suzanne McGuire, MA, BSc

- * Epilepsy - chronic neurological disorder characterized by recurrent seizures (Stein & Kanner, 2009).
- * Through treatment, many people with epilepsy (PWE) live outwardly normal lives, but, tend to experience:
 - decreased quality of life
 - employment issues
 - social problems
 - side effects i.e cognitive problems, drowsiness, fatigue, etc. (Sander, 2005)
- * Significant research is dedicated to epilepsy
- * Much is dedicated to medical & quantitative methods
- * There is a strong gap in terms of understanding what it means to live with epilepsy (Kale, 1997)

* Introduction

Purpose

- * To understand the essence of what it means to be a young adult woman living with and disclosing epilepsy in today's society

* Objectives

- * 1 hour semi-structured interviews were conducted with 5 women between 22 and 28 years living with epilepsy
- * Additionally, the researcher described her experiences living with epilepsy.
- * Topics discussed included experiences with medical diagnosis & treatment, social stigma, personal independence & epilepsy disclosure
- * In-depth data was captured through shared experiences
- * Data was transcribed and analyzed by the researcher using the 7 stages of heuristic inquiry

* **Methods & Analysis**

- * All participants are young, articulate individuals that were very interested in discussing their epilepsy.
- * No participants over the age of 30.
- * 2 were married and 1 had children.
- * Each expressed their dismay with epilepsy stigma and how awareness in society needs to increase.
- * Each participant's experience with epilepsy was unique - But I could not help but relate to nearly everything they said.
- * Whether or not a participant chose to hide or show their epilepsy, I could understand their reasons for doing so based on my own experiences.

* Participant Summary

*Results

*Three prominent themes emerged from the data:

1. Seizures

2. Medical Treatment

3. Social Relationships

Theme #	Theme Name	Theme Description
1	<u>Seizures</u>	<ul style="list-style-type: none">- The aspect of having seizures composed a significant amount of the interview time
1.1	<u>Fear of Future Seizures</u>	<ul style="list-style-type: none">- All participants said they were or are currently afraid to experience more seizures, especially if their seizures were controlled, or they were pregnant/caring for their child- Fear of hurting themselves or others
1.2	<u>Social Anxiety</u>	<ul style="list-style-type: none">- Developed anxious feelings around public seizures- Anxiety across various private and public experiences or thoughts with seizures

Theme #	Theme Name	Theme Description
2	<u>Medical Treatment</u>	- All participants received medical treatment for their seizures resulting in various effects on their lives
2.1	<u>Varied Diagnosis Processes</u>	- Diagnosis time periods to epilepsy were highly varied & unstandardized
2.2	<u>Medical Treatment Side Effects</u>	- All participants experienced at least one major side effect from their AED medication(s) - Significantly affected their lives due to factors like pain, drowsiness, headache, difficulty in the processing and expression of language, etc.
2.3	<u>Lack of Independence</u>	- Several participants expressed how their lives were limited in some way or another - All women stated frustration with the inability to drive, both previously and presently
2.4	<u>Frustration with Medical System</u>	- Due to problems/delays in diagnoses, five of the six participants often had an increase in frustration and anger with the public medical system - Frustration increased also when proper treatment could not be found

Theme #	Theme Name	Theme Description
3	<u>Social Relationships</u>	- Various aspects of the participants lives and social relationships were affected by their seizures and epilepsy diagnosis
3.1	<u>Surprised by Stigma</u>	- Participants expressed their dismay with public misunderstanding and stigma in epilepsy
3.2	<u>Varied Experiences, Similar Understanding</u>	- All participants had unique experiences - Differences & similarities across experiences - Even if the researcher and/or participant didn't have the same experiences with epilepsy, they could still identify with the other person's feelings and/or comfort them
3.3	<u>Development of Fictive Kinship</u>	- Fictive kinship was developed between the researcher and all participants as conversation around epilepsy and life was very fluid
3.4	<u>Epilepsy Disclosure</u>	- A participant's epilepsy disclosure did not depend on good or bad experiences - A person is not fully in or out of the shadows - their disclosure varies from situation to situation
3.5	<u>Patients Studying Patients</u>	- Once fictive kinship was established, the participants were more comfortable discussing their epilepsy and some expressed their motivation to be more confident with their epilepsy after contact with the researcher

*Discussion

* SEIZURES

“Even though it’s such a short walk to the bus terminal, I would get such bad anxiety sometimes that I wouldn’t want to go to work...What if I had a seizure right now just waiting for the bus? Then my heart would start to race.”

Adrienne

“I feel very anxious, to be honest. I’ve actually been at a state where I was seizure free for about a year and a half. And then I was driving and had a seizure while driving. Since that thing happened, to me now I feel like I’m just waiting for the ball to drop. I’m just waiting for it to happen and I think the more I go (seizure-free), the more I’m just waiting for it to happen. Because I was a year and a half before and now I’m 2 years. So now is my expiry date supposed to happen any time soon? And I think that is my biggest struggle now. When I was having seizures I felt more at peace because then it was, ok this is what I have. Where right now it’s like, do I? Don’t I? Do I? Don’t I? It’s hard!....I’m very anxious now...”

Amy

“We paid the thousand dollars or whatever it costs to get into Disney, realized I couldn’t do anything, so we just walked around and left! Like it was just one of those things where you’re like “Really?” like and that’s where it hits you. It’s not an everyday thing but there are moments where you’re like, this sucks. Like yes I’m thankful for how great it’s been because some people can’t even go like a minute without having a seizure or other crazy things like that. But then you get these other things where it’s like ‘ah this sucks!’.”

Katie

*MEDICAL TREATMENT

"I felt like I was high all of the time."

Daisy

"He`s an ass, he`s so rude. I had to ask for a second opinion because he just kept upping my dose of Tegretol with no control...He just never made me feel good...I had to ask for a second opinion as I wasn`t getting results...it was like he couldn`t wait to get me off of his hands."

Adrienne

"...when I started on it (Topamax), I had a really hard time remembering basic words. I would have these little moments where I would be trying to remember things like "dog". So it is getting a lot better now, but I have trouble with memory. Sometimes I think there`s a disconnect between what I think and then what comes out of my mouth. I just feel a little stupid..."

Carly

*SOCIAL RELATIONSHIPS

"I want to have my experience heard and I think my experience has a lot to do with my social circles ."

Carly

"It's not that I hide it, because I don't. So I don't share my story at all with anyone because I feel like they might not care. So why tell them? Then my family and my parents have been here for it all so it's not like I retell them the story. I want to talk about it but sometimes I feel like I don't have anyone I can talk to."

Katie

"It bothers me when people make assumptions about what I can or can't do, even though some of their assumptions may be right...I would prefer it if I am the one who decides what my limits are instead of making those choices for me...With family members, I know their actions come from a place of concern, but sometimes I would like them to realize that I am an adult and I can make my own decisions."

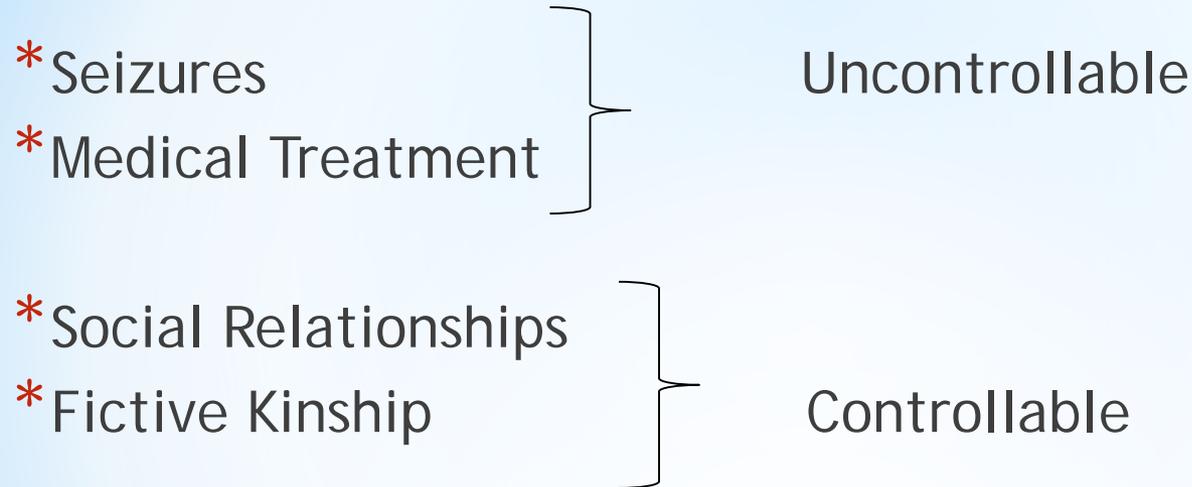
Carly

*The Revolving Door Metaphor

- * Epilepsy disclosure is not a door which is completely open or closed
- * Epilepsy disclosure is more like a “revolving door” whereby people living with epilepsy use strategies to decide whether or not to disclose their epilepsy
- * This was demonstrated by all study participants



Made up of 4 key components:



- The act of *"removing oneself from the shadow"* requires one to move past the uncontrollable components of epilepsy
- Work towards having *more* control over other aspects of their lives - the *amount & quality of their social relationships*

** The Epilepsy Management Model*

- * Small sample size
- * Highly specific study population
- * Difficulty obtaining participants
- * HI has the possibility to 'blind' the researcher from the true findings
- * To counter this, rigor was regularly practiced whereby the researcher would step back from the data and receive input from her graduate supervisor

However....

- * *Even with these limitations, the data was suggestive of the presented model*

* Study Limitations

1.) Life with epilepsy is a transformative journey that can alter a young adult woman's perceptions of personal relationships, independence, the medical system, and public society.

2.) When two young adult women living with epilepsy meet each other and discuss their lives, significant fictive kinship can develop between them.

3.) A young adult woman's amount of epilepsy disclosure in society is not necessarily related to their personal experience with seizures and epilepsy.

* **Conclusions**

- * Use a larger & more diverse study sample
- * Open study up to other specific populations of people living with epilepsy
- * i.e. Young adult males, children w/ epilepsy, parents of children w/ epilepsy, the elderly
- * This will ideally help to show the benefits of patients studying other patients in subjective health research

* Future Directions

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***QUESTIONS?**