



Barriers to accessing and continuing mental health treatment among individuals with dissociative symptoms

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ABSTRACT

Background: Dissociative disorders (DDs) are characterized by interruptions of identity, thought, memory, emotion, perception, and consciousness. Patients with DDs are at high risk for engaging in dangerous behaviours, such as self-harm and suicidal acts; yet, only between 28% and 48% of individuals with DDs receive mental health treatment. Patients that do pursue treatment are often misdiagnosed, repeatedly hospitalized, and experience disbelief from providers about their trauma history and dissociative symptoms. Lack of dissociation-specific treatment can result in poor quality of life, severe symptoms requiring utilization of hospitalization and intensive outpatient treatment, and high rates of disability.

Objective: Given the extensive and debilitating symptoms experienced by individuals with DDs and the infrequent utilization of treatment, the current study explored barriers to accessing and continuing mental health treatment for individuals with dissociative symptoms and DDs.

Method: A total of 276 participants with self-reported dissociative symptoms were recruited via online social media platforms. Participants completed a survey which featured 35 possible barriers to accessing treatment and 45 possible reasons for discontinuing treatment, along with open text boxes for adding barriers/reasons that were not listed.

Results: Results showed 97% of participants experienced one or more barriers to accessing treatment ($M = 9$ barriers) and 92% stopped treatment with a provider due to at least one of the reasons captured in the survey (e.g. limited insurance coverage, poor therapeutic alliance, disbelief from providers, etc.; $M = 7$ barriers).

Conclusions: The most frequently endorsed barriers were structural barriers, such as those related to finances, insurance, and lack of provider availability. It is imperative more service providers are trained to treat dissociation and that insurers and health care systems recognize the need for specialized, dissociation-focused treatment.

Barreras para acceder y continuar el tratamiento de salud mental entre personas con síntomas disociativos

Antecedentes: Los trastornos disociativos (TD) se caracterizan por interrupciones en la identidad, pensamiento, memoria, emoción, percepción y conciencia. Los pacientes con TD tienen un alto riesgo de participar en conductas peligrosas, como autolesiones y actos suicidas; sin embargo, solo entre el 28–48% de las personas con TD reciben tratamiento de salud mental. Los pacientes que buscan tratamiento a menudo son mal diagnosticados, hospitalizados repetidamente y experimentan incredulidad por parte de los proveedores sobre su historial de trauma y síntomas disociativos. La falta de un tratamiento específico para la disociación puede resultar en una mala calidad de vida, síntomas graves que requieren hospitalización y tratamiento ambulatorio intensivo y altas tasas de discapacidad.

Objetivo: Dados los síntomas extensos y debilitantes que experimentan las personas con TD y la utilización poco frecuente del tratamiento, el presente estudio exploró las barreras para acceder y continuar el tratamiento de salud mental para las personas con síntomas disociativos y TD.

Método: Un total de 276 participantes con síntomas disociativos auto-reportados fueron reclutados a través de plataformas de redes sociales en línea. Los participantes completaron una encuesta que presentaba 35 posibles barreras para acceder al tratamiento y 45 posibles razones para interrumpir el tratamiento, junto con cuadros de texto abiertos para agregar barreras/razones no incluidas en la lista.

Resultados: Los resultados mostraron que el 97% de los participantes experimentó una o más barreras para acceder al tratamiento ($M = 9$ barreras) y el 92% interrumpió el tratamiento con un proveedor debido al menos a una de las razones capturadas en la encuesta (por ejemplo, cobertura de seguro médico limitada, pobre alianza terapéutica, incredulidad por parte de los proveedores, etc.; $M = 7$ barreras).

Conclusiones: Las barreras confirmadas con mayor frecuencia fueron las barreras estructurales, como las relacionadas con las finanzas, los seguros médicos y la falta de disponibilidad de proveedores. Es imperativo que más proveedores de servicios estén capacitados para tratar la

ARTICLE HISTORY

Received 29 October 2021
Revised 12 January 2022
Accepted 12 January 2022

KEYWORDS

Dissociation; dissociative disorder; treatment; treatment access; treatment barriers; insurance

PALABRAS CLAVE

Disociación; trastorno disociativo; tratamiento; acceso al tratamiento; barreras al tratamiento; seguro médico

关键词

解离; 解离障碍; 治疗; 治疗可获取性; 治疗障碍; 保险

HIGHLIGHTS

- Most dissociative individuals reported barriers to accessing and continuing mental health treatment.
- It is imperative more clinicians are trained to treat dissociation and that insurers and health care systems recognize the need for specialized, dissociation treatment.

disociación y que las aseguradoras y los sistemas de atención médica reconozcan la necesidad de un tratamiento especializado centrado en la disociación.

患有解离症状的个体获得和继续心理健康治疗的障碍

背景: 解离障碍 (DDs) 的特征是身份, 思想, 记忆, 情感, 感知和意识的中断。患有 DD 的患者从事危险行为的风险很高, 例如自伤和自杀行为; 然而, 只有 28–48% 的 DD 患者接受心理健康治疗。确实寻求治疗的患者经常被误诊, 反复住院, 并且体验到提供者对他们创伤史和解离症状的不信任。缺乏解离特异性治疗可能导致生活质量差, 需要住院和强化门诊治疗的严重症状以及高残疾率。

目的: 鉴于 DD 个体经历的广泛和衰竭性症状以及不频繁使用治疗, 本研究探讨了为患有解离症状和 DD 的个体获得和继续心理健康治疗的障碍。

方法: 通过在线社交媒体平台招募了 276 名自我报告有解离症状的参与者。参与者完成了一项调查, 其中列出了 35 个可能的治疗障碍和 45 个中断治疗的可能原因, 以及用于添加未列出的障碍/原因的开放文本框。

结果: 结果显示, 97% 的参与者在获得治疗方面遇到了一个或多个障碍 ($M = 9$ 个障碍), 92% 的参与者由于至少一个从调查中捕获的原因停止了治疗 (例如, 有限的保险范围, 差的治疗联盟, 提供者的怀疑等; $M = 7$ 个障碍)。

结论: 最常被认可的障碍是结构性障碍, 例如与财务, 保险和缺乏提供者可用性有关的障碍。必须培训更多的服务提供者来治疗解离, 并且保险公司和医保系统必须认识到需要特定聚焦解离的治疗。

Dissociative disorders (DDs) are characterized by interruptions of identity, thought, memory, emotion, perception, and consciousness (American Psychiatric Association [APA], 2013). DDs are empirically associated with a history of trauma (Dalenberg et al., 2012). While it is often thought these disorders are rare, studies show the prevalence of DDs ranges from 4% to 38% in inpatient, outpatient, and general populations (García, Rico, & Agráz, 2006; Gast, Rodewald, Nickel, & Emrich, 2001; Şar, Akyüs, & Doğan, 2007). Individuals with DDs experience impaired global functioning and are at high risk of engaging in dangerous behaviours such as self-harm and suicidal acts (Mueller-Pfeiffer et al., 2012; Nester, Boi, Brand, & Schielke, 2022; Nester, Brand, Schielke, & Kumar, 2022; Webermann, Myrick, Taylor, Chasson, & Brand, 2016). However, only 28–48% of these individuals receive mental health treatment, and of those that receive treatment, as few as 25% rate the treatment as appropriate to their needs (Leonard, Brann, & Tiller, 2005; Şar et al., 2007). Studies show individuals with DDs who do not receive dissociation-specific treatment experience high rates of disability, frequent hospitalizations, and poor quality of life (Leonard et al., 2005). These negative consequences, coupled with the low rate of treatment utilization, highlight the need for understanding and mitigating the barriers to treatment for dissociative individuals.

The most frequently endorsed mental health treatment barriers include preference to handle the problem oneself, internalized stigma and embarrassment, no or low perceived need for treatment, unaffordable or unavailable treatment, and perceived ineffectiveness of treatment (Andrade et al., 2014; Gulliver, Griffiths, & Christensen, 2010; Naifeh et al., 2016). Among traumatized individuals, the most commonly endorsed barriers are a lack of perceived need for treatment, preference to handle the problem oneself,

fear of judgement from others, and uncertainty about where to find treatment (Boscarino, Adams, Stuber, & Galea, 2005; Kantor, Knefel, & Lueger-Schuster, 2017; Koenen, Goodwin, Struening, Hellman, & Guardino, 2003). The barriers experienced by individuals with trauma are similar to those endorsed by other populations; however, there are some barriers unique to survivors of trauma (Kantor et al., 2017). For example, while adult trauma survivors endorse general barriers such as stigma and shame, they also experience trauma-specific barriers such as preferring to not talk or think about trauma, feeling helpless about their traumatic memories, and fearing their distressing memories may be overwhelming. Overall, trauma survivors with posttraumatic stress disorder (PTSD) endorse a greater total number of barriers to mental health care compared to individuals with other psychiatric disorders (Koenen et al., 2003). Further, there may be additional barriers present for trauma survivors with trauma-related dissociative symptoms, such as internal conflict among self-states (sometimes referred to as parts, alters, personalities, or identities).

Despite the research on treatment barriers experienced by individuals with a history of trauma, no research exists on treatment barriers experienced by individuals with dissociative symptoms. The present study aims to fill this gap by identifying barriers to accessing and continuing mental health treatment among individuals with trauma-related dissociation. We made the following hypotheses:

- (1) The majority of dissociative individuals would experience barriers to *accessing* mental health treatment.
- (2) The majority of dissociative individuals would experience barriers to *continuing* mental health treatment.

- (3) A subset of the dissociative individuals would experience barriers related to their dissociative symptoms.

1. Method

1.1. Participants

The sample was comprised of 276 individuals between the ages of 18 and 71 years old ($M = 31.09$, $SD = 9.76$) who self-reported experiencing dissociative symptoms. The most commonly endorsed dissociative symptoms were depersonalization (75.72%), derealization (71.71%), dissociative amnesia (70.29%), identity alteration (54.71%), and absorption (52.90%). Around 63.04% of participants endorsed intrusive experiences (e.g. flashbacks, nightmares), which are conceptualized as PTSD symptoms that are dissociative in nature. Most participants (79.71%) reported having been diagnosed with a DD or PTSD by a medical or mental health provider. The average number of years having been diagnosed with a DD or PTSD was 6.06 years ($SD = 4.83$). See Table 1 for a breakdown of dissociative symptoms and diagnoses.

A total of 91.30% ($n = 252$) individuals reported having received mental health treatment in their lifetime, and 70.29% ($n = 194$) were receiving mental health treatment at the time of the study. The average number of years receiving any form of mental health treatment was 8.52 ($SD = 7.87$; range, <1–40). Individuals receiving mental health treatment were meeting with their provider anywhere from two or more times a week to less than once a month. Most participants in treatment were being treated in a private practice (62.37%), outpatient clinic (23.20%), or higher level of care (9.79%) setting.

Participants were primarily from the United States (81.88%; $n = 226$), but were also from 16 different

countries, including the UK, Canada, Germany, Thailand, and Lithuania, among others (see demographics in Table 2). The participants were primarily female (46.01%; $n = 127$), male (27.90%; $n = 77$), or non-binary (9.78%; $n = 27$), and most were sexual minorities (58.70%; $n = 162$). The majority of participants indicated their race as white (77.17%; $n = 213$), and reported they had received a college or graduate degree (65.22%; $n = 180$), and were either middle class (37.32%; $n = 103$) or working class (35.87%; $n = 99$).

1.2. Measures

1.2.1. Demographic

Participants provided their demographic information, including age, gender, sexual identity, race/ethnicity, country, and socioeconomic status.

1.2.2. Treatment history and dissociative symptoms

Individuals responded to a series of questions related to their mental health treatment history, diagnostic history, and current mental health treatment. Participants also indicated what dissociative symptoms they experienced by responding to the prompt, 'Please indicate what dissociative symptoms you experience that seem unrelated to substance use, other medical conditions, other psychiatric disorders, or normal religious and cultural practices.' Participants could select which symptoms they experience from a list of eight dissociative symptoms or select 'unsure'; the list of dissociative symptoms queried is in Table 1. Each symptom was listed with a series of examples following the symptom name (e.g. Derealization [e.g. feeling detached from your surroundings; feeling like the world is foggy, dreamlike, or unreal]).

1.2.3. Treatment barriers

Our treatment barriers questionnaire was modelled after the treatment barriers portion of the World Health Organization's World Mental Health survey (Andrade et al., 2014) and available literature on barriers to accessing and continuing mental health treatment (e.g. Kantor et al., 2017; Naifeh et al., 2016). The questionnaire was adapted in an effort by all the authors of the present study. An informal panel of individuals with dissociative disorders then provided feedback on the questionnaire and the authors adapted the questionnaire based on the feedback provided. See Appendices A and B for the Treatment Barriers Questionnaires. These barriers spanned several domains, including structural barriers (e.g. financial/insurance difficulties, lack of provider availability, and competing needs such as time, low energy, and child-care), perception of problem barriers (e.g. individual did not think their problem was severe enough to require treatment, individual wanted to handle their problem on their own), perceived ineffectiveness of

Table 1. Reported dissociative diagnoses given by clinicians and symptoms.

		% Endorsed (<i>n</i>)
Dissociative Diagnoses	Dissociative Identity Disorder	43.84 (121)
	Other Specified Dissociative Disorder	18.84 (52)
	Depersonalization/Derealization Disorder	11.96 (33)
	Dissociative Amnesia	9.06 (25)
	PTSD – Dissociative Subtype	29.71 (82)
	PTSD – No Dissociative Subtype	6.88 (19)
	Unsure	3.26 (9)
	No official diagnosis	13.77 (38)
Dissociative Symptoms	Depersonalization	75.72 (209)
	Derealization	71.74 (198)
	Dissociative Amnesia	70.29 (194)
	Intrusive Experiences	63.04 (174)
	Identity Alteration	54.71 (151)
	Absorption	52.90 (146)
	Dissociative Trance	44.93 (124)
	Possession	19.20 (53)
	Unsure	0.36 (1)

Table 2. Participant demographic information.

Demographics		% (n)	M (SD)	Range
Age			31.09 (9.76)	18–71
Gender	Agender	1.45 (4)		
	Bigender	0.72 (2)		
	Female	46.01 (127)		
	Genderfluid	4.71 (13)		
	Male	27.90 (77)		
	Nonbinary	9.78 (27)		
	Trans-feminine	2.17 (6)		
	Trans-masculine	5.43 (15)		
	Other	1.81 (5)		
Race	Asian/Asian American	3.99 (11)		
	Biracial/Multiracial	5.07 (14)		
	Black/African American	6.88 (19)		
	Hispanic/Latinx	3.99 (11)		
	White/Caucasian	77.17 (213)		
	Other	2.54 (7)		
Sexuality	Asexual	5.07 (14)		
	Bisexual	18.12 (50)		
	Gay	5.43 (15)		
	Heterosexual	41.30 (114)		
	Lesbian	6.16 (17)		
	Pansexual	8.7 (24)		
	Queer	7.97 (22)		
	Questioning	3.99 (11)		
	Other	2.90 (8)		
	Socioeconomic Status	Poor	13.77 (38)	
Working Class		35.87 (99)		
Middle Class		37.32 (103)		
Upper middle class		10.51 (29)		
Upper class		1.09 (3)		
Education	Other	1.09 (3)		
	Some grade school	2.54 (7)		
	High school/GED	23.19 (64)		
	Trade, technical, or professional work training	6.52 (18)		
	College degree	41.30 (114)		
	Graduate degree	23.91 (66)		
Country	Other	1.09 (3)		
	Belgium	0.36 (1)		
	Canada	6.52 (18)		
	Czech Republic	0.72 (2)		
	Finland	0.72 (2)		
	Germany	1.45 (4)		
	Iceland	0.36 (1)		
	Lithuania	0.36 (1)		
	Netherlands	0.36 (1)		
	New Zealand	1.09 (3)		
	Norway	0.36 (1)		
	Poland	0.36 (1)		
	Slovenia	0.36 (1)		
	Spain	0.36 (1)		
	Thailand	0.36 (1)		
	Turkey	0.36 (1)		
	UK	3.99 (11)		
United States	81.88 (226)			

treatment, lack of trained providers in trauma and/or dissociation, anticipated or experienced stigma, anticipated or experienced negative response from providers, and beliefs about self, among others. Individuals who experienced identity alteration were provided a separate list of access and continuation barriers relevant to having dissociative self-states (sometimes referred to as parts, identities, personalities, or alters).

Participants endorsed any barriers that they experienced as preventing them from accessing or continuing mental health treatment. Individuals who indicated they experienced treatment barriers that were not listed in the survey had the option to include additional barriers in an open text box.

1.3. Procedure

After receiving institutional board approval, participants were recruited in December of 2020 via online platforms, such as Reddit, Twitter, and Facebook groups. An advertisement for the study was posted in areas oriented for individuals with trauma-related dissociation or DDs (e.g. Subreddits r/DID, r/Dissociation, r/cPTSD; trauma-focused hashtags on Twitter: #dissociation, #dissociativeidentitydisorder #PTSD). Participants had to be age 18 or older, read English, and have self-reported dissociative symptoms or report having been diagnosed with a DD by a mental health professional. After agreeing to the informed consent, participants completed surveys about their demographic information, diagnostic and

treatment experiences, and barriers to accessing or continuing mental health treatment. Upon completion, participants could choose to accept or decline a \$15 Amazon gift card.

1.4. Analyses

Descriptive statistics were completed on all study variables. Frequency data were calculated for each barrier domain. An inductive, conventional content analysis approach was utilized to analyse the open text box responses, such that the code and category development was reflective of the content featured in the qualitative data (Hsieh & Shannon, 2005; Kondracki, Wellman, & Amundson, 2002). Conventional content analysis was selected due to its usefulness in identifying and describing phenomenon when research on the topic is limited. First, the three members of the research team immersed themselves in the data. The research team independently reviewed the data and made notes of key concepts that were salient and/or repeated. The team members also reflected on their first impressions, thoughts, and initial analysis of the data. The research team then had two meetings to discuss key concepts identified, which were then used to create codes that reflected each key concept. These codes were then sorted into categories to create meaningful and distinct clusters (Coffey & Atkinson, 1996). The coding structure included operational definitions for each code and category. Two members of the research team independently coded the data, with 97% interrater reliability. Coding discrepancies were resolved through consensus building among all research team members. This was followed by a collective review of the coding structure, the labelling of categories, and the selection of exemplars for each category.

Each of the three research team members have clinical and/or research experience with trauma survivors and dissociative individuals. The range of experiences allowed the authors to approach the coding discussions with different perspectives, each of which were trauma- and dissociation-informed. The research team engaged in bracketing (i.e. actively reflecting on potential biases on the topic and reactions to the data; Tufford & Newman, 2012). This, in addition to the process outlined above, allowed the authors to increase the rigour of the process and ensure the credibility and dependability of the study (Bengtsson, 2016).

2. Results

2.1. Barriers to accessing mental health treatment

Approximately 96.73% ($n = 267$) of participants endorsed one or more barriers to accessing mental health treatment; see Figure 1. Participants reported having

experienced an average of nine different access barriers from the list of 35 potential barriers to treatment we provided. Participants encountered structural barriers (91.30%), including financial and insurance barriers, limited provider availability, and competing time, energy, childcare, or transportation needs which interfered with accessing treatment. Dissociative identity-related barriers (e.g. individual was fearful of communicating with parts, parts did not want to attend therapy, parts threatened to become unsafe; 56.16%) and negative beliefs about self (e.g. shame and embarrassment; 'I don't deserve help'; 51.45%) were the next most common barriers. A subset of participants feared a poor response from a provider (45.65%), most of whom indicated concerns that the provider would not believe their trauma history or dissociative experiences. Participants also endorsed barriers related to their perception of the problem (42.75%), perception of treatment effectiveness (40.94%), difficulty finding a provider trained in trauma and/or dissociation (35.51%), and stigma (32.25%).

2.2. Barriers to continuing mental health treatment

Approximately 92.03% of participants discontinued treatment with a provider in their lifetime, see Figure 2. Participants endorsed an average of seven different barriers from the list of 45 potential barriers to continuing treatment we provided. The most commonly endorsed continuation barriers were structural barriers (77.1%). Around 48.91% of participants indicated discontinuing treatment due to the therapeutic alliance they had with the provider, which included being treated poorly by a provider or feeling as though treatment was not adjusted to their individual needs. Dissociative identity-related barriers were endorsed by 46.38% of the sample; participants discontinued treatment because their parts caused interference due to feeling disrespected or powerless, or because learning about their parts was overwhelming. More than one third (i.e. 36.59%) discontinued treatment after working with a provider who they believed was not trained in trauma and/or dissociation. Another 27.54% endorsed experiencing a poor response from a provider, such as a provider not believing the individual's trauma history or dissociative symptoms. Participants also stopped treatment due to negative beliefs about the self (22.83%), their perception of the problem (20.65%), anticipated or experienced stigma (18.12%), or belief on behalf of the participant or their provider that the individual's symptoms were stable and treatment was no longer necessary (10.87%).

2.3. Content analysis

A total of 46 participants (16.67%) indicated they experienced barriers to accessing or continuing mental

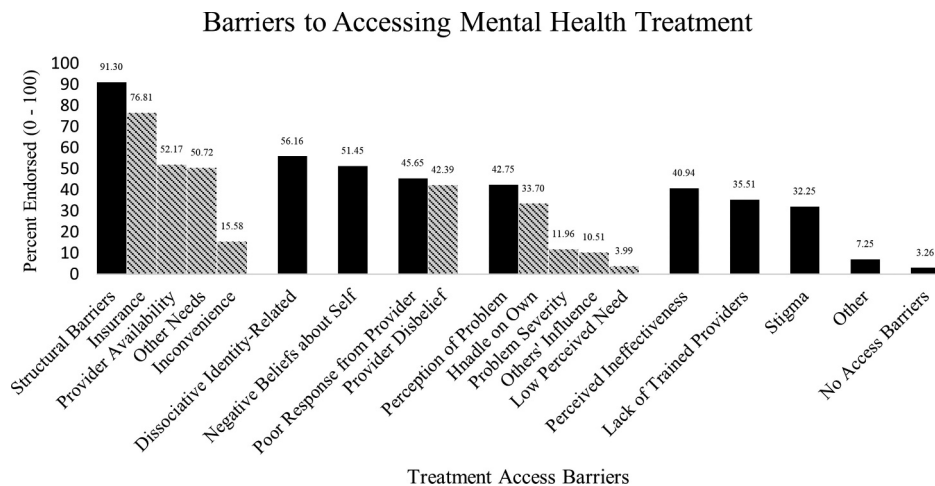


Figure 1. Barriers to accessing mental health treatment. Black bars represent barrier categories. Grey bars represent sub-categories of barriers represented within the category represented by the black bar to the direct left. Note that participants could endorse multiple sub-categories within each category.

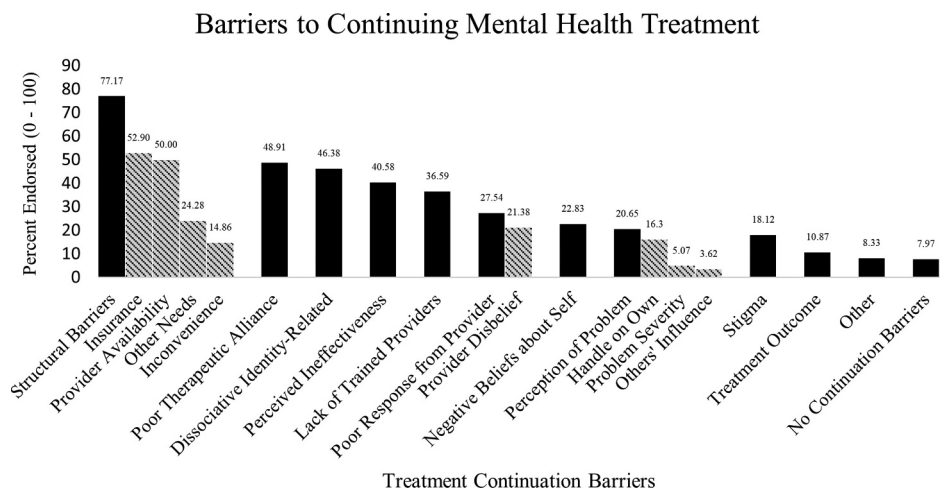


Figure 2. Barriers to continuing mental health treatment. Black bars represent barrier categories. Grey bars represent sub-categories of barriers represented within the category represented by the black bar to the direct left. Note that participants could endorse multiple sub-categories within each category.

health treatment that were not captured in the survey. A content analysis resulted in identifying seven different sources of barriers: (1) *Prior or Anticipated Negative Experiences in Treatment*, (2) *Internal Experiences of Dissociation*, (3) *Wrongful Provider Termination*, (4) *Marginalized Identity*, (5) *Others' Interference*, (6) *Lack of Dissociation Knowledge*, and (7) *Anticipated Consequences on Education or Career*. See Table 3 and Online Supplemental Material for participant quotes from each category identified using content analysis.

3. Discussion

Almost all of the participants (96.73%) reported experiencing barriers to accessing mental health treatment. Of the 91.30% of participants who reported receiving mental health treatment in their lifetime, 92.03% of them reported experiencing barriers to continuing mental

health treatment. Our dissociative participants experienced many barriers to accessing and continuing mental health treatment. These barriers included structural barriers (e.g. financial; insurance; time constraints), dissociation-related concerns (e.g. fear of communicating with parts), negative beliefs about the self (e.g. 'I don't deserve help'), prior or anticipated negative experiences in treatment (e.g. provider not believing in dissociation), an individual's perception of the problem or the ineffectiveness of treatment (e.g. low or no perceived need for treatment), limited providers trained in trauma and/or dissociation, and stigma. Barriers specific to accessing treatment included others' interference (e.g. family not allowing access to treatment in childhood), barriers related to the individual's identity (e.g. no providers who could accommodate specific disabilities; limited access to gender affirming care when also managing a DD diagnosis), the dissociative individual's lack

Table 3. Content analysis results.

Category	Examples
Prior or Anticipated Negative Experiences in Treatment	'I had a clinic director flat out tell me I was faking it and didn't need treatment, even after my psychiatrist got me a referral to a specialist. The director (at a well known HMO [Health Maintenance Organization]) refused to allow my referral to go through. I was kicked around to several providers in that clinic who told me there was nothing they could do.' 'Providers I reached out to receive treatment from have outright made fun of me by calling me hypersensitive or crazy.' 'I was misdiagnosed a lot over the course of 20 years, and I have additional trauma as a result of the medical and mental health systems. I was once sexually abused by a therapist. CBT [Cognitive Behavioral Therapy] hasn't been very helpful for the problems I have, but in many places it was the only kind of therapy I had access to.'
Internal Experiences of Dissociation	'The parts going to therapy were the ones that didn't need help, did not want help, or had little insight to work with. The parts that needed to be engaged for effective therapy work did not trust the therapist.' 'Dissociative amnesia and other dissociative symptoms prevented me from fully realizing or remembering what exactly I was needing mental health treatment for.' 'Phobia of parts between each other.'
Wrongful Provider Termination	'The provider concluded that they could not help me and that maybe I was just not meant to get better.' 'I went to one therapist for depression. They told me, "I can't help you until you can feel again." 'They discharged me because I completed their CBT course and there was nothing else they could do for me'.
Marginalized Identity	'Even when connecting with Rape crisis/sexual abuse recovery organizations, some therapists and staff were clearly not compassionate, respectful, or were prejudiced (had false negative assumptions) either due to my age/gender/race.' 'I'm trans in a country that only allows transition in the limited circumstances, and I was afraid that my genuine gender dysphoria will be treated as a sign of my identity disorder. I did not want to integrate to be cis, even if some of my alters were cis. I did not want this diagnosis to limit my access to medical transition.' 'Deafness- needed someone that could sign or does not require having an interpreter because that is another cost associated to therapy, and in group setting they would refuse admission because I required an ASL [American Sign Language] interpreter.'
Others' Interference	'Someone in my life talked to my treatment provider before I could, and their opinions on what I needed to work on mentally warped all of my following sessions. I was never able to discuss what I felt I needed help with without the provider constantly bringing up what the other person thought my problem was.' 'I was on parent's insurance and parents did not approve of/support seeking therapy. Could not find a way to use the insurance without them knowing, even after I turned 18.' 'My biological family is overcontrolling (and abusive) and, while I'm granted access to my father's insurance plan, I cannot stop the EOBs [explanation of benefits] from being sent directly to him. I tried calling the insurance company and they were perplexed but ultimately unable to do anything to change that.'
Lack of Dissociation Knowledge	'I didn't recognize my issues as dissociation, and therefore did not seek the correct treatment for years.' 'I didn't know about my parts and we had no internal communication other than memory sharing for continuity.' 'Conflict on how to describe or present symptoms, and what specific help to ask for related to them, eg "I experience these symptoms and need help coping with them" vs "I have convinced myself i experience this but I actually do not, and need help stopping that".'
Anticipated Consequences on Education or Career	'Certain job types require a full submission of your mental health if you have been to a doctor for your mental health in the past 10 years. I was told not to pursue any treatments in case it caused me to be unhirable for this field.' 'I found it difficult to find a provider who was not affiliated with the University/Healthcare systems in which I or others in my doctoral program work.'

of knowledge about dissociation (e.g. individual did not know they were experiencing dissociation), and anticipated consequences on education and career (e.g. would not be allowed to continue career if employer found out about mental health treatment). Barriers specific to continuing treatment included a poor therapeutic alliance, wrongful provider termination (e.g. a provider telling the individual they could not be helped) and feeling as if treatment was not personalized to meet the individual's needs. Given these barriers, it is imperative more service providers are trained to recognize and treat dissociation and that health care systems become informed about the need for specialized, dissociation-focused treatment.

Finance and insurance barriers were the most frequently endorsed barriers to both accessing (76.81%) and continuing (52.90%) mental health treatment. Finance-related barriers to mental health treatment are common across disorders and communities (e.g. Novak, Anderson, & Chen, 2018; Rowan, McAlpine, & Blewett, 2013), and have been documented as a barrier

to receiving therapeutic care among trauma survivors and dissociative individuals (Hunter, 2016; Kantor et al., 2017). In the present study, dissociative individuals indicated greater endorsement of finance-related concerns (up to 76.81%) than that which is found in other studies of trauma survivors (e.g. Koenen et al., 2003; 28.3%). This may indicate a particular need for financially accessible treatment for dissociative individuals. For many participants, insurance companies provided only a limited amount of coverage, and the remaining out-of-pocket costs were reported to be too high to begin or continue treatment.

Some participants were from countries with universal mental health care. While these individuals may theoretically have access to no- or low-cost mental health treatment, they reported having access only to providers who were untrained in trauma and/or dissociation or they were placed on long waitlists. Due to limited providers trained in trauma and dissociation, many participants in these countries elected to pursue dissociation-trained, mental health clinicians in

private practice which required that they self-pay for treatment. Similarly, many participants in countries with insurance-based health care coverage reported having to go to out-of-network providers and pay substantially higher costs for these services. These financial and health care system limitations create what was often reported to be insurmountable financial barriers for accessing quality, trauma- and dissociation-informed mental health treatment.

Despite the high cost of mental health treatment, it is notable that inpatient and outpatient costs gradually decrease over the course of DD-specialized treatment (Myrick, Webermann, Langeland, Putnam, & Brand, 2017). As DD individuals stabilize their symptoms and reduce their reliance on unsafe behaviours (e.g. non-suicidal self-injury and suicide attempts) during trauma and dissociation-focused treatment, the need for inpatient hospitalization and intensive outpatient treatment is reduced, resulting in lower costs for treatment (Myrick et al., 2017). Health care systems and policy makers need to be aware of the long-term financial benefits of providing specialized treatment to dissociative individuals, as well as the considerable improvements in symptoms, quality of life and daily functioning (e.g. Brand et al., 2013, 2019).

Dissociative-identity related concerns were the second most frequently endorsed access barrier (56.16%) and third most endorsed continuation barrier (46.38%). Dissociative experiences, more generally, were also barriers demonstrated in the qualitative responses. For example, some participants had internal conflict among self-states about their willingness to participate in treatment and/or perceived need for it. Participants reported they were misdiagnosed with disorders and symptoms such as 'psychosis' or 'delusions'. Several reported they had been mocked by clinicians when they discussed dissociation and trauma. Others were told they were faking their dissociative symptoms. Some reported that therapy had been invalidating and harmful (e.g. provider ended treatment sessions if the patient was dissociating). Many individuals were discharged from treatment and told they could not be helped, or that there was 'nothing else [the treatment provider] could do' for them. Ultimately, many individuals and their parts described feeling unsafe around their treatment provider; they feared they were not accepted, they did not trust the provider, and/or they felt misunderstood.

Participants' negative experiences in treatment, oftentimes with providers untrained in trauma and/or dissociation, can impact the therapeutic alliance (e.g. Cronin, Brand, & Mattanah, 2014; Hunter, 2016), and according to the participants, did damage the therapeutic alliance, which was the second most frequent cause of treatment discontinuation (48.91%) in the sample. Participants reported experiences where they felt misunderstood or judged by the provider,

were treated badly and/or had their boundaries violated (e.g. in one case, sexually assaulted by a provider), or felt that treatment was not adjusted to their specific needs. A stronger therapeutic alliance with dissociative individuals is associated with positive treatment outcomes (Cronin et al., 2014) and is a robust mediator of therapeutic change (Baier, Kline, & Feeny, 2020). Participants' negative experiences in treatment not only resulted in treatment discontinuation, but further contributed to patients' reluctance to seek treatment in the future.

Unfortunately, a significant number of clinicians hold stigmatizing and misinformed beliefs about dissociation (as reviewed in Brand et al., 2016), which may contribute to and perpetuate these individuals' negative experiences in treatment. Some clinicians believe that DDs are the byproduct of fantasy and suggestibility proneness or the iatrogenic effects of psychotherapy (i.e. 'Fantasy Model' of dissociation; Dalenberg et al., 2012). Fantasy Model hypotheses about fantasy and suggestibility being the aetiological cause of dissociation have been investigated and shown to have little empirical support (e.g. Dalenberg et al., 2012, 2014). Despite the lack of evidence for the Fantasy Model of dissociation, these debunked beliefs may still be held by clinicians, and, according to the participants, have had lasting negative effects on them (e.g. Leonard et al., 2005). Such misinformed beliefs and scepticism can also contribute to the mis- and under-diagnosis and treatment of DDs (e.g. Hayes & Mitchell, 1994; Perniciaro, 2014). Instead, there is overwhelming support that pathological dissociation is linked to experiences of traumatic stress (e.g. Dalenberg et al., 2012). The Trauma Model of dissociation posits that dissociation is a psychobiological response to threat which enhances survival during and after traumatic experiences (Dalenberg et al., 2012). Clinicians who have been trained about the Trauma Model of dissociation are less likely to challenge and shame their dissociative clients when they discuss and/or exhibit dissociative symptoms.

In order to identify and mitigate dissociation-related barriers, clinicians must be knowledgeable about trauma, dissociation, and the effects thereof; however, most mental health clinicians receive little systematic training in assessing for, diagnosing, and treating trauma-related difficulties (Courtois & Gold, 2009; Henning, Brand, & Courtois, 2021), and even fewer are trained in dissociation (e.g. Brand, Kumar, & McEwen, 2019; Nester, Schielke, Brand, & Loewenstein, 2021; Perniciaro, 2014). This was also apparent in the quantitative findings, as evidenced by the 36.59% of participants who reported untrained providers as a barrier to treatment. To remove this barrier to accessing and continuing treatment, more clinicians need training about providing treatment

that is consistent with expert consensus guidelines (Chu et al., 2011) and research-supported interventions for traumatized individuals with dissociative symptoms (Brand et al., 2012, 2019) so that treatment is both safe and effective. These findings illuminate that it is essential that treatment providers become knowledgeable about recognizing and treating dissociation, including how to work with individuals with dissociative self-states and treatment approaches that facilitate building trust and are rooted in a trauma-informed, compassionate framework.

In an effort to increase engagement with treatment and reduce the likelihood of premature drop-out, it may help for providers to consider the barriers dissociative individuals experience that are unique to their experience with trauma and dissociation (e.g. fears of addressing painful trauma memories, fears about improving communication with parts; Kantor et al., 2017). Other trauma-specific barriers that could compound barriers that are common to mental health clients include psychological trauma-related barriers (e.g. intrusive re-experiencing symptoms; shame; suicidality) physical trauma-related barriers (e.g. trauma-related injuries or disabilities), environmental barriers (e.g. loss of home or resources as a result of conflict with the perpetrator of their trauma), social barriers (e.g. estrangement from family if trauma occurred within the family system), and societal barriers (e.g. stigma; political instability perpetuating blame towards survivors of trauma). Anticipating and mitigating these barriers could increase treatment access and continuance for individuals.

The frequency of treatment utilization among our sample is noteworthy. A total of 91.30% ($n = 252$) of the participants reported having received mental health treatment in their lifetime, and 70.29% ($n = 194$) were receiving mental health treatment at the time of the study. These rates of treatment utilization were substantially higher than the 28–48% of DD individuals receiving mental health treatment in other studies (Leonard et al., 2005; Şar et al., 2007). There may be several causes for these differences. In this study, participants were recruited via online platforms specifically oriented for people who experience dissociation. As such, individuals who were recruited must have had some awareness and familiarity with dissociation and had the understanding that their personal experiences were dissociative in nature. Such understanding and awareness may have been gained through the process of receiving treatment. In addition, individuals who receive a mental health diagnosis or treatment may be more inclined to find online communities to better understand their condition and to connect with others who share the same experience. Thus, the recruitment procedures may have produced a dissociative sample with higher than usual treatment utilization.

It is also important to note that the present study primarily consisted of individuals residing in the United States (81.88%), whereas the other two studies featured Turkish (Şar et al., 2007) and Australian (Leonard et al., 2005) samples. Variations in cultural norms surrounding mental health stigma, access to mental health treatment, treatment utilization, and understandings of dissociation may influence these differences in treatment utilization across samples and across time.

3.1. Limitations and future directions

These findings must be considered in light of the study's limitations. Not all disorders with dissociative symptoms were queried (e.g. panic disorder, borderline personality disorder), meaning the results may not generalize to those disorders. Instead, the study's recruitment procedures focused on individuals with trauma-related dissociation, making the external validity strongest for individuals with such. Recruitment was conducted using online social media platforms, primarily Reddit. While this allowed for recruitment of a diverse and commonly hard to reach population, it poses limitations, such as self-selection bias (Shatz, 2017) and a skewed effect towards individuals who were aware of their dissociation and were a part of online support communities. Additionally, the study's recruitment procedures resulted in a sample of participants who were primarily located in the United States (81.88%), meaning the generalizability of the results to other countries remains unknown. The psychometric properties of the survey were not tested although they were based on research findings about treatment barriers. The data are retrospective self-report; some barriers (e.g. discontinuation due to clinician's lack of training in dissociation) are based on the individual's perception rather than objective evidence. Nonetheless, the insights gained from the self-reported lived experiences of dissociative individuals is valuable for clinicians to understand.

Future research should investigate facilitators of treatment access (e.g. social support, prior positive experience in mental health treatment, desire for change), as well as individual and systemic variables that encourage help-seeking among dissociative individuals. Continued research should seek to learn more about dissociative individuals' motivation for seeking and remaining in mental health treatment, along with clarifying what steps result in successful entry into and continuation of dissociation-focused treatment. Applied research should focus on improving clinicians' attitudes and knowledge about working with highly dissociative individuals. Lastly, financially affordable and easily accessible interventions (e.g. mobile health apps and online interventions such as the TOP DD

Network study [Brand et al., 2019]), which might mitigate some of the barriers to treatment for individuals who live with trauma-based dissociation, should be investigated.

4. Conclusion

In the present study, almost all of the dissociative individuals endorsed barriers to accessing (96.73%) and continuing (92.03%) mental health treatment. The most commonly endorsed barriers included structural barriers (e.g. financial; insurance; time constraints), dissociation-related concerns (e.g. fear of communicating with parts; internal conflict among parts), prior or anticipated negative experiences in treatment (e.g. provider did not believe in dissociation), and a poor therapeutic alliance. It is essential that service providers are trained in trauma, dissociation, and the effects thereof, as well as expert-recommended and evidence-based practices for treating individuals with trauma-related dissociation (e.g. Brand et al., 2019; Chu et al., 2011). Insurers and health care systems should be made aware of and acknowledge the long-term financial and quality of life benefits that result from providing specialized treatment to dissociative individuals. Furthermore, these systems need to provide financial support for these therapeutic services.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

Our work was funded by the International Society for the Study of Trauma and Dissociation David Caul Grant, Towson University Graduate Research Grant, and Sheppard Pratt Health System's Trauma Disorders Program.

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Data availability statement

Data is not publicly available to protect the confidentiality of participants.

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Appendix A.

Table A1 Treatment access barrier questionnaire for dissociative individuals.

Barrier	Prompt
Structural	<p>Financial/ Insurance</p> <p>It was too expensive and/or I was concerned about how much money it would cost.</p> <p>I do not have health insurance.</p> <p>My insurance did not cover mental health treatment.</p> <p>There are limitations to what my insurance covers and I have exhausted those options.</p> <p>My insurance only pays for a part of mental health treatment and I cannot afford to pay what it does not pay for.</p> <p>Availability</p> <p>The provider I would like to see does not accept my insurance.</p> <p>No available, trained providers are close to where I live.</p> <p>The provider I would like to see is not taking new clients.</p> <p>I emailed/called but never heard back.</p> <p>I did not know who (or where) to ask for help.</p> <p>Inconvenience</p> <p>It would be an inconvenience to my schedule and life.</p> <p>Other Needs</p> <p>Lack of transportation.</p> <p>Lack of childcare.</p> <p>Lack of energy.</p> <p>Lack of time.</p>
Perceived Ineffectiveness	<p>I did not think treatment would work.</p> <p>I received treatment before and it did not help me.</p>
Stigma	<p>I was scared of receiving a dissociative disorder diagnosis.</p> <p>I was concerned about what others might think of me if they found out I was in treatment.</p> <p>I was concerned that people in my life would think I am crazy.</p>
Perception of Problem	<p>Handle on Own</p> <p>I wanted to handle this on my own.</p> <p>I thought my problems would get better on their own.</p> <p>Problem Severity</p> <p>My problems do not bother me that much.</p> <p>My problems are not bad enough for treatment.</p> <p>Others' Influence</p> <p>People I care about do not want me to get mental health treatment</p> <p>Low Perceived Need</p> <p>I have never felt that I needed to access mental health treatment.</p>
Providers' Response	<p>I was concerned that my provider would think I am crazy.</p> <p>Provider Disbelief</p> <p>I was scared that a provider would not believe in my dissociative symptoms.</p> <p>I was scared that a provider would not believe in my history of being traumatized.</p>
Lack of Trained Providers	<p>I could not find a provider specializing or trained in dissociation.</p> <p>I could not find a provider specializing or trained in trauma.</p>
Belief about Self	<p>I do not feel like I deserve help.</p> <p>I was scared to talk about painful things from my past.</p> <p>I was too ashamed or too embarrassed to reach out for help.</p> <p>I do not believe I can change or improve things in my life.</p>
No Barriers	<p>I have never experienced barriers that prevented me from accessing treatment.</p>
Other	<p>Other _____ (open text box)</p>
Dissociative Identity Related	<p>Some of my parts did not want me to go to therapy.</p> <p>I was scared to communicate with my parts.</p> <p>Some of my parts threatened to become self-destructive in treatment.</p> <p>My parts have not interfered with my accessing mental health treatment.</p> <p>Other _____ (open text box)</p>

Appendix B.

Table B1 Treatment continuation barriers questionnaire for dissociative individuals.

Barrier	Barrier	Question
Structural	Financial/Insurance	It was too expensive and/or I was unable to continue paying.
		I did not have health insurance.
	Availability	My insurance no longer covered mental health treatment.
		There are limitations to what my insurance covers and I exhausted those options.
		My insurance only paid for some of my mental health treatment and it was still too expensive.
		The only trained provider I could find was too far away.
		I emailed/called but never heard back about scheduling more appointments.
		My provider left or moved away.
	Inconvenience	My provider closed their practice.
		My provider got ill or passed away.
Other Needs	I moved away.	
	I became too ill to continue going to treatment.	
	It was an inconvenience to my schedule and life.	
	Lack of transportation.	
Perceived Ineffectiveness	Lack of childcare.	
	Lack of energy.	
	Lack of time.	
Stigma	I tried treatment but it did not work for me.	
	I was not getting any better.	
Perception of Problem	I was getting worse.	
	I was scared of receiving a dissociative disorder diagnosis.	
	I was concerned about what others might think of me if they found out I was in treatment.	
	People thought I was crazy.	
Providers' Response	People were saying negative things about me being in treatment.	
	I wanted to handle this on my own.	
	I thought my problems would get better on their own.	
Lack of Trained Providers	My problems did not bother me that much anymore.	
	People I care about wanted me to stop going to therapy.	
Belief about Self	I was scared that my provider believed I was crazy.	
	My provider hospitalized me when I did not think I needed it.	
Therapeutic Alliance	My provider did not believe that my trauma memories were real or valid.	
	My provider did not believe in dissociation or dissociative disorders.	
	The provider was not trained or specialized in dissociation .	
Treatment Outcomes	The provider was not trained or specialized in trauma .	
	I felt like I did not deserve help.	
No Treatment Termination	I did not want to talk about painful things from my past.	
	I was too ashamed or too embarrassed to continue.	
Other	My provider said or did something that made me feel like they could not understand or help me.	
	I was treated badly or unfairly by the provider.	
Dissociative Identity Related	I felt like my provider was judging me.	
	My therapist did not adjust treatment to fit my specific needs.	
Dissociative Identity Related	A treatment provider violated boundaries.	
	I did not need help anymore.	
Dissociative Identity Related	My symptoms were stable and my treatment team determined I no longer needed it.	
	My symptoms were stable and I felt that I no longer needed it.	
Dissociative Identity Related	I have never stopped treatment with a provider.	
	Other _____ (open text box)	
Dissociative Identity Related	My parts interfered with me being in treatment.	
	My parts felt that the therapist was trying to take away their power or control.	
Dissociative Identity Related	My parts felt disrespected by the therapist.	
	I felt overwhelmed by learning about my parts.	
Dissociative Identity Related	My parts have not caused me to stop treatment with a provider	
	Other _____ (open text box)	