ACTIVATION IN PERSONS WITH OPIOID USE DISORDERS IN INTENSIVE

OUTPATIENT TREATMENT

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ACTIVATION IN PERSONS WITH OPIOID USE DISORDERS IN INTENSIVE OUTPATIENT TREATMENT

Persons with opioid use disorder (OUD) often receive intensive outpatient treatment (IOT) but these programs are associated with low rates of completion and high rates of relapse. Enhancing patient activation - taking an active role in one's healthcare would likely improve outcomes for persons with OUD in IOT. The overarching purpose of this dissertation is to describe how persons with OUD experience IOT, especially regarding activation. The dissertation includes three components. The first is an integrative review of 29 studies of activation in persons with mental health disorders generally. Results revealed that activation was related to several heath and treatmentrelated factors and some interventions, most notably educational programs, increased activation. The second and third components were based on interviews with 14 persons who had been enrolled in an IOT program in academic health centers. The second component was a constructivist grounded theory study conducted to describe the process people undergo as they participate in an IOT program. Participants described a process of connecting and disconnecting that included eight stages: (1) connecting with drugs, (2) disconnecting from everyday life, (3) connecting with the IOT program, (4) connecting with others in the IOT program, (5) disconnecting from drugs, (6) reconnecting with others, (7) reconnecting with self, and (8) disconnecting from the IOT program. The third component was a qualitative descriptive study conducted to describe types of instances in which persons play an active role in their IOT (activation). Participants described six types of instances: (1) making and enacting one's own treatment decisions, (2) actively

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engaging in treatment planning with staff, (3) choosing to actively engage in groups, (4) making a commitment to treatment, (5) taking responsibility for one's own recovery, and (6) taking actions to avoid relapse. The results of this dissertation will inform the development of strategies to enhance activation among persons with OUD in IOT with the goal of improving engagement and program outcomes.

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LIST OF ABBREVIATIONS

Abbreviation	Term
DSM-V	Diagnostic and Statistical Manual 5th Edition
ΙΟΤ	Intensive Outpatient Treatment
IRB	Institutional Review Board
MOUD	Medications for Opioid Use Disorder
OUD	Opioid Use Disorder
PAM	Patient Activation Measure
PRISMA	Preferred Reporting Items for Systematic Reviews
	and Meta-Analyses
SAMHSA	Substance Use and Mental Health Services
	Administration
SUD	Substance Use Disorder

KEY TERMS

Intensive Outpatient Treatment (IOT). IOT is a treatment approach that provides ambulatory services for persons with substance use disorders who do not need residential or inpatient treatment but who need more support than weekly or bi-weekly treatment sessions (McCarty et al., 2014). IOT is a structured approach that includes substance use and mental health psychoeducation and individual, group, and/or family therapy (Substance Abuse and Mental Health Services Administration (US), 2006). Goals of IOT include addressing persons' unique recovery needs, ensuring adequate psychosocial support, and supporting the development of coping and relapse management skills (McCarty et al., 2014). IOT is considered most suitable for patients with a strong support system, a stable home life, and good physical and mental health (National Institute on Drug Abuse, 2018).

Opioid Use Disorder (OUD). Opioid Use Disorder (OUD) is a mental health disorder marked by significant impairment or distress resulting from problematic opioid use (Centers for Disease Control and Prevention, n.d.). Examples of criteria for OUD as outlined in the Diagnostic and Statistical Manual, Fifth Edition (American Psychiatric Association, 2013) include the following: (a) taking opioids in a larger amounts over a longer period of time than intended, (b) craving for opioids, (c) continuing opioid use despite having persistent social/interpersonal problems, and (d) using opioids in physically hazardous situations. Based on the number of criteria met, OUD is determined to be mild (2-3 symptom criteria), moderate (4-5 symptom criteria), or severe (6 or more symptom criteria) (Kampman & Jarvis, 2015).

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Patient Activation. Patient activation is defined as a characteristic of patients who understand of their role within the healthcare process and have the confidence and ability to self-manage their health and healthcare (Greene & Hibbard, 2012). Patients with higher levels of activation report higher engagement in illness self-management, stronger collaborations with health care providers, and better health maintenance (Hibbard & Greene, 2013).

Integrative review. An integrative review is a research review strategy that provides a comprehensive understanding of a phenomenon using a systematic and rigorous approach to summarize diverse research study methodologies (Whittemore & Knafl, 2005).

Grounded theory. Grounded theory is a qualitative research approach that allows for flexible yet systematic collection and analysis of narrative data for the purpose of theory construction (Charmaz, 2014).. Grounded theory, which is based on symbolic interactionism, is used to identify a psychosocial process shared by a group of persons who share a common challenge. The main analytic strategy of grounded theory is constant comparison analysis (Charmaz, 2014).

Constructivist grounded theory. Constructivist grounded theory is a specific approach to grounded theory that is based on the assumptions that human experiences are influenced by social contexts, researchers and participants interact to co-construct findings, and findings are developed and refined through consensus (Charmaz, 2014).

Qualitative description. Qualitative description is a research approach that yields a comprehensive summary of narrative text based on the surface words of the participants. The approach provides a straightforward description of events related to the

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phenomenon of interest (Sandelowski, 2000). Common procedures associated with the approach include purposive sampling, semi-structured interviews, and content analysis (Sandelowski, 2000).

CHAPTER ONE

INTRODUCTION

The purpose of this dissertation is to describe how persons with opioid use disorder (OUD) experience intensive outpatient treatment (IOT), especially regarding activation. The dissertation project includes three components: an integrative review, a grounded theory study, and a qualitative descriptive study.

OUD is a prevalent public health problem associated with many negative health effects. OUD is a mental health disorder marked by significant impairment or distress resulting from problematic opioid use (Centers for Disease Control and Prevention, n.d.). OUD affects 2 million Americans in the United States (Substance Abuse and Mental Health Services Administration, 2019) and can result in serious disability and death (National Institute on Drug Abuse, 2017a). Long-term recovery from OUD is a challenge. Sobriety maintenance for people with OUD observed for 10 to 30 years is less than 30% (Hser, Evans, Grella, Ling, & Anglin, 2015).

Due to high rates of OUD and its negative health consequences, effective treatments are critically important for this population. IOT is one of the most widely available treatment programs for persons with OUD in the United States. IOT is a treatment approach that provides ambulatory services for persons with substance use disorders who do not need residential or inpatient treatment but who need more support than weekly or bi-weekly treatment sessions (McCarty, 2014). Research shows that IOT can be as effective as inpatient and residential treatment, but rates of program completion are low (Dalton, Bishop, & Darcy, 2021; Loveland & Driscoll, 2014) and relapse rates

are high (Hser et al., 2015). Moreover, longer retention in treatment has been found to be associated with an increased rates of sobriety (Hser et al., 2015).

Improving patient activation in IOT among persons with OUD might improve engagement and treatment outcomes. Patient activation occurs when persons' understand their role within the healthcare process and have the confidence, knowledge, and skills to self-manage their health and healthcare (Greene & Hibbard, 2012). Research shows that high levels of patient activation have been associated with many positive health-related outcomes including effective self-management of chronic diseases (Muralidharan et al., 2019) and collaborative relationships with providers (Denneson, Pisciotta, Hooker, Trevino, & Dobscha, 2019). Activation is thus likely to be an important aspect of IOT. While there is a growing body of literature on activation in mental health treatment (Muralidharan et al., 2019; Singla et al., 2020), little is known about activation in persons with OUD. In order to develop strategies to improve treatment outcomes for persons with OUD, a deeper understanding of activation in the context of substance use treatment is needed.

BACKGROUND

The OUD Crisis in the United States

OUD is a public health crisis in the United States. Opioids include prescription pain killers such as hydrocodone (e.g., Vicodin) and oxycodone (OxyContin) as well as heroin. Addiction occurs in an estimated 3-19% of persons taking prescription opioid medications (American Psychiatric Association, 2018). Dependence can develop quickly with opioid use (within 4-8 weeks) and abrupt cessation leads to severe withdrawal symptoms (e.g., pain, chills, nausea/vomiting) (American Psychiatric Association, 2018).

The national cost of OUD was estimated to be more than \$78.5 billion; this includes the financial burdens of lost productivity, health care, and treatment (Florence, Zhou, Luo, & Xu, 2016).

Opioid medications can be a gateway drug to heroin use given their similar pharmacologic effects (National Academies of Sciences Engineering and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Pain Management and Regulatory Strategies to Address Prescription Opioid Abuse, 2017). For example, approximately 80% of people who use heroin first took prescription pain medications (Muhuri, Gfroerer, & Davies, 2013). Growth in heroin use has occurred in demographic groups that historically have had lower rates of substance use, including women, persons with higher incomes, and persons who are privately insured (National Academies of Sciences Engineering and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Pain Management and Regulatory Strategies to Address Prescription Opioid Abuse, 2017). Over the past decade, heroin use in the 18-25 age group has doubled (National Academies of Sciences Engineering and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Pain Management and Regulatory Strategies to Address Prescription Opioid Abuse, 2017).

Mortality rates for persons with OUD can be up to 20 times higher than the general population (Saha et al., 2016). In 2017, more than 70,000 people died from a drug overdose, making it a top cause of injury-related death in the U.S. From 2015-2017, almost all racial/ethnic groups in the U.S experienced an increase in opioid-related deaths, with the largest increase occurring among persons who are Black, ages 45-64, and living in large metropolitan areas (Centers for Disease Control and Prevention, 2019).

The state of Indiana experienced over 1,800 drug overdose deaths in 2018, ranking 14th in the nation (Indiana State Department of Health, 2019). From 2016-2017, the Indiana Health Department reported a 22% increase in overdose deaths, with opioids accounting for 63% of the deaths (Indiana State Department of Health, 2019).

Effective treatments for OUD include a combination of medications and other therapeutic approaches (American Psychiatric Association, 2018). However, only 20% of people with OUD receive specialty addiction treatment (McCance-Katz, 2018; Substance Abuse and Mental Health Services Administration, 2019) and, of those do, attrition rates range from 40% to 80% (American Addiction Centers, 2020; Loveland & Driscoll, 2014).

IOT Programs for Persons with OUD

Throughout 1990s, IOT programs became the most widely used treatment for people with addiction. IOT serves as an important step in the continuum of care for people with OUD. The continuum of care includes the following services: (1) level 0.5 early intervention; (2) level I - outpatient; (3) level II - intensive outpatient or partial hospitalization; (4) level III - residential or inpatient; (5) level IV - inpatient medically managed (Substance Abuse and Mental Health Services Administration (US), 2006). This continuum reflects opportunities for persons with OUD to enter the level of treatment best suited to their needs and make program adjustments (i.e., increase or decrease program intensity) as they engage in recovery.

Persons with OUD commonly transition into IOT at some point in their recovery journey due to the flexible nature of these programs. IOT can provide a treatment entry point, care step-down, and care step-up (Substance Abuse and Mental Health Services

Administration (US), 2006). IOT programs use a behavioral approach in which individual, group, and/or family therapies often combined with medications for opioid use disorder (MOUD) (Substance Abuse and Mental Health Services Administration (US), 2006).

IOT programs allow individuals to remain in their homes and communities, which is thought to improve their adjustment to community life. The goals of IOT are to help persons learn early-stage relapse management and coping strategies, ensure they have psychosocial support, and address their unique symptoms and needs (McCarty et al., 2014). When compared to residential or inpatient programs, IOT programs have resulted in equivalent reductions in problem severity and increases in abstinence days, with abstinence reported by 50 to 70% of participants at follow-up (McCarty et al., 2014).

Despite positive effects of IOT, barriers to engagement in treatment exist. Research has shown attrition rates of up to 80% in IOT programs (Loveland & Driscoll, 2014) and relapse rates as high as 70% (Hser et al., 2015). Barriers to engagement include lack of social support, financial insecurity, fragmented care, mental illness, and physical symptoms/limitations (Zulman et al., 2018).

Patient Activation

Enhancing patient activation is a patient-centered approach aimed at leveraging patients as partners and active participants in their healthcare. Patients with chronic illness in particular must be active participants in their own health to maintain optimal functioning (Hibbard, Mahoney, Stockard, & Tusler, 2005).

Research on patient activation in the past decade has shown a strong link between patient activation and positive health behaviors and outcomes in people with chronic

disease (Almutairi, Hosseinzadeh, & Gopaldasani, 2020; Golubinski, Oppel, & Schreyögg, 2020; Hibbard & Greene, 2013; Hibbard, Greene, Shi, Mittler, & Scanlon, 2015; Kinney, Lemon, Person, Pagoto, & Saczynski, 2015). A national survey of adults in the United States (U.S.) found that higher levels of activation were associated with fewer chronic conditions, better self-rated health, higher education, higher income, and age (Smith et al., 2016). Moreover, patients who have higher activation levels are more likely avoid health-threatening behaviors, such as smoking and illicit drug use (Hibbard & Greene, 2013). Systematic reviews have identified that people with higher activation reported less emergency room use and hospitalizations (Kinney et al., 2015) and increased activation resulted in improvements in hemoglobin A1C in persons with diabetes (Almutairi et al., 2020). A descriptive study involving patients with atrial fibrillation found attributes such as higher education, being employed, less symptom burden, less depression and anxiety, and tobacco abstinence to be associated with higher levels of activation (McCabe et al., 2018). A large panel survey involving people with chronic disease (e.g., hypertension, diabetes, depression, asthma, heart disease) over four years found higher levels of activation led to better self-management, improved functioning, and less costly healthcare use (e.g., emergency department visits, hospitalizations) over time (Hibbard et al., 2015). Additionally, a scoping review identified lower levels of depression, higher self-efficacy, higher health status, and hope to be the most common psychosocial/psychological factors associated with patient activation (Golubinski et al., 2020).

Patient Activation in Persons with OUD

Patient activation is likely to be an important factor of successful addiction recovery. OUD is a chronic mental health disorder (Hser et al., 2015) and a goal of treatment is to facilitate persons assuming responsibility for their own recovery (Zulman et al., 2018). Despite this, very few studies have focused on activation in persons with SUD. Only one study on activation enrolled people exclusively in outpatient addiction treatment (Weisner et al., 2016), and a few others (Lara-cabrera et al., 2016; Alegría et al., 2014; Salyers et al., 2009) enrolled a small number of patients with mental health disorders and co-existing addiction. Research with persons with mental health disorders more generally, however, have shown that people with high levels of activation tend to accept their mental health illness, perceive recovery and hope in their treatment, utilize positive health behaviors (e.g., avoiding risky substances, adopting self-management behaviors), and collaborate in their treatment planning (Kukla, Salyers, & Lysaker, 2013; Salyers et al., 2009; Salyers, Matthias, Sidenbender, & Green, 2013). In contrast, those patients with low activation tend to not accept their mental health diagnosis, perceive control over their illness, or be able to identify supporting resources, treatment groups, and medications (Salyers et al., 2013).

Phenomena similar to patient activation, such as engagement and shared decisionmaking, have been explored in patients with alcohol and other substance use disorders (Yarborough et al., 2018; Neale, Nettleton, & Pickering, 2013; Eliacin, Salyers, Kukla, & Matthias, 2015). For example, a study investigating patients' perceptions of shared decision making found factors such as perceived inadequacy, fear of being judged, and the nature of the patient-provider relationship influenced willingness to engage in

treatment decisions (Eliacin et al., 2015). Moreover, one study revealed that persons in heroin detoxification indicated that playing active roles in decision-making was an important aspect of their treatment (Neale et al., 2013). These findings suggest that activation is likely to be important in addiction treatment, but more research is needed to determine how patient activation is manifested in IOT.

THEORETICAL FRAMEWORK

The proposed dissertation is guided by a patient activation theory (Hibbard & Mahoney, 2010), which is informed by a consumer driven healthcare approach and the chronic illness care model (Hibbard et al. 2004). Consumer driven healthcare is based on the assumption that access to information about the quality and cost of healthcare information will lead consumers to make wiser health decisions, ultimately increasing activation (Hibbard, Stockard, Mahoney, & Tusler, 2004). The chronic illness care model reflects the integration of patients and families into the care team, highlighting patient-centered care (Bodenheimer, Lorig, Holman, & Grumach, 2002). The model suggests that patients need to experience activation to effectively participate in the care team (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

The initial application of the patient activation theory was in the domain of public health and focused on the information, skills, and motivations that persons with chronic illness (e.g., diabetes, heart disease) need to be full participants in their healthcare (Hibbard et al., 2004). The stages are (1) recognizing the importance of playing an active role in one's health, (2) gaining the knowledge, skills, and confidence to take action, (3) taking action, (4) continuing positive health behaviors in the presence of stress (Hibbard et al., 2004). The theory also includes four levels of activation: Disengaged and

Overwhelmed (Level 1), Becoming Aware but Still Struggling (Level 2), Taking Action and Gaining Control (Level 3), and Maintaining Behaviors and Pushing Further (Level 4), as shown in Figure 1. The framework originally focused on activation in chronic physical illnesses, but has since been applied to mental health disorders.

By locating patients on the activation continuum (i.e., Levels 1-4), clinicians can determine what interventions or strategies are needed to increase activation (Hibbard et al., 2004). For example, if a patient is assessed to be at Level 1, clinicians might help break down the disease process, providing small doses of education to patients. If a patient is assessed to be at Level 2, clinicians might educate patients on disease self-management strategies. If a patient is assessed to be at Level 3, clinicians might encourage patients to assume healthy lifestyle activities, such as healthy eating and exercise. If a patient is assessed to be at Level 4, clinicians might reinforce their healthy stress coping strategies.

Figure 1: Patient Activation Level	S
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LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	
Disengaged & Overwhelmed	Becoming Aware, But Still Struggling	Taking Action	Maintaining Behaviors and Pushing Further	
Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor.	Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals.	Individuals have the key facts and are building self-management skills. They strive for best- practice behaviors, and are goal-oriented.	Individuals have adopted new behaviors, but may struggle during stressful times. Maintaining a healthy lifestyle is a key focus.	
Their perspective: "My physician is in charge of my health."	Their perspective: "I could be doing more."	Their perspective: "I'm part of my healthcare team."	Their perspective: "I'm my own advocate."	
© 2021 Insignia Health. Patient Activation Measure® (PAM®) Survey Levels. All rights reserved.				

The patient activation measure (PAM) was developed and tested to provide a reliable and valid instrument to measure patient activation (Hibbard et al., 2004). The

assumptions of the measure include that (1) knowledge, skills, and beliefs are developmental and activation occurs in a sequential order, and (2) interventions implemented to increase activation relies on the baseline stage of the individual (Hibbard et al., 2004). The PAM is a 22-item measure that has been widely used to measure activation in a variety of patient populations. Examples of items from the PAM include "I understand the nature and causes of my health condition; "I know how to prevent further problems with my health condition; "I am able to handle problems of my health condition on my own at home. (Hibbard et al., 2004)."

OVERVIEW OF DISSERTATION PROJECT

Problem Statement

OUD is a chronic mental health disorder associated with high morbidity and mortality. IOT is the most widely used treatment for OUD, and while it is shown to be effective, engagement is a significant problem that can impede recovery and relapse is common. As patient activation theory would suggest, improving activation in persons in IOT would likely increase engagement and improve outcomes, but little is known about activation in this population.

Purpose and Aims

The purpose of this dissertation is to describe how persons with OUD experience intensive outpatient treatment (IOT), especially regarding activation. The specific aims are to (1) synthesize studies of activation in persons with mental health disorders generally, (2) describe the experiences of persons with OUD in IOT from enrollment through program departure, and (3) identify instances of activation in IOT. The dissertation project includes three components: (1) an integrative review, a (2) grounded

theory study, and (3) a qualitative descriptive study. The second and third components are based on interviews conducted with 14 persons who had been enrolled in an IOT program in an academic health center. The dissertation is organized as follows:

Component 1 (Chapter 2). Activation in Persons with Mental Health

Disorders: An Integrative Review. The first component, described in Chapter 2, is an integrative review based on the review method described by Whittemore and Knafl (2005). The purpose of the review was to summarize and synthesize research articles investigating patient activation in persons with mental health disorders. The specific aims were as follows: (1) identify factors associated with levels of activation in persons with mental health disorders, and (2) determine what interventions have shown to be effective in increasing levels of activation in persons with mental health disorders. Results are described in Chapter 2.

While the original intent of the review was to examine activation in persons with substance use disorders, very few studies addressed this topic, and I broadened the focus to persons with mental health disorders more generally. As substance use disorders are a class of mental disorder according to Diagnostic and Statistical Manual, Fifth Edition (American Psychiatric Association, 2013), the results from this review provided foundational information that grounded Components 2 and 3 and provided directions for further research on activation with persons with OUD.

Component 2 (Chapter 3): The Experiences of Persons with Opioid Use Disorder in an Intensive Outpatient Treatment Program: A Grounded Theory Study. The second component, described in Chapter 3, is a constructivist grounded theory study based on procedures outlined by Charmaz (2014). The purpose of this

grounded theory study was to describe processes people with OUD undergo as they participate in an IOT program. The specific aims were as follows: to describe how people with OUD experience (1) enrolling in an IOT, (2) acclimating to an IOT, and (3) receiving treatment in an IOT as it unfolds. Results are described in Chapter 3.

Component 3 (Chapter 4): Activation of Persons with Opioid Use Disorder in Intensive Outpatient Treatment. The third component, described in Chapter 4, is a qualitative descriptive study based on procedures outlined by Sandelowski (2000). The purpose of this qualitative descriptive study was to describe types of instances in which persons play an active role in their IOT (activation) and, conversely, types of instances in which they play a more passive role in their IOT or their treatment is directed by others (non-activation). Results are described in Chapter 4.

Chapter 5 will summarize the findings of the three components of the dissertation, examine cross-cutting themes, discuss the strengths and limitations of the dissertation, propose clinical and policy implications of the findings, and provide suggestions for future research.

CHAPTER TWO

INTRODUCTION

Promoting patient activation, a healthcare strategy aimed at leveraging patients as partners and active participants in their health care, could be an important component of treatment for persons with mental health disorders. Patient activation is defined as an understanding of one's role within the healthcare process and having the confidence, knowledge, and skill to self-manage one's health and healthcare (Hibbard et al., 2004). Persons with high levels of activation have collaborative relationships with their health care providers and are actively engaged in maintaining their health conditions (Hibbard et al., 2004). Hibbard's four stages of activation are as follows: (1) believing an active role is important, (2) having knowledge and confidence to take action, (3) taking action, and (4) staying on track in the presence of stress (Hibbard et al., 2004).

Research has revealed positive associations between patient activation and positive health behaviors and outcomes. Patients with higher levels of activation are more likely to engage in positive health behaviors (e.g., eating well, exercising regularly), seek preventive care (e.g., obtaining immunizations, having regular check-ups) (Hibbard & Greene, 2013), report less emergency room use and fewer hospitalizations (Kinney et al., 2015), have better self-management, improved functioning, and less costly healthcare use over time (Hibbard et al., 2015), and experience enhanced surgical recovery (McDonall et al., 2019; Skolasky, Mackenzie, Wegener, & Riley, 2011). In contrast, evidence indicates that persons with lower levels of activation have lower levels of knowledge related to self-management, poorer medication adherence, more health risk behaviors (e.g., smoking, using illicit drugs), more hospitalizations, and higher emergency room utilization (Hibbard et al., 2015).

Several factors have been shown to be associated with patient activation. A national survey of adults in the United States found that fewer chronic conditions, better self-rated health, higher levels of education, greater income, and certain age groups (i.e., ages 61-70) were associated with higher levels of activation (Smith et al., 2016). Additionally, a scoping review revealed that less depression, higher self-efficacy, better health status, and hope were associated with higher levels patient activation (Golubinski et al., 2020). Moreover, positive associations have been found between patient activation and patient perceptions of empowering or quality relationships with nurses (Jerofke, Weiss, & Yakusheva, 2014) and physicians (Alexander, Hearld, Mittler, & Harvey, 2012).

Several interventions have been developed to improve patient activation. In a review of evidence, Hibbard & Greene (2013) described a variety of activation interventions used in healthcare, community, and workplace settings that result in improvements in activation. These interventions tend to focus on skill development, problem-solving, and peer support (e.g., disease self-management programs); changing the social environment (e.g., workplace information campaigns); and tailoring support to persons' level of activation (e.g., tailored coaching).

Evidence that higher levels of activation promote positive health outcomes in patients with chronic disease suggests that enhanced activation in patients with mental health disorders may aid in their treatment and recovery. Mental health disorders, a wide range of conditions that affect persons' mood, thinking and behavior (World Health

Organization, n.d.), are prevalent in the United States and represent a major public health concern. In 2017, approximately 46.6 million adults, or one in five Americans, lived with a mental health disorder (National Institute of Mental Health, 2019). Mental health disorders are the fastest growing medical conditions in the United States (U.S.), with an estimated expenditure in 2013 of \$201 billion (Roehrig, 2016). Compared to the general population, persons with mental health disorders are at higher risk for developing co-morbid health concerns such as metabolic, cardiovascular, viral, and respiratory diseases (Hert et al., 2011). Worldwide, an estimated 8 million deaths (14.3%) are attributed to mental health disorders annually (Walker, McGee, & Druss, 2015).

Due to the high prevalence and disease burden of mental health disorders, treatment and recovery are important concerns. A large body of evidence supports the effectiveness of a number of mental health treatments including psychotherapy, medication, case management, hospitalization, complementary and alternative medicines, and self-help and peer support programs (Mental Health America, 2020). Yet underutilization and poor treatment outcomes are common in mental health populations. Experts estimate that less than half of persons diagnosed with a mental health disorder receive adequate treatment (National Institute of Mental Health, 2019), contributing to high rates of relapse (Dixon, Holoshitz, & Nossel, 2016). For example, relapse estimates for patients diagnosed with schizophrenia or bipolar disease range from 70 to 95% within 1 to 5 years of completing treatment (Ayano & Duko, 2017; Emsley, Chiliza, Asmal, & Harvey, 2013; Price & Marzani-Nissen, 2012).

Research suggests that persons with mental health disorders have less activation than persons with other chronic diseases and therefore enhancing their activation may

improve treatment utilization and treatment outcomes (Chen, Mortensen, & Bloodworth, 2014). In order for psychiatric mental health nurses and other clinicians to develop therapeutic strategies to enhance activation, information is needed about factors that are associated with activation in persons with mental health disorders and about interventions that have been shown to be effective in improving activation in this population. Although over the past decade researchers have begun to investigate patient activation in persons with mental health disorder to summarize this research. Therefore, the aims of this integrative review are to (1) identify factors associated with levels of activation in persons with mental health disorders, and (2) determine what interventions have shown to be effective in increasing levels of activation in persons with mental health disorders.

METHODS

An integrative review, based on procedures outlined by Whittemore and Knafl (2005), was conducted to address study aims. An integrative review is a systematic and rigorous process used to summarize research studies of diverse methodologies in order to provide a comprehensive understanding of a phenomenon of interest (Whittemore & Knafl, 2005). This method was used for this review because it allows for inclusion of a broad range of evidence and was thus consistent with our goal of identifying factors associated with activation as well as identifying effective interventions. Review stages include problem identification, search of the literature, data evaluation, analysis of data, and presentation of findings (Whittemore & Knafl, 2005). The review team was led by a doctoral candidate in nursing (AK, first author) and included three senior nurse

researchers (YL, UO, CBD, second, third, and last author, respectively) and a senior public health researcher (OM, fourth author).

Problem Identification

The problem identification stage involves a clear selection of a phenomenon of interest and clarification of review purpose (Whittemore & Knafl, 2005). As stated above, research has been conducted on factors associated with patient activation, as well as on interventions to increase activation among persons with mental health disorders, but this information has not been synthesized. Such a synthesis is needed to inform the development of therapeutic strategies to increase activation in this population.

Literature Search

The literature search included a number of strategies that ensured all relevant literature on the topic of the review was included. First, the authors determined the inclusion and exclusion criteria for determining relevant articles. Inclusion criteria included (a) peer-reviewed articles published in English between the years 2004 and 2020, (b) study samples included persons with mental health disorders, identified by formal diagnosis or self-report, and (c) indices of correlations between any measure of activation (e.g., Patient Activation Measure [PAM], Premium Abbreviated Activation Scale [PAAS]) and a measure of any other factor OR indices of the efficacy of any intervention on patient activation were provided. Articles were excluded if the study samples included persons with a range of chronic illnesses and findings related specifically to mental health disorders could not be disentangled from findings related to other illnesses. The search was limited to articles published after 2004 as that was the year that the PAM instrument was developed and research related to patient activation

became prominent in health services research (Hibbard et al., 2004). Articles were excluded if studies included measures of concepts closely related to activation, such as patient engagement and shared decision-making, but did not include measures of patient activation.

Second, a search was conducted by the first author (AK) using the following databases: APA PsycInfo, CINAHL, ProQuest Public Health, and PubMed. In consultation with the university's Research Engagement and Scholarly Services Coordinator, the following search terms were selected: "patient activation" AND ("mental health" OR "behavioral health" OR "anxiety" or "depression" OR "posttraumatic stress disorder" OR "bipolar disorder" OR "schizophrenia" OR "severe and persistent mental" OR "personality disorder" OR "obsessive compulsive" OR "addiction" OR "substance use" OR "substance abuse"). The search process is presented in the Preferred Reporting Items for Systematic Reviews and Data Analysis (PRISMA) diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) in Figure 2.

Data Evaluation

The authors used the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Tool to evaluate level and quality of articles in the final sample (Dang & Dearholt, 2017). The articles were appraised so we could assess the strength of evidence available for each conclusion we make in our review rather than to eliminate articles for poor quality. The evidence of each study was categorized into Level I (randomized controlled trial or experimental study), Level II (quasi-experimental study), or Level III (nonexperimental descriptive, comparative, or correlational study) (Dang & Dearholt, 2017). The quality of each article was determined to be high (A), good (B), or

low (C) based on 15 questions. The items in the appraisal tool address specific quality criteria such as clear presentation of study purpose, current literature review, sufficient sample size, instrument reliability and validity, and discussion of limitations (Dang & Dearholt, 2017). Each article was evaluated independently by two authors. Discrepancies were easily resolved by discussion and consensus by the authors following review of the questions on the appraisal tool. The results of the data evaluation for each article are displayed in Tables 1 and 2.

Analysis of Data

The goal of data analysis is to synthesize evidence through a detailed summary and interpretation of the findings of the studies in the review (Whittemore & Knafl, 2005). To conduct the analysis, information was extracted from the articles by the first author (AK) and displayed in two tables - one for each review aim. The information displayed on the tables was independently verified by at least one other author. Table 1 includes basic information extracted from articles in which correlations between measures of activation and measures of other factors were provided. Conclusions were drawn were based on how many studies examined each factor, how many studies revealed significant correlations between activation and each factor, and the quality of the articles that yielded significant findings.

Table 2 includes information extracted from the articles of intervention studies in which at least one outcome was level of patient activation. Articles about the same or similar types of interventions were grouped together. Conclusions were drawn based on the number of studies that examined each type of intervention, how many studies revealed significant positive outcomes, and the quality of the articles. Conclusions based

on both tables were proposed by the first author (AK) through regular discussions with the last author (CBD). All conclusions were then verified by the other authors (YL, UO, AM).

FINDINGS

Search Results

The initial database search revealed 482 articles (see Figure 2). All citations were examined and 138 duplicate articles were removed. Next, the abstracts of the remaining articles were screened and 294 articles were removed. Most of the articles were removed because the study did not exclusively include persons with mental health disorders, patient activation was not measured, or no correlation indices or intervention outcomes related to activation were reported. A review of the remaining 50 full-text articles led to the additional removal of 21 articles for reasons similar to those stated above. The final sample included 29 articles.

Associations Between Levels of Patient Activation and Other Factors

Ten studies examined associations between activation and other factors (Table 1). The factors fell into three groups. The first group was individual-level factors, which included factors reflecting individual differences among persons (e.g., demographic characteristics, health status). The second group was community-level factors, which included factors reflecting characteristics of communities where persons reside (e.g., population demographics, available health resources). The third group is treatment relationship factors, which include factors related to the quality of interactions between patients and providers (e.g., therapeutic alliance, quality of communication). Some studies examined one type of factor whereas other studies examined two or three types of factors.

Of the ten studies, six used correlational cross-sectional designs (Chen, Mortensen, & Bloodworth, 2014; Eliacin et al., 2018; Ivey, Shortell, Rodriguez, & Wang, 2018; Kukla et al., 2013; Pinto, Greenblatt, Williams, & Kaplin, 2017; Sacks, Greene, Hibbard, & Overton, 2014), one used a correlational longitudinal design (Allen et al., 2017), two were secondary analyses from randomized controlled trials that reported baseline associations between activation and other factors (Oles, Fukui, Rand, & Salyers, 2015; Singla et al., 2020), and one was a randomized pragmatic clinical trial (Mccusker et al., 2016). Most of the participants in the studies were recruited from primary care clinics, mental health centers, and communities. Sample sizes ranged between 60 (Pinto et al., 2017) and 5,253 (Sacks et al., 2014). Activation was measured in six studies with the PAM-13 (Hibbard et al., 2005), in three studies with the PAM-Mental Health (MH) (Green et al., 2010), and in one study with the Premium Abbreviated Activation Scale (PAAS) (Kanter, Mulick, Busch, Berlin, & Martell, 2007).

Based on the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Tool (Dang & Dearholt, 2017), nine studies were evaluated to be a Level III as they used non-experimental designs. One study was evaluated as Level I because it was a randomized controlled trial that examined factors associated with activation at baseline. Six studies were rated high quality (A) and four were rated good quality (B). The results are grouped according to the three type of factors identified above. The number of studies that examined associations between the factors and activation are first reported followed by report of the number of significant associations found.

Individual-level Factors

Demographic characteristics. Six studies examined associations between demographic characteristics and activation, but few associations were found. Studies examined associations between activation and education, gender, age, employment status, or insurance but found none (Allen et al., 2017; Chen et al., 2014; Kukla et al., 2013; Mccusker et al., 2016; Oles et al., 2015). Only two of the five studies that examined associations between race/ethnicity (Allen et al., 2017; Chen et al., 2014; Eliacin et al., 2018; Kukla et al., 2013; Oles et al., 2015) found associations, and both these studies found that White persons had higher levels of activation that Black persons (Chen et al., 2014; Eliacin et al., 2018). One study found associations between activation and residence in several U.S. Census Divisions (i.e., geographical sub-divisions used for statistical rather than governmental purposes) (see Table 1 for these associations) but did not find significant associations between activation and marital status, family size, family income, language, and location (large metro, small metro, nonmetro) (Chen et al., 2014). One study found no association between activation and housing status (i.e., homelessness) (Kukla et al., 2013).

Health-related factors. Nine studies examined associations between activation and a wide variety of health-related factors. Studies found positive associations between activation and self-reported mental health status (Allen et al., 2017; Mccusker et al., 2016); emotional, social, and physical functioning (Ivey et al., 2018); self-reported health status (Chen et al., 2014); and lower comorbidity (Mccusker et al., 2016) and negative associations between activation and number of disability days (Allen et al., 2017) and presence of emotional discomfort symptoms (Kukla et al., 2013). Conversely, some

studies found no significant associations between activation and physical health status (Mccusker et al., 2016), presence of chronic disease (Chen et al., 2014), diagnosis (Kukla et al., 2013), and mild cognitive impairment (Mccusker et al., 2016).

The results of five studies that examined associations between psychiatric symptoms or diagnoses and activation were mixed. Most of these studies focused on depression. Studies found negative associations between activation and the presence of depression symptoms and/or depression severity (Pinto et al., 2017; Sacks et al., 2014; Singla et al., 2020), although one study found no association between activation and depressive symptoms (Mccusker et al., 2016). One study found positive associations between activation and depression remission and depression treatment response (Mccusker et al., 2016). The one study that focused on mental health more broadly found no association between activation and primary mental health diagnosis (Allen et al., 2017).

Six studies examined associations between activation and health attitudes and behaviors, and several associations were reported. In regard to health attitudes, studies found positive associations between activation and hope (Kukla et al., 2013; Oles et al., 2015) and global perceived recovery (Kukla et al., 2013). In regard to health behaviors, studies found positive associations between activation and better illness self-management (Kukla et al., 2013), more frequent exercise (Mccusker et al., 2016), transitioning to a normal body mass index, and meeting clinical recommendations for Papanicolaou (PAP) smears (Sacks et al., 2014). Yet studies found no associations between activation and smoking status/quitting smoking (Mccusker et al., 2016; Sacks et al., 2014), alcohol consumption (Mccusker et al., 2016), frequency of everyday activities (e.g., social

activities, solitary activities) (Mccusker et al., 2016), medication adherence (Kukla et al., 2013), and meeting mammography guidelines (Sacks et al., 2014).

Four studies examined associations between health service utilization and activation. One study found an association between activation and having a usual care source (e.g., physician's office, emergency department, outpatient clinic) (Chen et al., 2014). Other studies, however, did not find associations between activation and number of physician visits and nonpsychiatric specialty visits (Mccusker et al., 2016), attendance ratio in treatment and length in treatment (Allen et al., 2017), or treatment modalities (e.g., antidepressant medications, number of medications, counseling) (Mccusker et al., 2016).

Community-level Factors

One study examined the association between activation and community factors and found that higher per capita income, lower percentage of foreign-born populations, and availability of more community mental health centers were associated with activation (Chen et al., 2014).

Treatment Relationship Factors

Four studies examined the associations between activation and the nature of the treatment relationships between persons with mental health disorders and their providers. The studies found positive associations between activation and therapeutic alliance task/goal factor [i.e., extent of patient/provider agreement on tasks/goals to complete in treatment] (Allen et al., 2017), working alliance (Eliacin et al., 2018), quality of patient/provider communication, self-appraisal of communication skills with providers (Pinto et al., 2017) and therapy quality (Singla et al., 2020). The only treatment factor

that was found not to be related to activation was bond factor [i.e., extent of patient/provider caring, respect, and trust within the relationship] (Allen et al., 2017). *Summary*

Few strong conclusions can be drawn regarding associations between individuallevel, community-level, and treatment relationship factors and activation in persons with mental health disorders. While there is a robust body of evidence linking these factors and activation in other chronic illness populations, we found only ten studies that have examined such links in persons with mental health disorders. While the studies reviewed were evaluated to be of high or good quality, they focused on a wide variety of factors and thus provided little evidence to firmly support associations between any one factor and patient activation. For example, with the exception of some evidence that race/ethnicity and residence in certain U.S. Census Divisions may influence activation, no evidence exists that ties any demographic factor to activation. Similarly, some evidence suggests that measures of health and well-being are tied to activation but because there was little consistency in the health indices measured (e.g., mental health status, general health status, social/emotional/physical functioning), it is difficult to draw any definitive conclusions about overall health and activation in persons with mental health disorders. Moreover, some evidence indicates that depression symptoms/severity are tied to lower activation, but more evidence is needed to draw firm conclusions about the role of depression in activation. Additionally, some health outlooks (e.g., hope, perceived recovery) and some health behaviors (e.g., self-management, frequent exercise) were tied to higher activation but only in a few studies. Only one study examined the relationship between community-level factors and activation and thus any conclusions

linking the communities in which persons with mental health disorders live and activation are limited. For persons with mental health disorders receiving treatment, some evidence indicates that positive therapeutic relationships are linked to higher activation, but more information is also needed to understand this link.

Patient Activation Interventions

Twenty studies examined the effects of interventions on patient activation in persons with mental health disorders (Table 2). A number of outcome variables were targeted in the studies, but here we focus on only the outcome of activation. The interventions included the following approaches: education, case management/patient navigation, use of a web-based patient portal, coaching, self-referral to treatment, and implementation of a patient feedback system. Of these studies, eleven were randomized controlled trials, eight used quasi-experimental designs, and one used a comparative effectiveness design. Most of the participants in the studies were recruited from outpatient community mental health centers, primary care clinics, medical centers, and hospital outpatient facilities. Sample sizes ranged from 17 (Bartels et al., 2013) to 1,259 (Guo et al., 2019). Eleven studies used the PAM-13 (Hibbard et al., 2005) to measure activation, three used the PAM-22 (Hibbard et al., 2004), three used the PAM-MH (Green et al., 2010), and three used other measures of activation. Based on the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Tool, 12 studies were rated Level I (n=12) and eight were rated Level II (n=8). Fifteen studies were rated as high quality (A), and five were rated as good quality (B). The results are grouped according to the types of interventions examined in the studies. The number of studies

that examined each type of intervention is first reported followed by report of the number of interventions found to have positive outcomes on activation.

Educational Interventions

Eleven of the studies examined the effects of educational interventions on patient activation. These interventions typically assisted persons to learn about their illness, ask questions of their providers, be involved in treatment decisions, and learn communication or self-management skills. Of these interventions, five were led by professionals (Alegría et al., 2014; Chiang et al., 2019; Fujita et al., 2010; Kaltman et al., 2016; Weisner et al., 2016), one was led by peers (Druss et al., 2010), and five were led by a combination of professionals and peers (Bartels et al., 2013; Goldberg et al., 2013; Lara-cabrera et al., 2016; Muralidharan et al., 2019; Turner, Realpe, Wallace, & Kosmala-anderson, 2015). The number of sessions ranged between one (Lara-cabrera et al., 2016) and thirteen (Goldberg et al., 2013), with an average of seven sessions. Six of the studies were randomized controlled trials (Alegría et al., 2014; Chiang et al., 2019; Druss et al., 2010; Goldberg et al., 2013; Lara-cabrera et al., 2016; Muralidharan et al., 2019), and five used quasi-experimental designs (Bartels et al., 2013; Fujita et al., 2010; Kaltman et al., 2016; Turner et al., 2015; Weisner et al., 2016). Nine interventions were delivered to patients (Alegría et al., 2014; Druss et al., 2010; Fujita et al., 2010; Goldberg et al., 2013; Kaltman et al., 2016; Lara-cabrera et al., 2016; Muralidharan et al., 2019; Turner et al., 2015; Weisner et al., 2016) and two were delivered to patients and providers (Bartels et al., 2013; Chiang et al., 2019).

In the five studies that tested educational interventions using a quasi-experimental design, four interventions were found to be effective in improving activation pre- to post-

test (Bartels et al., 2013; Fujita et al., 2010; Kaltman et al., 2016; Turner et al., 2015), whereas one study found no differences (Weisner et al., 2016). In the six studies that tested educational interventions using a randomized control design, five found the intervention group was more effective in improving activation than a treatment-as-usual (Alegría et al., 2014; Druss et al., 2010; Goldberg et al., 2013; Lara-cabrera et al., 2016) or attention control group (Muralidharan et al., 2019), and one found no difference between the intervention and control group (Chiang et al., 2019). Two studies examined if positive effects in activation were maintained post-intervention; one found that effects were maintained at four-month follow-up (Lara-cabrera et al., 2016), and one found effects were not maintained at two-month follow-up (Goldberg et al., 2013).

Case Management/Patient Navigation Interventions

Four studies examined the effects of case management/patient navigation interventions on patient activation (Cabassa et al., 2018; Chinman et al., 2013; Guo et al., 2019; Schuster et al., 2018). These interventions typically facilitated healthcare provider visits, health service coordination, and co-creation of care plans. The interventions were found to be effective in improving patient activation in a pre-posttest comparison (Cabassa et al., 2018) and when compared to a treatment-as-usual group (Chinman et al., 2013). In a comparative effectiveness cluster-randomized study, a provider-supported group and a self-directed group both increased activation but the provider-supported group increased activation more rapidly (Schuster et al., 2018). In a three-year pragmatic trial, no differences were found between an intervention and control group at years one and two follow-ups, but the intervention group was shown to be more effective in improving activation at year three (Guo et al., 2019).

Web-based Portal Interventions

Two studies examined the effects of web-based portal interventions on patient activation (Denneson et al., 2019; Kipping, Stuckey, Hernandez, Nguyen, & Riahi, 2016). These interventions provided training for patients and access to their electronic health information. Both web-based interventions were found to be effective in improving patient activation in pre-posttest comparisons (Denneson et al., 2019; Kipping et al., 2016).

Other Interventions

Three of the studies tested interventions that differed from those discussed above. One study was a randomized pragmatic clinical trial examining the efficacy of a coaching intervention on activation (Mccusker et al., 2016). The intervention involved access to a mental health toolkit and assignment to a lay coach. The study found no difference in activation between the intervention and control groups (Mccusker et al., 2016). One study was a parallel group randomized controlled trial to evaluate the efficacy of a self-referral to inpatient treatment (SRIT) contract on patient activation (Moljord et al., 2017). The intervention was designed to improve patient access and participation in treatment through self-referral. The study compared the intervention to a treatment-as-usual group (Moljord et al., 2017) and found no differences in activation but did find the intervention was effective with participants with a patient activation score below a specific threshold (i.e., patient activation scores below 47) (Moljord et al., 2017). One study was a parallel group randomized controlled trial evaluating efficacy of implementing the Partners for Change Outcome Management System (PCOMS) on patient activation (Rise, Eriksen, Grimstad, & Steinsbekk, 2016). The intervention collected and used patient feedback in

treatment sessions, but the study found no difference between the intervention and treatment-as-usual group (Rise et al., 2016).

Summary

Evidence suggests a variety of interventions may be effective in improving activation in persons with mental health disorders. We identified 20 intervention studies of good or high quality that were delivered to persons with mental health disorders and that included activation as one of the outcome measures. The majority of these interventions used educational approaches and most of these interventions were found to have a positive effect on activation, although little is known about whether these effects last over time. Other studies demonstrated some positive effects on activation with other approaches, such as case management/patient navigation and the use of web-based portals, but due to the small number of studies examining each approach no strong conclusions can be made about the efficacy of these approaches on patient activation.

DISCUSSION

Because patient activation is a key component of illness self-management and an important goal of treatment for persons with mental health disorders, it is important to determine what factors are associated with activation in this population. Although more research is needed, our review reveals that factors that may be associated with higher levels of activation in this population include better health status, lower depression, positive health attitudes and behaviors, and higher quality therapeutic relationships. These findings, although tentative, are consistent with other studies and reviews of activation in persons with mental health disorders and other health conditions. Similar to our findings, for example, the health attitude of hope was revealed to be positively

associated with activation in a scoping review examining psychosocial and psychological factors in patients with chronic and other health conditions (Golubinski et al., 2020). Moreover, consistent with our findings, other studies with persons with chronic illness and mental health disorders revealed that the quality of relationships with healthcare providers (e.g., interpersonal communication quality, goal setting involvement by the patient) is positively associated with activation (Alexander et al., 2012; Allen et al., 2017; Eliacin et al., 2018). In one mixed methods study, persons with schizophrenia with high levels of activation highlighted collaborative treatment experiences with providers in their narratives (Salyers et al., 2013). Other studies, however, have explored factors that did not figure prominently in our review. For example, in the mixed methods study cited above, patients with higher activation were more likely to acknowledge and accept their disease, while persons with lower levels of activation were less likely to perceive control over their illness (Salyers et al., 2013).

Interventions that increase activation in persons with mental health disorders could be important components of mental health treatments. Our review reveals evidence that suggests a variety of interventions, most notably educational programs, can improve activation in this population. This finding is consistent with prior systematic reviews and meta-analyses that have shown that a variety of interventions increase patient activation in a number of different chronic disease populations (Hosseinzadeh, Verma, & Gopaldasani, 2020; Lin, Weng, Apriliyasari, Van Truong, & Tsai, 2020).

What Study Adds to Existing Reviews

Other published reviews have synthesized research findings on factors associated with activation (Golubinski et al., 2020) and interventions used to increase activation

(Hosseinzadeh et al., 2020; Lin et al., 2020), but these reviews have focused primarily on chronic disease populations. To our knowledge, our review is the first comprehensive review that examines factors associated with activation and interventions aimed at improving activation in persons with mental health disorders. By focusing specifically on this group, the conclusions can provide information that enables psychiatric mental health nurses and other clinicians to tailor programs and implement strategies to increase activation in persons with whom they work.

Limitations

Our conclusions should be considered in relationship to the limitations of the body of literature reviewed. The studies that investigated factors associated with activation covered a broad range of factors, but no one factor was examined by a sufficient number of studies to provide conclusive evidence of associations. Moreover, most of the studies used a cross-sectional design so we cannot make claims about causal relationships. For example, available evidence does not allow us to ascertain if depression dampens levels of activation or if lower levels of activation contribute to depression.

A number of limitations were also noted in the intervention literature. While a number of studies revealed that educational interventions increased activation, the interventions varied so widely it was impossible to compare across studies or conclude what components of the interventions resulted in change. The interventions varied on dose (e.g., 1 to 13 sessions), length of sessions (i.e., 30 minutes to 4 hours), intervention content, and interventionists (i.e., providers or peers). In addition, while most studies used some variation of the PAM (Hibbard et al., 2004) as an outcome measure, four studies used investigator-developed or other instruments to measure patient activation

(Alegría et al., 2014; Chiang et al., 2019; Kipping et al., 2016; Singla et al., 2020), thus limiting comparison across studies. The instruments used in the majority of studies were self-report, which may have introduced participant bias into the findings. In addition, because many of the intervention studies included all persons with serious mental illnesses, but did not report outcomes according to diagnostic group, we were unable to ascertain which interventions were most likely to be effective with which diagnosis.

The majority of both the correlational and intervention studies included samples of persons with a variety of mental health disorders, and, with the exception of studies on depression, few studies focused on persons with a specific mental health disorder (e.g., bipolar disorder, schizophrenia). Therefore, no conclusions could be drawn about whether particular types of mental health disorders influence activation differentially. One group that was notably underrepresented in the studies were persons with substance use disorder. Only one study exclusively recruited persons with substance use disorder (Weisner et al., 2016), and two studies included persons with substance use and another mental health disorder (Alegría et al., 2014; Lara-cabrera et al., 2016).

Limitations to our review methods also restrict our conclusions. For both the correlational and intervention studies, we focused on activation but did not examine constructs that likely overlap with activation such as self-efficacy, self-management, and shared decision-making. We also did not examine the impact of activation on other health outcomes such as quality of life, decrease in disease burden, or treatment utilization. More work is thus needed to understand the complex role that activation plays in the treatment and recovery of persons with mental health disorders.

Research Implications

We recommend that future studies focus on common factors (e.g., depression, treatment relationships) thought to be associated with activation, use well-established and standardized self-report measures of activation, and obtain observational measures of activation (e.g., independent ratings of activated behaviors within treatment sessions) in addition to self-report. We also recommend more longitudinal studies to allow conclusions regarding causal relationships among activation and other factors and to provide a better understanding of complex relationships among them. Research is also needed to develop a standardized intervention that can be tested in a variety of mental health groups. For example, the chronic disease self-management program (CDSMP), a widely used effective self-management workshop for persons with a variety of chronic illness, has been successfully adapted for use for persons with mental health disorders (Druss et al., 2010; Goldberg et al., 2013; Muralidharan et al., 2019). The program focuses on decision-making, problem-solving, and action planning and thus addresses key components of activation. With continued development, such standard programs for persons with mental health disorders could then be implemented and scaled-up in a wide variety of mental health settings.

Clinical Implications

Despite the limitations of the review, the findings suggest that psychiatric mental health nurses and other clinicians should consider activation as an important treatment goal. Routine assessment of persons' levels of activation using the PAM (Hibbard et al., 2004) could inform the development of individualized treatment plans. Clinicians should consider persons with mental health disorders as partners in treatment planning,

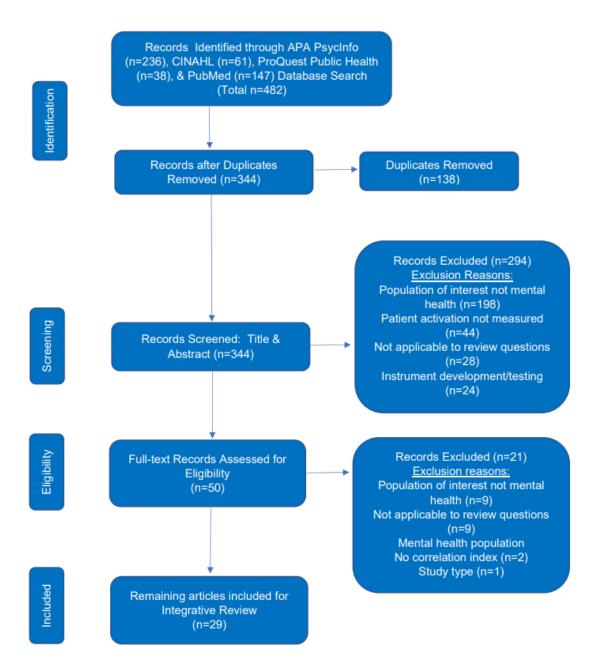
encourage their active participation in their health care, and encourage self-management of their illness. The review points to therapeutic approaches that could improve activation in persons with mental health disorders. For example, our findings suggest that clinicians may be able to increase activation by using strategies that focus on health attitudes, beliefs, and behaviors, such as incorporating discussions of hope, perceived recovery, and self-management of illness into therapeutic work. Additionally, because treatment quality appears to affect activation, clinicians should always attend to the nature of their relationships with patients and continually aim to enhance therapeutic communication and strengthen the working alliance. Moreover, as our review provides information on a variety of interventions that have been shown to improve activation in persons with mental health disorders, psychiatric mental health nurses and other clinicians can consider providing such interventions in their practice settings and evaluating their effectiveness.

CONCLUSION

This is the first review we are aware of that provides a systematic synthesis of research on factors associated with patient activation in persons with mental health disorders and on interventions that target activation. Such information is important to because persons with mental health disorders have high rates of morbidity and mortality, treatment underutilization, and poor outcomes and because improving activation may be one approach that could enhance their treatment and facilitate their recovery. The review points to some factors that are likely associated with activation and provides evidence that some interventions, especially educational programs, improve activation in this population. Although more research is needed to fully understand the role of activation in

the treatment and recovery of persons with mental health disorders, psychiatric mental health nurses and other clinicians should assess levels of activation and use therapeutic strategies to improve patient activation in their clinical practice.

Figure 2: PRISMA Diagram



Author (year)	Design	Purpose	Sample/ Setting	Activation Variable (Measure)	Other Variables	Associations between PAM and other variables	Evidence Level, Quality
Allen et al. (2017)	Correlational, longitudinal	"To estimate the unique effects of communication and therapeutic alliance on patient activation both cross sectionally and longitudinally in patients attending community- based mental health clinics" (p. 432)	Patients from 13 community- based mental health clinics in the United States (U.S.) (N=264)	Patient activation (Patient Activation Measure-13 [PAM-13]) (Hibbard et al., 2005)	Therapeutic alliance (Working Alliance Inventory-Short [WAI- SR], (task/goal and bond factors) (Tracey & Kokotovic, 1989) Communication (Kim Alliance Scale) (Kim, Boren, & Solem, 2001) Clinical characteristics (self-reported mental health status, primary mental health diagnosis, disability days, attendance ratio, self- reported length in treatment) Socio-demographic characteristics (gender, race/ethnicity, age, immigrant, education, employment status, insurance status)	At baseline, linear regression adjusting for clinical contributors and patient factors revealed that activation was positively associated with the therapeutic alliance task/goal factor $(\beta=0.54, p=0.01)$; however, communication $(\beta=0.28, p=0.50)$ and therapeutic alliance bond factor $(\beta=0.00, p=0.99)$ were not significant. At baseline, linear regression adjusting for clinical contributors and patient factors revealed that activation was positively associated with being an immigrant $(\beta=-5.20, p=0.07)$, mental health status $(\beta=6.47, p=0.01]$ [excellent], $\beta=-7.91, p=0.02$ [very good], $\beta=7.73, p=0.01$ [fair], $\beta=8.63,$ $p=0.14$ [poor]), and disability days $(\beta=-0.25, p=0.02)$; non-significant associations were observed for patient activation and gender $(\beta=3.01, p=0.18),$ race/ethnicity $(\beta=0.29, p=0.94$ [Latino], $\beta=0.58, p=0.88$ [Black], $\beta=6.79, p=0.14$ [other race]), age $(\beta=2.94, p=0.28$ [35- 49], $\beta=2.53, p=0.39$ [50-64], $\beta=-5.62,$ $p=0.56$ [65+]), education $(\beta=-1.59,$ $p=0.51),$ employment status $(\beta=1.48,$ $p=0.56),$ insurance status $(\beta=-3.21,$ $p=0.35$ [private only], $\beta=0.99, p=0.69$ [public only], $\beta=11.34, p=0.42$ [other insurance]), diagnosis $(\beta=1.36, p=0.70)$ [anxiety disorder], $\beta=-2.79, p=0.62$ [psychotic disorder], $\beta=-2.79, p=0.89$ [adjustment disorder], $\beta=-4.83, p=0.14$	III, A

Table 1: Individual-level, Community-level, and Treatment Relationship Factors

						[other diagnosis]), attendance ratio (β =-0.14, p=0.98), length in treatment (β =0.01, p=0.65).	
Chen et al. (2014)	Correlational, cross- sectional	"Examine the association between contextual factors and self- reported activation levels among patients with depression" (p.614)	Data from the Health Tracking Household Survey 2007 and Area Health Resource File 2008 for people with diagnosed depression in U.S. (N=1670)	Patient activation (PAM-13) (Hibbard et al., 2005)	Usual source of care (yes/no) Care source (physician office, emergency department, hospital outpatient clinic or health center, other care source) Community characteristics (number of mental health institutions, number of psychiatrists for every 1,000 citizens, percentage of foreign- born citizens, percentage of non-White citizens, college or higher education level, per capita income) Population characteristics (age, sex, race/ethnicity, marital status, family size, education, income, location)	In multivariate linear regression controlling for site of care, patients utilizing hospital outpatient clinics (coef -3.59, p<0.05) or emergency department (coef -5.04, p<0.05) had lower activation index than those using physician's offices as usual care source. In a multivariate linear regression controlling for community characteristics, higher activation was associated with higher per capita income (coef 0.14, p<0.05), lower percentage of foreign-born populations (coef -0.31, p<0.01), and availability of more community mental health facilities (coef 0.14, p<0.05) at the county level. In a multivariate linear regression controlling for both sites of care and community characteristics, patient activation was associated with race/ethnicity (coef=-3.80 [African American compared to White] p<0.05), U.S. Census Division (East North Central, coef=3.07, p<0.05), (South Atlantic, coef=-6.11, p<0.001), (Pacific, coef=-6.11, p<0.001), (fair, coef=-5.97, p<0.001), (good, coef=- 4.55, p<0.001); non-significant relationships (p>0.05) were observed for Latino (coef=-1.82) and "other" race/ethnicity category (coef=-1.32), age (coef=0.16), gender (coef=0.49), marital status (coef=1.89), family size (coef=- 0.16), years of schooling (coef=-0.14	III, A

						[12-16 years], coef=1.90 [more than 16 years]), family income (coef=-0.17 [200-400% Federal Poverty line]), chronic disease (coef=2.08 [diabetes], coef=-0.33 [arthritis], coef=-0.06 [hypertension], coef=-0.16 [heart disease], coef=2.21 [cancer]), health insurance (coef=-0.92 [uninsured], coef=-0.54 [Medicare], coef=0.86 [Medicaid], coef=-1.60 [other public health insurance], language (coef=- 3.38), location (coef=0.90 [small metro under 200,000], coef=0.45 [nonmetropolitan area]).	
Eliacin et al. (2018)	Correlational, cross- sectional	"To examine the association between race and two key aspects of patient engagement: patient activation and working alliance" (p. 187)	African- American (AA) and White veterans from outpatient mental health clinics in Indiana (N=152)	Patient activation (PAM-MH) (Green et al., 2010)	Working alliance (WAI- SR), (Tracey & Kokotovic, 1989) Race (AA or White); gender; age; education; employment; length of time with employer (self- report and medical records)	In stepwise regression analysis, significant association between race and activation was identified (p=0.002). White veterans (M=65.3+/-15.5) had significantly higher activation scores than African American veterans (M=56.6+/-14.7). In linear regression, after controlling for demographics, working alliance predicted activation (R2 = 0.297, F(7,100) = 6.044, p < 0.001).	III, B
Ivey et al. (2018)	Correlational, cross- sectional	"To assess the extent to which practices with patient-centered cultures, greater shared decision- making strategies, and better coordination among team members have better patient- reported outcomes	Patients with cardiovascular, diabetes and coexisting mental health diagnosis from participating primary care practices (N=606)	Patient activation (PAM-13) (Hibbard et al., 2005)	Emotional functioning (Patient Health Questionnaire 4 [PHQ-4]) (Kroenke, Spitzer, Williams, & Lowe, 2009) Physical functioning (12- items from Patient- Reported Outcomes Measurement System [PROMIS]) (Cella et al., 2010)	In hierarchical linear regression, patient activation was positively associated with social (β =0.62, P≤0.001), emotional (β =0.33, P≤0.001), and physical functioning (β =0.42, P≤0.001).	III, B

		(PROs) for patients with diabetes and/or cardiovascular and comorbid mental health diagnoses" (p. 551)			Social functioning (8- items from PROMIS) (Cella et al., 2010)		
Kukla et al. (2013)	Correlational, cross- sectional	"To understand the relationship between patient activation and symptoms, medication adherence, recovery attitudes, and hope (p.339)"	Patients with schizophrenia at a community mental health center in Indiana (N=119)	Patient activation (Patient Activation Measure-Mental Health [PAM- MH]) (Green et al., 2010)	Demographic characteristics (sex, ethnicity, diagnosis, education, housing, employment status) Psychiatric symptoms (Positive and Negative Syndrome Scale [PANSS]) (Kay & Fiszbein, 1987) Medication adherence (Morisky Medication Adherence Scale [MMAS]) (Morisky & Green, 1986) Global perceived recovery (Recovery Assessment Scale [RAS]) (Corrigan, Faber, Rashid, & Leary, 1999) Hope (Adult State Hope Scale[AHS]) (Snyder et al., 1996) Global illness self- management (Illness Management and Recovery scale [IMR]) (Mueser et al., 2004)	Bivariate correlations revealed that patient activation was positively correlated with global perceived recovery (r=0.66, p<0.01), hope (r=0.57, p<0.01), and illness self-management (r=0.42, p<0.01) and patient activation was negatively correlated with emotional discomfort symptoms (PANSS) (r= -0.28, p<0.01); patient activation was not significantly related to medication adherence (coef=-0.18, p<0.01). In stepwise regression, hope (R2=0.49, F[2,105]=50.1, p<0.01) and global perceived recovery (R2=0.44, F[1,106]=83.6, p<0.01) predicted patient activation. Patient activation. Patient activation, housing, or employment status (p=>0.01) [†] .	III, B

McCusker	Randomized	"To describe the	Patients from	Patient activation	Severity of depressive	Multivariate regression analysis found	I, A
et al.	pragmatic	cross-sectional	41 family	(PAM-13)	symptoms (Patient Health	high patient activation was positively	
(2016)	clinical trial§	and longitudinal	doctors in	(Hibbard et al.,	Questionnarie-9 [PHQ-	associated with French language	
		associations of	Montreal with	2005)	9]) (Kroenke, Spitzer, &	$(\beta=5.01, p<0.01)$, being born outside	
		activation and	at least one		Williams, 2001)	Canada (β =4.50, p<0.05), frequent	
		self-efficacy	chronic			exercise (β=0.68, p<0.05), lower	
		with	condition or		Physical and mental	comorbidity (β =-4.58, p<0.05), and	
		demographic,	chronic pain		health status (12 Item	higher mental status (β =0.21, p<0.05).	
		physical and	and minimum		Short Term Survey [SF-		
		mental health	of mild		12] Physical Component	Multivariate regression analysis found	
		status, health	depression		Summary [PCS] and	non-significant associations (p>0.05)	
		behaviors,	(N=215)		Mental Component	between patient activation and age (β =-	
		depression self-			Summary [MCS]) (Ware,	$2.75[55-64], \beta=-1.04[65+]),$ smoking	
		care, health care			J. E., Kosinski, M., &	status (β =0.94 [past smoker], β =-0.30	
		utilization, and			Keller, 1996)	[current smoker, $], \beta=-4.62$	
		use of self-care				[current smoker, >/14/day]), alcohol	
		tools; and to			Exercise, activity	consumption (coef=2.73 [1-6	
		examine the			frequency,	drinks/week], coef=-4.44[7+	
		effects of a			smoking/alcohol intake,	drinks/week], everyday activities	
		depression self-				(coef=0.13 [social activities	
		care coaching			Sociodemographic (age,	times/week], coef=0.33 [solitary	
		intervention on			birthplace, preferred	activities times/week]), physical health	
		these two			language, health service	(coef=0.13), depressive symptom	
		outcomes"			utilization, treatments)	severity (coef=-0.01), mild cognitive	
		(p.716)			utilization, d'outilionts)	impairment (coef=-3.30), number family	
		(p./10)				physician visits (coef=-1.04),	
						nonpsychiatric specialty visits	
						(coef=1.74); and treatments including	
						antidepressant medication (coef=1.23),	
						number of medications (coef=-0.02),	
						and counseling (coef=-3.10).	
Oles et al.	Secondary	"To examine the	Patients with	Patient activation	Hope (AHS) (Snyder et	Cross lagged panel model showed	III, A¶
(2015)	analysis from	prospective	schizophrenia	(PAM-MH)	al., 1996)	positive correlation between hope and	111, A
(2013)	randomized	relationship	receiving	(Green et al.,	ai., 1 <i>9</i> 70)	patient activation at baseline (r=0.57,	
	control trial	between hope	mental health	(Green et al., 2010)	Demographics (gender,	p<0.001, 9 months (r=0.62, $p<0.001$),	
	control trial	and patient	(MH) services	2010)	age, race, education)	p < 0.001), 9 months (r=0.62, p < 0.001), 18 months (r=0.67, p < 0.001).	
		activation over	at VA Medical		age, face, education)	10 monuls (1-0.07, p<0.001).	
			Center or			Correlation matrix showed non-	
		time" (p. 273)					
			community MH			significant associations (p>0.01)	
			center in			between patient activation and gender	
						(coef=-0.09 [9 months], coef=-0.06 [18	

			Indiana (N=118)			months], age (coef=0.01 [9 months], coef=-0.02 [19 months], race (coef=- 0.13 [9 months], coef=-0.16[18 months], and education (coef=-0.08 [9 months], coef=0.03 [18 months]).	
Pinto et al. (2017)	Correlational, cross- sectional	"Explore the predictive relationships of the clinical encounter, which includes communication functions and proximal outcomes to improve health outcomes" (p. 533)	People with self-reported depression in Northeast Ohio (N=60)	Patient activation (PAM-13) (Hibbard et al., 2005)	Quality of interaction with a provider (Quality of Provider-Patient Interaction [QQPPI]) (Bieber, Muller, Nicolai, Hartmann, & Eich, 2010) Self-appraisal of communication skills with providers (Patients' Self Competence Subscale [PSC]) (Cegala, Coleman, & Turner, 1998) Depressive symptom levels (depressive symptom subscale of the Hospital Anxiety and Depression Scale [HADS]) (Zigmond & Snaith, 1983)	Path analysis revealed that the quality of patient-provider communication (β = .43, p < .01) and self-appraisal of communication skills with providers (β = .30, p < .05) (communication functions) had direct effects on patient activation (R2 = .45, p < .01) (proximal outcome). Patient activation was found to have direct effects on depressive symptoms (β =-0.55, p<0.01).	III, B
Sacks et al. (2014)	Correlational, cross sectional	"Explore the relationship between baseline patient activation in depressed patients and depression outcomes one year later" (p.2)	Patients with moderate to severe depression receiving care at Fairview Health Services Minnesota (N=5253)	Patient activation (PAM-13) (Hibbard et al., 2005)	Depression (PHQ-9) (Kroenke et al., 2001); depression treatment response, depression remission, and depression severity variables Self-reported depression recovery variables (quitting smoking, lowering BMI, newly meeting clinical recommendations for Papanicolaou (PAP)	In bivariate regression, patients with more severe depression had a tendency to be less activated ($p<0.001$) [†] . In multivariate regression, patients with the highest level of patient activation (PA) were more likely to experience a reduction in depression symptoms (coef=-2.04, $p<0.001$), depression remission (OR=2.15, $p<0.001$), and higher level treatment response (OR=1.84, $p<0.001$).	III, A

					smears, newly meeting clinical recommendations for mammography)	In multivariate regression, initiation of health-promoting lifestyle change, such as transition to a normal BMI (PA level 4, OR=1.54, p<0.05) and newly meeting PAP smear guideline (PA level 2, OR=1.85, p<0.001), (PA level 3, OR=1.45, p<0.05), (PA level 4, OR=1.46, p<0.05), were related to level of patient activation; patient activation level was not associated (p>0.05) with quitting smoking (PA level 2, OR=0.70), (PA level 3, OR=0.91), (PA level 4, OR=0.79) or newly meeting mammography guidelines (PA level 2, OR=1.19), (PA level 3, OR=0.97), (PA level 4, OR=1.05).	
Singla et al. (2020)	Secondary data analysis from two parallel controlled randomized trials	"Explore the potentially predictive and mediating roles of treatment and patient behaviors on depression and drinking outcomes at 3- months post- enrollment" (p.69)	Study participants from Health Activity Program [HAP] and Counseling for Alcohol Problems [CAP] studies in India (N=100)	Patient activation (PREMIUM Abbreviated Activation Scale [PAAS] based on Behavioral Activation For Depression Scale) (Kanter et al., 2007)	Depression (depressive symptoms severity scores from the PHQ-9) (Kroenke et al., 2001) Therapy quality (HAP and CAP Therapy Quality Scale [TQS] includes general and treatment- specific subscales) (Singla et al., 2014)	In multiple linear regression, patient activation was positively associated with therapy quality treatment-specific (r = 0.303 , p = 0.034) and general skills (r = 0.346 , p = 0.015); patient activation was negatively associated with depression (r = -0.458 , p = 0.0008).	III, A¶

[†]Correlation coefficient not reported. [§]Data for correlational objectives reported from multivariate model (data for intervention objective reported in Table 2) [¶]Appraisal based on current sub study (not parent studies)

Author (year)	Design	Purpose	Intervention	Sample/Setting	Activation Variable (Measure)	Findings	Evidenc e Level, Quality
Educationa	l interventions						
Alegria et al. (2014)	Randomized clinical trial (mixed efficacy- effectiveness)	"To determine whether the DECIDE intervention improves patient activation and self-management, as well as engagement and retention in behavioral health care" (p. 557)	-DECIDE is an educational program to help patients ask questions and make decisions with providers. -3 in-person sessions over 3 months (30-45 minutes per session) led by bilingual care managers	Patients from 13 outpatient community mental health clinics in the U.S. and Puerto Rico; were generally low- income Latino/other minority (N=647)	Patient activation (Patient Activation Scale [PAS]) (Alegría et al., 2008)	In mixed regression analysis, the intervention group had higher patient activation (β = 1.74 [0.58]; P = .003) compared to control.	I, A
Bartels et al. (2013)	Quasi- experimental, pre-post pilot	"To pilot test study feasibility and potential effectiveness of a collaborative activation training in primary care (CAT-PC)" program (p. 278; 279)	-CAT-PC includes co-led patient education and training and training for primary care providers. -9 weekly peer co-led patient education and skills training session (90 minutes per session) over 2 months; interveners were PhD social worker + 2 wellness peer specialists; 45 minute video-based training for primary care providers	Patients with a serious mental health illness and cardiovascular health risk conditions from 2 primary care mental health centers in New Hampshire (N=17)	Patient activation (PAM-13) (Hibbard et al., 2005)	In t-test repeated measure analysis, improvement was found for patient activation (ES=0.54, p=0.03) post intervention.	II, B
Chiang et al. (2019)	Randomized clinical trial	To explore "the effect of DECIDE-PA program (Decide the problem; Explore the questions; Closed or open-end questions; Identify the who, why, or how of the problems; Direct questions to your health care professional; Enjoy a shored solution) on both	-DECIDE-PA is a training program that supports patients to learn about their illness and learn communication skills to discuss treatment options and communicate needs with health care professionals -DECIDE-PC is an intervention that incorporates coaching and	13 hospital-based and community outpatient Massachusetts mental health clinics (N=312)	Patient activation (modified version of PAS) (Alegría et al., 2008)	In multilevel, mixed-effects models, patient intervention and dose of clinician interventions had no effect on patient activation (t=-0.06; p=0.95).	I, A

Table 2: Patient Activation Interventions

		mental illness symptoms and patient activation, as well as the relationship between symptoms and activation, in a diverse clinical sample" (p.697)	workshops to improve clinicians' skills to facilitate shared decision making. -12-hour workshop delivered by behavioral health and communication experts to clinicians + up to 6 coaching calls; up to 3 training sessions (60 minutes) delivered to patients				
Druss et al. (2010)	Pilot randomized control trial	"To describe the development of [Health and Recovery Program] to assess its feasibility and potential to improve self- management and health outcome" (p. 265)	-The Health and Recovery Program is adapted from the Chronic Disease Self- Management Program (CDSMP) delivered by mental health peers to mental health consumers -Up to 6 group sessions led by mental health peer leaders	Patients with a severe mental health illness and one or more chronic condition from an urban community mental health center in the Midwest (N=80)	Patient activation (PAM-13) (Hibbard et al., 2005)	In random regression analyses, the intervention group had a greater increase in patient activation (p=0.03) ⁺ / ₄ . compared to the control group (52.0 +/- 10.1 intervention vs. 44.9 +/- 9.6 control, p=0.01).	I, B
Fujita et al. (2010)	Quasi- experimental, pre/post	"To investigate the feasibility and outcomes of the illness management and recovery program in Japan." (p. 1157)	-Intervention was an illness management and recovery program to help patients learn about their illness and acquire self-management skills -60-90 minute session 1-2 times per week (9 total modules) delivered by research team (psychiatrist, nurse, 2 clinical psychologists, occupational therapist, psychiatric social worker)	Patients with schizophrenia from 2 outpatient hospital facilities (N=18)	Patient activation (PAM-MH) (Green et al., 2010)	In t-test analyses, activation improved post-treatment (t=5.22; p<0.05).	П, В
Goldberget al. (2013)	Randomized controlled trial	"To examine the effectiveness of a modified version of Living Well for	-Living Well is a modified version of the CDSMP, a peer-facilitated intervention that includes training in disease self-management.	Patients with serious mental illness with at least one chronic condition from 4 mental health	Patient activation (PAM-13) (Hibbard et al., 2005)	In mixed effects models, the intervention group had significantly greater improvements in activation level (ES=0.55, t=2.08;	I, A

		individuals with serious mental illness" (p. 51)	-13 weekly sessions (60-75 minutes) co-led by mental health peer, mental health professional, and/orpeer provider	settings (outpatient clinics, psychiatric rehab) in Maryland (N=63)		p=0.042) post-program, compared to control group. However, results were not sustained at two month follow-up.	
Kaltman et al. (2016)	Quasi- experimental, pre-posttest feasibility	"To examine the feasibility, acceptability, and safety of the intervention in anticipation of ultimately conducting a full-scale randomized controlled trial of the intervention" (p. 89)	 The integrated self- management intervention was developed with patients, family members, and providers and included motivational interviewing and behavioral activation techniques. 6 weekly individual sessions (45 minutes) + 2 booster sessions led by chronic care managers 	Latino immigrants with uncontrolled diabetes and depression receiving care at a primary care clinic in the U.S. (N=18)	Patient activation (PAM-13) (Hibbard et al., 2005)	In paired t-tests, participants had a significant improvement patient activation (t = -5.59, P < .001)	II, B
Lara- Cabrera et al. (2016)	Parallel group randomized controlled trial	"To evaluate the effect of a peer co-led intervention, added to treatment as usual, on patient activation in out-patient mental health care settings. Secondary aims were to assess the effects on patient satisfaction, well-being, mental health symptomatology, motivation, and treatment participation in mental health services" (p. 761)	-The pre-treatment education intervention was designed to encourage patients to actively participate and take a role in their personal health, based on principles of self- management, patient involvement, and peer support -4 hour group seminar led by psychiatrist, clinical psychologist, peer educators, social worker, physiotherapist, therapist (nurse, psychologist)	Patients from 2 outpatient mental health centers in Norway (N=52)	Patient activation (Norwegian PAM-13) (Inger Elise O. Moljord et al., 2015)	In mixed linear models, the intervention group experienced higher patient activation from baseline to one month (95% CI: 1.71, 12.2; p=0.01) and four months (95% CI: 0.35, 11.8; p=0.04) follow up compared to control.	I, A
Muralidhara n et al. (2019)	Randomized controlled trial	"To conduct a large RCT comparing Living Well, a 12-session group intervention co- led by a peer (a veteran with co-occurring	-Living Well intervention, based on the CDSMP, provides education and training in problem solving and action planning to	Patients with serious mental health illness receiving outpatient services at one of three VA medical centers in the Mid-	Patient activation (Patient Activation Measure-22 [PAM-22])	In linear mixed effects models, participants in the living well intervention experienced greater increases in	I, A

		mental and physical health conditions) and a nonpeer facilitator, with 12 sessions of a didactic Medical Illness Education and Support group led by a nonpeer facilitator" (p. 20)	enhance motivation and self-efficacy -12 sessions (75 minutes) co-led by peer and non- peers	Atlantic region of the U.S. (N=242)	(Hibbard et al., 2004)	patient activation (t=2.08, p=0.038) compared to control group.	
Turner et al. (2015)	Quasi- experimental, longitudinal pre-post	"To evaluate a co- produced and co- delivered depression self-management program (SMP) on patient activation, depression, anxiety, health status, quality of life and self- management ability outcomes of people living with depression" (p. 245)	-The Depression SMP was designed to increase activation and self-efficacy and decrease learned helplessness through self- management training. -7 weekly group-based sessions (3 hours) co-led by psychologist and peer	Patients diagnosed with depression in mental health centers in the United Kingdom (U.K.) (N=114)	Patient activation (PAM-13) (Hibbard et al., 2005)	In intention-to-treat and protocol analyses, patient activation improved post- intervention (d=0.61; p <0.001).	II, A
Weisner et al. (2016)	Quasi- experimental nonrandomized controlled trial	"To examine the effects of an intervention aiming to link patients receiving addiction treatment with health care" (p. 804)	-LINKAGE intervention provided education and skills building with use of a patient portal and collaborative communication with healthcare providers. -6 group-based sessions (45 minutes, 2 per week) led by clinical psychologist	Patients from a San Francisco outpatient addiction treatment clinic (N=503)	Patient activation (PAM-13) (Hibbard et al., 2005)	In linear regression analysis, patient activation in both intervention and control groups improved (increase of 3 or more points) but there was no difference between groups (OR=1.32, 95% CI: 0.91-1.91, p=0.14).	II, A
	<u> </u>	navigation intervention					
Cabassa et al. (2018)	Quasi- experimental, pilot pre-post	"To examine the acceptability and feasibility of Delivering Bridges to Better Health and Wellness (B2BHW) to explore its initial impact on	-B2BHW is a cultural adaptation for Hispanics with SMI of the primary care referral and evaluation (PCARE) program, an intervention where health care managers coordinate,	Hispanics with serious mental illness at risk for cardiovascular disease from an outpatient mental	Patient activation (PAM-13) (Hibbard et al., 2005)	In linear mixed models, improvements were seen at 12 months for patient activation (ES=0.56, p =0.001),<br moderate effect compared to baseline.	II, A

			. 1 1	1 14 1			ı
		patient activation, self-	connect and coach patients	health clinic in New			
		efficacy, patient-rated	to facilitate primary care	York (N=34)			
		quality of care, receipt	visits				
		of preventive primary	-Individual 12 monthly				
		care services, and	sessions (60 minutes per				
		quality of life" (p. 164)	session); intervener social				
			worker				
Chinman et	Cluster	"To incorporate peer	-PS functioned as part of	VA psychiatric	Patient	In mixed effect regression,	I, A
al. (2013)	randomized	specialists (PSs) into	the case management team	inpatients in the	activation	patient activation improved	
	controlled trial	traditional VHA case	while drawing on personal	Southwest U.S.	(PAM-MH)	more in the peer specialist	
		management teams and	lived experiences to deliver	(N=282)	(Green et al.,	group than in usual care	
		test the impact of PSs	a variety of functions such		2010)	(z=2.00, df=01, p=0.05) at	
		on greater a broad range	as leading group, meeting)	one year follow up.	
		of recovery outcomes	with veterans, developing			one year rono w apr	
		. it was hypothesized	recovery plans, delivering				
		that the involvement of	medication, and going with				
		PSs would lead to	veterans to appointments.				
		greater gains—at the	-PS training and				
		0 0	8				
		individual patient	supervision involved 30				
		level—in recovery,	hours of recovery training,				
		quality of life, patient	basic counseling skills and				
		activation, and to a	psychosocial rehabilitation				
		lesser extent,	+ 2 day training in illness				
		symptoms." (p. 111)	management and recovery				
			+ supervision by internal				
			and external supervisor				
			weekly				
Guo et al.	Randomized	"To examine whether	-The Wellness Incentive	Medicaid enrollees	Patient	In generalized linear mixed	I, A
(2019)	pragmatic	the Wellness Incentive	Intervention (WIN)	with co-occurring	activation	models, both intervention and	
× ,	clinical trial	and Navigation (WIN)	provided patients with a	physical and	(PAM-13)	control groups had an increase	
		intervention can	personal navigator and a	behavioral health	(Hibbard et	in patient activation across all	
		improve health-related	flexible wellness account.	concerns in Texas	al., 2005)	study years. The intervention	
		quality of life	-Initial visit + monthly	(N=1259)	, 2000)	group experienced higher	
		(HROOL) among	telephone call + quarterly	(1,-120))		patient activation (67.2 vs	
		Medicaid enrollees with	in-person meeting for a			64.8; t = -2.21; P = .027) at	
			total of 3 years			year 3 compared to control	
		co-occurring physical	total of 5 years			-	
		and behavioral health				group.	
		conditions."					
		(p. 1156)					

Schuster et al. (2018)	Comparative effectiveness, cluster- randomized design	"To assess the impact of two behavioral health home approaches, Patient Self-Directed care and Provider- Supported care, on several patient-centered outcomes, including activation in care, health status, and engagement " (p. 249)	-Behavioral health home intervention involving partnering with mental health providers to focus on holistic health and foster a wellness culture amongst staff. -Self-directed group were given access to web-based portal (could access independently or with wellness coach); patient autonomy encouraged. -Provider-supported group had a staffed registered nurse available for consultation to wellness coaches and provided care coordination services.	Medicaid enrollees with serious mental health illness receiving services from a participating provider in Pennsylvania (N=1229)	Patient activation (PAM-22) (Hibbard et al., 2004)	In multivariate analysis, patients in the provider- supported group had a more rapid increase in patient activation compared to self- directed behavioral health homes as evidenced by a treatment by time interaction f (4,3164)=6.70, p<0.0001).	I, A
Denneson et al. (2019)	Quasi- experimental, switching replications design, pre/post	"To evaluate whether the web-based educational program improved patient- clinician communication and	A web-based educational program in which patients read their mental health notes online.	Patients engaged in mental health treatment at the VHA medical center in the Pacific Northwest U.S.	Patient activation (PAM-MH) (Green et al., 2010)	In fully adjusted mixed models, patient activation scores in healthcare interactions increased significantly between the pre and post training assessments	II, A
Kipping et al. (2016)	Quasi- experimental, observational cohort	communication and increased patient activation" (p.4) "To conduct a benefits evaluation of a patient portal for patients undergoing treatment for serious or persistent mental illness" (p. 2)	Intervention was a web- based portal that obtains health information from the electronic medical record	Northwest U.S. (N=247) Web-based portal users undergoing treatment for serious or persistent mental illness in a tertiary (inpatient or outpatient) mental health facility in Canada (N=91)	Patient activation (Mental Health Recovery Measure [MHRM] used as a proxy for activation) (Bullock, 2005, p. 36- 40)	and post training assessments (PAM: pre-post score change b=2.71 [1.41, 4.00], p<0.01). In t-test analyses, activation increased post-intervention (t=-2.636, df=130, p=0.01)	II, A

Other interv	ventions						
McCusker et al. (2016)	Randomized Pragmatic Clinical Trial	"To (1) describe the cross-sectional associations of activation and self- efficacy with demographics, physical and mental health status, health behaviors, depression self-care, and health care utilization; (2) describe the longitudinal associations of changes over time in activation and self-efficacy with changes in health behaviors and use of the Toolkit; and (3) determine whether the coaching intervention increased activation and/or self-efficacy at follow up" (p. 717)	-Intervention involved access to a toolkit (informational DVD, mood monitoring tool, antidepression skills workbook) and assignment to a lay coach. -Assigned lay coach (trained/supervised by clinical psychologist); weekly calls (10 minutes) offered for up to 3 months + 6 monthly calls	Patients with at least one chronic condition and a minimum of mild depression recruited from 41 family doctors in Canada (N=215)	Patient activation (PAM-13) (Hibbard et al., 2005)	In linear regression analyses adjusting for depression, education, counseling, antidepressants, and other psychotropics, both coached and noncoached groups experienced an increase in activation at 6-months compared to baseline, with no difference between groups (ES=0.14, 95% CI: -0.11, 0.42; p=0.324).	I, A
Moljord et al. (2017)	Parallel-group randomized controlled trial	"To assess the effect of a self-referral to inpatient treatment (SRIT) contract on the primary outcome patient activation (PAM-13). The secondary outcomes were recovery (RAS) and behavior and symptoms identification (BASIS-32) after 12 months compared to those who received treatment as usual (TAU)" (p. 1145)	-The SRIT intervention was designed to improve patient participation and access to treatment. -After referral, patients received consultation with psychiatric nurse.	Patients from a community mental health center in central Norway (N=53)	Patient activation (Norwegian PAM-13) (Inger Elise O. Moljord et al., 2015)	In a linear mixed model, there was no significant effect of SRIT on patient activation (95% CI: 7.49, 6.67; p = 0.91) compared to TAU. In post hoc linear regression, SRIT had a significant effect on patient activation for patients with a PAM score below 47 (95% CI: 0.03, 39.04; p = 0.049).	I, A

Rise et al.	Parallel-group	"To investigate the	-The intervention involved	Patients from a	Patient	In analysis of covariance,	I, B
(2016)	randomized	effect on mental health	implementation of a	Norway outpatient	activation	there were no differences in	
	controlled trial	and patient activation	PCOMS feedback system,	unit within a mental	(PAM-22)	activation between the	
		after 6 and 12 months	creating opportunity to	health hospital	(Hibbard et	intervention and control group	
		from using the PCOMS	collect and use patient	(N=75)	al., 2004)	at 6 months (est. diff=3.2;	
		(partners for change	feedback on treatment			95% CI: -8.7, 2.3; p=0.25)	
		outcome management	sessions			and 12 months (est. diff=4.9;	
		system)" (p. 164)				95% CI: -0.7, 10.5; p=0.082).	

[‡]Comparison index not reported.

CHAPTER THREE

INTRODUCTION

High rates of opioid use disorder (OUD) are a public health crisis. Opioids are chemicals that reduce the perception of pain through interaction with nerve cell receptors (American Psychiatric Association, 2018). OUD includes a pattern of opioid use that causes significant distress or impairment (American Psychiatric Association, 2013). In 2018, OUD affected approximately 2 million Americans (Substance Abuse and Mental Health Services Administration, 2019). OUD is comparable to other substance use disorders but is unique because dependence can develop quickly (within 4-8 weeks) and abrupt cessation leads to severe withdrawal symptoms (e.g., pain, chills, nausea/vomiting) (American Psychiatric Association, 2018). Addiction occurs in an estimated 3-19% of persons taking prescription opioid medications (American Psychiatric Association, 2018). Overdoes of synthetic opioids, especially fentanyl, heroin, and prescription pain killers, have led to a sharp increase in overdose deaths (American Psychiatric Association, 2018). Opioid overdoses led to nearly 400,000 deaths from 1999 to 2017 (Scholl, Seth, Kariisa, Wilson, & Baldwin, 2019). The economic burden of opioid misuse is estimated to be more than \$78.5 billion annually in the United States, with most costs related to lost productivity, health care, and substance use treatment (Florence et al., 2016).

The recovery process from OUD requires personal changes to enhance health and wellness so persons can lead self-directed lives to overcome addiction (National Institute on Drug Abuse, 2017a). Persons experience a number common stages in their journey from addiction to abstinence (CRC Health, n.d.). Recovery stages include the following:

early sobriety (first year), sustained sobriety (1-5 years), and stable sobriety (5+ years) (Groshkova, Best, & White, 2013).

Several treatments have shown to be effective for persons recovering from OUD. Evidence-based treatments for OUD include medication, group and individual counseling, and behavior therapies (American Psychiatric Association, 2018). Medications for opioid use disorder (MOUD) include medications such as methadone, buprenorphine, and naltrexone. MOUD helps block the opioid's euphoric effects and relieve cravings and withdrawal symptoms (American Psychiatric Association, 2018). Cognitive behavioral therapy is often used to address beliefs and behaviors that contribute to addiction and teach relapse prevention skills (American Psychiatric Association, 2018). Treatment programs can include long-term therapeutic communities, inpatient treatment, intensive outpatient treatment (IOT), and outpatient counseling (American Psychiatric Association, 2018).

IOT is a program that incorporates several evidence-based treatments. Unlike inpatient or residential treatment, persons receiving IOT can remain in their homes and communities. The goals of IOT are to help persons learn early-stage relapse management and coping strategies, provide psychosocial support, and address individual symptoms and needs (McCarty et al., 2014). Patients usually attend IOT three to four days a week and may participate in up to 20 hours of programming a week. A review of substance abuse IOT programs revealed that these programs resulted in reductions in problem severity and increases in abstinence days that were comparable to residential or inpatient programs (McCarty et al., 2014). Overall, 50 to 70% of participants in these programs reported abstinence at follow-up (McCarty, 2014).

Despite the availability of evidence-based treatments for OUD, including IOT, many persons do not receive specialty treatment or complete treatment programs. Of the two million Americans with OUD in 2018, for example, only 400,000 (19.7%) received treatment at a specialty facility (Substance Abuse and Mental Health Services Administration, 2019). For those who do begin addiction programs, many do not complete a full course of treatment. For example, research has shown attrition rates as high as 80% in some IOT programs (Loveland & Driscoll, 2014). Barriers to engagement include lack of social support, financial insecurity, fragmented care, mental illness, and physical symptoms/limitations (Zulman et al., 2018).

Despite the promise of IOT coupled with problems with patient engagement, few studies have examined how patients experience these programs from when they enter them until they leave. To improve IOT outcomes for persons with OUD, including increasing enrollment and retention, more information is needed about patient experiences with IOT. The purpose of this study is to describe processes people with OUD undergo as they participate in an IOT program. The specific aims are to describe how people with OUD experience (1) enrolling in an IOT, (2) acclimating to an IOT, and (3) receiving treatment in an IOT as it unfolds.

MATERIALS AND METHODS

A constructivist grounded theory approach was used to conduct this study. Grounded theory is a flexible, yet systematic, qualitative research approach that enables the development of a theoretical framework through the iterative collection and analysis of narrative data (Charmaz, 2014). Grounded theory is used to identify a psychosocial process shared by a group of persons who share a common challenge. Constructivist

grounded theory is based on the assumptions that human experiences are influenced by social contexts, researcher and participant interact to co-construct findings, and findings are developed and refined through consensus (Charmaz, 2014). The constructivist grounded theory method was chosen for this study because the research team believed persons with OUD share a common problem and sought to co-construct a theoretical framework describing how the psychosocial process of recovery unfolds in the social context of IOT. The Consolidated Criteria for Reporting Qualitative Research (COREQ), a checklist developed to promote comprehensive reporting of results of interview studies, guided the presentation of findings (Tong, Sainsbury, & Craig, 2007).

Participants and Setting

The sample consisted of 14 persons diagnosed with OUD who received IOT. Participants were recruited from IOT programs within two adult academic health centers that are part of a large healthcare system in the Midwest. The IOT programs offer day and night options that meet 3 to 5 times per week for a minimum of 9 hours weekly. Program completion is dependent on the achievement of goals set forth in individual treatment plans and progress within the program. The IOT programs provided individual therapy, group therapy, MOUD, psychiatric medication management for co-occurring disorders, and peer coaching.

Inclusion criteria were (1) age ≥ 18 years old, (2) able to read/speak English, and (3) diagnosis of opioid use. Exclusion criteria were (1) had cognitive impairment that impacted performance of daily activity performance, (2) had severe health issues (e.g., currently receiving advanced cancer treatment, hospice care, or hip, knee, or other major

surgery), and (3) had significant mental health issues not controlled by medication (e.g., severe depression, schizophrenia, bipolar).

Participant Recruitment

Following IRB approval from the investigators' institution and study site approval from IOT program managers and directors, potentially eligible participants were identified. A report was generated of past and present IOT participants and their medical records, accessed only for recruitment purposes, were provided. The first author [AK, a nursing PhD candidate with training in grounded theory] screened the records for inclusion and exclusion criteria by examining program intake paperwork and clinician progress notes. Recruitment letters were mailed to persons meeting study criteria. The letters briefly described the study purpose, procedures, and risks/benefits and invited persons to contact the study team. A follow-up text message was sent within 2 to 4 weeks of the mailed letter to persons who had not contacted the study team. In addition, recruitment flyers provided at both study sites invited persons meeting study criteria to contact the study team. Potential participants were screened over the phone to verify they met study criteria. For those who remained interested, verbal consent to participate in the study was obtained, and interviews were scheduled.

Data Collection

AK conducted interviews using a semi-structured interview guide. Because of restrictions due to the novel coronavirus 2019 (COVID-19) pandemic, interviews were primarily conducted via videoconference or phone from a private home office. One interview was completed face-to-face using established social distancing guidelines when restrictions were lifted. The interviews began with the following statement: "Tell me

about your experiences in your IOT recovery program. I am interested in how you came into the program, how you adjusted to the program, and how you experienced the program as your treatment unfolded. I am interested in both what went well and what was difficult." Questions that followed invited participants to describe their IOT experiences when they first entered the program [e.g., "Now let's start with when you were admitted to the program. Tell me about your first day in the program."], as they acclimated to the program [e.g., "Tell me about a day that happened in the middle of the program – maybe your second or third week of the program. What activities did you take part in that day?"], and as they exited the program [e.g., "Tell me how it was decided you would leave the program."]. Interviews were audio recorded and AK kept field notes to capture impressions of the interview and emerging analytic thoughts. At the end of the interview, participants were asked to complete a demographic survey that included questions about age, gender, race, substance use type, number of weeks in IOT, and total number of weeks in treatment. Interviews were conducted from September 2020 to April 2021.

Data Analysis

All interviews were audio recorded, transcribed verbatim, and checked for accuracy by AK. AK led analytic activities with input from the last author, a senior nurse researcher with expertise in grounded theory [CBD]. Four analytic stages like those described by Charmaz (2014) were followed. First, AK conducted initial coding on the transcripts by labeling relevant text units (i.e., words, phrases, sentences related to the study aims) with short phrases (codes) that captured the essence of the text units. When possible, the codes were formatted as gerunds to capture actions and interactions that were important to the IOT experiences of the participants (Charmaz, 2014). CBD verified

the codes by reexamination of transcript data. Second, AK grouped similar codes into potential categories with the aid of a data display table arranged according to the research aims. AK and CBD discussed the potential categories, re-examined the data, refined the categories, and labeled them with a descriptive phrase. Third, to construct the final framework, AK and CBD determined the properties of the categories and relationships among the categories through discussion and consensus. Fourth, AK wrote a narrative summary describing the components of the theoretical framework, and the summary was reviewed and verified by second author [YL], a senior nurse researcher and the third member of the research team.

RESULTS

Ninety-four persons were sent study announcements, 21 contacted the researcher to express interest in participation, and 14 were enrolled. All participants had been enrolled in an intensive outpatient treatment (IOT) program in one of two adult academic health centers within a large health system in the Midwest. The participants ranged in age from 23 to 56, with a mean age of 31. Nine participants (64%) were female, and five (36%) were male. All were White. The participants reported a history of polysubstance use (combination of opioids and other drugs) (n=8), heroin and prescription opioid use (n=3), prescription opioids use only (n=2), and heroin use only (n=1). The interviews were conducted by video conferencing (n=8), telephone (n=5), and in-person (n=1). The interviews ranged from 31 to 75 minutes with an average of 57 minutes.

In general, participants were very willing to share their experiences of drug use and especially their experiences in IOT. Most provided detailed descriptions about what brought them to the program, how they experienced the program, and how they

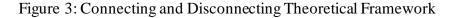
transitioned out of the program. Some participants appeared distressed when discussing life traumas or losses they had experienced because of their drug use, such as loss of employment or custody of their children. Others appeared upbeat when discussing their experiences of recovery and how their lives had improved because of their participation in IOT. Although they were invited to stop the interview at any time, none chose to do so.

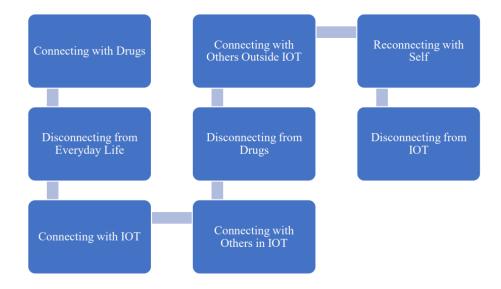
Theoretical Framework

Participants described a series of stages in which they became connected or disconnected from drugs, other people, the IOT program, and themselves. The research team therefore labeled the central psychosocial process by which the participants' experiences in IOT unfolded as *connecting and disconnecting*. The processes of connecting and disconnected were often linked. For example, participants described how when they connected with drugs they often disconnected from others and how when they connected with their IOT program they began to disconnect with drugs. The participants' experiences in IOT could be best be described as a complex and progressive process by which their engagement with drugs was replaced by engagement with other aspects of their lives.

The eight stages of *connecting and disconnecting* included the following: (1) connecting with drugs, (2) disconnecting from everyday life, (3) connecting with the IOT program, (4) connecting with others in the IOT program, (5) disconnecting from drugs, (6) connecting with others outside the IOT program, (7) reconnecting with self, and (8) disconnecting from the IOT program. Although the process is presented as a series of stages that are depicted in a one-dimensional theoretical framework, the process was not rigid or linear for all participants. Rather, while some participants experienced aspects of

all eight stages in the order they are presented, some experienced only a few stages, some reverted to early stages due to relapse, and some experienced the stages simultaneously. Therefore, the framework presented below is a conceptual rendering of how persons' experiences in IOT unfold through a series of connections and disconnections, as shown in Figure 3.





Connecting with Drugs

The research team labeled the first stage as *connecting with drugs* because most participants started their narratives by discussing when their drug use began and how it escalated to addiction. Some participants described periods of sobriety and relapse. *Connecting with drugs* included first using drugs, being overtaken with drugs, and reconnecting with drugs.

First Using Drugs

Several participants discussed the circumstances in which they first used drugs. A few were prescribed opioids for pain after a surgical procedure or for chronic pain, such

as back pain. For example, a 56-year-old woman who attended the program for three days stated:

I had two back surgeries in 2000..... It helped out but five or six years later my back started hurting again. I go for injections, but I get so many injections that I can only go once a year . . . so for a while I got oxycodone.

Some participants attributed their beginning drug use to negative life experiences such as childhood trauma. A 29-year-old woman who spent six weeks in the program said, "I found through recovery that I had a lot of inner child or daddy issues . . . I always would take my frustration and my previous traumas in life out on substance abuse." Others did not specify when they began to use drugs but indicated they had used since they were adolescents. A 27-year-old woman who was in the program for about eight weeks said, "I have been facing addiction since I was 16 years old. I have had many periods of sobriety and relapse."

Being Overtaken by Drugs

Many participants described how at some point drugs began to overtake their lives. A couple of participants who were prescribed opioids for pain began to use heroin and seek drugs on the street because they could not find a healthcare provider to prescribe pain medications. As some participants' drug use began to escalate, they came to feel "like nothing else mattered." Most felt that they were "headed down the wrong path" and their lives were "going downhill." Some felt ashamed and frightened, and some felt that they had "lost everything" because of drug use. A 27-year-old man who attended the program for about three months stated:

You start selling your stuff because you are low on money because your job isn't paying enough. Then you start missing work because you can't go to work because you are sick because you don't have enough money

(for drugs). Then you lose your job and then you lose your car and then you lose your house. Everything just happens extremely fast when it comes to drugs. That's kind of what happened to me.

A couple of participants had overdosed and required medical treatment. A 38-year-old man who spend three weeks in the program said, "I would kind of fall asleep and stop breathing and then she (his wife) would wake me up and I would fall asleep and stop breathing. She took me to [hospital] and they actually admitted me to the hospital." Participants got money for drugs by selling valued possessions or dealing drugs themselves. Some put themselves and others in danger to purchase drugs. A 56-year-old woman who was in the program for three days said, "We (she and her daughter) went over there (dangerous area of town) to meet this person that I barely even knew at midnight in a minivan.... They could have come up and shot us and nobody would have known...."

Reconnecting with Drugs

Several participants had enjoyed a period of sobriety but had relapsed, in some cases while they were in IOT. Several participants had relapsed on several occasions. A 31-year-old woman who spent less than three weeks in the program said, "I really just wasn't ready to get sober . . . I went home and then went back (to IOT) . . . I relapsed and failed a drug screen." Some returned to drugs to avoid withdrawal. A 43-year-old man who spent about a month in the program shared, "I'm going through withdrawal very badly. So then another drug came my way and I was like, "Oh hell yeah. I have got to get through this withdrawal." Some participants were highly committed to sobriety but began using again, nonetheless. A 38-year-old man who spent three weeks in the program said:

Definitely with the way I would quit doing drugs and be really motivated to stay clean.. You know my life is definitely not going to get better if I keep doing drugs, it's only going to get worse. But as I'm clean for a few weeks to a month, I kind of start forgetting that.

Disconnecting from Everyday Life

The research team labeled the second stage as *disconnecting from everyday life* because many participants discussed how they became disconnected from several aspects of their day-to-day lives as drugs overtook them. Most became detached from things that they cared about and felt they had lost much due to their addiction. *Disconnecting from everyday life* included breaking relationships with others, disengaging from work, and being removed from society.

Breaking Relationships with Others

Some participants discussed becoming estranged from others who were important to them and described a number of broken relationships. A few participants experienced a strain on their relationships with their significant others. They indicated that they risked losing a spouse or a partner because of their drug use. A 38-year-old man who spent three weeks in the program said, "My wife said if I used again, she is going to divorce me, which I don't blame her." A couple of participants faced the loss of custody of their children. A 38-year-old woman who was in the program for approximately 6 weeks stated:

I had lost my boys during all of this. That was one of the bigger struggles for me. It almost kept me in a stagnant place where I was so miserable and missing them that I kept using to cope.

Other participants had lost of the trust of others because of the participants' behaviors while using drugs. A 29-year-old woman who was in the program for about six weeks

said, "I stole money from my both of my parents. Of course, I lied about it when I was using. That is what we do."

Disengaging from Work Life

Several participants discussed disengaging from their work life. Some indicated they got "into trouble" at work because of behaviors such as buying drugs while at work, exhibiting withdrawal symptoms on the job, or missing work because of their drug use. A 38-year-old man who spent three weeks in the program said, "I'm kind of in a situation where I could get arrested and lose my job. I ordered some drugs online. They got intercepted by the postal service and I'm really freaked out." Several participants risked losing, or lost, professional positions due to their addiction. A 41-year-old nurse who spent about 8 months in the program stated, "I self-disclosed (drug diversion) to the emergency room director . . . That led me to being on FLMA (family medical leave)." A 39-year-old woman who spent about five weeks in the program said, "When I was teaching high school and I started taking Vicodin and all of those things I lost my job . . . Just the stress of that job and resorting to things that didn't work in the end."

Being Removed from Society

A few participants discussed being removed from society by being jailed or incarcerated after being arrested for drug use or possession of drugs. While jailed, they were kept from the outside world. A 56-year-old woman who spent three days in the program said, "I picked up a drink one day and that cost me a nice little stent in jail. I was in there for two days . . . I had never experienced something like that. It was horrible." A 40-year-old man who was in the program about four weeks shared, "When I left for work, the maids went in my room and found some paraphernalia and called the DNR

(Department of Natural Resources)... I go back to [hotel] and they (the cops) were waiting on me."

Connecting with the IOT Program

The research team labeled the third stage as *connecting with the IOT program* because many participants described how they first became engaged with the program. Most indicated they entered treatment to change their lives and obtain the help they needed help to achieve and maintain sobriety. Some participants had IOT previously and some were entering into a program for the first time. *Connecting with IOT* included deciding to connect with the IOT program, making the first connection with the IOT program, and coming to feel connected with the IOT program.

Deciding to Connect with the IOT Program

Participants discussed how they decided to seek treatment and enter IOT. They provided a variety of reasons why they sought treatment when they did. Participants had hit "rock bottom," were "writing a new chapter," had become serious about recovery, wanted to feel better, and felt treatment was "the next thing in front of them." Some participants entered treatment because the sober house in which they were staying required it, a friend or family member encouraged it, or a healthcare provider, recovery specialist, or probation officer recommended it. A 33-year-old woman who spent about six weeks in the program shared:

I was sick and tired of being sick and tired ... There was nowhere else for me to go except for up . .. I decided to go to sober living (after residential)... They work closely with [hospital] because they (sober living) highly suggest that you enroll in an IOT.

A few entered IOT because it was required to receive MOUD. Some participants chose the specific IOT program they attended because they were familiar with the health system that provided the program, were aware of the reputation of the health system, or the program was close to the sober house in which they were staying. A 41-year-old woman who spent about eight months in the program said, "I basically just contacted and found out where the closest ones (IOTs) were and [hospital] was it. Having worked for [hospital] for [many] years already, I just figured it would be a good program."

Making the First Connection with the IOT Program

The participants' initial connection with the IOT program typically included an initial assessment or intake. Although some participants were hesitant to begin the program, most had a positive experience during the assessment. They felt safe to "open up" and share their stories and did not feel judged. Several noted that "getting set up" for the program was easy and the staff "walked them through" the process. A 40-year-old man who was in the program for about four weeks said, "He (staff member) was really nice, like a really calm demeanor and he walked me through everything . . . It was a good experience.... the intake was. And I just felt good energy from the place."

Participants felt a myriad of emotions before beginning the treatment group. A few were exited and anxious to get started. A 32-year-old woman who was in the program for about six weeks said, "In my head I was just like if I am going to do this long term I have to go here. I was very excited about being there. I felt like I was beginning a new chapter." However, many of the other participants felt intimidated, scared, or nervous. Several participants were quiet in group at first but felt staff gave them the "space" they needed to become comfortable. A 33-year-old woman who attended the program for six weeks said, "At first in the beginning it was awk ward (in group). I didn't say a whole lot." Another participant described the initial group

encounter as "taking it all in." Most participants felt good at the end of the first day and experienced a sense of optimism. Several indicated they were very willing to come back. A 25-year-old woman who attended the program for about two months shared, "It felt pretty good (at the end of the first day). It felt like I was going to come back. I felt like I might really like the class." Only one participant revealed that he was high on the first day of the program and thus felt no benefit.

Coming to Feel Connected to the IOT Program

Most participants indicated that they became more comfortable with their treatment, especially sharing in group, as they settled into the program and "learned the ropes." They became acclimated to the program, came to feel more at ease, learned to "trust the process," and appreciated what they learned about addiction. They became familiar with the IOT schedule and understood program expectations. A 39-year-old woman who attended the program for five weeks stated:

At first, you don't know about it (the program) and you are just kind of listening and trying to adapt to the new situation. In the middle, I felt more adapted. It was easier for me to express things and then relate to people.

Many actively engaged in group discussions and shared personal experiences. A 25-yearold woman who attended the program for about two months shared, "I gave more feedback to people and started talking about what was bothering me at home or how I was feeling triggered or stuff like that (once settled into the program)." Most were enthusiastic about program activities such as yoga, art, watching videos, having guest speakers, and doing readings. A 39-year-old woman who was in the program for about five weeks stated, "We did 15 minutes of exercise (in the morning). It might be yoga. I think we only did yoga a couple of times but that was my favorite." A few participants, however, did not believe in the program, did not come to feel connected to it, and resisted some of the activities. A 26-year-old man who spent about three months in the program said, "It was just obvious that they (staff) didn't really care. So why would I participate in something that I just don't give a shit about?" Other participants complained that the lack of engagement of other IOT patients discouraged the participants from investing in the program or actively participating in the groups. A 23-year-old man who was in the program for about two weeks shared, "I think it was hard for me too because some people were there to actually recover and some people were there working off probation. So it was like, 'Okay he doesn't care. She doesn't care. " Others felt that the activities of the IOT program became repetitive and therefore less helpful as time went on.

Connecting with Others in the IOT Program

The research team labeled the fourth stage as *connecting with others in IOT* because participants discussed how they were able to build meaningful relationships with other patients and staff. Participants felt that connecting with others was a critical aspect of their treatment. *Connecting with others in IOT* included sharing one's story with others, bonding with IOT patients, and bonding with IOT staff.

Sharing One's Story with Others

Several participants began connecting with others by sharing their stories of addiction and discussing other painful life issues in group sessions. They had "hard needed conversations" and "talked about things you might not want to be real about." Some participants were sharing their stories for the first time, while others were sharing stories for the first time in a long time. A couple of participants shared traumatic

experiences such as childhood abuse and, as a result, experienced intense emotions. Some became overwhelmed and tearful during group sessions. A 41-year-old woman who spent about eight months in the program stated, "I remember just crying and it all (story) came out, all this stuff that I didn't feel like I could tell anybody thus far. Even some things my husband doesn't know. It all just came out." The participants felt vulnerable when sharing their stories but felt it was necessary for their recovery and sobriety. A 32-yearold woman who was in the program for six weeks said, "Although it was uncomfortable and I did not particularly like being vulnerable and sharing some of the things that happened in my past, it allowed me to heal from those things or begin to heal from those things." Some felt that sharing in IOT prepared them for sharing their stories in long-term recovery programs.

Bonding with IOT patients

Participants bonded with other patients in their IOT program and felt these bonds aided recovery. Most identified with the stories of other IOT patients and felt that they were all "in it together," knew where each other "was coming from," and gave each other "the courage to share." A 56-year-old woman who spent three days in the program said, "Other people have the same song you do, but maybe it is done in a different way, but it's basically the same. Those kind of people is what I am." Several participants formed good friendships while in the program. A couple of participants felt like they were part of a family, which they referred to as building their "sobriety tribe." A 27-year-old woman that was in the program for about six weeks stated, "We had lunch and breaks together. We really got to know each other on a more personal level and talked about issues in our life other than just sobriety." Several participants felt bonds were strengthened because they had shared a vulnerability while in groups. A 32-year-old woman who was in the program for about six weeks said, "By being open like that and being vulnerable and saying some of the things that happened to me, other people were able to begin to deal with the same things they may have experienced."

A few participants, however, did not connect well with others in the program because the participants felt like others did not care about maintaining sobriety or did not want to be in the program. A 38-year-old man who spent about three weeks in the program said:

Two of the people (in group) worked for a union and they got in trouble for failing a piss test. I could tell they didn't really want to stop smoking pot... Sometimes that kind of make it hard to share because I felt like they would think that I was an idiot or like I was a weak person or something.

Bonding with IOT Staff

Most participants also bonded well with the staff. They felt the staff created a non-judgmental environment, took recovery seriously, genuinely cared about the participants' recovery, and were empathic. Participants felt especially comfortable with staff who were addiction survivors themselves and thus had "combat experience." Many participants appreciated that these staff members truly understood their challenging histories and stories. A 40-year-old man who was in the program for about four weeks said, "I liked the fact that the people who work there didn't just know about substance abuse from a textbook. They lived it."

On the other hand, a couple of participants found it difficult to connect to staff, especially those who had not struggled with addiction. A 23-year-old man who was in the

program for about two weeks said, "I don't mean this in a bad way, but I don't know if he has had substance abuse issues, the facilitator. It was kind of hard to relate to him."

Disconnecting from Drugs

The research team labeled the fifth stage as *disconnecting from drugs* because many participants discussed the process of obtaining sobriety while in the program. *Disconnecting from drugs* included having hope about moving beyond drugs, seeing others move beyond drugs, working to move beyond drugs, and connecting with MOUD.

Having Hope about Moving Beyond Drugs

Some participants had little hope that they would recover from their addiction when they entered IOT but began to feel hopeful at some point during the program. A few began to feel hopeful upon beginning the program. A 40-year-old male who spent about 4 weeks in the program said, "I was very hopeful (at the end of the first day) and I even called my father and told him about it...." Some came to believe for the first time that things would get better. They started "to look beyond today," envisioned a better future for themselves, and came to believe they could have a "normal" life. A 33-year-old woman who was in the program for about six weeks said, "Once you find something that ignites that hope everything else kind of falls into place." Some participants were able to feel hopeful because others "believed" in them A 32-year-old woman who was in the program for six weeks stated:

I was so very hopeful about the steps I was taking to maintain long term sobriety. I could feel my life changing. I could feel other people starting to believe in me and it made me want to keep going.

Seeing Others Move Beyond Drugs

A few participants became hopeful they could become sober because they were "surrounded by those that had maintained recovery." Participants were inspired by other persons who stuck with the program, began recovery, and successfully graduated from the program. A 33-year-old woman who was in the program for six weeks said, "It was encouraging to watch people evolve from where they were at the beginning and see people graduate. That was really exciting, and you were like 'I want to be the one graduating and having this big to do." In particular, IOT staff who had recovered from addiction motivated participants. A 39-year-old woman who was in the program for about five weeks said, "I found it helpful that they (IOT staff) ... had similar experiences that I did and were able to beat it (addiction) and still have successful jobs and be successful in life and have social status."

Doing the Work to Move Beyond Drugs

Most participants described the work they had to do to move beyond drugs. They recognized that they would "get out of the program what they put in," took charge of their recovery, and took advantage of "all the program had to offer." Participants worked on their sobriety by finding ways to avoid temptation, developing coping skills, and engaging in healing activities. A 56-year-old woman who was in the program for three days stated, "I have a bad back. I am in pain all of the time, but I do the things that we talked about in recovery, whether it be Tylenol or getting in the hot tub or Epsom salts. I do it all." Others found ways to deal with everyday stressors by "learning how to retrain your brain," "letting go of things outside my control," and "staying in my lane to focus on me." Some participants "changed people, places, and things" to avoid returning to drugs

once outside of IOT. A 27-year-old woman who was in the program for about eight weeks said:

I make sure to avoid places that might make me relapse. I don't go to bars even if it is to play pool. I don't go back to the areas that I would go to pick up drugs. I also make sure that I got rid of the bad influences in my life.

Many participants engaged in "putting pieces of the recovery puzzle together" by going to narcotics anonymous (NA)/alcoholics anonymous (AA) in addition to IOT and working with a sponsor. A few participants found working through the steps with a sponsor helpful. A 32-year-old woman who spent approximately six weeks in the program stated, "Step four ends up being extremely intimate with your sponsor. That is where you take an inventory of all of the things that you have done."

Connecting with MOUD

To help them move beyond drugs, several participants were prescribed MOUD (e.g., suboxone, Subutex, vivitrol) while in IOT. Some were offered MOUD as part of their treatment while in the program, some requested MOUD, and some enrolled in the program specifically to receive MOUD. A 31-year-old woman who was in the program less than three weeks said, "I know that it (suboxone) really does help with cravings. The vivitrol shot is pretty much the same thing so I asked (IOT staff) if I could get the vivitrol shot." Participants were able to use MOUD as a "crutch" to help with their cravings. Some experienced success with their first MOUD prescription and were on the same script for 1 to 2 years. A 41-year-old woman who was in the program for about eight months said:

I was on that (naltrexone) for two years . . . My refill ran out a month or two ago and I realized I was using it as a crutch and I just didn't need it anymore. I have been off of it for a couple of months now.

However, a few participants found that MOUD did not help them as the medications had severe side effects or they found the prescriptions were too costly.

Connecting with Others Outside the IOT Program

The research team labeled the sixth stage as *connecting with others outside the IOT program* because some participants discussed seeking engagement with important people in their lives as they disconnected from drugs. In some cases, the participants reconnected with those whom they had distanced from while taking drugs and in, some cases, the participants formed new relationships with others. Some participants refocused their energy towards rebuilding relationships with family members. They worked to regain trust with significant others, reunited with their children from whom they became estranged, and rebuilt relationships with their parents. A 29-year-old woman who spent six weeks in the program felt she was able to "take a breath of fresh air" after admitting to stealing from her parents. She said:

I didn't feel confident enough to look my parents in the eye and tell them so I had my counselor tell them while I am sitting in the room. Stuff like that was really awkward but liberating at the same time. It's like 'I don't have to lie about this. They are going to forgive me. They are my mother and father. They just want their daughter back.'

In some cases, participants connected with others through their long-term recovery programs such as AA, sometimes in the role of sponsoring others. The 29-year women quoted above said that being a sponsor brought "back human connection, genuine human connection." She said, "You feel so empty before. People are using you and you are using people . . . Rebuilding the genuine connection."

Reconnecting with Self

The research team labeled the seventh stage as *reconnecting with self* because some participants discussed building a new relationship with themselves as they disconnected from drugs. They had reaped the benefit of their work in IOT by becoming more confident and connecting with their "sober self." Some no longer defined themselves as addicts and replaced harmful behaviors with positive ones. Several felt they had experienced intrapersonal growth as they came to appreciate their strength, experience happiness, and "spread their wings." A 41-year-old woman who was in the program for eight months said, "Addiction chose me. I didn't choose it. I really grew from that."

Some participants, however, were challenged to reconnect with themselves. Some had considered themselves as addicts for so long they had trouble embracing a new identity. A 32-year-old woman who was in the program for six weeks said:

I spent so long doing drugs that once I got clean I was like 'I don't even know who I am anymore. I don't know what I'm good at. I don't see anything good about myself.' I just really identified as 'I'm just an addict' for a long time.

Disconnecting from the IOT program

The research team labeled the eighth and final stage as *disconnecting from IOT* as most participants discussed either graduating from the program or leaving it. Graduation was a ceremony to celebrate persons' achievement in the program and readiness for the next step in recovery. Staff initiated the graduation ceremony when a person had met criteria such as program attendance, participation in activities, and progress with goals. Most participants had witnessed others graduating from the IOT program and were

motivated "to see how far others had come." Some were inspired to achieve that same success for themselves.

Only a few participants, however, had graduated. These participants decided, along with IOT staff, that they were ready for graduation. A 32-year-old woman who spent about 6 weeks in the program said, "It was mentioned (by IOT staff) like 'Hey, how do you feel about graduating?' I was like. 'I honestly feel like I'm ready.'" These participants engaged in a graduation ceremony or "coin ceremony." In this ceremony, the group passed a coin around and all persons in the group would share something positive about the graduate. One participant said, "Others noticing change was icing on the cake." Most participants found positive statements encouraging, although others experienced mixed emotions and felt uncomfortable when others talked about them. A 29-year-old woman who spent six weeks in the program said, "It was awkward (watching my coin go around). The attention was awkward." Participants generally experienced excitement, relief, or sadness the last day in the program. A 33-year-old woman who spent six weeks in the program stated, "It (graduation) was exciting and a little bit relieving... I felt really accomplished. It took me forever it felt like to get sober and to have a chance at staying sober." Most participants felt ready for life outside the program, and some had difficulty leaving people they had formed relationships with behind. A 41-year-old woman who was in the program for about eight months said, "It was emotional (the last day). I had made friends with some people I will never forget, and I have seen them on their journey."

Many participants did not graduate from the program. Some needed to leave before graduation due to external circumstances such as the onset of COVID-19, housing

issues, or having a baby. A 56-year-old woman who attended the program for three days said, "I got down there (to IOT) and I only got to go three days when the COVID virus stopped that completely... I was really looking forward to it (continuing program)." A few participants chose to attend a different treatment program because they needed more intensive treatment, preferred different MOUD options, or had a bad experience while in the program. One participant overheard a staff member sharing a conversation he had had with her "in confidence" with other staff members and left the program feeling a betrayal of his trust. A 40-year-old man who attended the program for four weeks said, "I had to leave for legal reasons ... with a pending case that I had for possession, they (attorney) wanted me to do an inpatient program instead of outpatient." A couple of participants left the program because they were "not ready to get sober" and put their treatment on the "back burner." A 23-year-old man who spent two to three weeks in the program shared:

I felt like it (IOT) was becoming more of a problem than it was beneficial. I'm getting help but I'm also not getting enough sleep. I'm not getting things done that I need to get done . . . 'I got it. I'm okay. You know what I mean?' And then things happen. Probably not a good idea.

DISCUSSION

The findings revealed that the process of enrolling, acclimating, and receiving treatment in an IOT involves an overarching process of *connecting and disconnecting* with drugs, others, the program, and the self. The eight stages of *connecting and disconnecting* included (1) connecting with drugs, (2) disconnecting from everyday life, (3) connecting with the IOT program, (4) connecting with others in the IOT program, (5) disconnecting from drugs, (6) reconnecting with others outside the IOT program, (7) reconnecting with self, and (8) disconnecting from the IOT program.

The experiences of connecting and disconnecting intersected in a variety of ways as the participants' experiences in the IOT program unfolded. Although the study design prohibits claims about causality, the participants' narratives implied that connecting with drugs led them to disconnect from others and from their everyday lives when drugs overtook their lives. The experiences of connecting and disconnecting were also highly interwoven in the IOT program. Participants suggested it was their connections with the program, other patients, and staff that enabled their disconnection from drugs, which in turn allowed them to reestablish important connections outside the IOT.

The findings of this study are similar to the findings of several qualitative studies exploring persons' experiences in substance abuse treatment. For example, a grounded theory study by Wilson, Shaw, and Roberts (2018) of 10 adults receiving MOUD also revealed that the pathway to addiction included an event that led to an opioid initiation, often a prescription for pain medication, and a pull toward opioids that resulted in risky behaviors and damage to relationships. The participants in the Wilson et al. (2018) study also experienced a turning point in which they had had enough and decided to seek help. Moreover, just as the findings of the current study highlighted connections and disconnections from others, the findings of Wilson et al. study centered on the "relationship spectrum" (p. 248), which were encounters with persons that ranged from supportive to non-supportive of the participants' recovery (Wilson et al., 2018). Also consistent with the findings of the current study, a qualitative study of persons receiving treatment for alcohol use disorder in a variety of treatment settings revealed that supportive relationships and a non-judgmental treatment environment were related to satisfaction with treatment (McCallum, Mikocka-Walus, Gaughwin, Andrews, &

Turnbull, 2015). These factors were also highlighted in a qualitative study of 12 rural women in substance use treatment (Godlaski, Butler, Heron, Debord, & Cauvin, 2009) who revealed that welcoming attitudes of staff, being with other women who shared their experiences, and being respected by both staff and patients were key to their comfort in treatment.

Whereas the current study focused on relationships between IOT patients and staff or other patients as key to engagement with treatment, other studies focused on health and external factors that were barriers to engagement. For example, a qualitative study of 20 program leaders and clinicians from 12 IOT programs identified physical symptoms, mental illness, care fragmentation, lack of social support, and poor social and neighborhood conditions, such as poverty, food insecurity, family discord, and health literacy challenges, as barriers to treatment (Zulman et al., 2018).

The current study adds to the literature as it is the first to present a central psychosocial process to describe how persons with OUD experience IOT over time. The focus on connections and disconnections and how these processes intersect provides a dynamic view of persons' experiences in IOT.

Limitations

Study findings should be considered in the context of several limitations. First, because all participants identified as White, conclusions cannot be drawn about the experiences of persons of color as it is likely they have different experiences in IOT than White persons. For example, several studies suggest that there are racial/ethnic disparities in substance use treatment attrition as Black and Hispanic persons are less likely to complete treatment compared to White persons (Mennis & Stahler, 2016; Saloner &

Cook, 2013; Stahler & Mennis, 2018). Future research should therefore ensure inclusion of participants from diverse racial/ethnic groups so researchers can explore possible group differences in IOT experiences. Second, participants were recruited from two IOT programs within one health system. The findings could therefore reflect the unique substance abuse treatment philosophy and practices of the health system and not be generalizable to other programs. Larger studies of persons in a variety of IOT programs in different geographical locations are warranted. Third, this study was initiated during the COVID-19 pandemic. Considering 13% of Americans increased or initiated substance use during COVID-19 (Czeisler et al., 2020), the experiences of participants might not have been typical. Moreover, the timing of the study presented challenges for recruitment as the study settings temporarily shut down and programs were transitioned to virtual delivery. As a result, whereas 20 to 30 participants are typical for grounded theory studies (Grove, Burns, & Gray, 2013; Morse, 1994), the research team was only able to enroll 14 persons because the pandemic constrained the patient census in each of the programs. Although a larger sample might have enabled a more detailed theoretical framework, recruiting was stopped at 14 because these persons provided enough information to develop a robust framework and repeating patterns were noted in the interviews. Future research should explore IOT participation in a larger sample outside the context of a global pandemic.

Implications

Findings from this grounded theory study can be used by to facilitate discussions with patients regarding the connections and disconnections they experience as they progress through the program. Morse, Hutchinson, & Penrod (1998) have suggested that

qualitatively derived assessments guides can be developed by researchers and used by clinicians to facilitate conversations with patients on topics that qualitative study findings indicate are salient. Major findings are reformulated as open-ended questions that probe relevant topics. For example, patients' experiences *connecting with IOT* could be explored by querying how they decided to begin the program, how they are "settling in," and how they are "learning the ropes." Table 3 provides examples of an assessment guide with potential open-ended questions that could be used to explore how patients are moving through the stages of *connecting and disconnecting* as their IOT experience unfolds.

Connecting and	Description	Open-ended Questions
Disconnecting Stage	•	х с
Connecting with the IOT	First becoming engaged	How did you decided to begin the
program	with the program	program at this time?
Deciding to connect with		What has it been like for you to start the
the IOT program		program?
Making the first connection		How are you "settling in"? Can we help
with the IOT program		you with that?
Coming to feel connected		How are you "learning the ropes"?
with the IOT program		
Connecting with others in the	Building meaningful	What has it been like for you to share
IOT program	relationships with other	your stories in group?
Sharing one's story with	patients and staff in the	How have you connected with others in
others Bonding with IOT	program	the program?
patients		How have you connected with members
Bonding with IOT staff		of the staff in the program?
Disconnecting from drugs	Obtaining sobriety	Tell me about hope you have for your
Havinghopeaboutmoving		sobriety.
beyonddrugs		What has it been like seeing others
Seeing others move beyond		become sober?
drugs Working to move		What work do you see as most important
beyonddrugs		for you to become sober?
Connecting with MOUD		How has MOUD fit in with your
C		recovery?
Connecting with others outside	Seeking engagement with	Who in your life is important to your
the IOT program	important people in one's	sobriety?
	life outside the program	What is your relationship like with them
	as one becomes sober	now?
		What new relationships might you like to
		form?

Reconnecting with self	Building a new relationship with oneself as one becomes sober	How have you looked at yourself differently while becoming sober?
Disconnecting from the IOT program	Graduating from or leaving the program	What will tell you when you are ready to leave the program?

The study findings also underscore several issues IOT staff should consider as patients move through each of the stage. During the stage *connecting with the IOT* program, participants indicated that an "easy" assessment or intake process encouraged them to come back the second day. Staff should therefore ensure that entry to the program for newly enrolled patients is a non-threatening and welcoming process. However, many participants experienced anxiety prior to engagement in group work and felt particularly vulnerable when asked to share personal experiences. Clinicians should allow time and space for patients to gradually settle into groups and disclose at their own pace. Connecting with others in the IOT program was an integral stage, and clinicians should facilitate the exchange of shared experiences between IOT group members and encourage supportive and trusting relationships with a variety of staff members. One participant who left the program when staff shared what he thought was private information with other staff provided an example of dire consequences that can occur when trust with staff is broken. Several participants felt particularly connected to staff who had addiction histories, and IOT program administrators should consider the importance of including staff who have had personal experiences with recovery.

Findings related to the stage *disconnecting from drugs* suggested that beginning sobriety was a multi-dimensional process that included becoming hopeful, committing to the program, taking advantage of program activities, adopting new ways of thinking, learning new behaviors, taking MOUD, and connecting with 12-step programs. These findings reinforce that IOT programs need multiple components as recovery is a complex process that evolves over time. Moreover, findings that participants reconnected with others and certain aspects of themselves toward the end of treatment suggests that these issues are important topics for discussion as persons prepare to leave IOT. Some participants indicated that graduation ceremonial activities helped them view themselves in new ways.

As mentioned above, changes in the programs' delivery due to COVID-19 was disruptive for some participants, especially those who just entered the program. IOT programs depend heavily on group and staff interactions, and programs will likely need to refine procedures for remote delivery and evaluate their effects on patient recovery.

CONCLUSION

Findings from this study suggest that the unfolding of persons' experiences in IOT programs are described as *connecting and disconnecting*. Connections and disconnections are highly linked as persons connect with drugs they disconnect with other aspects of their lives and as they disconnect from drugs they reconnect with other aspects of their lives. Connections with the IOT program, other patients, and IOT staff are central to beginning sobriety. Although the findings were limited by the homogeneity and size of the sample, the findings indicate that clinicians should foster these connections and provide a multi-dimensional experience that enable patients to begin recovery.

CHAPTER FOUR

INTRODUCTION

Patient activation occurs when persons have the motivation and ability to manage their own health and healthcare (Greene & Hibbard, 2012). Patients with high activation self-manage their illnesses, access high quality care, collaborate well with health care providers, and engage in activities to optimize their health (Hibbard et al., 2004). Activation exists on a continuum and includes four stages: (1) believing in the importance of an active role in health, (2) possessing confidence and knowledge to take action, (3) taking action, and (4) maintaining health behaviors in the presence of stress (Hibbard et al., 2004).

High patient activation is associated with many positive health benefits among persons with chronic illness. These benefits include receiving more preventative care, engaging in healthy eating habits and exercise (Hibbard & Greene, 2013), having fewer hospitalizations and less emergency room use (Kinney et al., 2015), and experiencing enhanced recovery from surgery (McDonall et al., 2019). Moreover, high patient activation is associated with increased physical functioning, better health selfmanagement, and lower healthcare costs (Hibbard et al., 2015). Conversely, low patient activation is associated with lower illness self-management knowledge, more risky substance use, poorer medication adherence, and more hospital visits (Hibbard et al., 2015).

While levels of activation are associated with a wide variety of health effects in persons with chronic illness, the role of activation in recovery from opioid use disorder (OUD) is unclear. OUD is a national public health crisis that has affected approximately

two million Americans (Substance Abuse and Mental Health Services Administration, 2019). A diagnosis of OUD is based on distress or significant impairment caused by problematic use of opioids (Centers for Disease Control and Prevention, n.d.). The mortality rate of persons with OUD is more than 20 times higher than the general population (Saha et al., 2016). From 1999-2017, opioid overdoses led to approximately 400,00 deaths in the United States (Scholl et al., 2019), and the annual social and economic cost burden is estimated at \$78.5 billion (Florence et al., 2016). Several effective treatments are available for persons with OUD, including behavior therapies, individual and group counseling, and medication (American Psychiatric Association, 2018). Experts estimate, however, that only 20% of persons with OUD receive substance abuse treatment (McCance-Katz, 2018), and retention rates in treatment programs range from 12 to 84% (Dalton et al., 2021). Moreover, relapse rates for persons with OUD range from 40 to 60% (American Addiction Centers, 2020).

Improving activation in persons with OUD might be one way to increase engagement with treatment and improve outcomes in this population (Weisner et al., 2016). Although only a few studies have explored activation in persons with any type of substance use disorders (SUD), evidence from these studies indicates high patient activation is associated with less substance use, better illness self -management (Salyers et al., 2009) and fewer depressive symptoms (Singla et al., 2020). Moreover, qualitative studies with persons involved in substance use treatment reveal a connection between treatment engagement and belief in one's ability to leverage program resources (Dillon, Kedia, Isehunwa, & Sharma, 2020) and having an active role in decision-making (Neale et al., 2013). Evidence-based activation interventions, therefore, may be a useful

component of substance use treatment. For example, an intervention using the electronic medical record and a patient activation approach to link persons receiving addiction treatment with healthcare revealed the intervention was effective in helping patients engage in healthcare and increase communication with their physicians (Weisner et al., 2016).

Patient activation may be particularly important for persons with OUD who are receiving intensive outpatient treatment (IOT). IOT provides ambulatory services that allow persons to stay in their homes and communities while learning early-stage coping strategies and relapse management (McCarty et al., 2014). These programs are considered standard care for entry into treatment and early recovery (Substance Abuse and Mental Health Services Administration (US), 2006). IOT programs are associated with positive outcomes such as increased abstinence days and decreased problem severity (D. McCarty et al., 2014) but have attrition rates as high as 80% (Loveland & Driscoll, 2014). While the goal of substance abuse treatment is to increase the ability of persons to self-direct their lives to improve their health and well-being to obtain sobriety (National Institute on Drug Abuse, 2017b), improving activation would seem to be an important treatment goal in IOT programs. However, little is known about how patient activation is manifested or addressed in IOT.

The purpose of this study is to describe types of instances in which persons play an active role in their IOT or show self-determination in their recovery more generally (activation) and, conversely, types of instances in which they play a passive role in their IOT or have their recovery directed by others (non-activation). This typology will inform

the development of strategies to enhance activation, and ultimately improve program engagement and treatment outcomes, in persons with OUD receiving IOT.

METHODS

Data for this analysis were drawn from a larger study using grounded theory methods to explore how persons with OUD experience IOT (Keen, Lu, & Draucker, 2021). Inclusion criteria for the study were (1) age \geq 18 years old, (2) ability to read/speak English, and (3) OUD diagnosis. Exclusion criteria were presence of (1) cognitive impairment impacting daily activity performance, (2) severe health issues, and (3) significant mental health issues not controlled by medication.

Recruitment was conducted in two IOT programs within a large healthcare system in the Midwest. After receiving Institutional Review Board approval from the researchers' institution and approval from the IOT programs, a chart review was conducted to compile a list of eligible persons (n = 94). Eligible persons were sent information about the study by letters and texts that invited them to contact the principal investigator (PI) if they were interested in participating. Twenty -one persons contacted the PI, and 14 enrolled in the study. The seven participants who did not enroll met criteria but did not respond to subsequent contacts by the PI. Verbal consent was obtained prior to scheduling interviews. Data were collected from September 2020 to April 2021. . Recruiting procedures ceased after 14 interviews for the larger grounded theory study because repeating patterns emerged in the interviews and sufficient data was generated to develop a robust framework (Keen et al., 2021).

Interviews were conducted by the PI who is a doctoral candidate in nursing with training in qualitative research (AK). Due to COVID-19 pandemic restrictions, interviews

were conducted mainly via teleconferencing. Interviews ranged in length from 31 to 75 minutes, with an average of 57 minutes. A semi-structured interview guide was used to conduct the interviews. The interviews began with the following statements: Tell me about your experiences in your IOT recovery program. I am interested in how you came into the program, how you adjusted to the program, and how you experienced the program as your treatment unfolded. I am interested in both what went well and what was difficult. Short probes were used to elicit descriptions of program activities and participants' progression through IOT. Toward the end of the interview, several questions were asked specifically related to activation. Examples of these questions included the following: (a) What were some of the important decisions made about your treatment while you were in the IOT program?, (b) To what extent do you feel like you were in charge of your treatment?, (c) Tell me about some of the decisions that you made while you were in the program, and (d) Tell me about some decisions others made for you. Demographic data were collected at the end of each interview. The interviews were recorded and transcribed. Field notes were made during and at the completion of each interview.

Additional information about study procedures and the resulting theoretical framework are presented elsewhere (Keen et al., 2021). While grounded theory guided the larger study, a qualitative descriptive approach (Sandelowski, 2000) was used to explore activation more specifically. This approach yields a comprehensive summary of narrative text based on the surface words of the participants rather than an abstract rendering of data (Sandelowski, 2000). This approach was chosen as the aim was to create a typology that provides a straightforward listing and description of the instances

of activation and non-activation that appeared in the participants' transcripts. Presentation of findings were guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ), a comprehensive checklist designed to improve reporting of interview studies (Tong et al., 2007).

Data were analyzed using content analysis (Miles, Huberman, & Saldana, 2018), a common data analysis approach used in qualitative descriptive studies (Sandelowski, 2000). A team approach to data analysis was used. AK first extracted any text unit (e.g., word, short phrase, sentence) from the transcripts in which a participant discussed instances of activation or non-activation based on the definition of activation provided above. These data were either embedded throughout the transcripts or provided in response to the interview questions related to activation as described above. Although we recognize that activation occurs along a continuum, for the purpose of this analysis, text units in which participants clearly described themselves as active in their IOT treatment or in their recovery were labeled as "activation" and text units in which participants clearly described themselves as passive in their IOT treatment or in their recovery were labeled as "non-activation." AK then coded the text units with a short phrase that captured the essence of each example of activation or non-activation.

To verify the codes, two senior nurse scientists with expertise in qualitative research or activation (YL, UO) independently coded the transcripts using the same procedures. AK and a senior nurse scientist with expertise in qualitative research (CBD) compared codes assigned by AK and those assigned by other team members. To reflect agreement, codes did not need to be worded identically but needed to reflect a similar meaning. Because the data were straightforward and did not depend on a high level of

interpretation, there were few discrepancies in coding, and any discrepancies were easily resolved by a re-examination of the data.

AK and CBD met to discuss the final codes and, with the use of data display tables, grouped similar codes into categories to create a typology that reflected a variety of ways in which instances of activation or nonactivation were revealed in the participants' transcripts. AK developed a narrative description of the typology and included verbatim quotes from participants as supporting evidence. The results were reviewed by CBD, YL, UO, and a senior scientist with expertise in health policy and management (OM).

RESULTS

The sample included 14 adults ages 23 and 56 diagnosed with OUD who had attended one of two IOT programs. Five were men, and nine were women. All identified as White. Six types of instances in which persons played an active role in their IOT or recovery from OUD were identified in the participants' narratives. We refer to these as activation instances. For many of these instances, there were also corresponding instances in which persons played a more passive role in their treatment or recovery. We refer to these as nonactivation instances. Types of activation instances included the following: (1) making and enacting one's own treatment decisions, (2) actively collaborating with staff, (3) self-determining one's disclosure in groups, (4) making a commitment to treatment, (5) taking responsibility for one's recovery, and (6) taking actions to avoid relapse. These types are described below, and when applicable, corresponding types of non-activation instances are described as well. Verbatim quotes from participant transcripts that exemplify each of the types are provided.

Making and Enacting One's Own Treatment Decisions

Activation. Participants described instances in which they were actively involved in their own treatment decisions or made treatment decisions autonomously. Some participants made an independent decision to attend IOT. These participants determined they were "ready for a new chapter." A 38-year-old man who was in the program for three weeks said, "I was there of my own volition. If I really didn't want to do it (IOT), I could have just left." Once they had made the decision to seek treatment, several decided what program they would attend. They made these decisions based on program reputation, location, and procedures used to ensure patient anonymity. Some participants made their own decisions about medications for opioid use disorder (MOUD) – whether to take medication, what medication to take, and when to "wean off it." A 27-year-old woman who spent about eight weeks in the program said, "I wanted to get off my suboxone... I wanted to get off of that and I got to do that in a safe environment (residential program)." A few participants decided that the IOT program they were attending did not meet their needs and sought out a different program they believed was better suited for them.

Non-activation. Conversely, participants described instances in which others made, or heavily influenced, the participants' treatment decisions. Several participants enrolled in IOT only because it was a requirement of their residential living arrangement, and others enrolled in IOT because it was required for them to receive MOUD. Some sought treatment at the insistence of a family member or a healthcare provider and were thus less engaged in the program. A 31-year-old woman who was in the program for about two weeks said, "I don't think I was ready to get sober to be honest. I think I went

because of my mom. I think that is why I relapsed right after I left treatment." A couple of participants attended IOT because an employer or professional organization dictated they enroll. A 41-year-old nurse who had diverted drugs at work and who was in the program for about eight months said, "I self-disclosed (the drug diversion).... In order to keep your (nursing) license, you have to go through the [state] Professionals Recovery Program . . . The case worker determined my treatment plan (IOT)."

Actively Collaborating with Staff

Activation. Participants described instances in which they actively collaborated with staff in the IOT program to determine a treatment plan. Many participants received recommendations from staff regarding their treatment but took ownership of setting personal goals. A 38-year-old man who was in the program for three weeks said, "Talking to the counselors and going over what I'm doing for recovery and what I was going to do going forward (was most helpful in the program)." Some participants described shared decision-making regarding their MOUD. These participants informed staff what medications had worked well for them in the past and discussed concerns about symptoms such as anxiety and sleep loss. A 23-year-old man who was in the program for about three weeks said, "I got to pick the medication I had been on before and what works best for me."

Non-activation. Conversely, participants described instances in which they felt they lacked autonomy because staff "took control" of some aspects of their treatment. Several participants were particularly bothered by being monitored by IOT staff. Some resented that staff did daily breathalyzer tests or random drug screens, and others disliked that staff monitored their attendance by having participants "sign in." A 23-year-old man

who was in the program about three weeks said, "I understand it (the monitoring), but part of me was like 'We're all adults.' I felt like I was in preschool when we would line up . . . There was someone standing outside of the bathroom door (during urine collection)." A few participants felt MOUD decisions were driven by staff. A 43-year-old man who was in the program about four weeks said, "They prescribed it (MOUD). They were the ones that told me this is what you need to take and start on that immediately. And I was just listening." A few participants indicated that staff alone determined if participants were ready to graduate. A 33-year-old woman who was in the program for six weeks said:

They (IOT staff) meet with you once a week to talk about your progression . . . Once you do all of those things (program milestones) and they feel like you are in a good place or there is not much more for them to offer in the program . . . (They say), 'It's time for you to spread your wings and learn how to be sober in the real world.'

Self-determining One's Disclosure in Groups

Activation. Participants described instances in which they took charge of their group participation by determining when and how much they wanted to reveal in group. Some took the time they needed to feel comfortable before sharing their "stories," whereas others were able to share early in the program. A 41-year-old woman who was in the program about eight months said, "I just told my whole story (on the first day). I found out later, 'Wow you opened up on that first day. Most people don't." Many participants felt vulnerable discussing sensitive issues such as past abuse or ways they had hurt others by their addiction but decided to risk disclosing these experiences as they believed it would aid in their recovery. A 33-year-old woman who was in the program for six weeks said: There are a lot of really bad things that you did and said and situations that you put yourself in in active addiction.... They are hard conversations that have to take place. Topics that you have to explore if you want to stay sober.

Non-activation. On the other hand, some participants felt pressured by staff to participate in group and divulge personal experiences, perhaps before the participants were ready. A couple of participants felt "nudged" to engage in group discussions or chided for not talking during group. A 26-year-old man who was in the program for about four months said, "They (IOT staff) would say, 'As long as you show up and participate, you don't have to talk'... (Then) they would yell at me (in group) for not talking."

Making a Commitment to Treatment

Activation. Participants described instances where they made a definite commitment to "stick with" the program and "finish what they started." A 39-year-old woman who was in the program for five weeks said she decided "to continue going (to IOT) when I moved out from the [sober living house] and deciding I was going to graduate. I wasn't going to give up on the program." Some participants were determined to keep doing "the next right thing" to graduate from the IOT program. A 38-year-old man who was in the program for three weeks said, "I was committed to finishing it (IOT) ... You know going to meetings, be in touch with people, have a sponsor, work the steps ... I was going to stick with it."

Non-activation. Conversely, a few participants described instances where their continued participation in IOT was motivated by external influences rather than an internal sense of commitment. These participants kept going to IOT because others insisted the participants should complete the program or participants felt they had no choice. A 26-year-old man said, "They (IOT staff) put in your head every day that you

aren't good enough and you are a drug addict . . . They want you to think that you need them." A 32-year-old woman who was in the program for six weeks considered leaving

IOT midway through the program. She said:

I voiced that I was feeling that way (ready to leave the program) to one of the staff and it got me an individual counseling session. They quickly found all of the reasons that I needed to finish and continue . . . What I had to lose was my sober living arrangement . . . That nudged me to finish because if I didn't complete IOT or dropped out of the program I would immediately be removing myself from the sober living house.

Taking Responsibility for One's Own Recovery

Activation. Participants espoused a general philosophy that persons with addiction are fundamentally responsible for their own sobriety. Some indicated they had to "choose abstinence," "take charge to stay on the right path" or take "ultimate accountability for sobriety." A 27-year-old woman who was in the program for about eight weeks said:

Everyone's sobriety is 100% their responsibility. I don't believe that relapse is anyone's fault but your own. While we all have triggers, we are taught coping skills and it is our responsibility to use our coping skills and not put ourselves in situations where we would relapse and to handle situations where we would relapse.

Non-activation. In contrast, some participants indicated that they were not

capable of assuming responsibility for sobriety, especially early in their treatment. Some

believed that because they were addicted, they had to abdicate responsibility for their

sobriety to others, at least initially. A 41-year-old woman who was in the program about

eight months said:

You can't rely on the patients to make all the decisions or choices because that's what got you there in the first place. It's your bad choices. They have to have some control over us because it's a fine balance between letting us make our own choices and then making it for us. We obviously aren't the best choice makers or we wouldn't have been there.

Taking Actions to Avoid Relapse

Activation. Participants described instances in which they actively engaged in actions to stay sober. Many implemented coping strategies they learned in IOT. They used non-opioid pain management strategies to deal with chronic pain, "filled time to stay sober," set boundaries with others, and practiced anger management and assertiveness. Several participants avoided "people, places, and things" from their past to maintain sobriety. A 43-year-old man who was in the program about four weeks said, "The friends that I use to have I don't have. I have secluded myself. I have changed my whole environment and that has worked well for me." Many participants attended narcotics anonymous (NA)/alcoholics anonymous (AA) meetings outside IOT and obtained a sponsor. A 32-year-old woman who was in the program for six weeks said, "For me, personally, IOT combined with going to outside meetings combined with working with a sponsor has been successful. IOT kind of laid some groundwork for later steps and work that I would do."

Non-activation. Conversely, a few participants engaged in actions that lead to, rather than helped avoid, a relapse. These participants described instances where they resumed interactions with people and frequented places that had been part of their "addiction lifestyle." A 31-year-old woman who was in the program about two weeks said, "The people I hang out with [in hometown] are my friends but not the good kind. Every time I come back, I usually relapse." In some cases, participants reconnected with persons who supplied their drugs. A 25-year-old woman who was in the program about six weeks said, "I had forgotten my suboxone . . . I pass through [town] and I stopped at my person's (dealer) house and got some heroin and meth."

DISCUSSION

A typology was developed that includes six types of instances of activation and corresponding instances of non-activation in persons with OUD who attended an IOT program. The instances of activation/nonactivation were evident in a variety of realms – when participants made treatment decisions, engaged with staff, participated in treatment groups, and engaged in efforts to achieve sobriety – as well in their attitudes toward treatment and their own responsibility for recovery. Participants provided rich examples of experiences in which they were active in directing their treatment, self-managing their recovery, and assuming responsibility for their sobriety as well as examples of when their addiction precluded such activation.

Given our study design, we cannot make a causal claim that activation led to improved program engagement or treatment outcomes. Nevertheless, the participant examples that supported the typology indicate the participants generally felt that an active role in their treatment was important to their success in the program. For example, participants linked making their own decisions to enter treatment with completing the program, whereas they linked others making that decision for them with relapse. Similarly, actively collaborating with staff and self-determining one's disclosure in group were associated with satisfaction with the program and positive connections to staff, whereas having staff monitor participants' behaviors was connected to disgruntlement with staff. Moreover, participants clearly associated making a commitment to treatment, taking responsibility for one's own recovery, and taking actions to avoid relapse with sobriety success.

Several of our findings resonate with findings of prior studies of activation conducted with a variety of populations. For example, our overarching finding that activation plays a salient role in IOT is similar to the findings of a qualitative study examining the critical ingredients of an integrative rehabilitation program from the perspectives of therapists and patients with brachial plexus injuries (Janssen et al., 2019). The therapists and patients both reported that it was important for patients to self-manage their own recovery (Janssen et al., 2019), and the therapists remarked that "ultimately the patient is in charge" (Janssen et al., 2019, p. 1432). Our finding that collaborative interactions with staff were foundational to activation was similar to the findings of several studies. For example, a study of patients receiving treatment in mental health centers found that the strength of the therapeutic alliance was an important predictor of change in activation (Allen et al., 2017). The authors concluded that "improving patient activation may require addressing patient-provider interactions such as coming to collaborative agreement on the tasks/goals of care" (Allen et al., 2017, p. 431). Moreover, a study of the effects of clinical encounters on depressive symptoms in young adults revealed that patient-provider communication and self-appraised communication skills directly affected patient activation, which in turn directly affected depressive symptoms (Pinto et al., 2017).

Our findings also raise some issues that have not been well addressed in prior studies. While most instances of activation were described by participants in a generally positive light, a few maintained that they were not ready to take an active role in their treatment planning early in recovery. These participants welcomed it when staff made decisions for them and feared that "too much" autonomy would increase their risk of

relapse. An essay on the ethics of patient activation raises the issue of the potential harm of activation approaches in which patients are encouraged to adopt attitudes of selfefficacy toward behaviors they are unlikely to achieve and as a result develop a sense of hopelessness (Gibert, DeGrazia, & Danis, 2017). Our participants' suggestion that such a focus on self-determination early in treatment can impede rather than enhance recovery should be considered further. Moreover, a focus on autonomy and agency, key aspects of activation, can come into tension with some traditional recovery program philosophies and strategies. For example, many 12-step approaches includes steps such as "admitting powerlessness over the addiction" and "deciding to turn control over to a higher power" (American Addiction Centers, 2021). The ways in which activation approaches can be best integrated with such philosophies with persons with OUD need to be further explored. Finally, our findings indicate that activation occurs in several realms, and this calls into question the conceptualization of activation as a single state or a series of progressive stages (Gibert et al., 2017; Hibbard et al., 2004). The term "activated" patient is commonly used as an overarching term, but our findings indicate persons may be "activated" in one realm (i.e., making a commitment to treatment) but not in other (i.e., taking actions to avoid relapse). This finding suggests that multidimensional nature of activation might need to be considered in the measurement of the construct.

Practice Implications

High activation in mental health populations is associated with high treatment engagement (Allen et al., 2017; Eliacin et al., 2015) and improved treatment outcomes (Mccusker et al., 2016; Sacks et al., 2014). Such findings suggest that incorporating activation approaches in treatment for persons with OUD is likely to be beneficial as

well, although no such approaches have been developed and tested for this population. However, several educational programs to increase activation in persons with mental health disorders have been shown to be effective (Muralidharan et al., 2019; Turner et al., 2015), and these programs might be adapted for persons with OUD. For example, a communication-focused intervention with a patient (DECIDE-PA) and a clinician (DECIDE-PC) component was designed to improve patient activation in behavioral healthcare clients by enhancing their capacity for learn about their illness, communicate what they need, discuss their treatment options, and ask providers questions about their care (Chiang, 2019). Such an approach, if modified, might effectively improve activation in persons with OUD and could easily be provided as a component of IOT.

Beyond the need for an evidence-based activation intervention, the results of our study indicate that IOT treatment staff should engage in best practices to ensure persons with OUD are actively involved in their treatment. These practices would include encouraging mutual goal-setting and shared decision-making (Allen et al., 2017), establishing a strong working alliance (Eliacin et al., 2015), bolstering patients' commitment to "sticking with" treatment, and supporting active strategies to prevent relapse. Our findings also suggest, however, that an ill-timed focus on activation early in treatment might be problematic. IOT staff need to consider persons' stages of recovery to determine how they might best benefit from taking on an active role in their treatment. For example, working collaboratively with staff to establish small goals might be indicated for persons with OUD before focusing on acquiring additional knowledge and skills to self-manage recovery while advancing through the program.

Limitations and Future Research

The findings should be considered in light of some study limitations. The study was conducted in two programs within the same health system in the Midwest, which limits the generalizability of the findings. In addition, all participants in the study sample identified as White, limiting conclusions that can be drawn about activation among persons from racial/ethnic minorities who receive IOT. The level of activation of the participants was not measured with a standard instrument such as the PAM (Hibbard et al., 2004), and thus conclusions cannot be drawn about how overall levels of activation are associated with the types of instances of activation. Moreover, IOT staff were not interviewed so their perspectives do not inform the findings about patient/staff interactions that contribute to or detract from activation as described by participants.

Considering these limitations, we recommend larger studies be conducted that draw participants from several IOT programs with diverse populations in order to describe the role of activation in IOT programs more fully. A mixed methods approach could be used to quantitatively examine associations among objective indices of activation, program engagement (e.g., enrollment and recruitment), and program outcomes (e.g., abstinence) and qualitatively analyze patient and staff narratives to explain these associations. Ultimately, researchers should adapt and test current activation interventions that are effective in improving outcomes in other populations. Finally, because our findings suggest activation is a multi-dimensional phenomenon that may benefit patients to different degrees at different times, we agree with Gilbert et al. (2017) that additional conceptual and ethical analysis of the concept of activation is needed, especially in an OUD population.

CONCLUSION

The findings of this study indicate that activation is a multi-dimensional experience and instances of both activation and non-activation are common in the IOT experience. While instances of activation are typically experienced positively by participants and seem to contribute to treatment engagement and positive program outcomes, activation approaches introduced too early in treatment may also impede recovery. IOT staff should thus leverage best practices to engage patients as active participants in mutual goal-setting and shared-decision at a measured pace. Future research on activation in IOT should include multiple settings with diverse populations to provide a more nuanced understanding of the role of activation in IOT treatment. Based on findings from these studies, activation interventions found effective with other populations could be adapted and tested for persons with OUD.

CHAPTER FIVE

INTRODUCTION

The purpose of this dissertation is to describe how persons with OUD experience intensive outpatient treatment (IOT), especially regarding activation. The specific aims are to (1) synthesize studies of activation in persons with mental health disorders generally, (2) describe the experiences of persons with OUD in IOT from enrollment through program departure, and (3) identify instances of activation in IOT.

The dissertation includes three components and findings are disseminated in Chapters 2, 3, and 4. Chapter 2 presents an integrative review that identifies factors associated with levels of activation and interventions shown to be effective at increasing levels of activation in persons with mental health disorders. Chapter 3 presents a grounded theory study conducted to describe processes people with OUD undergo as they participate in an IOT program. Chapter 4 presents a qualitative descriptive study conducted to describe types of instances in which persons play an active role in their IOT or show self-determination in their recovery generally (activation) and, conversely, types of instances in which they play a more passive role in their IOT or have their recovery directed by others (non-activation). Chapter 5 provides a synthesis of the findings of the three components by identifying cross-cutting themes, discussing the findings through the lens of *patient activation theory* (Hibbard & Mahoney, 2010), and summarizing the strengths and innovation, limitations, research implications, and clinical implications of the dissertation.

SYNTHESIS OF FINDINGS

Key Finding 1: For persons in treatment for OUD, and for mental health disorders more generally, a strong collaborative relationship with providers or staff is an important component of treatment and has been shown to be associated with high activation.

Each of the three components of the dissertation reveal the importance of collaborative relationships in mental health and/or substance use treatment. The integrative review (Chapter 2) provides some evidence that the nature of treatment relationships between persons with mental health disorders and their providers are associated with activation. Specifically, some studies revealed that activation is enhanced if patients and providers agree on tasks and goals of treatment, the dyad has a strong working alliance, and communication between patients and providers is strong. The grounded theory study (Chapter 3) builds on these findings by focusing on persons with OUD in IOT. The findings from this study reveal that bonding with IOT staff was critical to participants' progression in the program. Participants felt connected to staff who were non-judgmental, caring, and empathic and felt especially allied to staff who also had an addiction history. Findings from the qualitative descriptive study (Chapter 4) provide further evidence about the importance of collaborative relationships with providers for enhancing activation. Engaging collaboratively with staff was one of the instances of activation identified in the typology; participants appreciated treatment recommendations from staff but valued taking ownership of their own treatment goals. Taken together, these three sets of findings point to the benefits of collaborative relationships with providers and treatment staff as a strong alliance, good communication, and shared

decision-making provide the foundations of positive treatment experiences which in turn can enable activation.

Key Finding 2: The experience of IOT unfolds as a series of stages involving connecting and disconnecting from drugs, others, the IOT program, and oneself and includes a variety of instances of activation and non-activation.

The findings of grounded theory study (Chapter 3) and the qualitative descriptive study (Chapter 4) taken together provide an in-depth description of how persons with OUD experience IOT. The grounded theory study (Chapter 3) yielded a theoretical framework that depicts how experiences of connecting and disconnecting intersected in a variety of ways as the IOT program unfolded. For example, participants revealed that it was their connection with the IOT program, other patients in the program, and IOT staff that enabled their disconnection from drugs, which in turn allowed them to reestablish important connections outside the IOT. The qualitative descriptive study (Chapter 4) used data from the grounded theory study to focus specifically on the experience of activation in IOT. The variety of types of activation and non-activation identified in this study reveals that activation is important in IOT and is evident in several different realms.

The findings of the grounded theory study (Chapter 3) and the qualitative descriptive study (Chapter 4) overlap as types of instances of activation can be linked to the stages of connection and disconnection. For example, making one's own treatment decisions (instance of activation) often played a role in connecting with the IOT program (stage of connection/disconnection) as participants stressed that they were more likely to engage in the program if they, rather than important others, drove the decision to enter IOT. Making a commitment to treatment (instance of activation), taking responsibility for

one's own recovery (instance of activation), and taking actions to avoid relapse (instance of activation) played a role in disconnecting from drugs (stage of connecting/ disconnecting) as participants clearly connected taking an active role in their recovery to success at obtaining sobriety.

Key Finding 3: Activation is a complex and multidimensional construct associated with a variety of positive health effects, although ill-timed use of an activation approach raises some ethical and clinical issues in persons with OUD.

The integrative review (Chapter 2) included several studies that found associations between levels of activation and a wide variety of health factors in persons with mental health disorders. Positive associations were found between high levels of activation and better health status and functioning, lower depression, greater degrees of positive health attitudes such as hope and perceived recovery, and better illness selfmanagement. Consistent with these findings, the qualitative descriptive study (Chapter 4) revealed that instances of activation seemed to benefit participants in their IOT program as most indicated that being active in their treatment enhanced their experiences throughout the program. However, a few participants maintained that they were not ready to take an active role in their treatment planning early in recovery and feared that "too much" autonomy would increase their risk of relapse early in recovery. This finding speaks to the complexity of the construct of activation as it suggests that support and direction, rather than autonomous decision-making, may be more beneficial early in treatment. Moreover, most of the studies in the integrative review (Chapter 2) measured activation as a single dimension, whereas the results of the qualitative description study (Chapter 4) suggests that activation is manifested in a variety of realms (e.g., treatment

decisions, actions to achieve sobriety, views of self in the recovery process) and may be a multi-dimensional phenomenon. These findings taken together suggest activation is complex experience that occurs in a variety of realms and functions differently at different stages of recovery. The implication of this conclusion is that increasing activation in persons with OUD is likely associated with positive outcomes but promoting activation too early in treatment may possibly cause harm.

DISSERTATION FINDINGS AND PATIENT ACTIVATION THEORY

The theoretical foundation for the dissertation was *patient activation theory* (Hibbard & Mahoney, 2010), as described in Chapter 1. In summary, the theory outlines four stages through which patients gain the knowledge, skills, and behaviors needed to manage their own health. The stages are (1) recognizing the importance of playing an active role in one's health, (2) gaining the knowledge, skills, and confidence to take action, (3) taking action, (4) continuing positive health behaviors in the presence of stress (Hibbard et al., 2004). The theory also includes four levels of activation: Disengaged and Overwhelmed (Level 1), Becoming Aware but Still Struggling (Level 2), Taking Action and Gaining Control (Level 3), and Maintaining Behaviors and Pushing Further (Level 4). The framework originally focused on activation in chronic physical illnesses, but has since been applied to mental health disorders. Applications of the theory call for the integration of patients into the healthcare team and encouraging patients to play an active role in their health (Hibbard & Greene, 2013).

Several of the constructs in the *patient activation theory* (Hibbard & Mahoney, 2010) were evident in the findings of the dissertation. For example, the underlying premise of *patient activation theory* (Hibbard & Mahoney, 2010) – that activation leads

to positive health benefits – was supported by the integrative review (Chapter 2) that revealed associations between activation and a number of indices of health and wellbeing and positive health behaviors. Moreover, the typology from the qualitative description study (Chapter 4) shared many constructs with the *patient activation theory* (Hibbard & Mahoney, 2010), including active decision making, personal responsibility, and collaborative relationships with providers, as well as with the general premise that being actively involved in one's healthcare (or IOT) is associated with a number of positive health benefits (or sobriety).

The stages of the *connecting/disconnecting framework* developed in the grounded theory study (Chapter 3) share many parallels with the levels of *patient activation theory* (Hibbard & Mahoney, 2010). For example, stages 1 and 2 of the *connecting/disconnecting framework* – connecting with drugs and disconnecting from everyday life - resemble Level 1 of patient activation theory (Hibbard & Mahoney, 2010) – disengaged and overwhelmed. These stages/levels highlight persons who are not actively engaged in their healthcare (or recovery) and who lack goal-orientation. Stages 3 and 4 of the *connecting/disconnecting framework* – connecting with the IOT program and connecting with others in the IOT program – resemble Level 2 and 3 of patient activation theory (Hibbard & Mahoney, 2010) – becoming aware but still struggling and taking action and gain control. These stages/levels highlight persons who are becoming goaloriented about their healthcare (or recovery) and beginning to make good use of services. Stages 5 through 8 of the *connecting/disconnecting framework* – disconnecting from drugs, connecting with others outside the IOT program, reconnecting with self, and disconnecting from the IOT program - resemble Level 4 of patient activation theory

(Hibbard & Mahoney, 2010) – maintaining boundaries and pushing further. These stages/levels highlight persons who adopt new health behaviors and who maintain a healthy lifestyle (or sobriety).

STRENGTHS AND INNOVATION

This dissertation is the first study to provide an in-depth description of the experiences of persons with OUD who receive IOT and to explore activation in persons with OUD and mental health disorders. The findings of the dissertation were unique in that the integrative review (Chapter 2) provided a broad-based overview of activation in persons with mental health disorders generally, and the grounded theory and qualitative descriptive studies (Chapters 3 and 4) built upon this work by focusing specifically on the experiences of persons with OUD in IOT. Because the dissertation included two different qualitative approaches, it yielded a theoretical framework depicting the unfolding of IOT experiences among persons with OUD, which then provided the context for a more specific examination of the role of activation in IOT. Activation in persons with OUD was therefore examined through several lenses. The use of three different inquiry methods supported the identification of the cross-cutting themes described above, which in turn provided the basis for several clinical implications and future research recommendations.

LIMITATIONS

The findings of the dissertation should be considered in light of the limitations of the integrative review (Chapter 2) and the grounded theory and qualitative descriptive studies (Chapters 3 and 4). For the integrative review (Chapter 2), studies were eliminated that examined constructs that likely overlap with activation, such as selfefficacy, self-management, and decision-making, if activation was not also measured. Including these studies may have provided a broader view of related person characteristics that influence active participation in one's health. Additionally, the review of the intervention studies examined only activation as an outcome variable, and other treatment outcomes such as quality of life, disease burden, or treatment utilization were not considered in the review, and thus no conclusions could be reached about the effect of activation interventions on these other measures. A limitation of the grounded theory (Chapter 3) and qualitative descriptive (Chapter 4) studies was that all participants identified as White, thus conclusions cannot be drawn about the IOT experiences of persons of other races or ethnicities. The opioid crisis is an urgent issue in the Black population (Substance Abuse and Mental Health Services Administration, 2020) in particular, with Black persons living in large central metro areas between the ages of 45-64 years experiencing the most significant increase in opioid-related deaths from 2015 to 2017 (Centers for Disease Control and Prevention, 2019). In addition, the small sample size (N = 14), although adequate to meet the study aims, likely constrained to some degree the complexity of theoretical framework and activation typology. Recruiting in only one health system limited the generalizability of the results as some findings may reflect the unique philosophies and practices of IOT within this one health system. Moreover, IOT staff were not interviewed so their perspectives do not inform the findings about patient/staff interactions as described by participants.

RESEARCH IMPLICATIONS

Research Implication 1: Future research with larger and more diverse samples conducted in multiple settings is needed to further develop the theoretical framework of *connecting and disconnecting* and to further expand the typology of types of instances of activation.

Because the theoretical framework developed in the grounded theory study (Chapter 3) and the typology developed in the qualitative description study (Chapter 4) were both based on the narratives of 14 persons all who identified as White, larger studies are warranted to provide additional data to describe more fully persons' experiences in IOT and the role of activation in recovery. These studies should include persons from diverse racial/ethnic groups and draw participants from a variety of IOT programs in different geographical locations. For example, studies have indicated that Black and Hispanic persons are less likely than White persons to complete substance use treatment (Mennis & Stahler, 2016; Saloner & Cook, 2013; Stahler & Mennis, 2018), and thus including participants from diverse racial/ethnic groups could allow exploration of possible group differences in the IOT experiences. Moreover, because IOT program philosophies and practices may differ from program to program and from region to region, including multiple IOT programs in one study will permit examination of the influence of program characteristics on participant experiences and activation.

As stated above, all three components of the dissertation revealed the importance of collaborative relationships between persons with mental health concerns and/or OUD and providers. While some provider perspectives were obtained in the studies reviewed in the integrative review (Chapter 2), the grounded theory study (Chapter 3) and the

qualitative descriptive study (Chapter 4) did not obtain the perspectives of IOT staff. To better understand how patient/provider interactions affect the experiences of persons with OUD in IOT, especially in regard to activation, studies which include provider interviews or observations of patient/provider interactions are needed.

Research Implication 2: Researchers should adapt and test educational interventions shown to improve activation in mental health populations.

The integrative review (Chapter 2) revealed that a variety of educational interventions have been shown to be effective in increasing activation in persons with mental health disorders, but that no such interventions are available for persons with OUD. Research is thus needed to adapt and test some commonly used activation interventions so they could then be integrated into IOT programs. For example, the chronic disease self-management program (CDSMP), a widely used effective selfmanagement workshop for persons with a variety of chronic illness, has been successfully adapted for use for persons with mental health disorders (Druss et al., 2010; Goldberg et al., 2013; Muralidharan et al., 2019) and might be adapted for the unique needs of persons with OUD.

CLINICAL IMPLICATIONS

Clinical Implication 1: Clinicians who work with persons with OUD should develop strong working alliances and engage in best practices of mutual decision-making and collaborative goal setting while considering the patients' stage of recovery.

Findings from the integrative review (Chapter 2) suggest that treatment quality and a variety of factors related to positive relationships with providers affect activation. Similarly, findings from the grounded theory study (Chapter 3) revealed that connecting with others in the IOT program supported achieving and maintaining sobriety, and the findings of the qualitative descriptive study (Chapter 4) revealed that engaging in collaborative relationships with IOT staff, especially those who themselves had experienced addition, was an instance of activation. All these findings suggest that providers should aim to always enhance therapeutic communication with patients and strengthen mutual decision-making and goal-setting within the relationship. Program administrators should consider hiring persons who had recovered from addictions as part of the IOT staff.

All three dissertation components support the need to adapt and test existing programs that have been shown to be effective in increasing patient activation for persons with OUD. Findings from the grounded theory study (Chapter 3) and the qualitative descriptive study (Chapter 4) inform how clinicians may adapt programs for persons with OUD. The grounded theory study (Chapter 3) found that many participants experienced anxiety prior to engagement in group work and felt particularly vulnerable when they were asked to share personal experiences. Clinicians should allow time and space for patients to gradually settle in groups and be allowed to disclose at their own pace. The qualitative description (Chapter 4) findings suggest that a focus on activation too early in treatment might be problematic. For example, working collaboratively with staff to establish small goals might be indicated early in treatment. As patients acclimate to the IOT program, they may be ready to focus on acquiring knowledge and skills needed to advance their recovery.

Clinical Implication 2: Once effective interventions are developed to improve activation in persons with OUD, they should be incorporated into IOT programming.

As discussed above, the results of all three components of this dissertation suggest that IOT programs might include evidence-based interventions aimed at enhancing activation. IOT clinicians should decide how to best implement such interventions in their overall program structure and, as discussed above, adapt them based on stages of recovery.

CONCLUSION

This dissertation is the first study to focus specifically on the IOT treatment experiences of persons with OUD and the first to describe how patients experience activation in these programs from their own perspectives. Findings suggest that activation is associated with a variety of factors in persons with mental health disorders, some effective programs that increase activation in this population have been developed, patients' experiences in IOT programs can be considered as an interwoven process of connecting and disconnecting, and activation is evident in a variety of realms in IOT. While additional research is needed to fully explore activation in persons with OUD, the findings of this dissertation indicate that clinicians should engage in collaborative relationships with patients and implement interventions that foster activation but should be aware that activation approaches introduced too early in recovery may be detrimental.

APPENDICES

APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE

- 1. What is your date of birth (day/month/year)?
- 2. What gender do you identify with?
- 3. What race/ethnicity do you most closely identify with?
- 4. What substances have you used in the past 12 months? Please include illegal substances and prescription pain relievers taken in any way not directed by a prescriber.
- 5. How many weeks of treatment did (or have) you complete in the IOT program?
- 6. What is your status in the program (graduated, left program, currently in program)?

APPENDIX B: INTERVIEW GUIDE

I am interested in understanding your experience in the IOT at Methodist Hospital. I would like to know how you came to the program and what the program [has been] [was] like for you. You may answer only those questions you wish to answer and we may stop at any time. Do you have any questions for me? May I turn on the tape recorder?

Tell me your status is in the program (graduated, left program, currently in program)?

When did you enroll in the program?

How many weeks of treatment [have you completed] [*did you complete*] in the program?

As you know our research is trying to understand what persons' experiences are like in intensive outpatient programs, like the one [you are attending] [*you attended*] at Methodist. I would like to know how it came to be you enrolled in program, what it was like when you started the program, what it was like when you were settled in the program, and what it was like when you left the program . . .

Let's start by talking about how it came to be that you enrolled in the program . . .

Tell me when your first heard about the program.

Tell me how you decided to enroll in the program.

Did others encourage you to go to the program? How so?

Did others discourage you from going to the program? How so?

Now let's start with when you were admitted to the program. Tell me about your first day in the program....

How were you introduced to the program?

What activities did you take part in the first day?

Tell me what you remember about [activity 1, activity 2, activity 3]. [note: ask about each activity, e.g., "Tell me what you remember about the group." "Tell me what you remember about your meeting with your counselor"]

What did you find most helpful that first day?

What did you find least helpful that first day?

What was most difficult or challenging about your participation in the program? Share an example of a difficult situation?

How did you feel at the end of the first day?

Were there things the staff did that made your first day helpful? Could have they done anything to make that first day more helpful?

Now let's talk about a time when you were more settled in the program – when things weren't so new. Tell me about a day that happened in the middle of the program – maybe your second or third week of the program. See if you can remember back to a specific day.

What activities did you take part in that day?

Tell me what you remember about [activity 1, activity 2, activity 3]. [note: ask about each activity, e.g., "Tell me what you remember about the group."]

Once you were settled into the program, what did you find most helpful?

Once you were settled into the program, what did you find least helpful?

Once you were settled into the program, what did the staff do that was most helpful?

Once you were settled into the program, what did the staff do that was least helpful?

Once you were settled into the program, what was most difficult or challenging for you? Share an example of difficult situation.

Was there one experience in the program that stands out for you – that would help me understand best what the program was like for you?

[For persons who completed the program]: Now let's talk about the time when you left the program.

Tell me how it was decided you would leave the program. [explore their role in the decision]

What was your final day in the program like?

How did you feel about leaving the program?

[For persons still in the program]: Now let's talk about the time when you will leave left the program.

How will it be decided when you would leave the program. [explore their role in the decision]

How will you feel about leaving the program?

Thank you. You gave me a good sense of your experience in the IOT. The other part of our research is trying to understand the extent to which persons in IOT are in charge of their own treatment. Research suggests that if people are in charge of their own treatment, they experience better outcomes. One way people are in charge of their own treatment is they make important decisions about their treatment in collaboration with their providers.

So I am going to ask you to think back and tell me about some decisions made about your treatment – the decisions could be about enrolling in the program, what activities you took part in in the program, what medications you took, when it was time to end the program, and the like. You might have been very involved in these decisions or maybe not very involved. Either way, I would like to talk about decisions made about your treatment.

What were some of the important decisions made about your treatment while you were in the IOT program.

Let's talk about [first decision].

How was that decision made?

What role did you have in making that decision?

[If no role or little role] Would you have liked to be more involved in the decision?

Repeat questions for several decisions mentioned by the participants.

Overall, to what extend do you feel you were in charge of your treatment in the IOT at Methodist?

Tell me about a time [if any] you felt in charge of your treatment in the IOT?

Tell me about a time [if any] you did not feel in charge of your treatment in the IOT?

How do you think staff can best ensure that people are in charge of their treatment in the IOT?

We have all being through the COVID pandemic; how do you feel that the pandemic [has affected] [is affecting] your participation in IOT?

Is there anything else I should know about your experience in the IOT at Methodist?

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CURRICULUM VITAE

Alyson Yvonne Keen

EDUCATION

- Doctor of Philosophy in Clinical Nursing Science (Minor-Health Policy Management), Indiana University, earned at IUPUI (May 2018-December 2021)
- Master of Science in Nursing, Indiana University, earned at IUPUI (Spring 2011-December 2013)
- Bachelor of Science in Nursing, Indiana University, earned at IUPUI (Fall 2002-December 2009)

PROFESSIONAL EXPERIENCE

- Program Manager, Research and Evidence-Based Practice, IU Health Adult Academic Health Center, Indianapolis, IN (2019-current)
- Research Assistant for Dr. Robin Newhouse, Indiana University School of Nursing, Indianapolis, IN (2018-2019)
- Clinical Nurse Specialist, IU Health Adult Academic Health Center, Indianapolis, IN (2014-2019)
- Outcome Specialist, IU Health Adult Academic Health Center, Indianapolis, IN (2013-2014)
- Registered Nurse, IU Health Adult Academic Health Center, Indianapolis, IN (2010-2013)

PUBLICATIONS

Published

- Keen, A., Lu, Y., Oruche, U.M., Mazurenko, O, & Draucker, C.B. (2021) [in press] Activation in persons with mental health disorders: An integrative review. *Journal of Psychiatric and Mental Health Nursing*.
- Keen, A., Thoele, K., Oruche, U., & Newhouse, R. (2021) Perceptions of the barriers, facilitators, outcomes, and helpfulness of strategies to implement screening, brief intervention, and referral to treatment in acute care. *Implementation Science*, 16(44).
- Anton, N.E., Athanasiadis, D.I., Karipidis, T., Keen, A.Y., Karim, A., Cha, J., Walke, N., Stefanidis, D. (2021). In Press. Surgeon stress negatively affects their non-technical skills in the operating room. *American Journal of Surgery*. <u>https://doi.org/10.1016/j.amjsurg.2021.01.035</u>
- Dbeibo, L., Kuebler, K., Keen, A., George, A., Kelley, K., Sadowski, J., Basham, L., Beeson, T., Schmidt, M., Beeler, C., Webb, D. (2020). Assessment of a universal preprocedural screening program for COVID-19. *Infection Control & Hospital Epidemiology*. Feb 2:1-3. https://doi: 10.1017/ice.2021.40
- Vaughn, S., Maxey, H., Keen, A., Thoele, K., & Newhouse, R. (2020). Assessing public behavioral health services data: A mixed method analysis. *Substance Abuse Treatment, Prevention, and Policy*, 15(85).
- Thoele, K., Ferren, M., Moffat, L., Keen, A., & Newhouse, R. (2020).
 Development of a toolkit to facilitate implementation of an evidence-based intervention. *Implementation Science Communications*, 1(86).

- Radecki, B., Keen, A., Miller, J., McClure, J., & Kara, A. (2020). Innovating fall safety: Engaging patients as experts. *Journal of Nursing Care Quality*, 35(3): 220-226.
- Keen, A., Thoele, K., & Newhouse, R. (2020). Variation in SBIRT delivery among acute care facilities. *Nursing Outlook*, 68(2):162-168.
- Keen, A., Thoele, K., Fite, L., & Lancaster, S. (2019). Competent patient refusal of nursing care: An innovative approach to a complex problem. *Journal of Wound Ostomy and Continence*, 46(5): 390-395.
- Davis, C., Keen, A., Holly, V., Balaguras, J., & Miller, W. (2018). Alcohol withdrawal assessment tool: Validity and reliability testing in acute care. Clinical Nurse Specialist, 32(6): 307-312.
- Keen, A., McCrate, B, Mclennon, S, Ellis, A., Wall, D. & Jones, S. (2017). Influencing nursing knowledge & attitudes to positively affect care of patients with persistent pain in the hospital setting. *Pain Management Nursing*, 18(3): 137-143.
- Keen, A., Embree, J., Lancaster, S. & Bartlett Ellis, R. (2017). Feasibility of using mixed-media vignettes to enhance nursing knowledge and attitudes about pain management. Continuing Education in Nursing, 48(6): 282-288.
- Cote, G., Lynch, S., Easler, J., Keen, A., Vassell, P., Sherman, S. . . Xu, H. (2015). Development and validation of a prediction model for admission following Endoscopic Retrograde Cholangiopancreatography. Clinical Gastroenterology & Hepatology, 13 (13): 2323-32.

Under Review

- Keen, A., Lu, Y., Oruche, U., Mazurenko, O., & Draucker, C.B. (2021).
 Activation in persons with opioid use disorder in intensive outpatient treatment [Manuscript submitted for publication]. Department of Nursing, Indiana University.
- Keen, A., Lu, Y., & Draucker, C. B. (2021). Connecting and disconnecting: Experiences of persons with opioid use disorder in intensive outpatient treatment [Manuscript submitted for publication]. Deptarment of Nursing, Indiana University.
- Keen, A., George, A., Stuck, B.T., Snyder, C., Fleck, K., Azar, J., & Kara, A. (2021). Nurse perceptions of a nurse family liaison role implemented during the COVID-19 pandemic: A qualitative thematic analysis [Manuscript submitted for publication]. Department of Quality/Safety, IU Health Adult Academic Health Center.

PRESENTATIONS

International

- Keen., A. & Kara., A. (2021, June 17). Perceptions of a Nurse Family Liaison Implemented during the COVID-19 Pandemic. Academy Health 2021 Virtual Annual Research Meeting.
- Crowder, S. J., Maxey, H.L., Oruche, U., Afuseh, E., Keen, A., Thoele, K., Newhouse, R. (2021, April 9-10). Improving Access to Care and Quality through Comprehensive Workforce Planning for People Who Use Substances [Poster presentation]. Sigma Theta Tau International Alpha Chapter Session, Indiana

Academies Symposium, Indianapolis, IN, United States.

https://whova.com/portal/webapp/beyon2_202104/Artifact/840.

 Keen, A., Thoele, K., & Newhouse, R. (2019). Screening, Brief Intervention, and Referral to Treatment Implementation Localization. Podium Presentation Sigma Theta Tau 45th Biennial Convention, November 16-20, 2019; Washington D.C.

National

- Davis, C., Newkirk, E., Keen, A., Compton, L., Rader, T. (2020, August 21).
 Psychometric Testing of the Alcohol Withdrawal Assessment (AWAT): The Journey Map [Webinar]. National Association of Clinical Nurse Specialists.
 https://global.gotowebinar.com/join/over.tmpl;jsessionid=EEE9E17CDA1BB0A1 3C4861F20EF6482A?webinar=6100063431384898576
- Anton N., Athanasiadis, D., Karipidis T., Keen A., Karim A., Cha J., Walke N., Stefanidis D. (2020, August 13) Surgeon Stress Negatively Affects Their Nontechnical Skills in the Operating Room. Abstract presented at Association for Surgical Education Virtual Highlights.
- Crowder, S., Maxey, H., Oruche, U., Afuseh, E., Keen, A., Thoele, K., Newhouse, R. (2020, February 10-11). Improving Access to Care and Quality through Comprehensive Workforce Planning for People Who Use Substances. Poster Presentation at the National Health Policy Conference, Washington, DC.

- Kenney, T., Keen, A., & Reynolds, G. (2017, October 12-15). Shifting Nurse Mindset to Delirium Prevention. Poster Presentation AMSN National Conference, Palm Springs, CA.
- Mahendraker, N., Keen, A., Fite, L., Fajardo, M., Mohapatra, D., Subramoney, K... Westfall, S. (2017, May 1-4). Tier Opiates for Potent Pain Management. Presentation at Hospital Medicine, Las Vegas, NV.
- Davis, C., Keen, A., Holly, V., Balaguras, J., & Compton, L. (2017, March 8-11). Alcohol Withdrawal Assessment & Management: Conquering Change Across a Health Care System. Symposium Presentation NACNS National Conference, Atlanta, GA.
- Keen, A. & Kraus, R. (2016, March 3-5). Leading by Influence. Podium Presentation NACNS National Conference, Philadelphia, PA.
- Keen, A. & Verwers, N. (2016, March 3-5). Organizational Learning through Post Fall Escalation. Podium Presentation NACNS National Conference, Philadelphia, PA.
- Keen, A. (2015, March 5-7). Improving Nurse Knowledge and Attitudes about Caring for Hospitalized Patients with Persistent Pain. Podium Presentation NANCS National Conference, San Diego, CA.
- Keen, A., Lancaster, S., Ellis, R., & Embree, J. (2014, March 3-6). Taking Control of Persistent Pain: Psycho-educational Interventions to Promote Optimal Pain Management in the Persistent Pain Population. Poster Presentation NACNS National Conference, Orlando, FL.

Regional

• Keen, A., Rosa, F., & Wyatt, J. (2013, March 27). CAUTI: Creating a Culture of Zero. Cohort Workgroup Session Presentation, Chicago, IL.

Local

- Rader, T., Keen, A., Dees, M. (2021, May 6). #betterposter: A Descriptive Evaluation of a Novel Poster Presentation Design. Indiana University Health Virtual Poster Conference. Indianapolis, IN, United States.
- Howell, R. & Keen, A. (2021, May 6). Proving Human Connection during the COVID-19 Pandemic. Indiana University Health Virtual Poster Conference, Indianapolis, IN, United States.
- Radecki, B., Gardner, D., Wallbank, B., & Keen, A. (2018, December 7). Building Evidence Based Practice Infrastructure: One Burning Question at a Time. Poster Presentation IU Health Nursing Research Conference, Indianapolis, IN.
- Newhouse, R., Maxey, H. & Keen, A. (2018, October 11). Referral to Treatment for People Admitted to Medical Surgical Hospital Units and Screened for Risky Substance Use: Barriers and Solutions. Podium Presentation Indiana Public Health Conference, Indianapolis, IN.
- Walden., B, Gardner, D., Gardner, S., Thoele, K., Keen, A., Fite, L., & Lancaster, S. (2016, November 29). Review of the Literature: Competent Patient's Refusal of Nursing Care. Poster Presentation & Innovation Forum IU Health Nursing Research Conference, Indianapolis, IN.

 Ducre, C., Keen, A., & Hunt, C. (2012, December 7). Around the Clock (ATC) Dosing. Poster presentation IU Health Research Conference, Indianapolis, IN.

GRANTS

- Principal Investigator, *Building Human Connection During the Merger of Two Global Pandemics*, American Organization of Nursing Leadership, \$10,000 (2021)
- Co-investigator, Use of Aromatherapy to Reduce Symptom Burden in Patients Receiving Stem Cell Transplantation, Indiana Organization of Nurse Excellence, \$6,118 (2020-2021)
- Principal Investigator, *Experience and Activation of People with Opioid Use* Disorder in an Intensive Outpatient Treatment, Sigma Theta Tau International Alpha Chapter, \$5,000 (2020-2021)

PROFESSIONAL MEMBERSHIPS

- Central Indiana Organization of Clinical Nurse Specialist (2014-present)
- Sigma Theta Tau Alpha Chapter (2019-present)
- Academy Health (2019-present)

CERTIFICATIONS AND LICENSES

- Clinical Nurse Specialist in Adult Health Nursing Certification, American Nurses Credentialing Center (2014 to Present)
- Registered Nurse, Indiana State Board of Nursing, (2010 to Present)
- Basic Life Support, American Heart Association (2010 to Present)

HONORS AND AWARDS

- Sherry Queener Graduate Student Excellence Award (2021)
- Sigma Theta Tau, Alpha Chapter (2020-current)
- IU School of Nursing Travel Fellowship (2019-2020)
- CIO-CNS Dayhoff Clinical Nurse Specialist Fellowship (2018)
- Pre-Doctoral Fellowship in Nursing Education (2018)