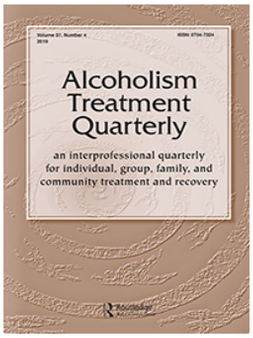

Alcoholism Treatment Quarterly

ISSN: 0734-7324 (Print) 1544-4538 (Online) Journal homepage: https://www.tandfonline.com/loi/watq20

A Mixed-Methods Exploration of the Role and Impact of Stigma and Advocacy on Substance Use Disorder Recovery

Robert D. Ashford, Austin M. Brown, Brent Canode, Jessica McDaniel & Brenda Curtis

To cite this article: Robert D. Ashford, Austin M. Brown, Brent Canode, Jessica McDaniel & Brenda Curtis (2019) A Mixed-Methods Exploration of the Role and Impact of Stigma and Advocacy on Substance Use Disorder Recovery, Alcoholism Treatment Quarterly, 37:4, 462-480, DOI: 10.1080/07347324.2019.1585216

To link to this article: https://doi.org/10.1080/07347324.2019.1585216

Published online: 20 Mar 2019.

ALCOHOLISM TREATMENT QUARTERLY
2019, VOL. 37, NO. 4, 462–480
https://doi.org/10.1080/07347324.2019.1585216

Taylor & Francis
Taylor & Francis Group

A Mixed-Methods Exploration of the Role and Impact of Stigma and Advocacy on Substance Use Disorder Recovery

Robert D. Ashford [a], Austin M. Brown [b], Brent Canode[c], Jessica McDaniel[b], and Brenda Curtis [d]

[a]Substance Use Disorders Institute, University of the Sciences, Philadelphia, Pennsylvania, USA; [b]Center for Young Adult Addiction and Recovery, Kennesaw State University, Kennesaw, Georgia, USA; [c]Oregon Recovers, Alano Club of Portland, Portland, Oregon, USA; [d]Treatment Research Center, Perelman School of Medicine University of Pennsylvania, Philadelphia, Pennsylvania, USA

ABSTRACT

Obstacles to intrapersonal and interpersonal growth, due to stigma and discrimination, may constitute a significant challenge to those in recovery. Engaging in recovery-related advocacy may serve as a buffer to the experience of stigma and discrimination. The purpose of this pilot study is to examine whether the perception of stigmatization is associated with common recovery measures such as recovery capital, self-esteem, and self-efficacy, as well as to explore the role of advocacy for individuals in recovery through thematic analysis. Statistically significant results suggest that individuals who believe they are stigmatized have less recovery capital and self-esteem than those who do not hold this belief. Several major themes related to the overall impact, perceived benefits, and perceived harms of engaging in advocacy emerged from the thematic analysis such as reduction in stigma, improving soft skills, service to others, and reduced ability to engage in self-care. Findings suggest that individuals who believe they are stigmatized have lower functional outcomes (recovery capital and self-esteem) and mitigating these effects may be important for future recovery success. Additionally, thematic results suggest that engaging in recovery related advocacy offers a multitude of potential benefits and positive impacts, but also may have important potential harms to consider.

KEYWORDS

addiction; substance use disorder; recovery; advocacy; stigma; bias; discrimination

Stigma is a multidimensional construct that exists across marginalized populations (Goffman, 1963), such as those in recovery from substance use disorders (SUD) (Ashford, Brown, & Curtis, 2018a). Goffman (1963) conceptualized stigma as, "being reduced from a whole person … to a discounted one" and the social identities of such persons are "spoiled" and thus must be managed by the individual to control their social devaluation. Inherent in Goffman's concept is the idea that permanent identity problems stem from stigma and require actions in efforts to correct for negative self-conceptualization in service to interactional normalization

CONTACT Robert D. Ashford rdashford@gmail.com 2111 Melvin St Philadelphia, PA 19131, USA.

viewed as a collective effort of sustained acceptances (Misztal, 2001) The actions or strategies to manage a socially devalued identity may involve positive and negative compensatory actions (Branscombe, Schmitt, & Harvey, 1999; Kessler, Mickelson, & Williams, 1999). Positively, these compensatory actions to manage spoiled identity often involve sociopolitical activism (Camlin et al., 2017) and identity reclamation (Ashford, Brown, & Curtis, 2018b). Self-advocacy, for those with SUD, may involve activism and identity reclamation as part of the recovery process.

Research has shown stigma to have a negative effect on individuals with SUDs in a number of ways. Stigma can reduce help-seeking behaviors, may be internalized, and therefore impact an individual's sense of self, and may also include public biases, which can lead to discrimination (McGinty, Goldman, Pescosolido, & Barry, 2015; Wu et al., 2017; Yang et al., 2007). Stigma has also been shown to impact quality of care within health settings in the way people with SUD are characterized by providers (Clement et al., 2015; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). Internalized stigma can negatively impact hope, self-esteem, and sense of personal empowerment (Livingston & Boyd, 2010). Those who are in recovery from SUD experience stigma in a number of different ways whether through public stigma, systemic biases, and/or self-stigma (Barry, McGinty, Pescosolido, & Goldman, 2014; Flanagan, 2013; McGinty et al., 2015; Polcin, Henderson, Trocki, Evans, & Wittman, 2012; Woods & Joseph, 2012). Additionally, those who are in recovery from SUD may experience multiple forms of stigma related to their recovery status and any number of other secondary sources of stigma from gender, health status (such as HIV/HCV-positive), ethnicity, criminal history, or mental health status (Goodyear, Haass-Koffler, & Chavanne, 2018; Kerrison, 2018; Lago, Bógus, & Peter, 2018; Stringer & Baker, 2018). This multilayered marginalization may compound the challenges that many people in recovery face as they move toward wellness. Individuals with SUD are one of the most stigmatized populations throughout the world. For example, a cross-cultural study conducted by the World Health Organization (WHO) in 14 countries found that alcohol use disorder was ranked as the fourth most stigmatized, whereas other drug use disorders were ranked first, as the number one most stigmatized condition (Room, Rehm, Trotter, Paglia, & Üstün, 2001). For such a stigmatized population, overt advocacy efforts to mitigate, counteract, and/or buffer the effects of such stigma may play an important role in recovery (Can & Tanrıverdi, 2015).

Advocacy for and by marginalized populations has historically functioned as a counterbalance to stigma and to promote policy change. This is particularly true in the mental health and disability recovery movement which began in the late 1980s and 1990s as a form of social and political activism (White, 2000, 2007). This helped shape many of the

community mental health models common today and served as the basis for legislative actions such as the Americans with Disabilities Act (ADA; 1990). These achievements helped to ensure that the rights and protections for those with mental health and disability concerns were acknowledged and protected. A distinct difference from the mental health community, SUD recovery has largely been situated within the framework of 12-Step mutual-aid groups, where anonymity as a key value may have slowed the progress of advocacy for recovering individuals (Williams, 1992). SUDs also have biopolitical implications and social consequences, such as incarceration and social isolation, which may be difficult to overcome (Dackis & O'Brien, 2005). A large portion of the US general public still leans toward SUD as a consequence of moral failing, though belief in the disease and psychological models of SUD are also prevalent (Broadus & Evans, 2015). However, in the last two decades, several advancements have been achieved in the advocacy movement by those in recovery.

Organizations dedicated to advocacy in the SUD and recovery community have grown quickly since the 2000s (White, 2007). Legislation regarding SUD and recovery, such as the Mental Health Parity and Addiction Equity Act (MHPAE; 2008), Comprehensive Addiction and Recovery Act (CARA; 2016), and the 21st Century Cures Act (CURES; 2016), have found success at the national policy level. These achievements have resulted in regulatory protections regarding equitable insurance coverage, as well as billions of dollars in appropriations, some of which was specifically earmarked for recovery support services for the first time (Gabay, 2017; Kennedy-Stewart, 2016). Although tangible gains – especially in terms of fiscal appropriations and protective regulations – are apparent, the role and impact that advocacy has on the individual in recovery, rather than the collective community, has yet to be examined.

The modern recovery advocacy movement seeks to address political and legislative actions as much as the movement seeks to address social misunderstanding, stigma, and discrimination. The burden of stigma remains a formidable obstacle for many. Advocacy, as a part of an individual's recovery pathway, may serve as a benefit to recovery while offering hope by providing vocal examples of successful recovery. The current study has two primary aims: 1) to explore the impact that the perception of stigmatization has on recovery-related outcomes (e.g., recovery capital, quality of life, self-esteem, and self-efficacy) in a small pilot sample, and 2) to identify the common themes of impact, benefits, and harms among individuals who engage in recovery advocacy activities. For our first aim, we propose an a priori hypothesis that individuals who believe they are stigmatized will have lower levels of recovery outcomes.

Methods

This mixed-methods study examines the impact of stigma on recovery outcomes utilizing several strength-based and well-validated measures (e.g., recovery capital, self-esteem, and, self-efficacy) that are increasingly being incorporated into the study of recovery (Brown & Ashford, 2019). Open-ended questions regarding the role and impact of recovery advocacy on the perceived benefits, potential harms, and overall impact were used to collect qualitative response from individuals in recovery. As a pilot study, these aims are combined as we hope to further explore whether engaging in advocacy activities may serve to moderate any existent negative effects of the perceptions of stigmatization at an individual level.

Participants

Participants (N = 35) had a mean age of 39.37 years (SD = 10.76), with an equal proportion of female/male (45.7% each), and a majority identifying as White (82.9%). Many participants were also married/domestic partnership (45.7%), held a graduate degree (34.3%), were employed (97.1%), and had a household income level of $50,000 or more (57.1%). Additionally, a large portion of participants (40.0%) had previously been on probation or parole but no longer were. Full participant demographics are available in Table 1.

All participants identified as a person in recovery, with a mean length of recovery time of 8.40 years (SD = 8.10). Most participants (62.9%) reported having a poly-substance use preference, had a co-occurring mental health disorder (88.6%), and had engaged in formal SUD treatment (88.6%). Full participant recovery and behavioral health descriptive characteristics are available in Table 2.

Data collection

Participants were recruited, following Institutitional Review Board (IRB) approval, from the Oregon Recovers e-mail listserv and a Facebook recruitment flyer (i.e. recruitment image) on the Voices To End Addiction & Inspire Recovery private group. Due to the pilot nature of this study, a maximum of 35 participants was included in the IRB approval. Maximum recruitment was reached within 1 hour of posting recruitment information. The listserv announcement and recruitment flyer were posted following moderator consent. Oregon Recovers is a nonprofit recovery community organization based in Portland, Oregon, and is comprised a network of individuals in recovery. Voices To End Addiction & Inspire Recovery is a private group of individuals in recovery seeking to provide or ask for support in personal or for a loved one's recovery. The listserv and Facebook announcement were made once in

Table 1. Participant demographic characteristics.

	(*N* = 35)	
	n	%
Age (years)		
M = 39.37, *SD* = 10.76		
Gender		
Male	16	45.7
Female	16	45.7
Other	3	8.6
Race		
White	29	82.9
Other	6	17.1
Ethnicity		
Hispanic/Latino	3	8.6
Marital status		
Single	13	37.1
Married/domestic partnership	16	45.7
Divorced/widowed/separated	6	17.1
Educational status		
High school grad/GED	10	28.6
Associates degree	8	22.9
Bachelor's degree	5	14.3
Graduate degree	12	34.3
Employment status		
Employed	34	97.1
Student	1	2.9
Annual income level		
$10,001– 29,999	9	25.7
$30,000– 49,999	6	17.1
$50,000 or more	20	57.1
Housing status		
Recovery Residence/transitional housing	1	2.9
Living with family member or loved one	4	11.4
Living in own apartment or home	30	85.7
Currently on probation or parole		
Yes	3	8.6
No, but was previously	14	40.0
No	18	51.4

June 2018. Inclusion criteria for interested participants was identifying as a person in recovery and having engaged in some form of recovery-related advocacy (e.g., speaking publicly about your recovery, engaging in community-based legislative events related to addiction and recovery, etc.).

Following recruitment, interested participants were directed to a Qualtrics (Provo, UT) data collection portal to read the informed consent and either consent or dissent from participation. Consenting participants then had until the survey cut-off date (10 days from initial consent) to respond to the full survey. Participants first were asked to complete a brief demographics questionnaire and then to provide open-ended responses to questions related to recovery advocacy activities. All consenting participants completed the survey within the prescribed time period.

Table 2. Participant recovery and behavioral health characteristics and history.

	(*N*= 35)	
	n	%
Recovery Length (years)		
M = 8.40, *SD* = 8.10		
Primary recovery program		
Mutual aid (12-Step)	21	60.0
Mutual aid (non-12-Step)	5	14.3
Religious/spiritual mutual aid	4	11.5
Harm reduction	2	5.7
Other	3	8.6
Feel stigmatized due to recovery		
Yes	29	82.9
Preferred substance to use		
Alcohol only	3	8.6
Heroin only	4	11.4
Prescription opioids only	3	8.6
Cocaine only	1	2.9
Amphetamines only	2	5.7
Poly-substance preference	22	62.9
Co-occurring mental health disorder		
Yes	31	88.6
SUD treatment experience		
Yes	31	88.6
MH treatment experience		
Yes	13	37.1
Recovery residence experience		
Yes	18	51.4
Medical complication in the past 12-months due to BH disorder		
No	28	80.0
Overall quality of life		
Very good or good	32	91.4
Overall satisfaction with health		
Very satisfied or satisfied	27	77.2

Note. SUD = substance use disorder; MH = mental health; BH = behavioral health.

Participants were notified at the beginning of the survey that they could stop participating at any point in time, that their responses would be confidential, and that the sole identifying factor (IP address/GeoTags) would not be collected via the secure survey portal, thus ensuring anonymity. Participant responses were stored electronically and then exported for analysis.

Measures

Brief Assessment of Recovery Capital

The Brief Assessment of Recovery Capital (BARC-10; Vilsaint et al., 2017) is a short, 10-item measure that examines recovery capital, a concept comprising the internal and external assets that can be brought to bear to initiate and sustain recovery from SUD (Cloud & Granfield, 2008).The BARC-10 is a brief form of the Assessment of Recovery Capital (ARC; Groshkova, Best,

& White, 2013). Items were selected from the ARC for the BARC-10 using item response theory. The BARC-10 measures a unidimensional construct of recovery capital across the original 10 subscales of the ARC. Probability validity was shown at a cut-off score of 47 at (r pb = .90) with high external validity at (α = .90) (Vilsaint et al., 2017).

WHOQOL-BREF

The World Health Organization Quality of Life Brief Survey Instrument (WHOQOL-BREF; World Health Organization, 1998) is one of the most commonly used quality-of-life instruments worldwide. It has been used in sick and well communities, translated into multiple languages, and across many demographic groups. Overall the instrument measures physical health, psychological health, social health, and environment with 26 items. It has been shown to be sensitive cross-culturally. It is considered to have excellent psychometric properties of consistency (Skevington, Lofty, & O'Connel, 2004). Test–retest reliability at 2 weeks yielded intra-class correlations of 0.75–0.84 (Koohi, Nedjat, Yaseri, & Charagi, 2017). Additionally, Skelvington and colleagues (2004), demonstrated that the measure contains high-quality psychometric properties and good validity through confirmatory factor analysis (.87 Physical, .95 Psychological, .83 Social Relationships, .84 Environment) across a large sample (N = 11,830) in 23 countries.

Rosenberg Self-esteem

The Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965) is a widely used measure as well. This unidimensional, 10-item assessment has been widely reviewed and has strong internal consistency based on the Guttman scale of coefficient reproducibility (0.92), and correlations of 0.85 and 0.88 in test–retest stability over 2 weeks (Rosenberg, 1979). Furthermore, the RSES has been analyzed across 53 countries in 28 languages for internal reliability (α = .81) (Schmitt & Allik, 2005).

General Self-Efficacy

The General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) is a short, 10-item measure that is designed to assess optimistic internal belief in one's ability to cope with a variety of difficulties in life. The GSE has been shown to be correlated to emotion, optimism, and work satisfaction whereas negative coefficients were found for depression, stress, health complaints, burnout, and anxiety. Test–retest validation found Cronbach's alphas between .76 and .90 (Schwarzer & Jerusalem, 1995).

Perception of stigma

A single self-report question, "Do you feel that you are stigmatized for your substance use disorder or current recovery status?" was used to identify participants belief that they were stigmatized. The question was dichotomously scored with either *no* = 0 or *yes* = 1.

Open-ended advocacy questions

Participants were asked three open-ended questions that were developed iteratively for this project between the research team and two community-based peer specialists in recovery. Each question prompt asked participants to be as expansive as possible when providing their answers and were not word or character limited. The first question was, "What impact does recovery related advocacy have in your life?" the second was, "What are the benefits of engaging in advocacy activities?" and the third question was, "What are the harms of engaging in advocacy activities?"

Data analysis

Descriptive statistics of participants, and recovery outcomes and stigma relationships were analyzed using SPSS V24. Statistical significance was defined a priori at .05 for the first specific aim (the relationship of stigma to recovery outcomes) and tested using independent samples *t* tests. Qualitative data analysis was completed using a qualitative description design and thematic analysis (Sandelowski, 2000). An open-coding process followed by an axial-coding process was completed (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This was done individually by each researcher (RA, AB), and then collectively as a research team (all authors). Throughout the coding process, we examined similarities and disagreements in individual coding designations to capture the varied perspectives of each researcher (Walsh & Koelsch, 2012). Themes that were identified as having higher disagreement amongst the initial coders (10% or higher during the first review) were reevaluated by all authors, via in-person discussion, and the coded response reclassified. Following the reevaluation and second review, interrater agreement was achieved at 100%. Data saturation was evaluated by using multiple triangulation techniques (Denzin, 2009, 2012). This involved prioritizing the collection of data from individuals in multiple parts of the country (e.g., Pacific Northwest, southern, and northeastern United States), with varied recovery lengths, and of different employment types and experience, and the use of multiple coders to interpret and analyze data.

Results

Recovery outcomes and stigma

Independent samples t test results found statistically significant differences for recovery capital and self-esteem, between individuals who believe they were stigmatized ($n = 29$) and those individuals who did not believe they were stigmatized ($n = 6$). For recovery capital, individuals who believed they were stigmatized ($M = 53.20$, $SD = 5.31$) had on average 4.95 point (10%) lower scores on the BARC-10, $t(33) = -2.219$, $p = .033$, (95% confidence interval [CI] [−9.51, −0.41]), $d = -1.178$. For self-esteem, individuals who believed they were stigmatized ($M = 31.48$, $SD = 5.39$) had on average 6.00 point (20%) lower scores on the RSES, $t(33) = -2.677$, $p = .011$, (95% CI [−10.59, −1.44]), $d = -1.509$.

Thematic results

Major thematic findings are grouped within three topics, which correspond with the questions asked to participants. These topics are a) overall impact of advocacy on your life, b) perceived benefits of engaging in advocacy, and c) perceived harms of engaging in advocacy. Overall, 15 major themes emerged (impact: 7 themes; benefits: 5 themes; harms: 3 themes). Responses averaged a length of 39 words. Table 3 provides each major theme by topic and includes prevalence of participant responses in each theme. Prevalence does not necessarily imply greater importance, only higher rates of theme appearance. Each theme is detailed with one participant answer example. Descriptions below follow in order from the topics above (impact, benefit, harm). Each theme is introduced here and then further discussed in the Discussion section.

Table 3. Major themes of the impact of advocacy on life, perceived benefits of advocacy, and perceived harms of advocacy.

Topic	Themes	% of Participants Responding
Impact on life	(1) Reduces stigma	51.28
	(2) Increases sense of self	32.34
	(3) Service to others	37.14
	(4) Sense of purpose and meaning	32.34
	(5) Soft skills	17.14
	(6) Employment and education	22.86
	(7) Community involvement and support	42.85
Perceived Benefits	(1) Mechanism to change self	31.43
	(2) Internal recovery support	54.29
	(3) Mechanism to support others	54.29
	(4) Mechanism to change systems	25.71
	(5) Public examples of successful recovery	31.43
Perceived Harms	(1) Experience of stigma/discrimination	20.0
	(2) Self-care reductions	11.43
	(3) Harm to the larger community/movement	31.43

(Impact) reduces stigma

Properties of this theme are consistent with reductions in external stigma by providing visual representation of successful recovery, allowing individuals to feel their past histories have meaning, and setting the stage for future individuals entering into recovery by educating stakeholders and policy makers as to what constitutes successful recovery:

> Working with everyone from local government to DEA and SAMHSA did a tremendous amount for my recovery, largely erasing self-stigma. My advocacy work has been largely behind the scenes, quiet, but dedicated to bringing as many people to the table as possible. (PID #17, Female)

(Impact) increases sense of self

Properties of this theme are consistent with allowing everyone to feel their history has meaning and can be used for the greater good and allowing one to be empowered by their experience by transmuting their experience into public action:

> Advocacy is a pretty large part of my recovery and daily life. I have been active in advocacy for 6+ years – engaging both in private and public advocacy – at the individual, community, state and federal level. Advocacy has absolutely positively impacted my recovery. (PID #1, Male)

(Impact) service to others

Properties of this theme are consistent with allowing everyone to be of service to their community and individuals in the community and providing a mechanism of "giving back" to the community that supports their recovery,

> "The importance of that kind of work was something I learned in recovery. It's not about me: it's about what we can do together" (PID #9, Female).

(Impact) sense of purpose and meaning

Properties of this theme are consistent with placing everyone at the nexus of personal truth and society in a way that allows their subjective experience to be considered specialized knowledge, using insider knowledge to create compassion and empathy for others, allowing everyone to participate in the larger political discourse from a position of expertise, and giving meaning to action, history, and context in the seeking of truth:

> I work in recovery advocacy, so it plays a huge role in my life. I can honestly say that it's the first time I've ever been a part of something so much bigger than myself that offers so many rewards. I truly love what I do and the people I get to work with. (PID #13, Female)
>
> "Doing advocacy work has had the greatest impact on my recovery, it's where my passion lies. Advocacy provides more purpose in my life than anything else" (PID # 10, Male).

(Impact) soft skills

Properties of this theme are consistent with increasing the ability to socially connect, appeal, and collaborate with others, and increasing marketable skills such as public speaking and political organization,

> "I am a staunch and persistent advocate for mental/behavioral health. I engage in everything from on the street distribution of Narcan to the testimony for bills in my states capitol" (PID #12, Male).

(Impact) employment and education

Properties of this theme are consistent with the ability to leverage advocacy involvement to improve professional skills, find employment in politics or the treatment field, as well as to inform and support educational attainment efforts,

> "Advocacy has been central to my recovery as well as my ongoing professional development in the field. It's provided me with a field of study and a livelihood" (PID #28, Male).

(Impact) community involvement and support

Properties of this theme are consistent with improving the ability to network with like-minded individuals, under the auspices of common purpose and values,

> "It keeps my head in the game and provides me with a source of passion and inspiration. It's allowed me to engage in recovery activities long after my own personal need for recovery activity" (PID #24, Female).

(Benefit) mechanism to change self

Properties of this theme are consistent with allowing a balance between self-esteem and humility, creating an open mind, learning valuable social skills, and increasing a positive sense of self:

> "Engaging in advocacy activities allows me to feel like I can finally forgive myself for the maladaptive decisions I have made while in my drug use. I feel like my experiences were not a waste and I am able to use them for good rather than feel shame or guilt in who I used to be or what I have done in the past." (PID #26, Male)

(Benefit) internal recovery support

Properties of this theme are consistent with serving as a mechanism for a program of recovery, creating opportunities to connect to others and a larger community, and decreasing external and internal stigma:

> "I feel the benefits for me are a greater sense of well-being and the confidence to keep going and helping those who were and are in the same place that I was once

in. It has strengthened my personal relationships and has given me a steady stream of satisfaction and a sense of accomplishment." (PID #21, Male)

(Benefit) mechanism to support others

Properties of this theme are consistent with creating a legacy of change for future people in recovery, allowing one to be empowered to educate others, and allowing for others to witness successful recovery:

"Advocacy work gives us that power, that voice, that opportunity for self-respect and self-determination back. And by doing so we may make the world just a little bit better for those who find recovery after us. It is a huge personal risk for many, but those of us who have the privilege of taking that risk ought to." (PID #7, Female)

(Benefit) mechanism to change systems

Properties of this theme are consistent with organizing around principles of wellness and wellness organization, directly addressing static systems, and providing examples of the need for change through lived experience:

"It slowly changes policy and slowly helps to educate decision makers on how to make resources more available to those who can't afford it. Hopefully another added benefit in the long run will be that it will hold treatment professionals more accountable to what they say they are doing." (PID #18, Male)

(Benefit) public examples of successful recovery

Properties of this theme are consistent with allowing the public to witness successful recovery, helping to decrease societal stigma, demonstrating the values of recovery in action, and serving as an example of health and the ability to overcome:

"A student once said that sharing his story in front of an all-women spirit student organization on campus – a group with very little to no experience with people in recovery – was the most empowering thing he'd done so far for his recovery." (PID #11, Female)

(Harm) experience of stigma/discrimination

Properties of this theme are consistent with telling one's story publicly carrying the risk of stigmatization or negative public opinions, and risk of negative public opinions or stigmatization becoming internalized:

"Someone could be fired for being open about their recovery status or pressured out of work because it makes others uncomfortable. Demi Lovato's recent hospitalization also exposed some underlying stigma. A parent came up to me when I was tabling the other day and talked about how she was a "bad role model" for young women. That is not something a parent would go out of their way to say about a celebrity that was hospitalized for a heart attack, or for low blood sugar, or for the recurrence of any other chronic disease." (PID #25, Female)

(Harm) self-care reductions

Properties of this theme are consistent with the activities being time consuming and emotionally draining, leaving little for personal relationships, loved ones, friends, and self-help affiliations:

> "I believe the harm for me would be I internalize people's issues because I have been where they are, and I care. I believe this comes with empathy and I am still learning how to take care of myself and not allow it to impact me." (PID #35, Male)

(Harm) harm to the larger community/movement

Properties of this theme are consistent with the potential for co-opting the larger community with personal agendas and the seeking of celebrity through advocacy, and the negative impact on policy efforts through divergent opinions and messaging:

> "Policy makers are being educated by people who don't even necessarily agree with each other and are getting mixed messages. And it can breed resentment amongst the public to refer to addiction as a disease for those who don't believe to be so and to compare it to cancer. I have personally witnessed people outraged to hear addiction compared to cancer and some people get angry to see addiction getting such public attention, because to them it is still a moral failing." (PID #4, Male)

Discussion

As individuals begin the recovery process from a SUD, could advocacy training and localized involvement in advocacy efforts be part of their recovery program? Although this study is meant to be exploratory, it raises valuable questions about best practices that may help facilitate ways in which individuals can overcome various obstacles often faced in recovery. As a marginalized population, those with SUD may experience multiple barriers to self-realization through stigma and disempowerment. Indeed, the preliminary findings partially supported our first hypothesis, insofar as participant perception of being stigmatized is correlated with lower recovery capital and self-esteem, though not self-efficacy. Recovery capital and self-esteem have previously been associated with likelihood of long-term success in SUD recovery (Laudet & White, 2008; Richter, Brown, & Mott, 1991), and any factors – such as the perception of stigma – that serve as a barrier to realizing growth in these recovery outcome domains is worth further study. Though the exact nature of relationship between the perception of stigma and recovery capital and self-esteem will require additional study, these preliminary findings suggest that such study is warranted and needed.

From the qualitative themes presented here, it appears as though engaging in advocacy activities may help the individuals to achieve a positive self-construal, increase self-esteem, help internalize their recovery identities, and

provide social networking opportunities to support recovery. Mutual-aid recovery programs, and particularly 12-Step mutual aid groups, are centered on ideals of altruism and service (Emrick, Tonigan, Montgomery, & Little, 1993), which may be further manifested beyond the group environment through advocacy, providing perhaps a synergistic effect. Many of the participants in the current study identified a primary program of recovery as 12-Step mutual aid. Such groups have clear guidelines as to the role of anonymity in recovery, which some may view as a barrier to engaging in public advocacy. However, for participants in this study, it would appear that this guideline is not a common barrier to public and community engagement outside of the group setting. At least, for the small sample here, there seems to be no tension between the traditions of anonymity and advocacy work. Participants felt advocacy may help reduce barriers for the next person seeking recovery by helping to create a more responsive recovery support system through their advocacy efforts. Although further exploration into advocacy's role is necessary, key indicators of recovery progress demonstrate that advocacy may help to increase, or at least buffer, negative effects upon critical aspects of recovery, such as recovery capital and self-esteem.

Research also suggests that the role of positive self-narration is bolstered by ownership of the positive aspects of archetypes that are socially constructed recover roles. Such narration may be involved in motivation, agency, and in resolving conflicting values (McConnell & Snoek, 2018). Positive contextualization of past experiences may also have predictive capacity regarding recovery-related outcomes (Dunlop & Tracy, 2013). However, reframing of the past without meaningful public advocacy is likely to fall short of actual systemic change and may fail to truly challenge the socially delineated negative aspects of archetypes of individuals who use drugs or those in recovery. As shown in multiple themes within the overall impact and perceived benefits of advocacy, the performative enactment of recovery, whereby the individuals recontextualize their experiences as a source of empowerment and meaning, while also signifying a departure from the politically and socially produced archetypes of addiction – often negative. This is a step beyond the benefits of self-narration and identity reformation in recovery (Fomiatti, Moore, & Fraser, 2017) and appears to be at the center of recovery advocacy. This active public engagement of the reinterpreted self, and the public enactment of opposition to negative and stigmatized aspects of archetypes, may provide new avenues for social and systemic change for individuals in recovery.

Not all findings suggest that engaging in advocacy is related to positive impacts and personal growth, however. Participants identified several detrimental possibilities, including the experience of additional stigma and discrimination, the reduced ability to engage in self-care, and the larger community impact of harm to the advocacy movement at large.

The first two potential harms, impacting the individual, are perhaps more concerning if the exploration of advocacy as a mechanism of support is to occur. Although engaging in advocacy may either promote successful recovery, or at least serve as a buffer to negative effects, it cannot be meaningfully used if the risk of becoming further stigmatized is greater or of a higher magnitude. Similarly, if the benefits of advocacy are less than the harms derived from inadequate self-care, then the action itself is not viable as a recovery support, though it is still beneficial as an act of societal progress. Additional study is needed into the personal benefits and harms to inform these key questions.

Future study of the role of advocacy as it relates to personal growth in recovery, as well as advocacy as compliment to recovery support activities, such a networking, is warranted. It is clear from this exploratory study that the role of advocacy may be interwoven within the recovery experience in personal and professional ways for some, but not all. The benefits of this relationship are not well understood but present a novel opportunity for expanding our knowledge of recovery support along personal and professional lines. More importantly however, is the future study of how challenges to structural realities, and even opposition to common identity or archetypal nuances in recovery, may fundamentally alter one's sense of self through advocacy. Of critical importance is the understanding that advocacy challenges the socially constructed realities of the person in recovery, as well as the systematic viewpoint of society regarding those who still use substances (Jacobson, 2001).

Limitations

Findings from the current study should be viewed in light of several limitations. First and foremost, the limited pilot sample places constraints on any generalizability. Additionally, the lack of diverse sampling is limiting as well. Lacking a representative sample, the results should be viewed as a pilot study, whereas future research should seek to replicate key methodology while expanding on the current findings. The use of a single-item self-report question on the perception of stigmatization may also have influenced the results, and future full-scale studies may elect to use a validated continuous measure of levels of perceived or internalized stigma. Key to future work will be identifying direction and causal relationship of the belief of stigmatization and levels of recovery capital and self-esteem, as the current study is unable to identify if stigmatization leads to lower levels, or if lower levels leads to stigmatization. More rigorous sampling methods, combined with more granular aims, will be required to provide more robust conclusions.

Conclusion

As an initial pilot, the results from the current study suggest that stigma, insofar as individuals perceive they are stigmatized due to their recovery, is related to recovery outcomes – particularly recovery capital and self-esteem. Stigma, bias, and discrimination have been found to have negative impacts across a range of societal and healthcare issues, and this is consistent within SUD and recovery. Although additional research is needed to determine causal relationships, it is critical that the field continues to address stigma as fiercely as it searches for more effective interventions and treatments. Thematic results from this study suggest that advocacy serves a dynamic role for the individual in recovery, as well as the larger community, and may be useful as a targeted activity to support and enhance individual recovery. Although potential harms exist to any marginalized population that publicly proclaims their identity, the diverse range of possible benefits from engaging advocacy – being of service, improving self-worth and self-esteem, finding a sense of purpose, among others – could serve as catalysts for long-term success in communities and in individual lives. For practitioners, these findings may suggest that discussion regarding the role of advocacy with clients in their recovery are warranted. This may include discussions involving how to talk about one's recovery, person-first language, referral to advocacy organizations, and general encouragement for clients to explore their recovery identity.

Acknowledgments

The authors would like to thank Oregon Recovers, Bill White, and the community-based recovery advocates across the country doing amazing work in their communities.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Robert D. Ashford http://orcid.org/0000-0003-3979-1754
Austin M. Brown http://orcid.org/0000-0001-9958-3696
Brenda Curtis http://orcid.org/0000-0002-2511-3322

References

Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990). Retrieved from http://library.clerk.house.gov/reference-files/PPL_101_336_AmericansWithDisabilities.pdf

Ashford, R. D., Brown, A. M., & Curtis, B. (2018a). Substance use, recovery, and linguistics: The impact of word choice on explicit and implicit bias. *Drug and Alcohol Dependence*, *189*, 131–138. doi:10.1016/j.drugalcdep.2018.05.005

Ashford, R. D., Brown, A. M., & Curtis, B. (2018b). The language of substance use and recovery: novel use of the Go/No–Go association task to measure implicit bias. *Health Communication*, 1–7. doi:10.1080/10410236.2018.1481709

Barry, C. L., McGinty, E. E., Pescosolido, B. A., & Goldman, H. H. (2014). Stigma, discrimination, treatment effectiveness, and policy: Public views about drug addiction and mental illness. *Psychiatric Services*, *65*, 1269–1272. doi:10.1176/appi.ps.201400140

Branscombe, N. D., Schmitt, M. T., & Harvey, R. D. (1999). Perceiving pervasive discrimination among African Americans: Implications for group identification and well-being. *Journal of Personality and Social Psychology*, *77*, 135–149. doi:10.1037/0022-3514.77.1.135

Broadus, A. D., & Evans, W. P. (2015). Developing the public attitudes about addiction instrument. *Addiction Research & Theory*, *23*, 115–130. doi:10.3109/16066359.2014.942296

Brown, A., & Ashford, R. D. (2019). Recovery-informed Theory: Situating the subjective in the science of substance use disorder recovery. *Journal of Recovery Science*, *1*(3), 1–15. doi:10.31886/jors.13.2019.38

Camlin, C. S., Charlebois, E. D., Geng, E., Semitala, F., Wallenta, J., Getahun, M., … Clark, T. D. (2017). Redemption of the "spoiled identity:" the role of HIV-positive individuals in HIV care cascade interventions. *Journal of the International AIDS Society*, *20*(4), e25023. doi:10.1002/jia2.25023

Can, G., & Tanrıverdi, D. (2015). Social functioning and internalized stigma in individuals diagnosed with substance use disorder. *Archives of Psychiatric Nursing*, *29*(6), 441–446. doi:10.1016/j.apnu.2015.07.008

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., … Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, *45*(1), 11–27. doi:10.1017/S0033291714000129

Cloud, W., & Granfield, R. (2008). Conceptualizing recovery capital: Expansion of a theoretical construct. *Substance Use & Misuse*, *43*(12–13), 1971–1986. doi:10.1080/10826080802289762

Comprehensive Addiction and Recovery Act of 2016, Pub. L. No. 114-198. (2016).

Dackis, C., & O'Brien, C. (2005). Neurobiology of addiction: Treatment and public policy ramifications. *Nature Neuroscience*, *8*, 1431–1436. doi:10.1038/nn1105-1431

Denzin, N. K. (2009). *The research act: A theoretical introduction to sociological methods*. New York, NY: Aldine Transaction.

Denzin, N. K. (2012). Triangulation 2.0. *Journal of Mixed Methods Research*, *6*, 80–88. doi:10.1177/1558689812437186

Dunlop, W. L., & Tracy, J. L. (2013). Sobering stories: Narratives of self-redemption predict behavioral change and improved health among recovering alcoholics. *Journal of Personality and Social Psychology*, *104*(3), 576. doi:10.1037/a0031185

Emrick, C. D., Tonigan, J. S., Montgomery, H., & Little, L. (1993). Alcoholics anonymous: What is currently known? In B. S. McCrady & W. R. Miller (Eds.), *Research on alcoholics anonymous: Opportunities and alternatives* (pp. 41–76). New Brunswick, NJ: Alcohol Research Documentation Inc.

Flanagan, O. (2013). The shame of addiction. *Frontiers in Psychiatry*, *4*. doi:10.3389/fpsyt.2013.00120

Fomiatti, R., Moore, D., & Fraser, S. (2017). Interpellating recovery: The politics of 'identity' in recovery-focused treatment. *The International Journal on Drug Policy*, *44*, 174–182. doi:10.1016/j.drugpo.2017.04.001

Gabay, M. (2017). 21st century cures act. *Hospital Pharmacy*, *52*(4), 264–265. doi:10.1310/hpx5204-264

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York City, NY: Aldine De Gruyter.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

Goodyear, K., Haass-Koffler, C. L., & Chavanne, D. (2018). Opioid use and stigma: The role of gender, language and precipitating events. *Drug and Alcohol Dependence*, *185*, 339–346. doi:10.1016/j.drugalcdep.2017.12.037

Groshkova, T., Best, D., & White, W. (2013). The assessment of recovery capital: properties and psychometrics of a measure of addiction recovery strengths: assessment of recovery capital. *Drug and Alcohol Review*, *32*(2), 187–194. https://doi.org/10.1111/j.1465-3362.2012.00489.x

Jacobson, N. (2001). Experiencing recovery: A dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*, *24*, 248. doi:10.1037/h0095087

Kennedy-Stewart, S. (2016). So what's all this talk of the CARA bill? *MedSurg Nursing*, *25*(6), S16.

Kerrison, E. M. (2018). Exploring how prison-based drug rehabilitation programming shapes racial disparities in substance use disorder recovery. *Social Science & Medicine*, *199*, 140–147. doi:10.1016/j.socscimed.2017.08.002

Kessler, R. C., Mickelson, K. D., & Williams, D. R. (1999). The prevalence, distribution, and mental health correlates of perceived discrimination in the United States. *Journal of Health and Social Behavior*, *40*, 208–230. doi:10.2307/2676349

Koohi, F., Nedjat, S., Yaseri, M., & Cheraghi, Z. (2017). Quality of life among general populations of different countries in the past 10 years, with a focus on human development index: A systematic review and meta-analysis. *Iranian Journal of Public Health*, *46*, 12–22.

Lago, R. R., Bógus, C. M., & Peter, E. (2018). An exploration of the relational autonomy of people with substance use disorders: Constraints and limitations. *International Journal of Mental Health and Addiction*, 1–16.

Laudet, A. B., & White, W. L. (2008). Recovery capital as prospective predictor of sustained recovery, life satisfaction, and stress among former poly-substance users. *Substance Use & Misuse*, *43*(1), 27–54. doi:10.1080/10826080701681473

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, *71*, 2150–2161. doi:10.1016/j.socscimed.2010.09.030

McConnell, D., & Snoek, A. (2018). The importance of self-narration in recovery from addiction. *Philosophy, Psychiatry, & Psychology*, *25*(3), 31–44. doi:10.1353/ppp.2018.0022

McGinty, E. E., Goldman, H. H., Pescosolido, B., & Barry, C. L. (2015). Portraying mental illness and drug addiction as treatable health conditions: Effects of a randomized experiment on stigma and discrimination. *Social Science & Medicine*, *126*, 73–85. doi:10.1016/j.socscimed.2014.12.010

Mental Health Parity and Addiction Equity Act of 2008, H. R. 1424-117. (2008).

Misztal, B. A. (2001). Normality and trust in Goffman's theory of interaction order. *Sociological Theory*, *19*(3), 312–324. doi:10.1111/0735-2751.00143

Polcin, D. L., Henderson, D., Trocki, K., Evans, K., & Wittman, F. (2012). Community context of sober living houses. *Addiction Research & Theory*, *20*, 480–491. doi:10.3109/16066359.2012.665967

Richter, S., Brown, S., & Mott, M. (1991). The impact of social support and self-esteem on adolescent substance abuse treatment outcome. *Journal of Substance Abuse*, *3*, 371–385.

Room, R., Rehm, J., Trotter, R. T., Paglia, A., & Üstün, T. B. (2001). Cross-cultural views on stigma valuation parity and societal attitudes towards disability. In Ü. T. Bedirhan (Ed.), *Disability and culture: Universalism and diversity* (pp. 247–291). Seattle, WA: Hofgrebe & Huber.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Rosenberg, M. (1979). *Conceiving the self*. Malbar, FL: Robert E. Krieger.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Nursing Health*, *23*, 334–340.

Schmitt, D. P., & Allik, J. (2005). Simultaneous administration of the Rosenberg self-esteem scale in 53 nations: Exploring the universal and culture-specific features of global self-esteem. *Journal of Personality and Social Psychology*, *89*, 623–642. doi:10.1037/0022-3514.89.4.623

Schwarzer, R., & Jerusalem, M. (1995). Generalized self-efficacy scale. In J. Weinman, S. Wright, & M. Johnston (Eds.), *Measures in health psychology: A user's portfolio. Causal and control beliefs* (pp. 35–37). Windsor, UK: NFER-NELSON.

Skevington, S. M., Lotfy, M., & O'Connel, K. A., WHOQOL Group. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research*, *13*, 299–310. doi:10.1023/B:QURE.0000018486.91360.00

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.

Stringer, K. L., & Baker, E. H. (2018). Stigma as a barrier to substance abuse treatment among those with unmet need: An analysis of parenthood and marital status. *Journal of Family Issues*, *39*(1), 3–27. doi:10.1177/0192513X15581659

van Boekel, L. C., Brouwers, E. P. M., van Weeghel, J., & Garretsen, H. F. L. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence*, *131* (1–2), 23–35. doi:10.1016/j.drugalcdep.2013.02.018

Vilsaint, C. L., Kelly, J. F., Bergman, B. G., Groshkova, T., Best, D., & White, W. (2017). Development and validation of a Brief assessment of recovery capital (BARC-10) for alcohol and drug use disorder. *Drug and Alcohol Dependence*, *177*, 71–76. doi:10.1016/j.drugalcdep.2017.03.022

Walsh, R., & Koelsch, L. (2012). Building across fault lines in qualitative research. *Human Psychology*, *40*, 380–390.

White, W. (2000). *Toward a new recovery movement: Historical reflections on recovery, treatment and advocacy*. Recovery Community Support Program (RCSP) Conference, Arlington, Virginia.

White, W. L. (2007). The new recovery advocacy movement in America. *Addiction*, *102*, 696–703. doi:10.1111/add.2007.102.issue-5

Williams, C. (1992). *No hiding place: Empowerment and recovery for our troubled communities*. New York, NY, USA: HarperCollins.

Woods, J. S., & Joseph, H. (2012). Reducing stigma through education to enhance medication-assisted recovery. *Journal of Addictive Diseases*, *31*(3), 226–235. doi:10.1080/10550887.2012.694599

World Health Organization. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, *28*(3), 551–558. doi:10.1017/S0033291798006667

Wu, I. H., Bathje, G. J., Kalibatseva, Z., Sung, D., Leong, F. T., & Collins-Eaglin, J. (2017). Stigma, mental health, and counseling service use: A person-centered approach to mental health stigma profiles. *Psychological Services*, *14*(4), 490. doi:10.1037/ser0000165

Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social Science & Medicine*, *64*(7), 1524–1535. doi:10.1016/j.socscimed.2006.11.013