

## **45th Biennial Convention (16-20 November 2019)**

### **The Lived Experience of Family Member Dealing With an Opioid Addicted Loved One**

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Substance use disorder is a national epidemic and urgent public health concern. Recently released provisional data reports an estimated 72,000 overdose deaths nationally (National Institute on Drug Abuse, 2018). This is an increase of 9,000 per year (63,632 deaths) that were reported in 2016 (Center for Disease Control, 2017). More than 63,000 overdose deaths in the United States with opioids involved in 66% of deaths (Centers for Disease Control, 2017). In 2016 Pennsylvania was ranked 5th in the nation with deaths due to drug overdoses (Centers for Disease Control, 2017), yet provisional data from 2017 suggests that Pennsylvania is now leading the nation death due to drug overdoses (Turner, 2018). While the cost in deaths and poor quality of life is the primary concern, the financial burden to individuals, families, cities/states, and healthcare is prohibitive. In 2007, the Economic Impact of Illegal Drug Use on American Society reported illicit drug use cost the U.S. economy \$193 billion; however, given the current climate of substance use disorder, the financial cost is estimated to be \$1 trillion (Amador, 2018).

In order to better understand the impact and outcomes of substance use disorder, specific data points including naloxone resuscitation, emergency room visits, and hospital admissions are being collected statewide (Commonwealth of Pennsylvania, n.d.). While statistics lend to examining geographic trends, data on issues surrounding the addicted individual, such as from management after Naloxone resuscitation, transition from law enforcement agencies to treatment, treatment options and strategies to maintain recovery are being explored. In response to this crisis Health and Human Services announced a 5-Point Strategy that is focused on improving addiction prevention, treatment and recovery services; gathering better data; conducting more focused opioid addiction research; managing pain more effectively; and targeting of overdose reversing drugs to improve outcomes (2018).

The opioid epidemic is complex problem. In order to provide a comprehensive intervention plan, we first need to understand the perspectives of all stakeholders. There are many stakeholders in this epidemic ranging from the individual, family, friends, the community, the state and the nation. There is limited research that explains the lived experience of individuals involved in this epidemic including the addicted individual and their families and friends. One can think of opioid addiction as a continuum with initiation to opioid use on one end of the trajectory and recovery or death at the opposite end. Recognizing that each person's substance use disorder trajectory is unique and that the individual may attempt treatment multiple times is well documented in the treatment-seeking research.

Using an interpretative phenomenological method of inquiry (van Manen, 1990), the purpose of the study is to understand the lived experience of a family member dealing with an individual with substance use disorder. University IRB approval was obtained. Using convenience sampling, participants that identified as a primary family to a person with substance use disorder were recruited. Prior to participating in the study, informed consent was obtained from each participant and all interviews were audio recorded. A semi-structure interview guide was used and interviews were conducted in a quiet, private location chosen by the participant. Interviews ranged from 60-90 minutes. Interviews were transcribed and identifiers (i.e., names, locations, facilities/treatment centers, etc.) were removed by the principal investigator. Transcripts were uploaded to NVIVO, which is a qualitative data analysis tool.

Demographic data was collected on each of the participants. Eight participants (n=8) included mothers, a father, a wife, a grandmother and an aunt. During the time of the interview, the persons with the substance abuse were in the following stages of the substance use disorder trajectory and included recovery (n=4), active addiction (n=1), and died from an overdose (n=3). Content analysis was completed on de-identified transcriptions by two researchers independently. Analysis revealed 4 themes of the lived experience of a family member dealing with an individual with substance use disorder (a) confirming the addiction, (b) living with addiction, (c) sorting out addiction and (d) reflecting on addiction.

Findings were supported by previous literature. The stigma associated with addiction and the shame of people finding out about the addiction were evidenced as participants discussed their experience in confirming and disclosing their loved one's substance use disorder (Goodyear, Haas-Koffler & Chavanne, 2018; Matthews, Dwyer & Snoek, 2017; Kulesza, Matsuda, Ramirez, Werntz, Teachman & Lindgren, 2016). As family members live with and sort out the addiction process, the family members discussed the complexity of navigating the system and coping with the daily struggles of dealing with a person with substance use disorder. One previous study supports the idea of an ultimatum or "tipping point", which was described by the participants (Rubio, 2016). This study allows us to better understand the lived experience of a family member of person with opioid substance use disorder including the experiences surrounding confirming and living with the substance. The participants revealed their shared journey as they faced the challenges and recognizing that entry into treatment is usually decided by the addicted individual. Future studies examining the complexities of insurance issues and privacy/confidentiality (Health Insurance Portability and Accountability Act, HIPAA) may help address barrier in the treatment process and assist family members as they support the person substance use disorder. Currently, there are crucial opportunities missed in the initiation and continuation of a comprehensive treatment plan. Even when the person with substance use disorder expresses the desire to seek treatment, the person and their family member meet many roadblocks. Capitalizing on these opportunities is critical when an addicted person chooses to seek treatment. A delay of hours or days can result in irreversible outcomes. Timely admission into treatment is a key component in fighting the opioid epidemic. Improved understanding of this journey, as revealed in this study, provides insight into how best support the needs of family and the addicted individual. Enhancing education and support for the family and friends has the potential to impact the addicted individual.

Recognizing the unique needs of this group reveals opportunities for healthcare provider and community-based interventions to maximize resources and support this growing population.

\*\*Authors note; the term “substance use disorder” was adopted while the study was in progress.

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**Title:**

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**Keywords:**

opioid addiction, substance use disorder and treatment

**References:**

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### **Abstract Summary:**

Substance use disorder is a national epidemic and serious public health concern. The opioid epidemic is a complex problem that involves many stakeholders including the primary family member. The purpose of this study is to explore lived experience of a family member dealing with an individual with substance use disorder.

### **Content Outline:**

#### I. Introduction

- A. Substance abuse disorder is a public health concern.
- B. Overdose deaths have increased (72,000) nationally.
- C. Financial cost of the opioid epidemic is estimated to be \$1 trillion.

#### II. Purpose, Methodology, and Findings

A. An interpretative phenomenological method of inquiry was used to understand the lived experience of a family member dealing with an individual with substance use disorder.

B. Using convenience sampling, eight (n=8) participants were interviewed (60-90 minutes) using a semi-structured interview guide.

- 1. Informed consent was obtained
- 2. Audio recorded interviews were transcribed and de-identified.

C. Content analysis was completed on transcripts.

1. Analysis revealed four themes

- a) Confirming the addiction
- b) Living with addiction
- c) Sorting out addiction
- d) Reflecting on addiction

#### III. Conclusion

A. This study allows us to better understand the lived experience of a family member of person with a substance use disorder.

B. Future studies examining the complexities and barriers in the treatment process.

First Primary Presenting Author

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**Author Summary:** Dr. Marianne Adam is a nurse educator for over 25 years. Dr. Adam is interested in the opioid epidemic and the impact on individuals, families and communities, she participates in community-based groups and meeting sponsored by local and state government. The focus of this study was identified by community stakeholders.

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**Author Summary:** Dr. Erin Kitt-Lewis is a nurse educator for 15 years and is interested in community-based health. As a member of the Community Based Research Network, Erin worked with key stakeholders to identify important research issues in the community. This study emerged as a result of the CBRN.