



PennState
College of Nursing

The lived experience of a family member dealing with an opioid addicted loved one

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Learner Objectives

- Discuss the impact of the opioid epidemic nationally, locally and individually
- Recognize the value of community-based substance use disorder (SUD) research
- Describe the objective of the Community-Based Research Network
- Summarize the lived experience of a family member dealing with an individual with SUD.
- Consider this information when interacting with individuals in practice role and in community.

Opioid Epidemic

National

- 2016 --63,632 overdose deaths (CDC, 2018)
- 2017 --70,000 overdose deaths with 47,600 involving opioids (NIDA, 2018)
- 2018 --67,000-69,000 provisional data (CDC, 2019)

Pennsylvania

- 2016 --Ranked 5th in the nation (CDC, 2018)
- 2017 --Ranked 3rd in the nation, behind West Virginia and Ohio (CDC, 2018)
- Preliminary data 19% decrease 2017 to 2018 (CDC, 2019)

Community Based Research Network

- Research Nurse Initiative (RNI): trained 27 nurse scholars across 12 Commonwealth campuses with a wide range of clinical specialties
- CBRN developed networks for community-based nursing research
- Great potential for building community partnerships to improve health outcomes, as scholars were:
 - Geographically diverse
 - Had a wealth of knowledge and experience related to community's infrastructure and health needs
- Scholars received training in research skills and ethics to gain the competencies needed to engage in clinical research targeting their communities
 - Identify health challenges in their community
 - Engage stakeholders

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Research Study

- Purpose: The purpose of this study was to explore lived experience of a family member dealing with an individual with substance use disorder (SUD).
- Method: An interpretative phenomenological method of inquiry was used to understand the lived experience of a family member dealing with an individual with SUD.
- Using convenience sampling, eight (n=8) participants were interviewed (60-90 minutes) using a semi-structured interview guide.

Study participants

- Participants included a mothers, a father, a wife, a grandmother and an aunt.
- During the time of the interview, the family members were in the following stages of the SUD trajectory
 - Recovery (n=4)
 - Active addiction (n=1)
 - Death from an overdose (n=3)

Data Analysis

- Recorded interviews were transcribed and deidentified
- Transcripts were uploaded to NVIVO, which is a qualitative data analysis tool.
- Researchers
 - Read the transcripts independently and open-coded the data
 - Discussed the codes until a consensus was reached; 28 codes
 - Categorized the data independently
 - Discussed the categorized data and agreed on distinct groups
- Four themes emerged from the categorized coded data
 - Sub-themes were identified and assigned to each theme

Four Themes

- Confirming the addiction
- Living with addiction
- Sorting out addiction
- Reflecting on addiction

Theme 1: Confirming the addiction

- **Subthemes (5)**
 - Starting point
 - Addiction not known
 - Suspicion of addiction
 - Acknowledgement of addiction
 - Initial reaction to knowing

Confirming the addiction: Starting point

A mother (B):

So, for me, yeah it profoundly changed my life and even early on, like when I, you know, when I was suspecting him of you know smoking pot. I wasn't thrilled about that, but we weren't yet to opiates.

Confirming the addiction: Acknowledgement of addiction

A mother (A):

Pulled up his sleeves and looked at his arms, and we knew instantly. I, I freaked out. I (laughs), I never in my wildest dreams imagined it had come to that. And that was how we found out.

Confirming the addiction: Initial reaction to knowing

A father:

Because I felt as though this was, um, I felt he was doomed. I felt this was a, a death sentence. I, as they say in the business, there aren't any old heroin ad-heroin addicts...

Theme 2: Living with addiction

Subthemes (10)

- Adapting to life with addiction
- Ultimatums
- Family member relieved
- Unconditional love
- Lying
- Stealing
- First attempt at treatment
- Relapse additional Treatment
- Seeking treatment
- Stresses not related to addiction

Living with addiction: Adapting to life with addiction

A mother (A):

You felt you couldn't leave the house...we had all our doors locked, bedroom doors, you had to carry keys around with you, and hide keys, ...I'd go to the bus stop outside my door and I have to carry my purse, I have this small child at home. I only have so much time in a day...I, I feel like I'm taking time away from raising him to, like, babysit a 20-something-year-old man, who shouldn't be consuming my time this much. But I always had guilt that I just was not giving enough time to my younger stepson.

Living with addiction: Ultimatums

A mother (B):

..."I'm gonna be fair, I'm gonna give you 30 days." And I said, "In 30 days, I'm taking you for a drug test." ..."You better be able to pass it." ..."If you knowingly and willingly continue in this lifestyle then we can't, we have to part ways. Because I can't." ..." I can't be a part of this."... "I wanna be up front with you." I said, "I cannot." I said, "I cannot participate in this."

Living with addiction: Family member relieved

A father:

...you know, the only time we really felt, uh, at ease was when he was in treatment...because he was safe...I mean, the only time, once we've, once we knew that he was using, the only time that we really felt at ease as parents was when he was in treatment.

Living with addiction: Unconditional love

A mother (C):

Hell. It's sheer hell. 'Cause you have these babies. You love them for everything they are and all they could be, and then they don't help themselves. Then you just, my heart aches.

Living with addiction: Lying

A mother (C):

It's hell to live with an addict....you're tangled up in the lies...It's just absolutely awful. And they lie to themselves that it's normal. That's the thing that killed me...this is not normal. You're living in a fantasy zone....a chemically induced state that allows you to believe this bullshit...But then, when you speak reality, they think that you're the enemy. So you're tied.

Living with addiction: First attempt at treatment

A mother (C):

It took me about a week to find a program in...So we kidnapped him, basically....to put him on a plane...he didn't know what we were doing. He thought he was coming home. He thought this was great, I'm going home. Like, no, we're gettin' on a plane, and he refused.

Living with Addiction: First attempt at treatment

A grandmother:

And, then, it got really bad, really bad. And, then, um, finally talked her into going somewhere. So, had to actually go into town and get her and I to actually **take her some place and wait in the car for her to go in and get heroin** to bring her here to my house to spend the night because we couldn't go there 'til the next day. **And, she was not able, she said, to spend a whole night without something...And, that was like one of the worst things in the world I ever had to do because I was scared to death.** Then took her. We went up to (nearby city).

Living with addiction: Relapse additional treatment

A mother (A):

...you know, tried to get treatment...he would go to a rehab and then he'd be home... And that day after he came home, I found him in the bathroom, he had overdosed...And I was a mess. He was a mess. And I think that all contributed to his relapse. The relapse was worse than the first time. It just, he was so bad and I think he gotten hold with other drugs as well...And at the moment he's under care again.

Living with addiction: Stresses not related to addiction

A grandmother:

... She said that if she could move away from here, that it would be easier, but I don't really don't know if that's true. She said because here, when you live here, um, you know where you could get it. So, if you're downtown, say you're away and you come home, you don't wanna do it but everywhere you go you know where it is..

Theme 3: Sorting Out addiction

- **Subthemes (3)**
 - Navigating the system
 - Revealing your secret
 - Time more awareness

Sorting out addiction: Navigating the system

A wife:

I mean, I never thought that I would be in this situation, uh, like, I've learned way more about addiction than I ever wanted to know.

A mother (D):

Oh, I would tell them get ready. Fasten your seat belts.

Sorting out addiction: Revealing your secret

A mother (A):

I was embarrassed and ashamed. I thought, if someone knows that my son is a heroin addict, I will be devastated.

A mother (D):

Everybody came together. My husband's family not so much....Um, we felt abandoned by a lot of them.

Sorting out addiction: Time more awareness

A wife:

"I'm really lucky to have the support system that I have," and she's like, "That's not luck, you created that support system for yourself." I was like, "Oh, yeah. Um, I'm involved in running group, I go to two book clubs, I have my co-workers...I think definitely one, is taking care of yourself first. And then, um, because if you are not taking care of yourself, you can't help anybody else."

A grandmother:

Don't give up on them. They're yours. Love them. Tell them you love them. Stick by their side. Do what you can. Have faith. Don't give up.

Theme 4: Reflecting on addiction

- **Subthemes (7)**

- Talking is healing
- Helping others/ Paying it forward
- Previous life
- Preconception profile of a person with SUD
- Previous mental health diagnosis
- Question their decision (treatment/addiction)
- Question parenting

Reflecting on addiction: Talking is healing

A mother (A):

Talking is a healing process (laughs)...Um, I'm glad I told the story because it's a really hard story to hold on to...This is so hard.

An aunt:

I had not shared the depth of the story from my perspective. From the "tap" into the darker spaces of my thoughts about this experience provided by the interview I have continued to divest myself of more feelings.

Reflecting on addiction: Helping others/ Paying it forward

A wife:

...when he passed away, I put it in the obituary, like how he died... and I said, "If this can help anyone-“...'cause it's so like hush hush, stigmatize, people don't talk about it...But, I think, it's a good thing and that it can hopefully help, um, others in the future. ...ever since I posted that in the obituaries, so many people...have said ... "I've never told anybody this, but my son is user...So, I think that's been really good...So, I would like to become a part of that, to help just like getting the word out and having it be less stigmatized.

Reflecting on addiction: Previous life

A mother (C):

...'Cause I can see, oh my God, this kid has everything. If he understood, he's gorgeous, he's smart, he's talented, he's physically talented, he's intelligent, he has no self-esteem. And I don't know why he doesn't have that. And it's hell as a parent. And, I know at some point, if he, if he runs into dif-, difficult times, there's a good chance that he is going to end up homeless or an addict...

Reflecting on addiction: Preconception profile of a person with SUD

A mother (A):

...he would stay home on weekends because he wanted to get in, the military academy. He wasn't the one who went out partying on, on the weekends. He stayed home with his family... Because he just wasn't your typical candidate that I always thought a heroin addict was.

Reflecting on addiction: Previous mental health diagnosis

A wife:

...he had surgery, so, it was like constantly he's being prescribed pain killers. He had social anxiety. So, it made him more social, and then he was like able to talk to people. Um, that was another reason why he used...So, I think he picked up on that too, like, "Well, your mom really likes me when I'm social," and have like depression too. Um, he- he had like always been depressed, like ever since I met him, like he had a tattoo on his leg that said, "Alone."

Reflecting on addiction: Question their decision (treatment/addiction)

A father:

Well, I don't, I know after, uh, when he, when he finally agreed to go to detox and rehab for the first time, I realized that I made a bad choice, uh, in, in selecting the program that I selected, but I did select it because first of all, they accepted health insurance-...So, uh, you know, I had never, I didn't know that much about this organization, um, but again, I knew that it accepted the insurance, and I thought, "Well, this is just the beginning, right?" Remember I said a little while ago, recovery starts when you get out.

Reflecting on addiction: Question their decision (treatment/addiction)

A mother (C):

He was just so not himself. It was the best thing we ever did. It was the hardest thing. I mean, I literally kidnapped my child....and have the, the wherewithal to listen to that inner gut saying this is the right program, even though, I knew nobody. But, oh my God, it's just, it's awful...literally, kidnapping them and taking them out of state to where you have authority over them is pretty damn stupid...And it was a good option. But, I'll tell ya, it was the scariest. I, I, the day we walked out of there and left him with strangers, was so hard.

Reflecting on addiction: Question parenting

A mother (C):

...And then there's the guilt of, what did I do wrong as a parent that my kid is turning to substances?... So, again, is it enabling or is it protecting? It's really a hard space to be in when you're the parent. But I didn't want my kids to have a record...So I didn't go that route. Part of me now wishes I had gone that route. Had I known how bad it was gonna be, I wish I had gone that route.

Discussion

- **Confirming the addiction**

- “Finding Out” – direct evidence, discovering paraphernalia, noticed changes (Choate, 2015)

- **Living with addiction**

- Pattern of chaos (Choate, 2015)
- Challenges of arranging treatment (Choate, 2015)
- Experiences as the problem escalated (Choate, 2015)
- Tipping point (Rubio, 2016)

Discussion

- **Sorting out addiction**

- Revealing secret, supportive and stigma, supportive responses, concern about stigma, stigma in treatment (Choate, 2015; Goodyear, Haas-Koffler & Chavanne, 2018; Matthews, Dwyer & Snoek, 2017; Kulesza, Matsuda, Ramirez, Werntz, Teachman & Lindgren, 2016; Stumbo, Yarborough, McCarthy, Weisner & Green, 2017)


- **Reflecting on addiction**

- Questioning parenting and treatment decisions (Choate, 2015)
- Relief from emotional distress (Stumbo, Yarborough, McCarthy, Weisner & Green, 2017)

Current/Future Projects

- Current project ---descriptive study, survey research *Families Forging a Path to Treatment for Opioid Addiction*
- Future project ---develop a novel intervention to support family members accessing care for a loved one

A mother (B):

 I had this hierarchy of things that I didn't want to hear..."Mom, I failed a test." You know when they were in high school...as they got a little, a little older... "Mom, I'm pregnant, Mom, my girlfriend is pregnant, you know Mom, I got fired from a job." But my number one thing I did not wanna hear was, "Mom, I'm a drug addict." And I heard that. And it's devastating, and for me like it's not like some people it's the stigma it's the embarrassment. I could care less, like that to me isn't an embarrassment, it happens. If you're a human being, you could become a drug addict...just the fact that this can control your life forever. Because he will always be an addict...Because he will carry that for the rest of his life, and for me as his mother...that's what really, it's torturous.

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Questions



