An interdisciplinary exploration of the treatment gap in self-injurious behavior in intellectual and developmental disabilities

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Overall Abstract

This is an exploratory multi-paper dissertation on the topic of treatment access for self-injurious behavior (SIB) in intellectual and developmental disabilities (IDD). In the introduction I orient the reader to the relevant history of science and methodological approach. Then, in three papers I harness the power of experiential knowledge and interdisciplinarity through reflexive thematic analysis and knowledge translation. In Paper 1, *A qualitative analysis of family caregiver experiences accessing treatment for self-injurious behavior in individuals with intellectual and developmental disabilities,* I explore the experiences of family caregivers interacting with providers to access treatment for SIB in IDD and present a working model of treatment pathways. In Paper 2, *Interdisciplinarity and self-injury: Toward an inclusive research and treatment paradigm,* I explore the possibility of an interdisciplinary study of self-injury in individuals with and without intellectual and developmental disabilities. In Paper 3, *Stakeholder beliefs: An interdisciplinary exploration of the treatment gap in self-injurious behavior in intellectual and developmental disabilities,* I consider the specific role of the beliefs of caregivers, researchers, and clinicians in treatment access. I conclude with a synthesis of the three papers, their shared contribution, implications for research and practice, limitations, and future directions.

Table of Contents

Overall Introduction

This is a multi-paper dissertation exploring treatment access in individuals with intellectual and developmental disabilities (IDD) and self-injurious behavior (SIB). In this introduction I aim to orient the reader to the relevant history of science and the overall methodological approach. By familiarizing the reader with the conceptual and methodological overarching frameworks, I intend to prepare the reader to understand the specificity of each of the following three manuscripts within the broader context of self-injury research and practice.

Orientation in Time and Place

Throughout recorded history, there is evidence that humans sometimes intentionally injure themselves. What exactly this looks like differs by time, place, and other factors. Historians interested in self-injury may discuss the self-flagellation or castration of devout religious followers in the middle ages, the self-mutilation of hysteric women in asylums in the Victorian era, the self-scarification of the indigenous Maori of New Zealand, or the delicate cutting of women in post-World War II media in the United States (Chaney, 2017; Te Awekotuku, 2020). In each of these examples, scholars use different words to refer to self-injury (*self-mutilation*, *scarification*, *delicate cutting*) and may propose different understandings of the behavior. Though how we understand self-injury today may differ, historians know to avoid *presentism*: projecting modern ideas onto the past.

A historian's way of thinking demonstrates a primary paradox of self-injury: self-injury is at once a highly personal behavior and a highly contextualized behavior. How self-injury is understood may be unique to every individual; yet, simultaneously, how self-injury is understood may be highly influenced by factors outside the individual such as time, place, culture, and who is aiming to understand it. For example, what meaning does an act of self-scarification or *ta*

moko hold for a Maori individual? What did a cultural interest in media depicting self-injury indicate about post-World War II American culture? Within and beyond the individual lens, context matters.

This dissertation is written in the specific context of the 21st century United States and with specific interest in the population of individuals with intellectual and developmental disabilities. In the history of psychiatry, this is the era of the DSM-5, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association). Released in 2013 and revised in 2022, the DSM-5 is the outcome of a 20th century focused on classification and categorization of mental illness (Angelotta, 2015). The phrase "self-injury" appears 73 times in the text of the DSM-5 (American Psychiatric Association). It is mentioned in the descriptions and diagnostic criteria of autism spectrum disorder, stereotypic movement disorder, and personality disorders. *Nonsuicidal self-injury disorder* is proposed as a condition for further study and researchers are investigating the validity of the proposed diagnostic criteria (American Psychiatric Association; In-Albon et al., 2013).

In the history of disability in the United States, deinstitutionalization is only the recent past. Not long ago people with disabilities, especially intellectual and developmental disabilities, were actively separated and excluded from participation in society. Only 65 years ago children with disabilities could be excluded from public schools for "producing a depressing and nauseating effect upon the teachers and school children" (Smith, 2004, p. 4). The disability rights movement has paved the way to the recent neurodiversity movement and disability justice movement, which aim to not only include disabled people, but to celebrate their unique contributions.

These contexts are broad and a dissertation is specific. Yet the current moment is highly relevant to how the following studies were conceptualized and may be interpreted. As the following manuscripts will elucidate, self-injury is understood as categorically different in individuals with and without intellectual and developmental disabilities (IDD). My work questions the validity and usefulness of this paradigm. I consider the phenomenon of self-injury with specific attention to the current structures of our time and place in order to imagine an interdisciplinary study of self-injury. I chose an empirical approach that is conceptually influenced by historical thinking because I believe that the current context has highly influenced how scholars and clinicians think about self-injury, whether we are aware of it or not.

This historical lens is highly conceptual, but the following studies are also pragmatic. I focused on the issue of treatment access in SIB in IDD. As the papers will discuss, not all who need treatment for SIB receive it. Many individuals with chronic SIB and their families continue to struggle to maintain a high quality of life, despite advances in biobehavioral treatment options for SIB (Moore et al., 2024). Though in the studies, particularly Paper 2, I discussed a wide variety of topics relevant to self-injury research and practice, I aimed to connect the overall interpretation of the three studies' findings back to the practical and pressing issue of treatment access for families who are in urgent need of support.

Orientation to Method

Methodologically, the primary data source in this dissertation was lived experience. The participants were stakeholders who live self-injury each day as caregivers, researchers, or clinicians. The method was qualitative and mostly inductive; I recognize the influence of my positionality on this research, but I do not purport to be the expert. Rather, the participants were the experts, and my role was to gather and make sense of their experiences. My attempt at

"making sense" was done through collaborative reflexive thematic analysis, as guided by the work of qualitative methodologists Virginia Braun and Victoria Clarke (2021; 2006).

I chose a qualitative approach because this research is exploratory and prioritizes depth over breadth. Scholars do not have a clear sense of why there is a gap between who needs treatment for SIB and who receives it (what I refer to as the treatment gap), so exploration and description is needed. SIB treatment is complex and likely differs across settings, so depth is more useful at this point in the research process than breadth. Insight about how the treatment process works lies with the stakeholders within it, so experiential knowledge is the data source. More specifically, the research questions in each of the three papers are appropriately answered through qualitative methodology, as they focus on the beliefs and experiences of stakeholders. The research questions are as follows:

1. *What are the experiences of family caregivers in interactions with providers for the treatment of SIB in individuals with IDD?* (Paper 1)
2. *What do clinicians and researchers believe is the role of interdisciplinarity in the study and treatment of self-injury?* (Paper 2)
3. *What do clinicians, researchers, and family caregivers believe about the cause(s) of self-injury and the goals of treatment for self-injury?* (Paper 3)

The methodological approach in all three papers prioritized reflexivity, which is an intentional process of reflection and self-awareness throughout the research process. This is because I believe my positionality, and those of my co-authors, is highly relevant to the research. I am the sister of an individual with IDD and chronic SIB as well as a SIB researcher. I know there is a treatment gap not only because I have read about it but because I have lived it. I discuss in the methods section of each paper how I have bracketed my own experiences while

conducting this research and I note the limits of bracketing in the overall limitations section. However, I ultimately believe my positionality is an asset in this program of research, most notably because this research may not exist if not inspired by my life experience.

Orientation to the Papers

Three papers in standalone manuscript format follow. They are the result of multiple analyses of two datasets collected between March 2021 and March 2023. The first dataset consists of semi-structured interviews with family caregivers, primarily mothers, of individuals with IDD and chronic SIB. The second dataset consists of focus groups with researchers and clinicians with expertise in the study and/or treatment of SIB or nonsuicidal self-injury (NSSI; self-injury in individuals without intellectual and developmental disabilities). Both datasets are samples of convenience and I do not purport that they are representative of the respective populations (see Overall Limitations section).

In Paper 1 I describe the treatment gap from the perspective of family caregivers of individuals with IDD and chronic SIB. In Paper 2 I consider interdisciplinarity and self-injury from the perspective of researchers and clinicians in SIB and NSSI. In Paper 3 I expand the results of Papers 1 and 2 by focusing specifically on the beliefs that the three stakeholder groups hold and how beliefs may influence the existence of the treatment gap and efforts to close it. I conclude with a brief integrated discussion of the papers, their limitations, and future directions. As you read each paper in their specificity, I ask you to do your best to simultaneously hold a broad perspective of context, including the history and culture that has led to the paradigms of self-injury research and practice today, and how those paradigms may ultimately influence the experiences of individuals with SIB and their families.

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A qualitative analysis of family caregiver experiences accessing treatment for self-injurious behavior in individuals with intellectual and developmental disabilities

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Abstract

Introduction

There is evidence of a gap between individuals with intellectual and developmental disabilities (IDD) who need treatment for self-injurious behavior (SIB) and those who receive treatment. The purpose of this study (n = 15) was to begin to understand the treatment gap from the perspective of family caregivers.

Methods

In semi-structured virtual interviews, family caregivers discussed their experiences of working with providers to treat their family member's self-injury. Through a systematic process of quasi-inductive thematic analysis, researchers transcribed and analyzed the interviews and developed a working model of treatment pathways.

Results

Caregivers described many barriers to treatment access. Themes include Caregiver Driven, Importance of the Provider-Caregiver Relationship, Beliefs and Perceptions about SIB, Practical Constraints, Knowledge Gaps, and Wait Until Crisis.

Conclusion

The findings highlight the power of providers to support families coping with SIB in IDD. Specific ways providers can better facilitate treatment access are suggested. Future research directions should include provider interviews and focus groups and, ultimately, the development of interventions that consider access pathways as a key feature of any effective treatment plan.

Keywords: qualitative, self-injurious behavior, caregivers, treatment access

A Qualitative Analysis of Family Caregiver Experiences Accessing Treatment for Self-Injurious Behavior in Individuals with Intellectual and Developmental Disabilities

> *"Nobody wants to help you until the ambulance comes. You know, until you reach a crisis point… that to me is- that's the real tragedy here, because I have been crying out, to everybody who will listen to me: I need help. I need help. I need help. And all of them go- wow, yes you do. But I can't help you. So good luck with that."*

Lifetime prevalence estimates indicate that 5-20% of individuals with intellectual and developmental disabilities (IDD) and as many as 30-50% of individuals with autism spectrum disorder engage in self-injurious behaviors (SIB) such as headbanging, eye poking, biting, or skin gouging (Dimian & Symons, 2022). The tremendous negative impacts of these behaviors on quality of life for individuals and their families are well-documented (e.g., Turnbull & Reuf, 1997), yet there is a paucity of research on the development of SIB or the experiences of caregivers seeking treatment for SIB.

There is, however, evidence that caregivers cannot reliably access treatments for challenging behaviors like SIB, despite advances in biobehavioral treatment options (Griffith & Hastings, 2014; Lunsky et al., 2014; Ruddick et al., 2015; Toms et al., 2015). Ruddick et al. described a significant discrepancy between the prevalence of challenging behaviors such as SIB in children with severe intellectual developmental disabilities (IDD) and those who were referred for, or received, services. Autistic adults involved in a participatory study described being dismissed for mental health services because "people like me don't get support" (Camm-Crosbie et al., 2019, p. 1434). Healthcare disparities for people with disabilities are especially

pronounced for individuals with IDD and mental health needs (Hall & Kurth, 2019; Iezzoni, 2011).

Outcomes for both caregivers and individuals with disabilities are poor without treatment. Without treatment, SIB is likely to continue and become more difficult to manage. Self-injury may become a chronic, intractable problem. For example, Taylor et al. (2011) reported that 84% of a study sample from 1987 still engaged in SIB in 2011. In a prospective cohort study, self-injury persisted in 44% of autistic individuals over ten years (Laverty et al., 2020). Family caregivers for individuals who engage in challenging behavior like SIB experience increased caregiver burden and stress and are vulnerable to lower well-being; unsurprisingly, these negative effects are worse without adequate access to information and services (e.g., Griffith & Hastings, 2014; Resch et al., 2010; Symons et al., 1999; Unwin & Deb, 2011). In the absence of support, caregivers may engage in dangerous practices to cope with SIB, such as physical restraint without safety training (Allen et al., 2006).

In addition to a lack of research on long-term treatment for severe challenging behavior, there is insufficient research on both access to SIB-specific treatment for individuals with IDD and the nature of treatment experiences. Frequently, researchers include SIB in the category of "challenging behavior" or "problem behavior," typically defined as "self-injurious behavior, physical and/or verbal aggression, destructiveness, inappropriate sexual behavior, antisocial behavior, disturbed sleep and overactivity" (James, 2013, p. 14). It is unknown whether SIB treatment access specifically differs from access for other challenging behaviors, or from other service delivery experiences, such as the experience of getting a diagnosis and services for autism (an area with a considerable research literature; Makino et al., 2019; Snijder et al., 2021).

A potential reason for the gap in SIB treatment services may be the everyday experiences of caregivers of individuals with SIB and IDD. The family caregiver perspective is crucial to understanding why the treatment gap exists and how researchers and practitioners can support family caregivers who are caring for a child or adult with SIB. The role of parent and family systems in developmental outcomes is robustly recognized by the research literature (Head & Abbeduto, 2007). This suggests that the knowledge and attitudes that a parent or a caregiver has about SIB and available treatments would influence the child's developmental outcomes.

The primary goal of this study was to explore the experience of accessing treatment for SIB in individuals with IDD from the family caregiver perspective. The central research question for this study is: What are the treatment experiences of family caregivers for individuals with IDD for SIB? The subquestion of this analysis is: What are the experiences of family caregivers in interactions with providers for the treatment of SIB in individuals with IDD? The term "provider" may refer to any service provider from across the medical, educational, and allied health disciplines providing services to address the issue of SIB. These research questions are broadly articulated and focused on the essence of an experience in the tradition of phenomenological research (Creswell & Poth, 2018). By harnessing the lived experience of family caregivers who cope with SIB each day, we aim to better understand the treatment gap, why it exists, and what can be done to close it.

Methods

We chose a qualitative interview approach to gather a depth of experiential knowledge. Qualitative methods are especially suited to capture the complexities of disability in the social context; specifically, they are ideally suited to "illuminating the often hidden interactions of cultural attitudes, institutional processes, public policies, and individual

lives" (O'Day & Killeen, 2002, p. 10). In the following sections, our approach is described in detail in pursuit of transferability (Anfara et al., 2002; Lewis et al., 2014).

Philosophical Assumptions

There are three primary epistemological and ontological assumptions underlying this work. In accordance with critical disability theory, the researchers believe that disability is a dimension of human difference and not a defect, the meaning of a disability depends upon the social context, and systemic ableism exists and influences participant experiences. Relatedly, the researchers accept the social constructivist idea that individuals construct subjective meaning of their experiences and it is the researchers' duty to value and accept a complexity of viewpoints co-constructed by historical and cultural norms (Creswell and Poth, 2018). For example, in accordance with our philosophical assumptions, we allowed the participant to self-define what qualifies as a chronic case of SIB, given the guideline that we were interested in SIB severe enough to interfere with daily life. Finally, this work is oriented toward pragmatism, with real-world applications a primary goal of this research.

Positionalities

We, the first and second authors, engaged in reflection on our personal orientations toward the issue of SIB and discussed with each other how our positionalities (i.e., our personal positioning in relation to the study topic and context) might influence our analysis (Braun & Clarke, 2021). The first author identifies as a semi-insider perspective in some ways; she is a caregiver for her brother, who has intellectual and developmental disabilities and engages in severe, entrenched SIB, though she is not currently his primary caregiver. The second author identifies as an outsider perspective, though she has experience as an educator for individuals with IDD who engage in SIB.

Ethics

This study was approved by the University of Minnesota Institutional Review Board. Eligible participants (see below) completed an informed consent process which included the purpose of the study and explanation of the right of participants to terminate their participation at any time. Prior and during the interview process, the researchers engaged in reflexivity regarding the ethical issues inherent in qualitative health research with sensitive topics, including issues of therapeutic interviewing, relational boundaries, and emotional impact for both researcher and participant (Kendall & Halliday, 2014). In this context, reflexivity refers to an intentional process of reflection and self-awareness through journaling and peer debriefing intended to enhance methodological and ethical rigor in the interview process. During the interviews, the researcher worked to cultivate an interview environment in which participants felt comfortable and used active listening skills. When participants became emotional, the researcher responded with empathy and a reminder that they could end their participation or take breaks at any time. Following data collection, the data was deidentified and stored securely on a Box server (including journaling documents).

Participants

Participants were recruited through convenience and snowball sampling via online support groups and personal networks. For example, this process included e-mailing parent support group listservs and asking participants for referrals from their social networks. An eligibility screening determined if they met the inclusion criteria: immediate family members over the age of 18 or legal guardians with direct involvement in the care for an individual with IDD who engages in SIB that is significant and pervasive enough to interfere with daily life. As this is an initial inquiry with a broad aim, a specific sample population, and an expectation of

high-quality dialogue given the interviewer's semi-insider status, *n* =15 was determined as the sample size according to the concept of information power (Malterud et al., 2016).

The participants were primarily mothers with one sibling and one father (Table 1). They were primarily white, non-Hispanic, well-educated, employed, and with an annual income greater than $50,001 (Table 1). They were located in Colorado, Minnesota, Idaho, Florida, and California. The family members they cared for were primarily white and the most common diagnoses were autism and developmental delay (Table 2). All but one caregiver indicated their family member had multiple IDD diagnoses. Nine individuals with IDD were male and four were female. Participants reported a variety of SIB topographies and all but one reported multiple topographies of SIB (Table 2). Two participants did not report demographic information.

Table 1
Caregiver demographics

Characteristic	*n*(13)	%
Gender		
Male	1	8%
Female	12	92%
Nonbinary/other	0	0%
Caregiver Relationship		
Mother	11	85%
Father	1	8%
Sister	1	8%
Race		
white	12	92%
Black or African American	1	8%
Ethnicity		
Non-Hispanic	13	100%
Hispanic	0	0%
Education level		
Less than high school degree	0	0%
High school graduate	1	8%
Some college but no degree	3	23%
Associates degree	1	8%
Bachelor's degree	3	23%
Master's degree	4	31%
Doctoral degree	0	0%
Professional degree	1	8%
Employment status		
Working (paid employee)	7	54%
Working (self-employed)	2	15%
Not working	4	31%
Income		
Less than $10,000	1	8%
$10,001-$50,000	1	8%
$50,001-$100,000	3	23%
$100,001-$149,999	4	31%
Prefer not say	4	31%

Note: Two participants did not provide demographic information. Participants were permitted to select more than one race. Percentages are based on reported data.

Table 2
Individual with IDD demographics

Characteristic	*n*(13)	*%*
Gender		
Male	9	69%
Female	4	31%
Nonbinary/other	0	0%
Race		
white	12	92%
Black or African American	1	8%
Asian	1	8%
Ethnicity		
Non-Hispanic	12	92%
Hispanic	1	8%
Diagnosis		
Developmental delay	11	85%
Autism	10	77%
Chromosomal or genetic linked syndrome	1	8%
Visual impairment or blindness	2	15%
Deaf or hard of hearing	1	8%
Other	9	69%
SIB Topographies		
Hits self with body part	12	92%
Hits self against surface or object	9	69%
Hits self with object	5	38%
Bites self	8	62%
Pulls hair or skin	7	54%
Rubs or scratches self	7	54%
Inserts finger or object	5	38%
Skin picking	6	46%

Note: All information about the individual with IDD is caregiver-reported. Respondents were permitted to select more than one race, diagnosis, and SIB topography. The SIB topography information was collected via the Self-Injurious Behavior Subscale of the Repetitive Behavior Scale-Revised (RBS-R; Bodfish et al., 1999). Two participants did not complete survey information for their family member. Percentages are based on reported data.

Procedure

Upon first contact with the researchers, participants completed an eligibility screening via Qualtrics. The first author followed up via e-mail to confirm their eligibility, gain informed consent, and schedule the virtual interview. Participants completed a survey before or after the interview, which included demographic data and the Repetitive Behavior Scale-Revised (Bodfish et al., 1999; reported in Tables 1 and 2). The survey had a response rate of 87%; two participants did not complete the survey, despite reminders.

The interviews were conducted virtually, using Zoom, between March and July 2021 and lasted between 45 min and 2.5 hr. We used the automatic transcription and recording features of Zoom for data collection. The first author conducted fourteen interviews and the second author conducted one interview, because of previously established trust between the second author and the participant (i.e., the second author was previously the participant's son's teacher). At the start of the interview, the researcher re-introduced herself and the project, reminded the participant of their right to end the interview at any time, and alerted them that Zoom was recording. The interviews were semi-structured. See Table 3 for an excerpt from the interview protocol, noting that the term "providers" was intentionally ambiguous to allow participants to discuss the types of providers most relevant to their circumstance. The first author disclosed her positionality as a semi-insider when she felt it was appropriate to earn the trust of the participant, but did so sparingly and thoughtfully, taking care not to deter the interview focus from the participant.

Table 3
Interview Protocol Excerpt

Questions	Additional probes
When did you first realize that your family member was self-harming? Tell me about this realization and what came next.	If you initiated treatment, how did you know that it was time to seek treatment for your family member's self-harm? If you initiated treatment, how did you go about seeking treatment? Who did you turn to?
Are you satisfied with the treatment your family member has received for self-harm?	If you are not satisfied, what do you wish you or providers had done differently? If you are satisfied, what treatment experiences have made you feel this way?
Imagine you have a friend who has a family member with similar disabilities as your own. This friend comes to you with concerns that their family member has begun engaging in self-harm. What would you suggest they do?	What would be the best way to inform people about how to find help?

Data Analysis

The researchers edited the Zoom transcriptions for clarity according to the video recording of the interview and uploaded the files into NVIVO software for qualitative coding. By conducting, viewing, editing, and transcribing the interviews, both researchers thoroughly familiarized themselves with the data (Braun & Clarke, 2006). The researchers engaged in an iterative process, involving open coding separately (a process of initial generation of concepts from the data), collaboratively discussing the data and developing a codebook, and continuing to gather and transcribe interviews while analyzing previously collected data. Codes and categories were added, renamed, and reorganized throughout the analytical process, consistent with an

iterative and quasi-inductive approach. Discussion between the first and second authors aimed to deepen analysis rather than achieve consensus (Braun & Clarke, 2021).

Following data collection and open coding of all 15 transcripts, the first and second authors visualized the codebook of categories and codes with a concept map (i.e., we conceptualized connections between codes and working themes on a whiteboard). The data included a richness beyond the initial research question, such as exploration of the caregiving experience and family stress. It was at this point that we decided to focus on interactions with providers for the initial analysis. We began a second stage of coding in which we individually wrote memos for each code under the category of Interactions with Providers. Each researcher, independently, re-read the coded data and wrote reflections, connections, and other thoughts; we then met and deepened our analyses through conversation. This systematic process led to revising and reworking potential themes. At this stage, we understood the data deeply enough to apply what we had learned to our second variable, the process of accessing treatment. We then developed the working model of treatment pathways, presented in Figure 1. We presented our findings to our research team for peer debriefing. Throughout the process, we maintained a thorough audit trail, revisited philosophical assumptions as needed, and engaged in ongoing reflexivity.

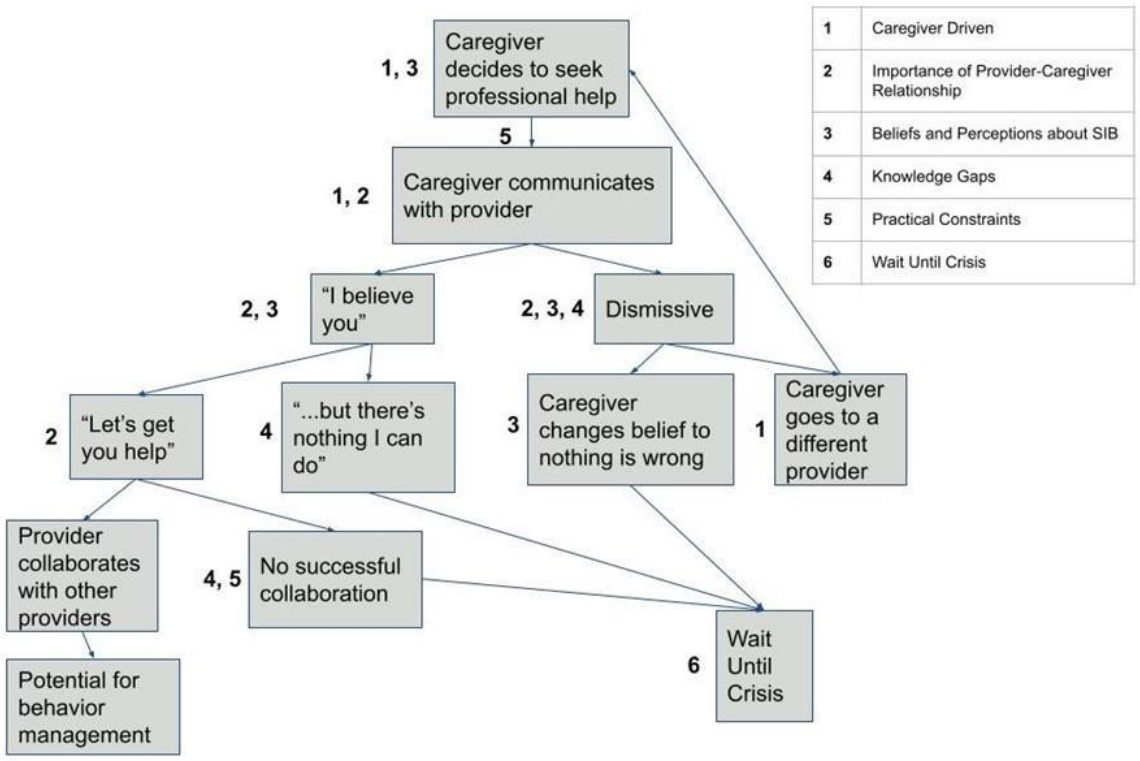

Figure 1. This working model represents caregiver pathways to treatment from the decision to seek professional help for self-injury. Numbers along the pathways correspond to themes as described in the legend.

Results

Participants described substantial barriers to effective treatment access at multiple levels. Our analysis led to the development of six themes to describe the participants' treatment experiences as they relate to interactions with providers. The themes are described in detail in the following sections. In summary, (a) primary caregivers tend to shoulder the responsibility of treatment access (Caregiver Driven), (b) treatment access tends to be a relational process (Importance of the Provider-Caregiver Relationship), (c) the caregiver's and the provider's

beliefs and perceptions of the SIB influence each other and treatment (Beliefs and Perceptions about SIB), (d) there are multiple gaps in treatment knowledge and case knowledge (Knowledge Gaps), (e) systemic practical constraints influence the caregiver-provider interaction (Practical Constraints), and (f) there is a tendency to put-off intervention until the SIB leads to a crisis such as severe injury (Wait Until Crisis). We found that although we did not ask participants to discuss a certain type of provider, participants tended to focus on interactions with providers in a medical context, particularly pediatricians and other primary care providers, and psychiatrists and psychologists.

Caregiver Driven

The Caregiver Driven theme describes the assumption of caregiver responsibility to initiate, coordinate, follow-up, follow-through, and ensure the treatment of the individual with SIB. This came up either implicitly or explicitly in all interviews. Some participants described the isolation and burden of the responsibility to procure and sustain treatment directly (e.g., "*I definitely feel that it has all been mother-driven"*). Other participants described more implicit barriers: they did not expect or anticipate proactive support from providers as they experientially learned that treatment access required persistent and ongoing "*pushing*." The word *pushing*, or similar words, occurred repeatedly across interviews: *"about three years ago is when we started doing the medication intervention. And that was mostly because I* ***pushed*** *for it," "so I kept* ***pushing*** *and* [name redacted] *received the diagnosis of autism spectrum disorder at about nine years old."*

Although a few participants mentioned partners, professionals, or other family members who shared this responsibility, for most participants, there was a primary caregiver (most often a mother) who consistently held the responsibility of treatment access. In some cases, the primary

caregiver went to remarkable lengths in pursuit of treatment, including in-depth research of medications and treatments in medical libraries (pre-internet), lawsuits and legislation, parenting classes, and traveling long distances for specialty care (particularly for participants from rural areas). For some caregivers, particularly older caregivers who had been seeking treatment for many years, advocacy had become a deep part of their identity and extended beyond their own adult child to the needs of their community.

This theme was inextricable from descriptions of individual, dyadic, and family stress. Ongoing pursuit of care was often stressful in and of itself, as well as motivated by the urgency of enormous family stress: "*there's only so much we can take on in terms of supporting her*," "*I just remember thinking, I don't want to live my life this way...I just pictured myself at eighty trying to restrain my big fifty-five-year-old*," "*he was starting to get more violent towards us*," "*when he has these fits I'm just trying to protect the two-year-old*."

This led to a paradox for caregivers of limited physical and emotional energy: as the SIB became more severe, the need for treatment and support from outside the family increased, but the energy of caregivers was depleted by coping with the severe SIB. Caregivers had little remaining energy to drive access to treatment, which required mental, physical, and emotional labor. Specifically, this labor involved logistically coordinating visits with new providers and also re-living the chronic trauma of SIB in every conversation seeking help.

Caregivers had varying reactions to this paradox, which seemed to align with where they were in the process of acquiring care. If the onset of the SIB was relatively new (within the last few years), caregivers were in the midst of going through multiple providers and multiple treatment types. Although they may have been angry and frustrated, they still retained enough energy and hopefulness to try new approaches and see new providers. Conversely, caregivers for

adults who had entrenched SIB that occurred for many years frequently exhibited symptoms of burnout and described their efforts to drive treatment access in the past. However, these caregivers tended to have a sense of hopelessness about new treatments in the present. Although the SIB was frequently still an ongoing, sometimes severe, problem, older caregivers had little interest or energy to try new treatment approaches beyond what they had already found helped to manage the behavior. One caregiver summarized this sense of stagnation in the following way:

> "*Parents become... they're disconnected from what they're doing in relation to managing their child and their child's injury and the genesis of the problem...They stop seeking solutions, because they get either shunned or ridiculed or put off or their insurance won't pay or- you know, people are disrespectful or whatever it might be, you know, the bureaucracy doesn't understand what they need, you know, and it just becomes- they're resigned to taking care of this. Rather than, how am I going to get out of this? How am I going to get my child served without me, you know, being the heart and soul of every single act and action?*"

In the last sentence above, this participant succinctly summarizes the Caregiver Driven theme and expresses one of its great dangers: when a primary caregiver is unable to drive treatment access for an individual with IDD who self-injures, what then?

Importance of Caregiver-Provider Relationship

Positive experiences came from positive caregiver-provider relationships, regardless of type of provider. When caregivers described positive experiences with providers, they tended to report that the provider made them feel listened to and supported, rather than the provider having a special sort of expertise. When talking about a positive experience with a provider, caregivers emphasized a sense of feeling listened to ("*he just listens to me*," "*he listened to me...he would*

take my calls") and lucky ("*extremely lucky... I mean we're talking really lucky,*" "*it's very lucky*," "*we're probably lucky*,") as well as validated in their sense of urgency ("*Dr.* [name redacted] *gets it. He understands that it can kill you*.") Their favorite providers tended to be those they had known a long time and who they felt knew their family well (they held case knowledge; see Knowledge Gaps theme). They were willing to go above and beyond when necessary, such as one family's experience of a doctor helping them access Medicaid.

Likewise, many descriptions of negative experiences emphasized how the provider made the participant feel: dismissed, reprimanded, hopelessly unusual, judged, like a burden, or a general sense of being misunderstood. They described bringing in pictures of injuries as "*proof,*" because the provider didn't believe the SIB was as severe as the caregiver said. Multiple caregivers described "*panicked*" phone calls and crying, out of desperation to make the provider believe them and adopt their sense of urgency. One mother described relief at her son's meltdown in the primary care doctor's office, in which he headbanged on the wall of the waiting room: "*at least the doctor saw it*."

Relationships also had the power to open-up or limit care options. One caregiver described when a neurologist refused to see her as he had heard from other providers that she was a "*hysterical parent*." Getting an appointment with a provider was sometimes the result of social capital: "*we are actually personal friends with* [name redacted]*,"* "*I finally got him into a psychiatrist, after I served on this board of directors*," "*one of my friends had worked for five years at* [name redacted]*."* This demonstrates privileged interaction with the care system for well-connected individuals, particularly given the high socioeconomic status and educational levels of the participants (see Table 1). One mother, who was also a leader in her local disability community, described how her son's care relied upon her status:

> "*The only way that I've been able to get anything is by doing the research myself. And then researching and talking to, I don't know how many people, because I'm really well-connected. I mean I'm in meetings all the time with all these different people who are in this business. So, my ability to find somebody to help him is like, probably 100 times better than the typical family. And I still haven't succeeded*."

Beliefs and Perceptions about SIB

As discussed in the methods section, the researchers assumed a philosophy of social constructivism. The researchers aimed to honor the complexity of meanings of SIB, treatment, or management, and other ambiguous concepts. This theme describes how those beliefs and perceptions play a role in treatment access.

Across families, the meaning of SIB varied, in terms of topography of behavior (skin picking versus headbanging; see Table 2), and also in more subtle ways, such as the delineation between a behavior which is injurious and a behavior that is restricted, repetitive, or nonnormative. For many caregivers, restricted and repetitive behaviors were typical for their child or sibling with disabilities. There was not a clear distinction between a behavior that was of little concern and a dangerous behavior that was likely to become a strong part of their behavioral repertoire. Caregiver judgment was therefore paramount.

Often, the caregiver's personal beliefs and perceptions of the behavior(s) were dynamic, changing across time and susceptible to influence by professionals, particularly at the early stages of behavior onset and diagnosis. At the point at which the caregiver first sought help from outside the family system, a belief change had occurred: the behavior was no longer 'nothing to worry about,' but perceived as (potentially) an issue in need of treatment. It was at this critical

point that a provider's own beliefs and perceptions had the power to shift the caregiver's beliefs and perceptions one way or another.

For participants, provider beliefs at this stage frequently shut-down treatment. There was an overall lack of a sense of urgency by providers. Caregivers recounted dismissive comments from healthcare providers at early consults: "*no no no he's not autistic in any way*," *"they don't see it as a big issue*," "*most of them don't take it very seriously*," "*oh no he's just a little boy... that's just what boys do*," "*oh he'll just knock himself out eventually*," "*well that's just autism*," and even "*I don't care*." These comments clearly remained with participants, who often relayed them years after they were uttered. Generalizations of providers such as "*they don't take it very seriously*" tended to come from caregivers of older individuals who had engaged in SIB for a long time.

Another crucial belief was the extent to which the caregiver believed SIB is treatable, curable, or manageable. Again, these beliefs were susceptible to influence by providers and often changed across time. As discussed in the Caregiver Driven theme, the time since SIB onset seemed to play a role in these beliefs. Caregivers newer to SIB tended to believe in the treatability and even curability of the SIB more than caregivers who had been managing SIB for many years, who often had witnessed years of SIB and many failed treatment interventions, which likely influenced their beliefs.

Culpability, and fears of misplaced culpability, were another relevant belief. Caregivers described fears of being accused of abuse; they proactively overexplained bruises and feared misunderstandings that could lead to the involvement of law enforcement or Child Protective Services: "*Who wants to bring your kid to the doctor worrying that the doctor is gonna call the ambulance and the cops?*" This fear was especially pronounced for caregivers of nonverbal

individuals who expressed themselves idiosyncratically: "*things could be interpreted in different ways, like I have a neighbor who...she called me, she's like, is everything okay? And my daughter actually had been laughing hysterically. She was really happy, but she thought she was screaming, like crying and upset."* These fears exist within a context of isolation. Although caregiving for someone with IDD is already an isolating, stigmatizing experience for many, SIB exacerbates the feeling of isolation: *"I mean there are families that are fearing for their lives. I mean they're- I mean I'm sure you understand this, they're so isolated in their homes. You know, even before the pandemic. They couldn't go out, you know, they have to lock children in their rooms to keep themselves safe and they're afraid*." Perceptions of SIB as very rare, shameful, and even impossible, lead to a context of stigma, isolation, and fear of caregivers and providers attempting treatment.

Knowledge Gaps

This theme represents gaps in knowledge and knowledge translation as they relate to the treatment of SIB, both in general and in specific cases. We identified five gaps in knowledge or knowledge translation that impeded treatment: (1) Providers lack the necessary knowledge or training to provide care ("*they had no clue about autism*"); (2) The belief that the knowledge does not exist (as stated in the previous theme, a belief that SIB is not treatable; i.e. science has not advanced enough to treat SIB); (3) Providers have the necessary knowledge, but they will not pass it on to caregivers (a caregiver perception that the providers don't care, or are unwilling to speak frankly with caregivers); (4) Providers do not have the case knowledge of the caregivers necessary to treat an individual (see below); and (5) Providers do not share knowledge with other providers involved in an individual's care (collaboration is minimal or nonexistent).

These knowledge gaps refer to two necessary types of knowledge: treatment knowledge and case knowledge. Treatment knowledge includes knowledge of the treatment options available, what will work best in a given case, and medical and behavioral expertise. Case knowledge is the in-depth understanding of the individual and their needs, including who they are, their behaviors, and their family and caregiver context. Both types of knowledge are necessary for effective intervention.

The case knowledge gap is exemplified by the following quote:

> "*It's not like you can ask the medical community or the educational community, the therapy community, none of them have the answers. They just all will try to help from their individual discipline, but they are not the family who sees the whole picture and who is trying to have a semi-decent life day to day*."

This mother describes how providers from different disciplines miss the reality of daily life with SIB and severe disability. To connect back to previously discussed themes, understanding of the daily reality of caregivers of individuals with SIB and IDD (case knowledge) comes from positive relationships between caregivers and providers and alignment of beliefs and perceptions of SIB. Without these, the third knowledge gap tends to occur, in which caregivers believe that providers are unwilling to pass on critical knowledge about treatment. Over time, this tends to lead to caregiver burnout and a resulting stagnation of treatment access, as discussed in the Caregiver Driven theme. It may also lead to the second knowledge gap, the belief that treatment for SIB does not exist, particularly when a provider insists that SIB is not treatable: "*And the doctors couldn't do anything about that. Yeah that's just how* [people with intellectual disabilities] *are, that's just, you know, that's just what you get."*

Practical Constraints

The Practical Constraints theme describes systemic and practical constraints that impede treatment access including insurance issues, bureaucratic red-tape, inflexibility of treatments, unreasonable distances to travel for specialists, and provider workforce shortages. These broader issues influence the dyadic interaction of caregivers and providers, as providers must operate within systems of care such as hospitals or clinics, and caregivers receive care within those systems and interact with other systems, such as insurance companies and social services.

A parent described the barrier of apparent inflexibility of intensive Applied Behavior Analysis (ABA) treatment, often provided at a dosage of 40 hours per week: "*So if we continue with ABA, can I survive?... that problem is much more complicated because I'm navigating this thing as basically an unemployed and unemployable single parent*." Many caregivers echoed frustrations of getting appointments with providers, child psychiatrists in particular, a field with a well-documented workforce shortage (Harris, 2018): "*We couldn't get an appointment with a psychiatrist*," "*it took five months to get in to see the developmental pediatrician which I guess nowadays is amazing*," "*I would drive an hour and a half north of here to do video appointments*," "*we were like, number 628 on the waitlist*." A caregiver reported difficulties with the standard 20-min appointments being sufficient for the exchange of case and treatment knowledge: "*I don't think they have enough time to gather enough information*." Families who had experienced emergency room or in-patient services sometimes found themselves stuck within a system of care ill-fit to their needs: "*They said, you can just take him back home, or continue to languish in the ER for weeks on end*." Although systemic issues are not the focus of this study, these quotes demonstrate how practical constraints influence the dyadic level of caregiver and provider interactions.

Wait Until Crisis

The culmination of the preceding themes is the caregiver perception that, more often than not, they do not receive help proactively. This theme is exemplified by these quotes: "*Nobody wants to help you until the ambulance comes*," "*It's like a secret, you know? No one really wants to help until it gets really bad*." Wait Until Crisis refers to the pattern of delaying intervention, the urge to "*wait and see*," sometimes on the part of both the provider and the caregiver, and ultimately leading to moments of family crisis. These moments of crisis were typically moments of especially severe SIB or aggression to others, that resulted in severe, sometimes permanent injury, hospitalization, or the involvement of law enforcement.

Caregivers resign themselves to the understanding that the emphasis on early intervention for other areas of their child's or sibling's life has not reached SIB. They encounter providers who have little to offer until the SIB is severe enough to warrant emergency hospitalization, heavy psychotropic medications, a padded room, or mechanical restraints. Caregivers, in some cases, do not feel ready to try certain treatments until the SIB is severe enough that they feel they have no other option:

> "[Interviewer:] *If you had tried risperidone a little bit sooner, that might have changed things.*
>
> [Participant:] *That's true. That's true. But then would I have been as willing?*"

In this way, the perceptions of severity can influence the tendency to postpone interventions, from both the provider and the caregiver. So can knowledge gaps, if providers do not know of treatment interventions other than the most invasive. Practical constraints may lead to a tendency to delay intervention, such as waitlists or insurance issues. Through no fault of their own, the exhaustion from having to strenuously push for care may lead caregivers to tend to

wait. Each of the preceding themes are connected to the overall tendency to Wait Until Crisis, as described in Figure 1.

Discussion

The primary research question of this study was: What are the treatment experiences of family caregivers for individuals with IDD for SIB? This analysis focused on the subquestion: What are the experiences of family caregivers in interactions with providers for the treatment of SIB in individuals with IDD? We aimed to address these questions through the thematic analysis of fifteen semi-structured interviews with family caregivers.

The interviews were rife with negative emotionality, including sadness, anger, and expressions of chronic stress. Caregivers expressed the exhaustion of daily coping combined with the frustration of inadequate treatment access and effectiveness. Stress was compounded by negative interactions with treatment providers and alleviated by positive interactions. This overall impression and the participants' descriptions seemed to confirm the treatment gap and the power of the provider to either bring relief to families struggling with SIB or deepen their frustrations.

In the analysis process, we noticed connections between themes and how the data fit into pathways of acquiring treatments. Figure 1 describes a working model of treatment pathways from the point of the caregiver's initial decision to seek professional help for SIB for their family member. Figure 1 is intended to integrate the themes from our analysis and reflect how treatment acquisition is an ongoing and dynamic process. Further, we believe the complexity of treatment access is better represented with a pathway model such as Figure 1 rather than as a dichotomous variable (i.e. treatment is either accessed or not accessed). Figure 1 was developed through in-depth analysis of the many stories and experiences shared in interviews. Participants described

traveling these pathways many times; their frustrations came from getting stuck with dismissive or unhelpful providers repeatedly. This left caregivers in a seemingly endless loop of fruitless help-seeking until they reached crisis. They then returned to help-seeking when short-term crisis interventions ended (e.g. emergency room visits).

The first stage of treatment acquisition is not necessarily behavior onset, but onset of the caregiver's belief that professional help is needed (Beliefs and Perceptions about SIB). The distinction acknowledges that many caregivers attempt to cope with challenging behaviors within the family system before seeking help from professionals. When the caregiver seeks a provider, they may encounter various barriers, such as the long waitlists and unreturned phone calls many participants described (Practical Constraints). Finding an appropriate provider and getting an appointment likely requires perseverance and persistence by the primary caregiver (Caregiver Driven). In the initial consultation, the caregiver and provider must develop rapport and trust, despite the sensitive nature of the presenting problem and possible systemic barriers, such as short appointments (Importance of the Caregiver-Provider Relationship, Practical Constraints). Crucially, the provider must believe the caregiver and perceive the behavior as in need of treatment (Beliefs and Perceptions about SIB). The provider must have sufficient treatment and case knowledge (Knowledge Gaps). The provider must be willing and able to collaborate with others (Practical Constraints, Knowledge Gaps), as treatment for SIB usually involves a combination of biological and behavioral approaches. The caregiver repeats this process with other providers who can offer complementary treatments or begins again if they are dismissed upon initial consultation (Caregiver Driven). As evident in Figure 1, if this process does not progress past each of these stages, the result is to Wait Until Crisis.

These findings are consistent with other areas of research on treatment access not specific to SIB. In focus groups with parents of children with fragile X syndrome, Down syndrome, or autism, Minnes and Steiner found common stressors in "dealing with the healthcare system," "negotiating relationships with practitioners," and a unanimous concern about clinician's lack of knowledge of IDD (2009, p. 255). In our framework, these findings would map onto the Practical Constraints, Importance of the Caregiver-Provider Relationship, and Knowledge Gaps themes, respectively.

Wright et al.'s (2015) meta-analysis of pathways to care for Attention Deficit Hyperactivity Disorder (ADHD) is a model paper in this area because of its well-developed evidence base and comprehensive representation of the complexity of treatment access. Barriers and facilitators identified in 27 papers in the categories of Wider Determinants, Identification of Need, Entry and Continuity of Care, and Interventions to Improve Access to Care contribute to a thorough, mixed methods description of ADHD care pathways at multiple levels (Wright et al., 2015). Many of Wright et al.'s findings align with the results of the current study, yet also demonstrate a complexity of treatment systems that is not captured in this initial inquiry. For example, Wright et al. identified the importance of parent perception in the process of identification of need; in ADHD, this manifested as parental perceptions of hyperactivity as a serious problem (e.g. Sayal, Taylor, Beecham & Byrne, 2002). Two studies in this meta-analysis found that parent race and ethnicity influenced this perception. For example, Black mothers endorsed hyperactivity, impulsivity, and concentration more frequently than white mothers (Hillemeier et al., 2007 as cited in Wright et al., 2015). This is just one example of the many variables yet to be explored for SIB in IDD and treatment access. Following significant further

research, it may be beneficial to model an analysis of treatment access for SIB in IDD after the Wright et al. meta-analysis of ADHD treatment access.

Practical Implications

This research demonstrates the power of the provider to support families affected by SIB by preventing crisis and promoting coping. There are multiple potential points of intervention in Figure 1 to increase access to prevention-oriented, collaborative, effective, family-oriented treatment.

At the dyadic level, providers can evaluate their beliefs and perceptions of SIB, strive for positive relationships with caregivers and their family members with disabilities, and build their expertise on the topic. Providers can recognize and address threats to caregiver morale by acknowledging the stress and complexity of seeking care for a family member with IDD and SIB. As discussed in the theme Importance of the Caregiver-Provider Relationship, active listening and validation can help establish trust. To establish productive and consistent beliefs and perceptions about SIB, providers can build and communicate treatment knowledge and actively seek case knowledge. This is consistent with existing research on health disparities for individuals with intellectual disabilities, which emphasizes the need for improved knowledge and skills related to serving patients with IDD, multidisciplinary approaches, and the particular importance of communication between caregivers, providers, and individuals with IDD (Krahn et al., 2006).

Of particular concern is the issue of diagnostic overshadowing, which in this context refers to the tendency to attribute SIB to the intellectual or developmental disability (e.g. "*yeah that's just how* [people with ID] *are, that's just, you know, that's just what you get*.") The diagnostic overshadowing bias has been shown with psychiatrists and clinical psychologists

providing services for individuals with IDD and can contribute to the underdiagnosis of mental-health difficulties (Mason & Scior, 2004). Providers can overcome this bias through further education on the diagnosis, assessment, and treatment of SIB and reflections on their beliefs about the meaning of an IDD diagnosis.

Many of the barriers described in the Practical Constraints theme must be addressed at a systems level. Systemic intervention will promote positive provider-caregiver interactions and treatment provision for all healthcare needs of individuals with IDD. However, there is a particular urgency for this issue given the many barriers to treatment described in Figure 1 and the burden placed on caregivers to navigate the care system. For providers, changes in educational training systems are particularly needed, to prepare healthcare professionals for the complexity of caring for individuals with severe IDD and behavioral health needs. Primary care physicians, which many participants identified as their first point of contact, often lack experience with individuals with IDD and feel they are "operating without a map" (Wilkinson et al., 2012, p. 243).

Limitations

Despite these outcomes, there are several limitations to this qualitative analysis. First, we had limited sample diversity (Tables 1 and 2). The sample was primarily caregivers who are highly educated, white, of high socioeconomic status, and mothers. Some caregivers may have been less likely to volunteer for an unpaid interview, such as those with lower socioeconomic status, those who had encountered little difficulty in treatment acquisition, or those for whom SIB had resolved. This limits the generality of the findings, as it is likely that caregivers of different backgrounds may experience different barriers to, or more difficulty with, accessing treatment.

Second, it is important to acknowledge that this research was conducted during the COVID-19 pandemic. Although most participants reflected on events that happened prior to the pandemic, there is evidence that individuals with IDD and their family members were significantly more impacted by the pandemic than those without IDD (Courtenay & Perera, 2020). The impact of the pandemic on treatment access was not explored directly in this study, though some participants commented on ways the pandemic had exacerbated existing treatment barriers or created new barriers (such as lack of in-person therapy).

Third, although reflexivity was practiced, the first author's lived experience with the issue of SIB in IDD may have produced bias in her interpretations of interview data, based on her experiences accessing treatment for her brother's SIB. Fourth, the methods focused on the dyadic level of caregiver and provider interactions. The issue of SIB occurs in more complex systems that were not fully captured, such as the triadic interactions of individuals with IDD and their caregivers and providers, the interactions of co-caregivers such as parents, the complexities of a family system, or the contributions of professional caregivers. Fifth, the choice of qualitative interviews with family caregivers prioritized a depth of knowledge over breadth; future studies with mixed methodologies, across diverse samples and contexts, are needed to fully understand this issue, as are researchers with a variety of positionalities. Finally, we prioritized the voice of the caregiver. Caregivers can play an important role by giving voice to individuals with complex communication needs who otherwise may not be represented in research. However, when available, the voice of individuals with IDD should be included in research according to the tenet of disability justice: nothing about us without us.

Research Implications and Future Directions

Given the results of this qualitative analysis, there are several important areas of future research. First, it will be important to scale to the collection of survey data and provider interviews and focus groups, to facilitate the development of interventions to improve treatment access. These findings could be foundational for survey development specific to documenting the breadth of the treatment gap issue and enhance sample heterogeneity. Second, it will be important to examine the provider perspective, through provider interviews coupled with focus groups. This will be critical for the development of interventions that close the treatment gap for SIB in IDD. Finally, it will be important to examine caregiver interactions with specific provider types, such as providers from medical or educational settings. This could identify impacts unique to specific provider types, such as the provider's ability to meet the needs of caregivers and family members with IDD. With this information, future interventions could be grounded in an implementation science approach, with attention to sustainment, scale-up, and spread in a public health or educational context (Hamilton & Mittman, 2018).

Conclusion

The issue of SIB in individuals with IDD is of urgent clinical significance. It is clear that for the families interviewed, the strain of coping with SIB is heightened by the inaccessibility of treatment. The treatment gap is complex, but this research also clearly points to the power of providers in facilitating treatment access and supporting families.

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Interdisciplinarity and self-injury: Toward an inclusive research and treatment paradigm

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Abstract

Background

Historically, the research and treatment of self-injury has been disciplinarily siloed. As a result, the behavior is understood and treated differently among individuals with and without intellectual and developmental disabilities. We explore the potential for an interdisciplinary research and practice agenda in self-injury.

Method

We conducted ten focus groups with experts in self-injury and analyzed discussions that resulted from the question: *"What is the role of interdisciplinarity in the study and treatment of self-injury?*"

Results

Through a reflexive thematic analysis we came up with actionable and positively-oriented themes: Interdisciplinarity at the Individual Level, Context of Needed Systems-Level Change, Highlighting Workforce Support, Strategic Use of Implementation and Dissemination Science, and The Pursuit of Integration. Each theme includes several subthemes that describe specific strategies.

Conclusion

An interdisciplinary approach is not only possible but worthwhile and would be particularly beneficial to supporting individuals with intellectual and developmental disabilities engaging in self-injurious behavior.

Keywords: Self-injury, self-injurious behavior, nonsuicidal self-injury, interdisciplinary, qualitative, intellectual and developmental disabilities

Interdisciplinarity and Self-Injury: Toward an Inclusive Research and Treatment Paradigm

According to an interdisciplinary studies approach, one discipline alone is inadequate to address the complexity of real-world challenges (Repko & Szostak, 2021). The applied health sciences are characterized by such complex challenges, and "the traditional divisions within health research may in some instances impede the pace of scientific discovery" (U.S. Department of Health and Human Services, 2023). In such cases, scientific and clinical progress requires the intentional integration of multiple disciplinary viewpoints and approaches.

In this paper, we suggest that disciplinary divisions have impeded progress in our collective understanding of self-injury and its treatment. Self-injury is an urgent clinical challenge with an estimated 1 in 5 lifetime prevalence in the global population (Lucena et al., 2022) and an estimated 5-20% lifetime prevalence in individuals with intellectual and developmental disabilities (IDDs; Dimian & Symons, 2022). In individuals without IDDs, self-injury is often referred to as *nonsuicidal self-injury (*NSSI) and defined as "the direct and deliberate destruction of one's own bodily tissue in the absence of lethal intent" and for reasons not socially sanctioned (i.e., tattoos, piercings; Nock, 2010, p. 340). In individuals with diagnosed intellectual or developmental disabilities, self-injury is often referred to as *self-injurious behavior* (SIB) and discussed under the broader category of *challenging behavior*. Definitions of SIB often include that the behavior is restricted, repetitive, and causes tissue damage (Rojahn et al., 2007).

Silos of Self-Injury

Research in SIB and NSSI typically occurs in separate settings with separate journals, conferences, and other dissemination outlets. In clinical settings, individuals with IDD and individuals with psychiatric diagnoses (other than neurodevelopmental disorders) are treated as separate populations with distinct needs and systems of clinical care (with the exception of individuals with dual diagnoses). The design and functioning of the academic, healthcare, and educational systems are such that limited knowledge sharing naturally occurs. The result is that interdisciplinary research and knowledge generation related to SIB and NSSI happens rarely, if ever.

This siloed context has led to distinct conceptualizations of SIB and NSSI and approaches to their treatment. SIB is typically understood from a behavioral psychology lens in terms of learning and reinforcement contingencies (Rojahn et al., 2007), while NSSI is typically understood from a developmental psychopathology lens as a form of affect regulation (Klonsky, 2007). Interventions for SIB often involve a functional behavior assessment to determine the function of the behavior and subsequent modifications of the social environment to reduce or replace it. In NSSI, interventions are likely to address an underlying mental health condition through a combination of pharmacological and psychological interventions. In other words, intervention approaches in SIB prioritize external factors and intervention approaches in NSSI prioritize internal factors.

However, for any particular individual engaging in SIB or NSSI, both internal and external factors may be relevant. These factors may be inadequately considered under the current disciplinary paradigms. For example, the potential role of emotional experience in SIB is understudied and self-report may be overrelied upon in the treatment of NSSI (Roberts & Symons, 2023). A holistic model is needed to appropriately address the complexity of self-injury

for any unique individual as well as advance our population level understanding, particularly our understanding of individuals with intellectual and developmental disabilities who have been historically dehumanized and excluded (Conrad, 2020). Further, a holistic model is necessary to incorporate an ecological lens that goes beyond the individual to "address the interplay between the dynamic systems within the individual and between individuals and their environments" (Prinstein, 2008, p. 2). An interdisciplinary approach integrating existing, but siloed, knowledge may represent such a model.

Research Aim

In this paper, we explore possible applications of interdisciplinary studies to address the complex problem of self-injury. We consider the possibility that current research paradigms *overemphasize* the differences between SIB and NSSI to the extent that the similarities between them are underrecognized and underutilized. Focusing on the differences between SIB and NSSI precludes interdisciplinary collaboration and mutual knowledge exchange. This work is grounded in our belief that a progression toward a holistic understanding of self-injury and inclusive treatment approaches would be beneficial to all stakeholders, and particularly beneficial for individuals with intellectual and developmental disabilities.

The following is a preliminary investigation of the possibilities of interdisciplinary work in self-injury. We conducted focus groups to create a space for interdisciplinary discussion and gain insight from experts with diverse and varied experiences researching and treating SIB and NSSI. This paper presents an analysis of the discussions that resulted from the question: "*What is the role of interdisciplinarity in the study and treatment of self-injury?"*

Methods

Study Design

Given the exploratory nature of this study and our interest in experiential knowledge, we chose the qualitative method of focus groups, as we are interested in the interactions between participants with diverse experiences in the field of self-injury research and treatment (Kitzinger, 1994).

Philosophical Assumptions

Our philosophical assumptions were social constructivism, pragmatism, and elements of community-engaged participatory research. In social constructivism, it is acknowledged that knowledge is co-constructed and multiple viewpoints are valued (Creswell & Poth, 2018). This philosophy is especially appropriate to interdisciplinary studies, which are defined by epistemological pluralism (Repko & Szostak, 2021). We demonstrate this philosophy by a respect for all contributions and opinions, even when seemingly contradictory. Toward our pragmatic philosophy, participants were encouraged to orient their discussion towards real-world impacts in healthcare, educational, therapeutic, and academic settings. We prioritized actionable strategies in the analytic process.

Further, though this study is not fully community-engaged participatory research (CBPR, because participants were not involved in the conceptualization or design of the study), our study design was influenced by the values of CBPR (Minkler & Wallerstein, 2008). Participants were instructed to strive to equalize implicit power dynamics that may be present due to varying professional titles, engage all participants, and uphold values of mutual benefit and trust between collaborators (see Appendix; Minkler & Wallerstein, 2008). To facilitate equal power dynamics, groups were matched by level of expertise when possible (see Procedure).

Positionalities

The first author (CR) is a doctoral candidate in educational psychology with training and mentorship in the study of SIB in IDD. In addition to her professional experience, she has lived experience as the sister of an individual with severe IDD and chronic SIB. She has gained interdisciplinary expertise through an interdisciplinary doctoral fellowship associated with the child and adolescent psychiatry department at the same university and participation in an interdisciplinary workgroup focused on the topic of self-injury. Her involvement in the fellowship and workgroup has impacted her positionality by imbuing the value of interdisciplinary spaces and work. The second author (ML) is a senior undergraduate researcher in child psychology and has a particular interest in the use of qualitative and interdisciplinary approaches to reduce research-to-practice gaps as well as the treatment of self-injury in elementary educational settings. The third author (FS) had a mentorship role and was not directly involved in data analysis.

Procedure

Following University of Minnesota IRB approval, we recruited via purposive and snowball sampling methods using personalized email invitations, direct social media messages, messages to organizations, and word of mouth and referral. Interested participants completed a short survey to collect demographic information and scheduling preferences as well as a written informed consent form via Qualtrics.

We organized focus groups based on participant availability, level of expertise, and diversity of experiences in NSSI and/or SIB. Ideally each group was matched in level of expertise (operationalized as years of experience and level of education) and included two SIB experts and two NSSI experts. Due to practical constraints this was not possible in every group. All groups had at least one representative from SIB and one representative from NSSI and two to

five participants. In total, the first author (CR) conducted ten virtual, semi-structured focus groups with 31 participants, lasting between an hour and an hour and a half (see Table 1; note that four participants participated in more than one focus group).

Table 4

Participant demographics $n = 31$

Gender identity	
Female	20
Male	10
Genderqueer/gender nonconforming	1
Race	
Asian	1
Black or African American	1
White or Caucasian	31
Hispanic or Latino origin?	
Yes	2
No	29
Highest degree earned or in progress	
BA	2
MA	4
PhD	22
PsyD	2
MD	1
Type of expertise	
Researcher who studies SIB in IDD	13
Clinician who treats SIB in IDD	13
Researcher who studies NSSI	11
Clinician who treats NSSI	6
Average years of experience	15
Settings	
Academic institution	24
Clinic	17
Hospital	11

School	5
Residential setting	4
Prison	1
Street outreach	1
Nonprofit agency	1
Regional center	1
Private research institution	1
Private practice	1

Note: Participants were permitted to choose more than one race, type of expertise, and setting.

Participants were given a protocol via email ahead of the focus group meeting which included information about the project's purpose, philosophical assumptions, research questions, and design as well as sample questions (see Appendix). Participants were invited to share information, thoughts, and ideas beyond the questions asked as relevant. This paper focuses on responses to the last question asked in each group: "*What is the role of interdisciplinarity in the study and treatment of self-injury?"*

Analysis

Data Preparation and Familiarization

Zoom recordings were uploaded to Trint (https://trint.com) for automatic transcription that was next edited by the first or second author to create de-individuated and accurate transcripts. Concurrently, the researchers familiarized themselves with the data through the process of manually editing the transcripts to match the recordings, as well as re-reading the transcripts and watching the recordings multiple times.

Analytic Approach

We initially framed the analysis deductively around the topic area of interdisciplinarity in self-injury research and practice according to our research question. Beyond this initial framing, our analysis continued inductively to capture the breadth of participants' contributions. We grounded the analytic approach in reflexive thematic analysis as described by Clarke and Braun (2021). Coding consisted of two rounds: independent exploratory open coding followed by researcher agreement through discussion and concept mapping (i.e. visualizing ideas on a whiteboard). Once the second draft of the codebook was finalized, we continued with the second round of coding in NVIVO software. NVIVO coding was followed by independent memoing and collaborative candidate theme development. We presented candidate themes to mentors and peer researchers for peer debriefing and revised as needed. We invited research participants to review the candidate themes in a member check process; eight participants volunteered to do so and those who responded indicated that the themes resonated and did not have revisions. We incorporated a reflexive process throughout via journaling and discussion.

Results and Discussion

Overall, participants emphasized the potential value of interdisciplinary work as well as numerous challenges to implementing interdisciplinary approaches. We expected beliefs in the value of interdisciplinary collaboration given the self-selecting nature of professionals who volunteer to participate in a focus group advertised as a space for interdisciplinary discussion. We also expected emphasis on the challenge of interdisciplinary work given the current nature of the study and treatment of self-injury as separate and siloed. As such, and given our philosophical assumption of pragmatism, we chose to focus our data analysis on actionable strategies to promote interdisciplinary collaboration in the study and treatment of self-injury (e.g., our use of verbs in theme names).

Further, we intentionally framed the strategies in a positive way. Rather than focusing on each barrier that must be overcome to engage in interdisciplinary work, we focused on facilitators. At times this meant re-framing the words of the participants; for example, many participants discussed the barrier of professional ego; we chose to name this subtheme "humility and open-mindedness" to emphasize a positive strategy rather than referring to the subtheme with the negatively connoted word "ego." However, we use quotes extensively to maintain a robust connection to the original voices of the participants.

We identified five main themes: Interdisciplinarity at the Individual Level, Context of Needed Systems-Level Change, Highlighting Workforce Support, Strategic Use of Implementation and Dissemination Science, and The Pursuit of Integration. Each of these themes has several subthemes that are discussed to capture the breadth and complexity of the thoughts that focus group participants shared.

Interdisciplinarity at the Individual Level

This theme focuses on the power individual professionals have to cultivate a mindset that facilitates their engagement in interdisciplinary work. A professional's thinking, beliefs, perceptions, and attitudes can impact their ability to engage in productive, meaningful interdisciplinary work. In the following subthemes, we describe specific strategies to facilitate a mindset of interdisciplinary collaboration in the field of self-injury.

Humility and Open-Mindedness

Multiple participants brought up professional ego as a barrier to effective interdisciplinary collaboration: *"We can't have a conversation about interdisciplinary work without also acknowledging the reality of professional egos sometimes getting in the way." "Professional ego"* was described as a belief in the superiority of one's own competence,

expertise, or approach to that of other professionals. This may include judgment of other disciplines: "*the behavior analyst would look at the wishy-washy fluff of the humanist counselor as, you know, warm fuzzies and that's it and completely ineffective."*

Professionals who work with individuals with IDDs and challenging behaviors sometimes experience a feeling of protectiveness that leads to mistrust of other professionals. This is understandable given the limited training and lack of understanding that some professionals have about intellectual and developmental disability, especially within the context of self-injury: *"I was really forced to have an open mind because I'm very protective and like, you know, there's misunderstanding what these children are doing and they're not aggressive. They're- okay, they're aggressive-appearing behaviors, but it's- you know, coming from different places. And I think- just challenging yourself to have an open mind and to really invite these concepts is so critical."* As this clinician describes, interdisciplinary collaboration may require "*challenging yourself to have an open mind"* in the sense of trusting other professionals.

According to an interdisciplinary studies perspective, self-injury is a complex phenomenon that no one individual can solve on their own, no matter their level of expertise. A recognition of the limitations of one's abilities, training, and disciplinary viewpoint will open up the professional to the contributions of other individuals and disciplines. As one participant put it: "*losing that ego and being like, I can learn something. I'm not an expert on the world. I need to always be learning from others."*

Calming Fear

Interdisciplinary approaches can promote measured and calm responses to incidents of self-injury and composed reactions will allow effective engagement with other professionals. This subtheme is a response to the common emotional reaction of fear at the prospect of self-

injury, particularly amongst professionals who do not specialize in SIB or NSSI: *"I do feel like there are a lot people who view* [self-injurious behavior] *as a very scary thing that they don't want to deal with."* Fear driven by concern for safety is a natural response from a caring, well-intentioned professional. However, fear-driven responses can escalate situations in a way that is unhelpful over the long-term: "*…they see a kid with a developmental delay who's, you know, hitting their head or whatever. And their immediate thing is, you know, restraints. We can't have him hurting himself… same thing with- they see a young person burning or cutting themselves, they try and take away every single implement in the house or in the dorm and like, this doesn't work."*

Fear-driven responses are especially likely to occur in contexts where the workforce has little understanding or training in self-injury. This is often the case in schools: "*when they find out someone has cut or, you know, might have some suicidal thoughts, they initially say, you can't be in school or it will become this reactionary kind of thing, which doesn't make things better."* Researchers recommend against strong negative reactions to incidents of self-injury as this can alienate students and may not promote the development of an alliance between adult and adolescent (Toste & Heath, 2010).

A positive strategy for avoiding reactionary, escalatory responses is the professional's own emotional regulation. Cultivating a calm response to situations involving self-injury can allow a professional to respond in an intentional manner and this will support effective interdisciplinary collaboration. As the same professional went on to say, *"...one way that interdisciplinary work can be done is have everyone on the same page about- what do we do in these situations, how do we approach this, how do we understand these behaviors?"* Proactive

discussions conducted from a place of calmness will support continued calmness when situations of self-injury arise.

Examining Assumptions

Critical thinking related to a professional's personal beliefs, training, or discipline can promote effective interdisciplinary collaboration. This may include beliefs about what self-injury is, what causes it, or how it should be treated, as well as broader beliefs about the nature of disability. One participant described the process of examining assumptions as: *"...challenging the views that we hold and questioning as times change, as we learn more. Are those views still useful?"*

An example of an assumption that may be present in a clinical space are beliefs about the function of self-injury. As described in the introduction, many behavior analysts are trained with a focus on external functions of SIB, such as environmental reinforcement contingencies. Conversely, many mental health counselors are trained to focus on emotion regulation in the treatment of NSSI, an internal function. Yet internal functions are certainly possible in cases of SIB, as are external functions in cases of NSSI. The disciplinary frames of behavior analysis and counseling are different; continuous exposure to the frame of one discipline over another can lead a professional toward biased implicit assumptions. The purpose of this subtheme is to take the time to examine such potential assumptions.

In research, examining the assumptions implicit in a researcher's approach, training, or discipline can lead to new and innovative research ideas. Participants in the focus groups who came from a research background were especially enthusiastic about interdisciplinary spaces to catalyze innovative thinking: *"It helps me think as I encounter other perspectives, whether they're lived experience perspectives or they're scientific models of how the research culture*

thinks about the phenomenon... So for me, the value is gaining perspective on how other people have pursued independently… their own model building." In this case, examining assumptions can promote research progress.

Since the disciplinary divide in self-injury is between individuals with and without intellectual and developmental disabilities, examining assumptions or beliefs about the nature of disability is highly relevant. A professional's awareness of disability issues and support of the inclusion of people with disabilities in mainstream spaces may impact their motivation to engage in interdisciplinary collaboration and their success. Whether the belief is implicit or explicit, a professional with little knowledge of disability issues or support for inclusion will be less successful at bridging the SIB-NSSI divide. A professional who examines their own assumptions about the meaning of disability and supports the inclusion of individuals of all abilities across multiple aspects of society is more likely to see the benefit in interdisciplinary collaboration as it relates to self-injury.

Focusing Attention

Finally, this subtheme refers to where professionals focus their attention. There are documented differences between SIB and NSSI, however, there are also many underrecognized similarities. Focusing on the similarities between SIB and NSSI can facilitate interdisciplinary collaboration between professionals who are systematically siloed. This subtheme is exemplified by this reflection on participating in the focus group:

> *This conversation has been interesting, trying to find the connective tissue between self-injury in intellectual disability and nonsuicidal self injury in typically developing youth, because I think that is a way in for more interdisciplinary work. If we can recognize that there are these things that are similar across both populations, and where the research*

> *can be shared between and among different previously siloed researchers, I think that's actually going to help move us forward in terms of understanding self injury and how to have an effective treatment for it.*

Focusing on points of convergence, or in this participant's words, "*the connective tissue,"* between seemingly disparate topics like SIB and NSSI can be "*a way in"* for professionals who are uncertain about how to approach interdisciplinary discussions and collaboration.

Context of Needed Systems-Level Change

The previous theme included strategies at the level of the individual professional, but it is important to contextualize these suggestions in the greater contexts in which these professionals function (i.e. hospitals, clinics, universities, schools). As many participants emphasized, they can try to implement interdisciplinary practices in their local contexts, but there are systems-level changes that are needed to sustain interdisciplinary models in both research and practice.

The need for systems-level change came up both implicitly and explicitly in focus group discussions. Some groups discussed explicitly how, as much as they would like to engage in collaboration, they faced systems-level barriers: "*the structures need to change in such a way as to make that happen*." Others referred to systemic barriers implicitly, as an implied part of the conversation that was so well-known in the field it did not require direct discussion. For example, one participant ended her description of her ideal model of interdisciplinary exchange with a pause and the comment "*...but nobody will pay for that,"* eliciting laughter from the other participants.

In clinical settings, insurance structures were a particular focus of discussion, whereas in research settings, features of academic structure were a focus. While insurance and academia are

not the only systems relevant to research and treatment in self-injury, we focused our analysis on these two subthemes because they were the systems-level contexts that came up most frequently.

Centering Funding Structure Change

Participants described how existing funding structures are not set up to facilitate clinician collaboration: *"the evil of insurance is that- if a speech pathologist and an ABA therapist are seeing the same child, only one can bill for that. And so that means there's a disincentive to bring these disciplines together."* This sentiment came from US-based participants (87% of participants were US-based). Some participants positioned "*the evil of insurance"* as the primary hurdle between their ideal value-based approach to their work and the practical reality of their job: "*the trans-disciplinary approach, it feels so beautiful... it's really unfortunate that I think a lot of hospitals are not able to do that... because of these* [insurance] *structures at play, I think so many people would love to."* This subtheme centers change in the funding structure as necessary to support professionals in implementing the individual level strategies described in previous themes. Focus group participants did not identify strategies within their power to affect change in funding structures; rather, they emphasized the power that funding structures hold over their ability to engage in interdisciplinary work, particularly for clinicians.

Centering Research System Change

Researchers in the focus groups identified changes needed within academia to support interdisciplinary research on self-injury. Participants confirmed the context of disciplinary silos as described in the introduction (*"NSSI researchers have spent their entire careers excluding neurodiverse populations"*). On the SIB side, this notion was expanded with the idea that a diffusion of disability research by specific diagnosis has further siloed the disability research

context, to the particular detriment of individuals with more severe disabilities (those most likely to engage in SIB; McClintock et al., 2003.)

> *There's an additional challenge on the DD side where the parent groups and advocacy is diffusing into small genetic syndrome groups... We now have a lot of separate agendas... the group we're talking about, who's, you know, lower functioning, no language ability, a lot of self-injury, those kids are eating their lunch. They can't- they don't have time to participate in this. They're not taking part in these kinds of debates. And so that voice gets lost.*

This research context influences what research questions are asked and what funders choose to fund. The siloed nature of the current research context does not reward questions that are interdisciplinary in nature. Researchers are disincentivized to pursue interdisciplinary work by a publication system they need to advance a career in academia; *"you're going to get beat down in your journal reviews and in your grant reviews. As much as everyone says- we want cross-disciplinary, blah, blah, blah- it's like, you'll get beat down for doing that, especially earlier in your career."*

One participant proposed a solution: "*Maybe it's like symptom-driven kinds of collaboration rather than diagnosis-driven, you know? Or a common-population-driven or demographic-driven. I think that can really impart important insights, finding important commonalities and helping with the collaboration."* Rather than studying, for example, borderline personality disorder or Smith Magenis syndrome (two diagnoses with high rates of self-injury), researchers could frame their study around the symptomology of self-injury, regardless of accompanying diagnosis. This perspective aligns with a Research Domain Criteria

(RDoC) approach in which mental health researchers focus on domains of neurobehavioral functioning rather than specific diagnoses (Insel et al., 2010).

Highlighting Workforce Support

The workforce is one element of a functioning mental and behavioral healthcare system. Our data source consisted of professionals, so it is unsurprising that workforce issues that directly impact the participants' daily work lives came up. However, these issues were so highly emphasized by participants, on both sides of the SIB-NSSI divide, that we decided to elevate workforce support to its own theme. Many participants described how there are simply not enough people equipped to treat self-injury: *"there's first of all a lack of trained and willing providers to treat this patient population," "just our number of people that can do the work and are doing the work is so low."* And participants emphasized the direct connection between a supported workforce and effective care provision: *"If the clinicians are all overwhelmed and all have to use waitlists and are experiencing their own levels of burnout... it can leave families feeling completely hopeless."*

Long waitlists for care in the mental health system are barriers to care for everyone, including individuals with IDDs who are not currently receiving that type of support: "*I mean I have enough typically developing* [potential clients] *who can't get in to see me, you know, that adding- doing this other whole sort of modified treatment protocol for the people with developmental delay or IDD spectrum*s [isn't feasible]."

A strong workforce is needed for successful interdisciplinary collaboration. Beyond the general issue of a limited workforce, we also highlight two subthemes related to how the workforce can be equipped to facilitate interdisciplinary approaches and how interdisciplinary approaches can support workforce wellbeing.

Effective Cross-Disciplinary Training

This subtheme responds to how most training programs do not prepare professionals for interdisciplinary work environments. Most graduate programs are designed with a disciplinary focus and do not typically include coursework in relevant neighboring disciplines. While full expertise in another discipline is by no means required to collaborate interdisciplinarily, some degree of understanding of other disciplinary approaches and language is needed. One participant described a current project designed to address this training gap by providing graduate students with coursework in a neighboring discipline (in this case, speech language pathology graduate students received basic coursework in applied behavior analysis). He described challenges with integrating the program into a traditional university environment: "*Students flat out love this... it's never the students who adopt this more rigid disciplinary perspective. It's the professors and the leaders in these organizations that do that. But in the same day, I can talk to a student who's on the training grant who's like- this is the best thing since sliced bread, and then have a meeting with someone who's leading a course, who's ready to kill us because, you know, we're changing their curriculum."* In line with an interdisciplinary studies perspective, effective cross-disciplinary training requires a dynamic university environment and a move away from, in this participant's words, "*a more rigid disciplinary perspective."*

For practicing clinicians, professional development may be a tool for cross-disciplinary training, however, participants with experience in such programs described the danger of insufficient understanding: *"you can sign somebody up for a one-day training and they're getting just enough to be dangerous... because they didn't understand the concepts."* This issue of *"just enough to be dangerous"* was especially a concern for applied behavior analysis, the primary

treatment approach for SIB. This participant went on to describe an example of a dangerous practice that had been reported with professionals under-trained in applied behavior analysis: *"the line staff are using behavior change as a punishment."* For professional development programs to effectively equip professionals to engage in interdisciplinary work, they need to be research-based programs implemented with fidelity. Further, professionals should be encouraged to maintain their scope of practice and trust the leadership of collaborators with more experience in areas outside of their scope.

Burnout Prevention and Relief

This subtheme describes how interdisciplinary spaces can support members of the workforce. Self-injury work is difficult and emotionally draining. Team-based approaches can support members of a workforce susceptible to burnout, as well as refresh motivation and energy for the work: "*Having ways to really connect and learn from each other is so important. I think it also reduces burnout in a really important way where it's like we can all sit together and be like, Yeah, this is hard… I think sometimes in this work it feels- as a provider and as a psychotherapist, it can feel siloed, because it's like, I'm the care team sometimes, right?"*

Interdisciplinary models can support the workforce by distributing skills amongst multiple professionals. As two clinicians lamented the administrative burden of facilitating the financial side of therapy, they reflected on how "*no one who is a clinician also has an undergrad in accounting."* One of these clinicians described the thrill of letting go of this responsibility in a new job: "*I went from at one point being very private practice and being in charge of all of the grant funding for every single individual client... to working at a huge hospital... I was so surprised that that's not part of my role because it's so common for it to be part of the clinician's role. And* [the clinical director] *said, But I hired you because you are a clinician. I'm going to*

hire an accountant to do the accounting work." Interdisciplinary collaboration can support the workforce by distributing work as well as fostering communities of mutual support for professionals with shared experience.

Strategic Use of Implementation and Dissemination Science

Implementation and dissemination science is the study of translating research findings into practice (Brownson et al., 2018). While the phrase *implementation and dissemination science* was not directly cited by participants in the focus groups, principles of the science were alluded to in discussions. Through our analysis, we connected the ideas of participants to the implementation and dissemination science in public health evidence base.

Emphasizing Local Context

While previous themes have emphasized systems-level changes, focus group participants simultaneously identified a need for specificity to local context. Participants had experience from a wide variety of contexts, including medical, educational, therapeutic, academic, and correctional environments. Each of their work environments were unique microcosms of treating or studying self-injury. While other themes have focused on the advantages of unifying knowledge from across contexts, this must be balanced with recognition of the need for specificity and adaptability to local contexts. A focus on context and the adaptability to local environments is a hallmark of implementation and dissemination science (Peters et al., 2014).

For example, one participant described the specific information needs of first responders in emergency rooms. The needs of this type of professional will be different from the information needs of, for example, an academic researcher, because of the breadth of an ER nurse's expertise and the fast-pace of their work environment; "*She had said, I need you guys to*

give me a training. I can't read a 30-page document about this child. I don't have time to do that, I'm an E.R. nurse. I've got 15,000 things going on."

Another example of a context with unique constraints and considerations was the correctional setting. One participant had experience treating self-injury in prisons and described how mandated treatment in this environment changed clinical care: "*they are required to engage in treatment. And as a clinician, I am required to provide that treatment to them, which is entirely different from somebody's motivation to engage in treatment and how effective the intervention might be depending on their engagement."* Under an implementation and dissemination science framework, mandated treatment is a consideration for the local context of a correctional setting that may influence what evidence-based practices are most appropriate or, for example, how a clinician might think about a patient's motivation to engage in treatment. Due to such contextualized and contrasting conditions, professionals working in disparate settings may find it challenging to participate in interdisciplinary collaborations. However, a holistic understanding of self-injury that is applicable across contexts and populations requires grappling with the many settings in which self-injury occurs and presents an opportunity for professionals with varied experiences to learn from each other.

Disseminating Information

A challenge of siloed systems is how information stays within each silo. Disseminating information across systems- whether settings or disciplines, research or practice- is a primary focus of implementation and dissemination science. Participants identified improved information dissemination as needed for interdisciplinary collaboration: *"We need a crosswalk between our counselors, our behavior analysts and the people that are actually experiencing the thing."* In this quote, this includes different types of professionals treating self-injury as well as individuals

with lived experience of self-injury. Dissemination of information is a critical focus of implementation and dissemination science, and the evidence base provides many strategies to improve information dissemination. For example, Kreuter et al. suggest creating a marketing and distribution system for disseminating information in public health, a concept borrowed from business practices (2012). Mittman suggests an approach to the dissemination of information aligned with interdisciplinary studies; he suggests research in healthcare undergo a "transformation into a coherent, integrated body of research encompassing multiple disciplines and domains" (2012, p. 400). While participants did not directly cite these scholars or strategies, they discussed improved information dissemination with a sense of hopefulness: *"if we can learn how to disseminate the information that we have across these fields… what can we do for the individual, knowing who and what to ask or to look for in another person's circle and clinical knowledge?"*

Adapting Interventions

Practical issues around intervention adaptation came up particularly among clinicians. For example, dialectical behavior therapy (DBT) is the most common therapeutic intervention for NSSI, and clinicians discussed the challenge of adapting DBT for individuals with IDD: "*how do I make accessible my treatment interventions to individuals who have different levels of intellectual functioning, especially with things like DBT, which is the gold standard for borderline personality disorder and a lot of the associated self-injurious behaviors?"* In implementation and dissemination science, the adaptability of an intervention is especially valued: "one size does not fit all...implementation science acknowledges that an intervention is not implemented in a vacuum, and contextual factors at multiple levels influence its success" (Baumann et al., 2017, p. 286). Criteria for evidence-based practices often emphasize reliability

across populations and settings; although this is valuable from a psychometric perspective, implementation and dissemination science balances this with recognition of a need for adaptability. Participants, such as in the quote above, suggest that "*the gold standard"* treatment from a psychometric perspective may not be the most suitable for some clients; for example, autistic clients. Rather, interventions which are adaptable to client needs are more suitable. Intervention adaptability is likely to facilitate interdisciplinary collaborations that serve individuals of all abilities.

Intentional Language Use

Many participants identified language as a barrier to interdisciplinary collaboration; terminology and semantics across disciplines often differ, and a process of translation is needed to promote understanding; "*you often need people who have a foot in both camps and can speak the language of the other group. Because I think we might use the same language to mean very different things."* For example, the phrase "self-injury" may recall a very different archetypal example to a counselor familiar with treating teenagers engaging in cutting and a behavior analyst who regularly treats autistic individuals who are headbanging. For example, ahead of the focus groups, it was necessary to explain what we meant by the distinction between SIB and NSSI, because these terms are used inconsistently (see Appendix).

A strategy to address language challenges is an intentional focus on language use in interdisciplinary spaces. In a review of the implementation science literature, Manojlovich et al. emphasize the importance of communication to facilitate implementation (2015). Interdisciplinary work requires shared understanding of concepts that may be referred to by different terms across disciplines. Explicitly acknowledging and discussing differences in

language, then committing to common terminologies, supports the development of shared understanding (Manojlovich et al., 2015).

The Pursuit of Integration

Finally, the last theme is exemplified by this quote: *"what I've seen with really wonderful people who care a lot- we're still all sort of holding our own hammers and seeing our own nails. We're talking to each other, and I think we're genuinely interested in each other's ideas. And then I think the next question becomes, how do you really integrate those ideas to optimize care and optimize insight?"* While she most clearly articulated it, this sense of needing to move beyond conversation toward real-world impact was shared by other participants; *"how do we really draw in that insight and help?"*

Interdisciplinary > Multidisciplinary

A key distinction for participants was the difference between a multidisciplinary team and an interdisciplinary team. Multidisciplinary teams are common in some contexts (such as special education in public schools), but multidisciplinary teams do not have a consistent practice of working together: "*I think of multiple specialists or providers that work separately for the child, versus an interdisciplinary team as multiple providers working together."* Some participants expressed frustration with multidisciplinary models: "*one of the challenges in the environment we're in is getting everyone on the same page and not having this giant cluster of a mental health professional, a speech therapist, a special education teacher, all essentially trying to do the same thing with different tools in this very unorganized fashion."* Integration requires alignment between providers and benefits from teamwork; integration requires interdisciplinarity rather than multidisciplinarity. To promote interdisciplinary collaboration, teams of providers should work together rather than in parallel.

Wrapping Around Services

Relatedly, participants brought up the idea of care coordination that serves the whole person. We chose to refer to this with the concept of wraparound services. A participant with experience at the policy level described the necessity of wraparound services, especially for individuals with IDD: *"The concept of wraparound planning in mental health is so critical and yet a lot of times in the disability field we only think about person centered planning and oftentimes those strategies don't have that same sophisticated consideration of service coordination that comes out of our mental health work."* Wraparound services for a concern such as self-injury are particularly appropriate given how self-injury can impact all aspects of life and rarely occurs in isolation from other concerns (Rojahn et al., 2007). Integrating care for self-injury with the other services an individual or their family is receiving will support care for the whole person and their family and professional caregivers: "*continuum of care is the answer."* A continuum of care requires interdisciplinary collaboration amongst professionals to be effective; a system promoting wraparound services would promote interdisciplinary collaboration.

Pursuing a Proactive Model

Interdisciplinary approaches have a role to play in the long-term pursuit of a care model that is proactive or preventative rather than the current reactive model: *"I think the benefit of that interdisciplinary work, too, can be that it can also be incredibly proactive."* Low-stakes interdisciplinary spaces created before a crisis situation develops can allow researchers and clinicians to plan for self-injury care rather than react to critical needs for care, as opposed to the current model, in which "*we converge right now in emergency departments."* With interdisciplinary approaches in research, we can develop new and innovative approaches to understanding that over time will support the development of a more proactive model and

preventative interventions to support people with and without IDD before self-injury develops. Clinicians can provide early intervention and preventative care rather than focus all their attention on crisis management.

Pursuing Holistic Understanding

The conclusion of our analysis is the idea that interdisciplinarity offers the possibility of a full understanding of the phenomenon of self-injury. Self-injury is an issue that crosses disciplines and populations. It is a human concern. If the ultimate goal of researching self-injury is to understand self-injury holistically- across ability levels, topographies, or contexts- then the way forward is interdisciplinarity. One participant from a philosophy background summed this subtheme up aptly:

> *How do these things work together? How is it that the behavioral and the chemical and the social and political all sort of interface to create the persons that we are? And my hope is that through that collaboration, we can come to a more holistic sense of who we are as persons and how persons hurt and heal, and particularly those persons who have historically not counted as persons for one reason or another.*

Conclusion

The results of this study inform our continued questioning of existing paradigms of research and practice in self-injury. We question whether studying self-injury separately in people with and without intellectual and developmental disabilities supports overall progress in our collective scientific understanding of the phenomenon as well as the clinical goal of supporting the behavioral health of individuals of all ability levels. We question the impact of silos in our current systems of research and treatment and consider the perspective of interdisciplinary studies in which complex challenges cannot be solved by one discipline alone

(Repko & Szostak, 2021). According to our results, many experts believe that, while challenging, interdisciplinary collaboration is necessary for progress. Further work is needed, but concrete strategies at multiple levels from the individual to the systemic can support the pursuit of interdisciplinary work.

Interdisciplinary Collaboration and Self-Injurious Behavior in Individuals with IDD

The study and treatment of self-injury in individuals with intellectual and developmental disabilities may especially benefit from interdisciplinary approaches. While researchers in the field of NSSI have incorporated insights from behavioral psychology to inform treatment approaches (such as functional analysis; Nock, 2010), there is little SIB research that borrows insights from NSSI. There are numerous topic areas with robust research in NSSI that have not been explored in SIB as well as evidence-based treatment approaches that may be relevant for SIB treatment (Roberts & Symons, 2023). Given the focus in SIB on biobehavioral approaches, interdisciplinary work could facilitate the application of psychosocial NSSI research to individuals with intellectual and developmental disabilities; interdisciplinary collaboration is needed to facilitate such knowledge exchange.

Limitations

This study is a first step toward a novel program of research and has several limitations. The convenience sample self-selected by interest in interdisciplinary conversation. Practical issues such as participant availability and lack of compensation limited the effectiveness of the focus group design as well as the member check process. Our sample was missing key stakeholder perspectives; we did not have representation from education or psychiatry, and we suspect this limited our understanding of the relevance of pharmacological or educational factors.

Our method centered researcher positionality and reflexivity. Our experiences in the field of self-injury, professionally and personally, as well as our belief in interdisciplinary work impacted our conceptualization and analysis. It is possible that researchers with different positionalities (such as NSSI researchers) would have conducted a different analysis.

Future Directions

"The underlying behavior I think is much more similar than different. And the function I think is probably very similar. But... I think both the research and the actual practice have different constraints, very different constraints." How can researchers and clinicians in the field of self-injury work within and outside of the "*constraints"* of the current siloed system? We have begun to identify strategies to address this question. Future work could explore the viability of these strategies across settings and professionals. This may include adapting interventions, applying NSSI treatment approaches to SIB in IDD, conceptualizing definitions and models of self-injury that cross populations, or reflecting on beliefs and assumptions. An interdisciplinary approach to the research and treatment of self-injury opens up many previously unexplored possibilities. These possibilities have the potential to provide new insights and innovations for the urgent and complex problem of self-injury. Ultimately, these insights could and should, in term, support individuals who are engaging in self-injury and their families.

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Stakeholder beliefs: An interdisciplinary exploration of the treatment gap in self-injurious behavior in intellectual and developmental disabilities

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Abstract

Introduction

There is a gap between individuals with intellectual and developmental disabilities (IDD) who need treatment for self-injurious behavior (SIB) and those who receive it. One contributing factor may be a multiplicity of beliefs about the nature of SIB and its treatment.

Methods

Using reflexive thematic analysis, we interviewed and integrated two knowledge sources: the perspectives of family caregivers for individuals with SIB and IDD and the perspectives of clinicians and researchers who treat and study self-injury.

Results

We present results from two primary categories of beliefs: perceptions of causal variables and treatment goals.

Conclusion

By contextualizing the current paradigms of research and practice in self-injury as siloed depending on whether an individual does or does not have IDD, we discuss ways to deepen our understanding of the process of treatment provision for self-injurious behavior to inform efforts to close the treatment gap.

Keywords: self-injurious behavior; stakeholder beliefs; treatment access; interdisciplinary; qualitative

Stakeholder Beliefs: An Interdisciplinary Exploration of the Treatment Gap in Self-Injurious Behavior in Intellectual and Developmental Disabilities

Over the past several decades, there have been significant advances in intervention research for self-injurious behavior (SIB) in intellectual and developmental disabilities (IDD; Moore et al., 2024). However, there is evidence of a gap between individuals with IDD who need treatment for SIB and those who receive it (Ruddick et al., 2015); what we hereafter refer to as the *treatment gap*. In previous research we interviewed family caregivers about their treatment experiences to begin to understand this treatment gap from the family perspective (Roberts et al., 2023). Caregivers described the immense stress of driving treatment access and many barriers to acquiring effective care for their family members. Of particular interest was the finding that caregivers had dynamic, often conflicting beliefs about SIB, including what SIB is, what causes it, and what treatment is available and worth pursuing (Roberts et al., 2023). We concluded that this multiplicity of beliefs and, simply put- confusion- was one reason why treatment access was often unsuccessful.

The current study aims to expand this previous study and further our understanding of how beliefs about SIB may influence treatment provision. Research indicates that perceptions of illness directly influence patient behavior, including treatment-seeking behavior (Petrie & Weinman, 2006). For parental caregivers of individuals with IDD and a mental health diagnosis, research by Werner et al. indicates that help-seeking behavior increases with lower family stigma, as mediated by enabling factors such as knowledge about services and previous experience with treatment (2019). Their study also found that help-seeking behavior was related to the attitudes of professionals and the services available (Werner et al., 2019). However, this study was not specific to the issue of self-injurious behavior.

Specific to self-injury, there is research on the attitudes of professionals toward individuals with intellectual disabilities (ID) who self-harm, though it is limited (Samways, 2022). Samways' review compared professionals' attitudes towards people with ID who self-harm (n = 4 studies) and people without ID who self-harm (n = 26 studies; 2022). She found patterns of similarities and differences in attitudes between the two groups; for example, both groups identified communication as a common function of self-injury, though professionals treating individuals with ID viewed self-injury with a communicative function less negatively than professionals treating individuals without ID (Samways, 2022). These results demonstrate the importance of considering how self-injury is understood differently in people with and without IDs and the influence of the beliefs of professionals in addition to caregivers. However, this study did not directly connect attitudes (or beliefs) to the process of treatment provision (Samways, 2022).

In light of this research context, the current study addresses two primary limitations of our previous study of family caregiver experiences. First, we did not get the input of researchers or clinicians in SIB, who were likely influential in the development of the caregivers' beliefs and are involved (either directly or indirectly) in the treatment process. Secondly, there is a complex context around how self-injury is studied and treated in individuals with and without IDD and this context was not represented in our initial inquiry. Namely, the validity and usefulness of existing paradigms of research and treatment in self-injury is open to question (Roberts et al., under review), in particular the structure of classification which defines SIB in individuals with IDD as a phenomenon that is studied, treated, and understood as categorically different from nonsuicidal self-injury (NSSI) in individuals who do not IDDs. It is our belief that this context is

relevant insofar as it complicates the current landscape of treatment provision and contributes to the multiplicity of beliefs about SIB.

To further our inquiry into the nature of the treatment gap in SIB, we chose to incorporate questions about beliefs into a larger study rooted in interdisciplinary knowledge exchange between professionals in SIB and NSSI. Specifically, we asked about beliefs about the cause(s) of self-injury and the goals of treatment for self-injury. We chose to focus on these two relevant belief categories because they reflect much of the interrelated components that previous researchers have identified are relevant to patient belief systems (Petrie & Weinman, 2006). Further, as we are particularly interested in processes of treatment access, we focus on beliefs that are highly relevant to the decisions to seek and maintain treatment. In addition, we re-analyzed the family caregiver interviews from the previous study to expand the Beliefs and Perceptions about SIB theme from that study (Roberts et al., 2023). We present the results of both analyses in this paper and explore how convergences and divergences in stakeholder beliefs about self-injury (both SIB and NSSI, both professionals and family caregivers) deepen our understanding of the treatment gap in SIB.

Methods

Other Publications from this Data

This paper presents select results from two datasets. Other results from the datasets are published or under review with full methods descriptions, therefore we provide a summary of the methods in this paper. See Roberts et al. (2023) in the *Journal of Mental Health Research in Intellectual Disabilities* for more details on the methods of the interviews with family caregivers of individuals with IDD and chronic SIB, as well as discussion of caregiver-provider interactions as they relate to the treatment gap in SIB and pathways to treatment. See the paper

Interdisciplinarity and self-injury: Toward an inclusive research and treatment paradigm for a full discussion of the methods of the focus group project involving experts in SIB and NSSI (currently under review).

Methods Summary

The first dataset is a collection of fifteen semi-structured interviews conducted with family caregivers of individuals with IDD and SIB that is severe and/or chronic enough to interfere with daily life (as identified by the caregiver). Interviews were conducted via Zoom between March and July 2021. All but one interview was conducted by the first author (CR), who is a semi-insider as she is a caregiver for her brother who has IDD and chronic SIB. For this paper, the CR re-analyzed the transcripts deductively, specifically under the categories of Perceptions of Causal Variables and Treatment Goals to align with the analysis of the focus group transcripts.

The second dataset includes ten semi-structured focus group transcripts collected via Zoom by the first author (CR) between November 2022 and March 2023. Thirty-one experts in the research and/or treatment of SIB and/or NSSI participated in the focus groups, which were framed as an opportunity for knowledge translation between professionals who otherwise have little opportunity for discussion given the siloed nature of the fields.

Both datasets were analyzed with a collaborative process of reflexive thematic analysis (Clarke & Braun, 2021). For added rigor, we employed reflexive processes including reflection on our positionalities and philosophical assumptions, as well as memoing and peer debriefing. Additionally, we used a member check process with the focus group dataset.

Results

We present results from two primary categories of beliefs: perceptions of causal variables and treatment goals. Each category begins with results from the focus groups with researchers and clinicians across the SIB-NSSI divide and continues with a summary of the beliefs of family caregivers.

Perceptions of Causal Variables

Focus Groups with Experts in SIB-NSSI

This category explores how focus group participants think about causes of self-injury. The five themes are: Cause is Complex, Timeline Framing, Uneven Consideration of Internal vs. External Functions, The Role of Self-Report and the Assessment of Internal Functions, and The Role of Comorbidities.

Cause is complex. SIB and NSSI researchers and clinicians agree that self-injury is multicausal, individualized, and context matters. There is consensus that there is no simple answer to the cause of self-injury. From a SIB clinician: *"I feel like when people say- why is my kid injuring? I go into this long tirade of, well... it's multifactorial, right? They don't have any functional communication. They have a genetic disorder. They are constipated and can't tell you. You know, you have seven kids in your home, right? There's so many things going on that it's hard to say that one reason why it may emerge or maintain over time."* Similarly, this response comes from a participant from the NSSI side: *"I think there's so many different reasons or theories or aspects of that. I just can't fully- at least for me, I can't boil that down into one easy, simple answer, because I think for the people I work with, it's very multifactorial and complex."*

Timeline framing. SIB and NSSI researchers and clinicians also agree that self-injury changes across time and can differ in the onset versus the maintenance of the behavior (i.e. why

the behavior begins and why it continues). However, SIB and NSSI stakeholders tend to conceptualize the development of self-injury across time differently and note different variables as relevant to change across time.

In SIB, onset is typically conceptualized in terms of developmentally appropriate proto-SIB in early childhood: "*We see it in typically developing kids all the time, young kids, toddlers who engage in headbanging or tantrum-like behavior, but it typically goes away. Whereas we see with the kids with intellectual developmental disabilities, we see really high persistence rates once they start engaging in self-injury."* In NSSI, onset is typically conceptualized in terms of accidental injury or peer contagion in adolescence: "*Like it accidentally happened and then she liked it. And then so she kept on doing it and she looked forward to it*," "*initially they may do it for group affiliation. So there's cutting clubs in schools, that kind of thing.*"

In SIB, entrenchment is typically conceptualized in terms of behavioral shaping and/or impulsivity. In NSSI, entrenchment is typically conceptualized in terms of an addiction model: "*we would say... it's usually a matter of satiation. Like they start with one or two and they increase the severity of the self-harm and the intensity to get the same response from the brain that they got the first time they did it."* Further, acquired capability for suicide across time is highly relevant to change across time in NSSI, and is not discussed in SIB.

Uneven consideration of internal vs. external functions. Internal and external functions of the behavior are not evenly considered in NSSI and SIB. Generally, NSSI researchers and clinicians tend to weigh internal functions more and SIB researchers and clinicians tend to weigh external functions more. For example, compare the following statements. An NSSI clinician's explanation of the cause of NSSI: "*...a difference in the ability to regulate emotions in response to, you know, certain stimuli that have been previously due to*

difficulties in attachment, previously sort of sensitized." A SIB clinician's explanation of the cause of SIB: "*In our field, it's pretty clear that those environmental contingencies are what maintains the behavior for a lot of people."* Further, there are commonly specified internal functions of NSSI that have been minimally explored or not explored at all in SIB, such as trauma exposure, marginalized identity status, or genetic temperament.

The role of self-report and the assessment of internal functions. While lack of self-report can create real challenges in the assessment and treatment of SIB (many who engage in SIB are nonverbal or otherwise unable to self-report; McClintock et al., 2003), the inaccessibility of self-report can also be used as an excuse not to consider internal functions of the behavior or pursue certain treatment avenues: "*part of this is the bias implicit in developmental disabilities where... the aura of the cognitive and intellectual disability, you assume implicitly or explicitly that more complex cognitive affective operations aren't happening, just because you don't have access to their language where they can tell you about that."*

In NSSI, self-report is more complex than is often acknowledged. Sometimes self-report is overrelied upon and at other times self-report is not trusted. Often, even individuals with typical cognitive function and verbal communication cannot articulate explanations for their own behavior: *"I mean, in general amongst humans, we're not always- we don't always understand why we do things when asked."* Further, some participants brought up the idea that topography, or the form of the self-injury, tends to be undervalued as a strategy for assessing internal functions: *"A closer objective view of the topography of the behavior could actually be hugely beneficial in clinical work... where physically on the body did it happen and what else was happening in that part of their body around the same time?"*

The role of comorbidities. In both SIB and NSSI, the presence of comorbidities complicates understandings of cause. In SIB, it can be difficult to discern if there is a mental health related comorbidity, because people with IDD are often excluded from the mental healthcare system. One clinician described her difficulty in determining a care pathway for a teen with IDD and mental health symptoms: *"I'm in a quandary right now with a non-speaking teenager because, you know, he's had sort of what we consider SIB his whole life in the form of hand to head. But, you know, I just did an evaluation with him and... there are some pretty significant indicators that suggest he is in the midst of a depressive episode, just based on his activity levels and tearfulness and things like that. And so now I'm in this quandary of- well, what do I call this? Is this still SIB, has it become NSSI?"* Post-traumatic stress disorder is a common comorbid diagnosis with NSSI but is not typically considered in SIB, even though there is evidence that people with IDD experience more trauma and abuse than people without IDD (Emerson & Hatton, 2018; Stalker & McArthur, 2010). On the NSSI side, it is sometimes difficult to disentangle compulsive diagnoses (i.e. Obsessive compulsive disorder, trichotillomania) from NSSI: *"...those kids, I think where there is almost like an OCD-ish component, are the ones that are really hard to treat because it's not clear what's what. It's kind of like mixed in together with the emotion regulation and the OCD behaviors."*

Interviews with Family Caregivers of Individuals with SIB

Family caregivers reported a variety of beliefs about why their family member engages in SIB. The most common beliefs were related to pain or an untreated medical condition, communication, sensory stimulation, or emotional expression (i.e. anxiety). Less commonly, caregivers expressed beliefs that the SIB was related to trauma, seizures, puberty, a social contingency, a sense of control, a dietary issue, a medication side effect, or habit. A few

caregivers expressed the idea that SIB is part of the intellectual or developmental disability: "*this is just part of the package."* One caregiver expressed: "*sometimes I think he thinks he's being funny. You know, like I'm doing this because I'm just being silly, kind of thing... a mixed up emotion."*

Each caregiver cited multiple potential reasons for why they believed their family member self-injures and they tended to express their perceptions with uncertainty. Part of the challenge of self-injurious behavior, the caregivers described, is that it is not clear why it is happening, and each case is unique: "*there's really no rhyme or reason. Like we don't know what was different yesterday versus, you know, any other day."* This uncertainty added to their stress: "e*specially a child who's nonverbal- it's really hard playing detective trying to figure out what is going on in every day, it could be something different."*

Treatment Goals

Focus Groups with Experts in SIB-NSSI

In this section we discuss NSSI and SIB researcher and clinician beliefs about the goal(s) of treatment for self-injury. The four themes are: Harm Reduction vs. Elimination, Risk and Early Intervention, Autonomy in Treatment, and Quality of Life.

Harm reduction vs. elimination. There is disagreement amongst NSSI researchers and clinicians about whether NSSI is a replacement behavior for suicide or if it demonstrates acquired capability for suicide. This belief in turn informs beliefs about the goals of treatment, specifically whether the behavior needs to be eliminated or treatment should take a harm reduction approach. For example, compare the following two beliefs: *"As long as someone's self-injury isn't kind of escalating to be putting them in quite a medically dangerous position, I think... we work on what else is going on for that young person. Particularly because one of the*

functions of NSSI is anti-suicide. So it's a way to prevent yourself from doing something worse. And we really don't want to be kind of removing that as a possibility from someone's toolkit." Compare this belief system to the following: *"I mean, the whole function of decreasing the self harm is, you can't move on to other- you can't move on to other goals treatment-wise as long as you're engaging in self-harm because the self-harm is- it opens the door to suicide."*

Harm reduction was not explicitly discussed by the SIB professionals, but the ideas were implicitly present, particularly in discussion of cases of chronic SIB: *"I'm trying to get it at a level that is more appropriate and increase more appropriate ways of coping or handling distress or managing expectations in their world. You know, I think that is kind of my goals for treatment is really to think about increasing functioning, increasing safety."*

Risk and early intervention. In general, risk is better understood in NSSI than in SIB. However, NSSI and SIB experts face similar challenges in terms of understanding the role of early intervention. For example, experts in both fields need a better understanding of the development of the behavior and how to intervene on a behavior that is not yet dangerous, but has the potential to become dangerous: *"In both fields what is really still emerging is how can we intervene at the antecedent and community level to not get folks into a situation where we're even having to intervene at the consequent level when there's already been damage that's been done."* Further, participants also described how efforts to promote early intervention come with similar challenges for both behaviors: *"You're basically telling parents whose children aren't really showing any massive problematic behaviors that you want to do some extra work with them to prevent something that they don't think is going to happen yet."*

Autonomy in treatment. Individuals with intellectual and developmental disabilities and adolescents facing mental health challenges are two populations who tend to lack high levels of

autonomy in their lives. There are parallel controversies in NSSI and SIB related to autonomy and the rights of individuals to refuse and guide treatment for self-injury. In SIB, the role of Applied Behavior Analysis (ABA; the most common behavioral treatment for SIB) is under debate: *"the campaign by autistic people to, you know, make behavioral analysts stop trying to get them to stop engaging in self-regulatory or self-stimulatory behavior."* In NSSI, the right of treatment refusal is under debate: *"We have a group who says we should change the stigma, not the behavior. That if I can do multiple piercings or tattoos, body art, why can't I have burns and cuts and bruises? I'm not in that camp, but in certain ways, I mean, it's a strong camp. It's a growing camp."*

Quality of life. In alignment with a harm reduction perspective, there is movement by both NSSI and SIB experts toward understanding the goal of treatment as improving quality of life rather than eliminating the behavior. This is understood broadly as ensuring safety, providing relief to caregivers, and incorporating elements of wraparound care. However, it is unclear who decides what is safe, what defines high quality of life, or how these concepts are measured. From an NSSI expert: "*It comes back to that quality of life thing, like- can you live well with a mental health condition? And I do believe that people can live well, like we don't need to cure people, but what would be really nice is to just make sure everyone is, you know, being able to do what they want to do, rather than being in a horrible situation where actually, someone's life is taken too early."* Notice how the same sentiments come through in a different way from a SIB expert: *"In IDD, self-injury predicts placement breakdown and lack of access to community services and lack of education access and increasing restrictive practices and- you know, pharmacology and all of those things. And actually, I guess the goal is- yes, we want to reduce self-injury, but it's so*

that you can have access to all of these things in your life and live a life that is absolutely your potential and that has all of the access to community that you deserve."

Interviews with Family Caregivers of Individuals with SIB

The most commonly expressed direct goal of treatment by family caregivers was for their family member to "*calm down*": "*you need to figure out what calms your child," "try to settle them down, you know, try to find ways to relax them," "start taking his own personal responsibility for calming down," "risperdal was a miracle drug because it helped a lot at just calming him down."*

Family caregivers cited access to specific types of treatment as a goal; namely, psychoactive medications, behavior therapy services, speech language pathology services, or occupational therapy services. The latter were related to beliefs that improved functional communication and sensory integration would support their family member in a way that ultimately reduced the SIB.

The goals of treatment were not framed only by what the individual with SIB needed; rather, family caregivers often stated goals that incorporated the needs of the caregivers and family. Several caregivers expressed feeling hesitation or having reservations about certain types of treatments (i.e. medication, restraints, protective gear like helmets). They expressed reservations because of the side effects of psychoactive medication (namely, sedation or personality changes), the way restraints limit their family member's freedom of mobility (and for some, how this limits learning), and the potential of protective gear to be stigmatizing. The caregivers expressed that whether they employed these treatments was as much a factor of if they believed they were needed as if they, the caregivers, were ready for them: "*for a long time I was very reluctant to try pharmaceuticals, because he's nonverbal... I didn't want to put him on a*

mind- you know, emotional manipulator, if he can't talk to me about it. But it got to the point where...we've got to do something." The caregiver's emotional readiness seemed to be related to a sense of reaching a limit of what the family could manage; as one caregiver put it: "*I was like, I can't live like this anymore."*

Sometimes the parent's readiness was more about practical considerations and the instrumental demands of caregiving than emotional readiness: "*if we stay with ABA, can we survive? That problem is more complicated because I'm navigating this thing as basically an unemployed and unemployable single parent;" "it's hard to be told try this and this and this and this, especially when you have two other young kids;" "he pretty much slept for three months straight. But we had a lot of family stuff going on.... I couldn't focus on* [name redacted] *24-7. So that helped us get through."* These quotes demonstrate how the goals of treatment may be influenced by the family context, including parent employment status, the needs of siblings, or the presence of other sources of family stress.

Multiple caregivers described a shift in their beliefs about pharmacological intervention specifically as the behavior became more severe: "*I don't want him to have to take medication for this forever. But I'm over that and it's like, it is what it is and if he has to take it to make our lives livable and bearable, then that's what we have to do;" "He had never been on pharmaceuticals ever in his life. We were very strongly opposed to that. But we quickly realized something was wrong."* Finally, among caregivers of adults who had been self-injuring for a long time, there was sometimes a sense of needing to accept that SIB was inevitably a part of their lives, and treatment was more about managing the behavior than eliminating it: "*It's not something we can fix. It's something to deal with;" "knowing that it's not going to go away. It's what we've got."*

Discussion

According to our analysis there are a variety of beliefs about the cause(s) of self-injury and the goal(s) of treatment amongst caregivers, clinicians, and researchers. In some areas there is consensus and in some areas there are clear differences between the beliefs of different types of stakeholders, different beliefs within stakeholder groups, or considerations that one stakeholder group is more concerned with than others. This confirms our previous study finding and expands it beyond family caregivers (Roberts et al., 2023). In the following sections, we will compare the reported beliefs of the stakeholder groups in order to explore how similarities and differences in those beliefs may impact treatment provision.

Areas of Consensus

Individualized Care

There is agreement between all of our included stakeholder groups that SIB is complex and treatment needs to be individualized. Self-injury in individuals of all abilities is a challenging clinical and research problem, though each stakeholder group had a different lens on the issue, and each participant had their own unique challenges in treating, studying, or caring for individuals with self-injury.

Reactive Care System

Each group particularly emphasized the issues of reactive care, lack of early intervention, and hesitation to implement interventions (for caregivers, this is exemplified in the previous study theme *Wait Until Crisis;* Roberts et al., 2023). The quote from a focus group participant "*we converge right now in emergency departments"* succinctly illustrates how the care systems for both SIB and NSSI, though initially siloed by separate service systems for individuals with

IDD or mental health concerns, ultimately end up in the same setting- the emergency room- because of the reactive, crisis management nature of the current system.

Autonomy in Treatment

Each stakeholder group brought up issues of autonomy and the rights of individuals and caregivers to guide and control treatment. Caregivers discussed the impact of their emotional and practical readiness for certain treatments, including initial opposition to certain types of treatments such as psychoactive medications, protective gear, or restraints. They indicated that a key part of the treatment access process was the caregiver's and family's decision to allow certain more invasive treatment options to be pursued, something providers may not typically take under consideration, especially those who are not familiar with their patient's family context. SIB experts brought up the relevance of controversy (particularly in the autistic community) around the most common treatment option for SIB, Applied Behavior Analysis (ABA). Similarly, NSSI experts brought up issues of bodily autonomy and the standpoint of a faction of self-advocates who believe it's their right to change their body how they choose, including through self-injury.

The ethics of autonomy in healthcare-related decision-making is an area of active scholarly discussion. At particular issue is the assessment of an individual's capacity to make informed decisions. Current guidance for medical professionals of all kinds instructs providers to engage capable adolescents in decision-making about their own healthcare; however, there is little guidance on how to assess adolescent capability (Duncan & Sawyer, 2010). Research indicates providers are susceptible to various biases in their assessments of patient competence, such as being more likely to presume competence if the patient makes what they perceive as the right choice about their treatment (Duncan & Sawyer, 2010). In individuals with intellectual and

developmental disabilities, *self-determination* is a common phrase to refer to the ability to make decisions about one's own life, though this concept is more commonly applied to decisions outside of healthcare. While *self-determination* is a buzzword in the disability service system, the nuances of its meaning in complex decisions like mental healthcare decision-making are not well-defined. For example, there are multiple theories of autonomy with different implications for the interaction between individuals with IDD and their healthcare providers (as well as third parties who may be involved, such as guardians or caregivers; Lotan & Ells, 2010).

Treatment Goals

Members of each stakeholder group brought up elements of quality of life and/or a harm reduction lens when discussing the goals of treatment for self-injury. Caregivers emphasized family life and the wellbeing of the whole family. This is aligned with qualitative research indicating that challenging behavior negatively impacts the entire family system (Fox et al., 2002). NSSI researchers and clinicians explicitly discussed the phrase *harm reduction*, which aligns with the addiction model more commonly applied to NSSI than SIB. SIB researchers and clinicians, however, discussed similar concepts with phrases like *wraparound services* and *person-centered planning.* Though different stakeholders used different words, they shared an implication of considering the broad impact of self-injury- beyond just the behavior itself- and considering treatment goals within the context of a person's life, including their family and community.

This consensus that treatment for self-injury requires a broad consideration of context contradicts the design and function of many current systems of care. In many settings, different professionals are responsible for different aspects of an individual's care (i.e. a psychiatrist manages medications, a behavior analyst provides behavior therapy) and rarely collaborate in

care provision. Stakeholder experiential knowledge suggests an interdisciplinary, team-based approach is needed for effective care provision. Innovative models emphasizing comprehensive care from an interdisciplinary team may provide a blueprint that could be applied to SIB in IDD (i.e. Gathright et al., 2016).

SIB Professional Beliefs in Contrast to NSSI Professional Beliefs

There were numerous differences in how SIB and NSSI professionals conceptualized cause and treatment. This is unsurprising given the current classification of NSSI and SIB as categorically different behaviors; however, our previous work has elucidated ways that SIB research and treatment may benefit from consideration of the many psychosocial factors that are commonly discussed in NSSI research and treatment (Roberts & Symons, 2023; Roberts et al., under review). We believe consideration of these factors and the development of treatment approaches that address them is highly relevant to addressing the treatment gap. In this section, we will discuss the translation of NSSI knowledge to SIB treatment, particularly with respect to factors which may have relevance to the SIB treatment gap.

Internal vs. External Functions

In our focus groups, SIB stakeholders were more likely to default to external functions of self-injury while NSSI stakeholders were more likely to default to internal functions of self-injury (Roberts et al., under review). Beliefs about the function of self-injury (whether based in an evidence-based assessment or not) will likely be highly influential in the treatment provision process, particularly in decision-making about what avenues of treatment are pursued. For example, a SIB clinician who does not consider internal functions of the behavior is unlikely to pursue treatments other than behavior therapy. The risk factors that are common to the NSSI literature and have not been considered for SIB, such as trauma exposure or marginalized

identity status, may relate to internal functions that are not considered in decision-making about treatment for SIB because they are underexplored by researchers.

Self-Report

Most assessments used in NSSI are self-report and most assessments used in SIB are not. The role of self-report in the treatment provision process is highly relevant. If an individual tells the provider *why* they self-harm (determines their own function) or what treatment they want to access, the weight the provider puts on self-report will determine its influence on decision-making about treatment. This may become complicated for individuals with complex communication needs; for example, a clinician may receive self-reports through an augmentative or alternative communication (AAC) device or a single-word utterance. This is related to the role of autonomy in treatment; a provider who believes strongly in patient capability and the patient's right to guide their own treatment would be more likely to give weight to self-report. This may happen in a proxy fashion for SIB, i.e. providers rely on the proxy report of family caregivers in decision-making about treatment for SIB. In that case, an additional layer is introduced in terms of the validity of the proxy report and how it relates to the individual with SIB's self-report (whether accessible or not).

Co-morbid Diagnoses

Both types of self-injury are highly likely to occur alongside co-morbid diagnoses. Whether an individual has other mental or physical health conditions may influence their treatment pathway for self-injury. More likely than not, an individual with NSSI will already be receiving treatment within the mental healthcare system, since NSSI is usually conceptualized as a symptom of another mental health condition rather than its own diagnosis (though this may change given the proposed non-suicidal self-injury disorder in the DSM-5; Buelens et al., 2020).

An individual with SIB is likely to already be enmeshed in the medical system for other conditions, given that individuals with IDD are significantly more likely than individuals without IDD to have physical health conditions (Cooper et al., 2015); however it is less likely that they are receiving mental healthcare specifically, since there is a well-documented issue of barriers to mental healthcare for individuals with intellectual disabilities (Whittle et al., 2017). These barriers include organizational barriers, transitional barriers, referral barriers, individual-level barriers, and diagnostic barriers (i.e. barriers to the diagnosis of mental health conditions in individuals with IDD; Whittle et al., 2017). Mental healthcare treatment access is especially problematic for individuals with severe IDD, those most likely to engage in SIB (McClintock et al., 2003; Whittle et al., 2017).

Timeline Framing

How clinicians think about the long-term progression of self-injury is likely to influence treatment decision-making. Our analysis described differences in how SIB and NSSI experts think about the progression, or timeline, of self-injury. A SIB clinician who has a view of SIB onset as developmental (i.e. a typical behavior in early childhood that may occur at a different chronological age for individuals with developmental differences) may be likely to forgo treatment with the idea that the behavior will naturally go away when the child reaches a new developmental stage. It's possible this sort of thinking contributes to the tendency to wait for treatment until crisis-level intervention is needed (see theme *Wait Until Crisis* in Roberts et al., 2023). Similarly, if a clinician believes the maintenance of the behavior is related to a process of behavioral shaping, they are likely to recommend a treatment course of behavior therapy.

Of particular relevance to decision-making is how providers think about the risk for suicide and self-injury. It is likely that providers who believe NSSI represents increased risk for

suicide (rather than a replacement behavior) would have more urgency in efforts for treatment access. Since suicide risk is not part of the discussion for SIB researchers and clinicians, this sense of urgency would not be relevant to SIB treatment access.

On a broader systems-level, the timeline framing of providers has implications for the development of a less reactive care system. As discussed in the Areas of Consensus section, all stakeholder groups in our study agreed that a more proactive care system is needed. However, early intervention for self-injury would require provider beliefs about the progression of self-injury cases to align with treatment decision-making that happens earlier in the process and does not wait for new developments such as increased behavior severity or developmental maturation.

Family Caregiver Beliefs in Contrast to Professional Beliefs

There were a few key differences in how family caregivers discussed their beliefs about self-injury compared to professionals. Importantly, SIB family caregivers emphasized emotions in a way that SIB professionals did not. As discussed in the Harm Reduction vs. Elimination theme, professionals tended to focus on the frequency of self-injurious behavior when they discussed treatment goals. In contrast, family caregivers did not tend to directly express a wish for the behavior to stop or reduce; rather, they focused on *calming down*, which implies that the self-injury stops but also implies lowered arousal and emotional stability. Family caregivers repeatedly described the goal of treatment in emotion-based words: "*relieve the anxiety*," "*chill," "calm," "ease the tension," "settle them down."*

An emotion-based lens is much more common to frames of NSSI than SIB. In some ways, it seems the family caregivers had beliefs that combined insights from the SIB and NSSI sides. In addition to emotion-based thinking, family caregivers cited both internal and external functions of the behavior in their discussions of cause (i.e. trauma exposure and social

contingencies). This finding is especially interesting given family caregivers are likely unaware of the context of self-injury research and treatment as siloed depending on whether an individual does or does not have IDD. Thus their thinking is probably not biased by this context (though it probably is influenced by the providers they interact with, who would be more likely to think in a behavioral frame if they were trained as SIB clinicians).

Finally, as discussed in the Areas of Consensus section, all stakeholder groups discussed how self-injury treatment must go beyond the behavior itself. However, family caregivers emphasized the impact on the family in a way that professionals did not. Family caregivers emphasized beliefs aligned with family systems theory: self-injury impacts the whole family, and the whole family impacts self-injury. This suggests a need for family-level interventions for SIB (Roberts & Symons, 2023).

Conclusion

The prevalence and potentially devastating impact of SIB in IDD will not be reduced by the development of new treatment approaches alone. It is vital to consider the process of treatment access and the many potential influences, including stakeholder beliefs, on how and if treatment is accessed and provided effectively. This study and the previous study (Roberts et al., 2023) have begun to demonstrate the complexity of the treatment access process in SIB. This process is made more complicated by the lack of clarity about the construct of SIB and how it is viewed categorically differently from NSSI. What is the nature of SIB and how do clinicians make treatment decisions for and with individuals with SIB and their caregivers? More research is needed to illuminate this complexity within a context that is deeply influenced by historical and disciplinary divisions in how self-injury is understood in people with and without IDDs. This context, as well as the unique perspectives of different stakeholder groups involved in the

treatment process, must be considered in further research on the treatment gap in SIB in IDD. Without a depth of descriptive knowledge of this issue, mental healthcare disparities for individuals with intellectual and developmental disabilities will persist (Hall & Kurth, 2019).

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We have no conflicts of interest to disclose.

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Overall Discussion

Synthesis of the Three Papers

In the overall introduction I positioned this research in the context of the 21st century United States. This is a time when the deinstitutionalization of people with disabilities is in the not-so-distant past and self-injury is classified depending on suicidality and disability diagnosis. Then, in three manuscripts I explored the topic of self-injury in people with intellectual and developmental disabilities with particular attention to the issue of the treatment gap, a phrase which I use to refer to the evidence that not all individuals who need treatment for SIB receive treatment (Ruddick et al., 2015). Together, these papers provided a detailed descriptive account of the complexity of the treatment gap through the lens' of key stakeholder groups: family caregivers in SIB and researchers and clinicians in SIB and NSSI.

Shared Contributions

The three papers demonstrate that there is no simple answer to the treatment gap. Based on these studies, I propose a critical conceptual re-framing of the phenomenon of self-injury in order to comprehensively address the challenges that have led to the treatment gap in SIB. This re-framing requires thorough reflection on the validity, usefulness, and impacts of a classification system in which self-injurious behavior is categorically different in individuals with and without intellectual and developmental disabilities. While there are documented differences between SIB and NSSI, attention to the similarities between the two types of self-injury, including the shared humanity between individuals with and without IDD, is needed. Further, uplifting and valuing the voices of stakeholder groups, particularly family caregivers, is required to understand the full scope and impact of self-injurious behavior.

Implications for Research and Practice

As I suggest in Paper 2, from a pragmatic perspective a focus on interdisciplinary knowledge translation is a path forward. Focus group participants indicated that interdisciplinary work in self-injury is feasible and worthwhile. Our analysis of the focus groups led to actionable strategies that can be implemented in both research and practice settings and many of these strategies address the challenges identified in Papers 1 and 3 related to pathways to treatment and beliefs. For example, it is possible to apply strategies from implementation and dissemination science to improve care pathways or promote consensus in stakeholder beliefs through the intentional use of language. Adapting interventions and agreeing on shared terminology will not close the treatment gap overnight, but strategies like these are concrete positive changes with potential long term impact on care systems and family treatment experiences.

From a research perspective, intentional interaction across disciplinary silos is needed. Trainees as well as established scholars and clinicians need exposure to ways of thinking and doing from outside their discipline. Without this exposure, professionals are susceptible to biased ways of thinking, such as overemphasizing external functions of SIB at the expense of considering relevant internal factors (Paper 2). Traditionally, academia has not been structured to support and advance interdisciplinary work. Yet as philosopher of science Karl Popper once said, *"we are not students of subject matter but students of problems. And problems may cut right across the borders of any subject matter or discipline"* (1952, p. 125). If it is our aim to address the problem of the treatment gap in SIB in IDD, we must make conscious efforts to cross the borders of disciplinary and conceptual silos.

Limitations

Sample

Both of the datasets analyzed in the three papers were gathered through samples of convenience. Participants self-identified and self-selected to participate in an unpaid research opportunity that was advertised primarily through word of mouth and referral. Sampling is a major limitation of these studies, because it is possible that individuals who volunteered to participate in this research differed in a systematic way from individuals who did not. For example, focus group participants were likely already interested in interdisciplinary approaches if they volunteered to participate in a focus group advertised as a space for interdisciplinary discussion. Family caregivers who volunteered for an interview were able to donate their time and held some degree of trust in the academic research process.

A major disadvantage of a relatively homogeneous sample is that these papers did not capture potential nuances in the treatment gap related to healthcare disparities in racially and ethnically minoritized groups. Research indicates that healthcare disparities experienced by individuals with intellectual disability are worse for individuals with IDD from minoritized racial or ethnic groups (Magaña et al., 2022). There are additional relevant factors for individuals with IDD of color that may be relevant to the existence of the treatment gap, such as distrust of healthcare professionals in Black and Latinx populations due to historical maltreatment (Li et al., 2021). An intersectional approach considering the nuanced interplay of disabled, racial, ethnic, and other identities is needed in future studies that expand the exploratory inquiries in this dissertation.

Method

Depth, but not breadth. I made methodological choices aimed at a depth of knowledge. The use of a qualitative approach and convenience sampling means that my co-authors and I cannot claim generalizability. The samples in both datasets are not representative of the

populations of family caregivers of individuals with SIB and IDD or researchers and clinicians in SIB and NSSI. While we identified many factors with relevance to the treatment gap, we do not know how these factors may generalize across settings.

The limits of bracketing. In qualitative research, *bracketing* is the process of consciously separating the researcher's positionality from the research they are conducting. As discussed in the overall introduction and each paper's introduction, I have relevant positionalities as a family caregiver and a researcher in SIB. While my co-authors and I practiced reflexivity throughout the research process, we also acknowledge that full bracketing of our personal experiences is not achievable. My personal and professional experiences have impacted this research. It is likely that a researcher with a different positionality (for example, an NSSI researcher, a clinician, or someone without lived experience in SIB) may have conducted a different analysis, identified different themes, or drawn different conclusions.

Future Directions

This work is a first step on a potentially long journey. I have made many conceptual and pragmatic suggestions for change in the study and treatment of self-injury. Given the complexity of the treatment gap and the strength of the status quo, I anticipate challenges in continuing this work. A key future direction is achieving buy-in that a paradigm shift is needed and possible from stakeholders in self-injury, particularly researchers and clinicians who have power in the fields of NSSI and SIB. Further, more data is needed, especially with respect to diversifying the samples so that we can address limitations. A future direction in a clinical setting would be pilot testing of the strategies suggested in Paper 2, such as adapting dialectical behavior therapy for use with autistic individuals who self-injure.

Overall Conclusion

Overall, it is clear that the treatment gap in SIB in IDD is complex. The process of SIB treatment is impacted by an ill-functioning care system (Paper 1), a classification system that impedes knowledge sharing and separates people with IDD (Paper 2), and a multiplicity of (at times conflicting) beliefs (Paper 3). Further, it is likely that the foci of these papers are not the only relevant factors in the existence of the treatment gap (see Limitations section). There are numerous reasons at multiple levels (individual, dyadic, family, system) that families do not receive effective treatment for SIB in IDD. Families face not only practical barriers as they navigate a care system that does not fit their needs, but cognitive barriers as they seek support for a phenomenon that is not well understood even at the expert level. It is no wonder that family caregivers often became emotional in interviews about their treatment access experiences as they described feelings of ongoing helplessness: "*I have been crying out, to everybody who will listen to me: I need help. I need help. I need help. And all of them go- wow, yes you do. But I can't help you.*"

I began this dissertation from a historical perspective and I would like to conclude it from a philosophical perspective. In philosophy there is a concept called *epistemic injustice* which refers to injustice "in which someone is wronged specifically in their capacity as a knower" (Fricker, 2007). One type of epistemic injustice is *hermeneutical injustice.* When someone experiences hermeneutical injustice "prejudicial flaws in shared interpretative resources prevent the subject from making sense of an experience which it is strongly in her interests to render intelligible" (Fricker, 2007). In lay language, hermeneutical injustice happens when an individual has experiential knowledge that does not fit existing societal concepts and their knowledge- their experience- is prejudicially dismissed. I believe that the concept of hermeneutical injustice

applies to SIB in IDD. The family caregivers I interviewed have deep experiential knowledge of self-injury, yet societal conceptions of self-injury do not include their experiences. Their experiences are separated into a category specific to IDD and considered exclusively in light of disability. They are lumped into the category of "problem behavior" or "challenging behavior," or even dismissed as an inevitable feature of disability ("*that's just autism."*) Many NSSI experts consider their experiences entirely different from self-injury in individuals without intellectual and developmental disabilities, and they are therefore excluded from the resources available to the wider population.

The strategies suggested in this dissertation- namely, interdisciplinary knowledge translation- are pragmatic. They are practical strategies to improve support for families and individuals with SIB. But on a deeper level, these strategies are aimed at justice. Full inclusion for individuals with disabilities is an ongoing journey in this context of the 21st century United States. Interdisciplinary approaches can support closing the treatment gap. They can also support achieving hermeneutical justice for families of individuals with IDD and SIB.

Overall Discussion and Conclusion References

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Appendix

Self-Injury Knowledge Translation
Focus Group Protocol

Thank you for donating your time and expertise to this research project. This project is funded by an Interdisciplinary Doctoral Fellowship from the University of Minnesota, hosted by the Masonic Institute for the Developing Brain, and supported by the Departments of Special Education and Child and Adolescent Psychiatry at the University of Minnesota, as well as the Institute on Community Integration.

The overall purpose of this project is to advance an interdisciplinary SIB-NSSI program of research…

…that bridges disciplinary silos and the research to practice gap.
…that leverages existing knowledge.
…that is informed by family systems theory.
…that is pragmatically-oriented.

The research questions for this project are:

1. What are the points of disciplinary convergence and divergence with respect to understanding case ascertainment, perceptions of causal variables, pathways to treatment, and treatment goals and outcomes?

2. How can SIB researchers and clinicians benefit from existing knowledge in the field of NSSI and vice versa?

Definitions

SIB: Self-injurious behavior (SIB) is defined as physical acts directed to one's own body that cause or have the potential to cause tissue damage, are relatively stable response patterns, and are clinically significant (Rojahn et al., 2007). **This term refers to self-injury by individuals with intellectual and developmental disabilities.**

NSSI: Non-suicidal self-injury (NSSI) is defined as the deliberate destruction of one's own body tissue, occurring without suicidal intent and for purposes not socially or culturally sanctioned (e.g., piercings, tattoos; International Society for the Study of Self-Injury, 2018). **This term refers to self-injury by individuals with typical development.**

Case Ascertainment: In this context, the phrase case ascertainment refers to how a case of SIB-NSSI is defined.

Perceptions of Causal Variables: This phrase refers to your individual beliefs about the mechanisms and/or variables involved in the onset and maintenance of cases of SIB-NSSI.

Pathways to Treatment: This phrase describes the process of how an individual and/or caregiver accesses treatment for SIB-NSSI, including initial onset, consultation, diagnosis, referral, professional collaboration, treatment experiences, outcomes, etc.

Discussion Format

The focus group will be **semi-structured.** Discussion questions are provided but participants are free to share information, thoughts, and ideas beyond these questions as relevant.

In the spirit of **community-based participatory research,** discussion members should strive to equalize power dynamics, engage all participants, and uphold values of mutual benefit and trust between collaborators (Minkler & Wallerstein, 2008).

This project is based in a philosophy of **social constructivism**, such that it is acknowledged that knowledge is co-constructed and multiple viewpoints are valued.

Discussion should be oriented toward **real-world impact** in healthcare, educational, therapeutic, and academic settings.

Potential Questions for Discussion

- What defines a case of SIB-NSSI?
- How are SIB-NSSI defined in the research literature?
- How are cases ascertained in clinical settings?
- To what degree do methods of case ascertainment in SIB and NSSI align?
- How can SIB researchers and clinicians benefit from existing knowledge about case ascertainment in the field of NSSI and vice versa?
- What is your perception or belief of the cause(s) of SIB-NSSI?
- What variables increase the likelihood of an individual engaging in SIB-NSSI?
- How can SIB researchers and clinicians benefit from existing knowledge in the field of NSSI as it relates to causal variables and vice versa?
- What is the goal of treatment for SIB-NSSI?
- In entrenched cases, is SIB-NSSI treatable?
- What are the typical pathways to treatment for SIB-NSSI?
- What facilitates treatment access? What hinders treatment access?

- How can SIB researchers and clinicians benefit from existing knowledge in the field of NSSI as it relates to pathways to treatment and vice versa?
- How can SIB researchers and clinicians benefit from existing knowledge in the field of NSSI as it relates to treatment goals and outcomes and vice versa?