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Exploring Perspectives of Individuals with Intellectual Disabilities and Histories of Challenging Behaviors about Family Relationships: An Emergent Topic in a Grounded Theory Focus Group Study

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ABSTRACT

The perspectives of individuals with intellectual disabilities (ID) about family relationships are underrepresented in the literature. The topic of family relationships emerged in a grounded theory exploratory focus group study that involved thirty dually diagnosed participants with moderate or mild intellectual disabilities and histories of challenging behaviors. Because of the dearth of existing information and the salience of the topic, this analysis explored properties of the participant's disclosures associated with family relationships. The aims were to offer treatment providers empirically based information that may inform service provision and increase the availability of ID-specific, psychological supports for dually diagnosed individuals. Participants reported different types and statuses of family relationships. Transactional processes described in positive family relationships included properties such as reciprocity, flexibility, accommodation, trusting, and expressing affection. Conversely, participants described transactional relationship barriers (e.g., victimizing, behavioral dyscontrol, and substance abuse) that involved dysregulated behaviors of both the participants and family members in conflicted and severed family relationships. These factors appeared to lead to co-dysregulation versus co-regulation within the family relationships. These findings are relevant given the consensus in the literature that environmental factors are associated with challenging behaviors. Not only do treatment providers need to understand potential family relationship patterns to provide individual supports, but these multilayered factors may warrant seeking additional treatment modalities that address emotion regulation deficits of the participants and family members, trauma-informed treatment, and family therapy. Additionally, conceptualizing family relationships as transactional may help families and collateral supports co-construct positive, collaborative transactions with dually diagnosed individuals that improve the quality of life of all involved.

KEYWORDS

Dual diagnosis; family relationships; transactional relationships

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Introduction

Individuals diagnosed with intellectual disabilities (ID) experience heightened health risks, higher prevalence of mental illness, and barriers to healthy life styles (Chaplin, O'Hara, Holt, & Bouras, 2009; Charlot & Beasley, 2013; Dean, 2014; Evans et al., 2012; Krahn, Fox, Cambell, Ramon, & Jesien, 2010; Lin et al., 2013; Shoneye, 2012). Dually diagnosed individuals with intellectual disabilities (ID) and mental health issues experience health and mental health-care disparities (Charlot & Beasely, 2013; Evans et al., 2012; Kim, Kim, & Hong, 2013). Emerson and Hatton (2014) explain that the scarcity of ID-specific services is a common barrier for health and mental health care access.

This analysis emerged from a broader qualitative study aimed at using empirical processes to enhance practice-knowledge of clinicians providing psychotherapy to dually diagnosed individuals as a step toward improving access to treatment. Because this exploration of transactional family relationships was an emerging code, it is necessary to understand the context and research methods of the original data collection as it is the foundation of this analysis of family relationships.

Constructivist Grounded Theory

Constructivist grounded theory (CGT) (Charmaz, 2014) was the methodology used in the study. Through a CGT lens, "Data do not provide a window on reality. Rather, the 'discovered' reality arises from the interactive process and its temporal, cultural, and structural contexts" (Charmaz, 2000, p. 524). CGT research provided a flexible, yet structured, iterative process that requires the researchers be steeped in data and actively acknowledging/utilizing reflexivity during all phases of the research process. Key elements of CGT methods (e.g., memo writing, theoretical sampling) are woven together, guiding the different levels of coding (initial/line-by-line coding, focus coding, and theoretical coding). As this iterative process evolves, the processes and properties that emerge from the data are intended to lead to theory development.

CGT was well suited to address the aims of this research. From a CGT perspective, research processes are co-constructed. Charmaz states, "We must take the researcher's position, privilege, perspective, and interactions into account" (2014, p. 13). This equal playing field was important because the participants being studied experience high levels of social stigmatization (Ali et al., 2013; Ditchman et al., 2013). The procedures related to reflexivity provided mechanisms to manage the multiple impacts of the primary investigator's 25 years of experience in the ID field. Memo writing and collaboration between research team members helped ensure that the analysis was data versus researcher driven. This constructivist-based methodology allowed

for exploration of intangible realms associated with therapeutic relationships in an empirical way.

Studies based on CTG often begin with a general frame of research interest rather than starting with a priori assumptions. The general frame of interest of this study was to illuminate emotional and cognitive strengths (e.g., processing and verbalizing abstract concepts) that emerge in clinical, non-test settings. To address the aim of understanding processes relevant to therapeutic interventions, a clinical sample of adults with mild or moderate ID, mental health diagnoses, and histories of challenging behaviors (CBs) were recruited.

Thirty individuals with dual-diagnoses and histories of CBs, who were receiving ID-specific therapeutic services at an out-patient clinic, participated in five 90-minute focus groups. Focus groups were used rather than intensive interviews because the format allowed maximum inter-participant versus facilitator-generated dialogue. Additionally, all of the participants had experience engaging in therapy groups as part of the outpatient clinical model; the participants being comfortable reduced cognitive load demands, optimizing opportunities to demonstrate strengths.

Participants

The participants were between the ages of 24–67 with a mean age of 39.5. Twenty-five were male and five were female. Six participants identified as Black, one as Hispanic, one as Cape Verdean, and the remaining twenty-two were White. Participants were asked about their level of severity of ID; few knew their mental health diagnoses, so permissions were sought to refer to the agency's files to obtain the disability severity levels. Twenty of the participants were diagnosed in the mild range of ID and 10 had moderate-severity ID. Twenty-nine participants live within 24-hour residential supports, one lived with a supported-living provider. All participants had histories of CBs that required 24-hour supervision at various times in their adult lives.

Informed Consent

Although this clinical sample offered unique opportunities, the vulnerability of the participants and public-type format mandated that multiple safeguards be in place to ensure the emotional and physical safety of all involved. The facilitator met with each participant for a 45-minute appointment to thoroughly review the informed consent form. The informed consent process oriented the participants to all perceived positive and negative aspects of this project using simplified language. Each participant was assured a $20 gift card for participating in the study.

Because all of the participants had histories of behavioral dysregulation, the risk of the focus group prompting emotional escalation was addressed

proactively. Two therapists that all the participant were familiar with were available in adjacent offices to the group room during all focus groups. The participants were encouraged to leave the group to seek support as needed; the facilitator also explained that she would prompt the individual to seek support if there were any overt behaviors that communicated distress. Despite the richness and intensity of the focus group data that emerged, none of the thirty participants left or was prompted to leave during the focus groups. In cases where traumatic information was disclosed, the facilitator coordinated a meeting directly following the focus group between the participant and his/her individual therapist to ensure the individual had an opportunity to seek additional supports prior to leaving the therapy office. The individual therapist assessed whether disclosures required reporting to the state quality assurance agency.

Data Collection

The five focus groups were held during a one-month period; six participants attended each group. The groups were held at the clinical office in a small conference room. All of the groups were facilitated by the first author and the same procedures were implemented for all groups.

Theoretical sampling, essential in CGT, was used to guide the iterative data collection and analysis procedures. CGT begins with broad questions and targets inquiries as salient topics emerge (Charmaz, 2014). Seven open-ended questions were asked in each group. The aim was to investigate cognitive strengths; therefore, questions were posed to each groups that prompted exploration of common or tacit knowledge about the human experience versus queries that addressed explicit knowledge-based topics.

These topics were designed to engender interest and discourse, fueling participation versus eliciting conflict or emotional escalation that would stifle the group process.

The following seven questions were asked:

(1) What thoughts do you have about the topic of relationships?
(2) What is a complicated relationship you have in your life?
(3) What are your relationships with your staff like?
(4) What are your thoughts about the topic of marriage?
(5) How is the relationship you have with yourself?
(6) What are your thoughts about God?
(7) What do you think happens after we die?

It is important to note that there was not a question asking directly about family relationships. Alternatively, there were general inquiries about "relationships" and then "complicated relationships." Because of the high rates of

victimization of people with ID (Sullivan & Knutson, 2000) and level of vulnerability of this clinical population, the research team evaluated that asking directly about family relationships was potentially destabilizing within a focus group format. Regardless, twenty-nine out of thirty participants contributed comments about family relationships.

Role of the Facilitator

In CGT the facilitator and participants co-constructed the data, making this an empirical process that was data-driven and required reflection and adjustment to accommodate the participants' cognitive impairments. For example, because the literature highlights that individuals with ID tend to defer to authority, it was important for the facilitator to foster dialogue without asking leading questions (Bowles & Sharman, 2014; Kaehne & O'Connell, 2010). The facilitator sought to craft comments to explore emerging topics by (1) promoting full participation and (2) ensure comprehension of points being made, allowing the group process to guide exploration of content. Given the vulnerability of these participants, the facilitator had to balance promoting exploration with not provoking emotional dysregulation (Kruger & Casey, 2015).

Despite the conscious decision to omit a direct question about family relationships, there was an unexpectedly high prevalence of disclosures of past stressful, even traumatic, childhood experiences. It was necessary for the facilitator to manage the safety and emotional/cognitive regulation status of the groups. When using CGT with a less vulnerable population, direct exploration of family relationships would have ensued, given the predominance and intensity of disclosures. It was a clinical decision and a specific accommodation for this population not to alter the facilitator's strategies (e.g., ensuring full participation and comprehension) due to the risk of emotionally/cognitively overloading the participants.

Foundational Data Analysis

One of the elements of theoretical sampling in CGT includes exploring emergent leads in the analysis process (Charmaz, 2014). The topic of "family relationships" was an emergent category that was relevant to the primary aim of the study of exploring factors associated with psychotherapy. Participants described transactional patterns, wherein the participant and the family member's behaviors were impacted and modified by actions of the other. More specifically, both positive and negative bidirectional transactional patterns emerged in this analysis. It is essential for clinicians to understand family transactions because many researchers in the field state that environmental factors are a controlling influence of CBs (Matson & Boisjoli, 2007; Matson, Kozlowski, Worley, & Shoemaker, 2011; Matson, Neal, Kozlowski,

2012). Increasing understanding of transactional patterns within families may help treatment providers assess and treat these complex behavioral health issues.

Literature Context on Transactional Family Relationships

Challenging Behaviors

CBs are "culturally abnormal behavior(s) of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities" (Emerson et al., 2001, p. 3). CBs are often a symptom reflecting a complex constellation of psychiatric and social factors that require enhanced supports (Grey, Pollard, McClean, MacAuley, & Hastings, 2010; Matson & Boisjoli, 2007; Tsiouris, Kim, Brown, & Cohen, 2011). Raina et al. (2005) explain that parenting demands of managing CBs impact both mental health statuses and functioning capacities of parents of youth with ID who engage in CBs.

Bidirectional Transactions

There is emerging literature that describes the relationships between parents and children with ID who demonstrates CBs as transactional. Neece, Green, and Baker (2012), in their study comparing transactional relationships between parents of typical developing children and those of children with ID, state: "Transactional family development is not the sum of individual mechanisms, but the product of ongoing interactions between the individual and the environment, with a particular focus on bidirectional or reciprocal effects" (p. 48). Their study found that "child behavior problems are an antecedent and consequence of parenting stress. These variables appear to have a mutually escalating, or deescalating, effect on each other over time" (p. 59). The authors explain that children with severe behavior problems require more supports, and that providing enhanced supports leads to increased parental stress, which in turn exacerbates the child's CBs (Foley, Dyke, Girdler, Bourke, & Leonard, 2012; Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Neece et al. (2012) found that the child with ID (A), who has intensified needs, increases demands on the family (B). The family experiences stress and is unable to provide consistent supports, increasing the child's emotional dysregulation (C). In the previous example, and throughout this article, the letters (e.g., "A," "B," "C") are added to demarcate the behaviors of the child/participant and the family member that transact in escalating patterns.

Insufficient Parental Scaffolding

Norona and Baker (2014) studied 225 families, examining transactional parenting behaviors and emotion regulation capacities of both ID and non-disabled youths across three time points. These authors found that children with ID were significantly more dysregulated at all time points when compared to non-disabled age-mates. Additionally, the mothers of the children with ID demonstrated fewer "scaffolding behaviors" at ages three and five. (p. 3209). Maternal scaffolding was described as the mother's ability to balance teaching strategies, motivate the child to complete goal-directed actions, and offer emotional supports that help the child build mastery and self-determination. The authors found that a lack of effective parental scaffolding behaviors transacted to impair the emotion-regulation skills of the children.

Transactions and CBs

Dialectical behavior therapy (DBT) is an empirically validated psychological treatment for individuals who experience emotion-regulation deficits (Linehan, 1993, 2015). The bio-social theory, the theoretical underpinning of DBT, posits that transactions between vulnerable individuals and invalidating environments create and maintain patterns of emotional, cognitive, and behavioral dysregulation in individuals. Linehan (1993), in her seminal work, explains that a transactional model "assumes that individual functioning and environmental conditions are mutually and continuously interactive, reciprocal, and interdependent" (p. 39), continually adapting and influencing each other.

It appears that individuals with ID and their families engage in a wide variety of transactional patterns throughout the individuals' lives. To understand transactional patterns, being aware of both the individuals' and the families' perspectives are essential. To date, there is little information about the individual's perceptions of family relationships (Hewitt et al., 2013; Mill, Mayes, & McConnell, 2010). Although examining one side of this transaction fails to illuminate the full transactional picture, these data may be a viable alternative, given the myriad of barriers to and disincentives for family members disclosing information that addresses behavioral dysregulation by family members.

Methods

The introduction provides background information about the recruitment, participants, and data collection of the foundational study from which this analysis emerged. This section will explain more specific methods associated with the analysis of the category of "family relationships."

NVivo 10

Hutchison, Jonston, & Breckon (2010) discuss how QSR-NVivo software can be utilized to answer essential questions in CTG projects (e.g., what are the key processes, what are the properties of the processes, how do the processes develop, how do participants respond related to the processes, and how these change). In NVivo, each coded passage ("reference") is placed into a "node"; the cumulative percent of the transcript that a node represents is called "percentage of coverage." Features of NVivo (e.g., node structures, coding stripes that mark co-occurring nodes, and coding inquiries) facilitate concept identification, foster examination of emerging data, and highlight complex relationships between processes that lead to theory development (Bradley, Getrich, & Hannigan, 2015; Hutchison et al., 2010). Matrix coding queries that compare the frequencies of references within nodes offer details about the relationships between concepts (Hutchison, et al., 2010).

NVivo 10 software was used to do the CGT analysis on the five focus group transcripts.

Through the "memo" process, it became clear that, due to the vulnerability of the population and issues related to research team reflexivity, it was essential to ensure these data were participant-driven. Therefore, the number of participants out of the 30 who contributed to a category, the number of references in categories, and coverage percentage helped the research team discriminate highly relevant from less-salient points. Although quantitative data are not customarily used in qualitative studies, empirical processes that promote theory development and transparency of these process are essential in CGT (Bringer, Johnston, & Brackenridge, 2007; Charmaz, 2014).

Ensuring Rigor

The following steps were taken to ensure the rigor of this research. To confirm accuracy, the transcript was reviewed to make any corrections in the transcription. Related to reliability, the research team, coauthors on this article, corroborated on coding decisions during the initial, focused, and theoretical coding phases. This collaboration allowed the research team to do parallel processing, exploring multiple realities through alternative views. Speaking to credibility, each member of this research team was an expert in the field of dual-diagnosis and/or taught research on the doctoral level. The research team forum facilitated the consolidation of perceptions related to the processes and properties of the processes that were essential in CGT analysis and theory development.

In addition to coding being deliberated, memos were written and discussed during the research process to ensure that the analysis and theory generation reflected the transcript data, improving trustworthiness. In-vivo

codes, phrases that directly reflect the participants' discourse, were used to increase reliability and credibility. Kaehne and O'Connell (2010) highlight methodological complications that are commonly encountered while running focus groups with individuals with ID. These authors recommend ample samples of participant verbatim quotations be provided to improve credibility.

Findings

Initial Coding

An initial line-by-line coding was completed on the focus group transcripts. A code labeled "family relationships" was generated as a general category demarcating any comments referring to family-oriented concepts. This code included 100 references (the second highest frequency of codes in the total analysis). The excerpts labeled "family relationships" were present in all five focus groups and covered 19% of the overall transcript. From this main category, 15 subcategories emerged, further differentiating family-related concepts.

Focus Coding

Focused coding was used to delve into the 15 subcategories in a comparative and iterative process to explore the relationships between concepts (Charmaz, 2014). Three main categories emerged: Types of Family Relationships, Family Relationship Status, and Transactional Family Relationship Barriers.

Types of Family Relationships

The highest number of references reflected participants discussing siblings (27 references), above mothers (including stepmothers) at 26. The nature of these sibling and mother-child relationships in these data appeared variable, prompting further analysis. The category of "extended family" (e.g., grandparents, aunts, uncles, nieces, and nephews), at 21, was nearly twice the number of references to "father" (including stepfathers) (11). The statuses of these relationships appeared to be a mix of positive and negative bonds, highlighting the need for further investigation.

Related to the high frequency of references about siblings, the literature describes that siblings have an emerging role in the lives of individuals with ID (Foley et al., 2012; Hewitt et al., 2013). Upon further analysis, though, 21 of the 27 comments related to siblings were associated with conflict versus support. Similarly, mothers/stepmothers were mentioned in a positive way five times out of the total 26 references, while half of the references about fathers/stepfathers were positive. Overall relationships with extended family were positive, with only two (of 21) references associated with conflict. Foley

et al. (2012) explain that grandparents are often common sources of informal supports; these data included seven positive references to grandparents with no negative comments.

Family Relationship Status

Three subcategories of family relationship statuses emerged from the analysis: "intact," "conflicted," and "severed" relationships. Ten of the 30 participants made 15 references of "intact" relationships, covering 2% of the transcripts (group 5 did not disclose any comments coded to this category). These references referred to any positive comments about a family member or interaction. Fourteen participants of 30 made 18 references coded as "conflicted" relationships, covering 4.7% of the transcripts. The label "conflicted" relationships demarcated stressful interactions within relationships where the individual and family member have ongoing interactions. Twelve participants of 30 made 16 references about "severed" relationships, representing 4% of the data. Severed relationships were conflicted and the individual had not seen the individual in several years.

Less than one-third of the references to family were positive and more than two-thirds described conflicted or severed relationships. If the coverage percentage of the conflicted and severed descriptions are combined to reflect articulated negative experiences in family relationships (8.7%), there was four times more negative than positive (2%) information disclosed during the focus group. These trends prompted further exploration to delve deeper into the properties and processes involved with these statuses.

Transactional Family Relationship Barriers

Twenty-four of the 30 participants described victimization/abuse, demonstrating CBs, and/or witnessing substance abuse by family members. This constellation was labeled as "transactional family relationship barriers" (TFRB). The references of TFRBs in each of the family statuses are presented in Table 1.

Properties of TFRBs are explored in more depth in "conflicted" and "severed" relationship sections below.

Theoretical Analysis

In CGT there is an emphasis on "going into emergent phenomenon and defining their properties" and "taking a phenomenon apart"; these are preliminary steps in theoretical analysis and development. The properties of the three statuses of relationship (i.e. intact, conflicted, and severed) and TFRBs that emerged from the participants' perspectives are presented in the following sections.

Table 1. TFRB and Family Relationship Statuses.

Relationship status	Victimization/abuse	Challenging behaviors	Substance abuse
Total references for TSRB	18	15	10
Positive-Intact	1	1	0
Conflicted	7	8	4
Severed	10	6	6

Intact Relationships

There were seven subcategories of factors associated with "intact" family relationships: "'I do stuff for her, and she does stuff for me,'" "periodic visits," "emotional support," "'I call him my father,'" "emotional connection," "'she helps me," and "repaired damaged family relationship." The following excerpts highlight examples of these seven subcategories. Each participant's name, gender, race/ethnicity, and severity level of ID are included to help add contextual information. The participants' names were changed to protect confidentiality. The term "Mod" represents the group moderator/facilitator's comments.

"I Do Stuff for Her, and She Does Stuff for Me." Three participants described having a reciprocal relationship with a family member. For example, Matt, a White male with moderate ID, described his relationship with his sister, "See, I do stuff for her, and she does stuff for me. That's trusting." Linehan (1993) describes reciprocity and interactivity as elements of transactional relationships. Matt states that (A) he helps his sister, (B) his sister helps him, and (C) the transaction leads to a trusting, bidirectional, synthesis relationship. This is an example of a positive family transaction.

Periodic Visits. Four participants described having periodic visits with family. Adam, a White male with mild ID states,

> Adam: "Yes, um, I have good relationships, um, with my family. Um, I—um, number one, my dad, um, I see him every—every weekend; every Sunday, he comes over brings me a sandwich and stuff. Um, number two, I see my grandfather once in a while, that he—he takes me out for lunch and stuff."

Marco, a Cape Verdean male with moderate ID, shares, "I've got a good relationship with my mother, and when I go over there, my mom cooks for me. We have a great time, great food, he me—he fe—he—she feed me more than good—we eat, we never give each other a hard time." Marco describes reciprocity in this relationship with his mother when he refers to how they treat each other well. It appears that Marco demonstrates positive relationship behaviors (he doesn't give her a "hard time") which transact with his mother's supportive stance (she doesn't give him a "hard time"), leading to a

mutually beneficial, positive transaction as evidenced by Marco being able to visit, his mother cooking for him, and eating together.

Emotional Support. Three participants verbalized feeling a sense of support from family members. Marco said, "I—before I thinking to do something bad, I think about my mother, because—and if I do something bad I hurt my mom plus I hurt that guy upstairs." In situations when Marco has urges to exhibit CBs, he reappraises his options incorporating his mother's (and God's) potential negative reactions, motivating him to engage in adaptive coping strategies to maintain a positive transaction with his mother.

Dan, a White male with mild ID, shares, "I think of people I lost, and I think about the strength as power to myself. And make myself better. And family is the most important to me now, and I want to keep the family strong." Dan highlights the transactional nature of his family relationships: (A) he is focused on improving his personal "strength," (B) his strength is a resource for his family, resulting in (C) the family is kept "strong."

"I Call Him My Father." Three participants referred to family members (e.g., stepfather, mother, and sister) as replacing either nonparticipatory or deceased primary caregivers. Rick, a Black male with moderate ID, explained one way he adjusted to the loss of his substance-abusing father: "But I get along with my stepdad, but I don't call him my stepdad, I call him my father. And I go home and see him every weekend. But, like, that's a—that's a good thing to have somebody close that you can, like, really go to." Steve, a White male with mild ID, remarks, "I have to say something about relationships with parents. I have a great relationship with my mother, um, my mother, she's been pretty much the mother and father of the relationship."

Rick has cultivated a father-son relationship with his sister's biological father (refers to him as his "stepdad") due to a severed relationship with his father. Similarly, Steve perceives his mother as fulfilling "mother" and "father" roles due to the inability of his father to provide adequate supports. Ouellette-Kuntz et al. (2014) discuss how adaptation to challenging situations is an expression of family resilience. Both Rick and Steve make accommodations for lacking relationships with their fathers with other family members to fulfill emotional needs.

Emotional Connection. Three participants directly expressed loving feelings for a family member. For example, Arthur, a Black male with mild ID, exclaimed, "Yeah, I, I miss—I miss my family, too. I want to—I want to be—I want to be, be, cl—. . . I—I'm, I'm really close to them." Bill, a White male with mild ID, expressed heartfelt sentiments: "I have a nephew whose birthday is coming up, and when I was over at the other house that he looked at, he ran—ran over to the window to scream, "'Bye Uncle,'" which is really—it

really just melted me. I was like, do I really have to leave? And, that was like, I think it was my—it was the day of my birthday, that—that really, tore me apart. It made me feel like there was some—some sort of a connection." Arthur and Bill articulate having awareness and gratitude for existing family relationships, yet simultaneously express a sense of loss associated with insufficient contact.

"She Helps Me." Three participants talked about family members giving gifts or offering logistical supports. For example, Stan, a White male with mild ID, expressed gratitude: "Uh, my relationship with my aunt—my aunt is very good. She helps me, gives me money on the side, and I feel good. I love my aunt, I trust her." Dan, a White male with mild ID, stated, "And my—my brother-in-law's a computer freak. Every time I have a problem with my computer, he's like, 'I'll fix it for you for nothing.'" Edward, a White male with moderate ID, shares about his sister (his tone had a mix of happiness and anxiety), "My sister went away on vacation, and I miss her. I want her to come back. And she told me she'd be back today or tomorrow. She bring something back for me tomorrow, like a souvenir. She does this once in a while."

Repaired/Damaged Family Relationship. Alexis, a White female with mild ID, shared, "I used to have a complicated relationship with my brother, like—because, um, I did something that I shouldn't have done with him, to him, but now we're like this (crossed fingers)." She added a few moments later, with a serious, yet positive demeanor, "Well, I, I… I accused him of something that I shouldn't have, and then I lost his trust. And, uh, when you lose somebody's trust, you, you have to earn it back. And I've earned it back."

Conflicted Relationships. The following excerpts contain examples of complex internal and external factors participants disclosed that led to the categorization as conflicted. TFRBs, physical abuse by a family member, and CBs by the participant are present. The passages are intentionally lengthier in these sections to provide expanded context for the reader.

Marvin

A disclosure by Marvin, a White male with mild ID, exemplifies a complex, bidirectional transactional pattern. Marvin describes being aggressive toward his mother and being assaulted by his brother in a neutral or reconciliatory tone:

> Yeah, we used to fight a lot. And I was… Uh, I don't know why, uh, we fought a lot. But like somehow I had anger in me—at a young age. But when I was younger, I remember I was mad at my mom and I actually picked up a chair from the table

> and I had it over my head. And I wa—thought, uh, was goin' to throw the chair at my mom. And I—uh, I know I shouldn't be trying to hurt other people, because it's not right. I had to kinda go—my mom put me in different places, even two different hospitals, to control my anger, to learn how to control myself so I wouldn't be acting out. I mean, the… And my brother—actually, one time we were on the hill and he actually tied me to a cross and was burying me in the sand —with a shovel. And my dad had to—had punished my brother for that. I thought my brother was goin' to kill me.

In this passage, Marvin described his own vulnerability as "somehow I had anger in me—at a young age" (A). Marvin discloses that his mother has difficulty managing his CBs (B). Marvin's behaviors appear to escalate, further increasing intra-familial stress (C). Within this chaotic environment, the parents appear to have difficulty providing adequate structure for Marvin and his brother.

In a therapy setting, it is important to assess potential experiences of abuse and behavioral dys-control. For example, the literature highlights how this population can experience difficulty reporting victimization and tends to communicate trauma through behavioral expression; in these cases, the CBs are frequently misattributed to other factors (Hollins & Sinason, 2000; McCarthy, 2001; Turk, Robbins, & Woodhead, 2005). Although Marvin does not describe the "fight" as abuse, a reader may interpret the description of Marvin's non-disabled brother tying him to a cross, burying him, and making him fear for his life as physical abuse. It is unclear whether the brother's self-regulation deficits and abusive actions exacerbate Marvin's vulnerabilities, or the brother's actions are a response to the increased family stress associated with caring for Marvin. Although Marvin reports there has been a reconciliation, the impact of these events may be related to his current functioning.

It is also helpful for clinicians to be aware of potential inter-sibling stresses. Dyke, Leonard, Bourke, Bebbington, and Bower (2007) explain that while some siblings reported positive experiences related to living with a sibling with ID, 61% of siblings reported disadvantages. These included: having less attention from parents, increased responsibilities, embarrassment related to the sibling's behavior, and reduced involvement in holiday celebrations.

Charlie

Charlie, a Black male with mild ID, responds after another participant disclosed being physically abused by a family member. He shares about his conflicted relationship with his mother. There is an angry tone in his voice.

> Mom did that to me, too—which was why she should go to jail for that—when I was young. Mom, sh—threw—n—Mom threw me down the stairs, kicked me

> down the stairs. Sh-she should have gone to jail for that, I said. They said they hate me. I sh—I should have called the cops on my mom for that.

Charlie perceived his mother's behavior as abuse. Issues related to victimization are particularly salient for this population due to higher rates of neglect, physical, and sexual abuse than the general population (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010; Mevissen, Lievegoed, Seubert, & Jongh, 2011; Sullivan & Knutson, 2000). Additionally, factors associated with the reporting of intra-familial abuse is complex. The literature states that victimization is underreported, citing stigma, fear of retaliation, fear of not being believed, and limitations associated with the disability as barriers (Bedard, Burke, & Ludwig, 1998; McCormack, Kavanagh, Caffrey, & Power, 2005).

When examining the transactional pattern being disclosed, it is difficult to state that the mother's actions (or the family's case in the previous scenario) were a result of family stress generated by Charlie and/or his enhanced support needs. Not conceptualizing the primary responsibility of emotional regulation as the parent's responsibility, blames the victim. Although it may be difficult to be certain, it appears that her throwing/kicking him down the stairs could be manifestation of intrinsic emotion-regulation deficits.

This situation is particularly conflicted for Charlie because his mother is currently his legal guardian. The issue of power differential between a non-ID parent and child with ID can create situations that are difficult for the participant to resolve. These types of complicated environmental factors are likely associated with Charlie's ongoing behavioral health issues.

Steve

In another group, Steve, a White male with mild ID, describes the complex relationship he has with his mother related to victimization perpetrated by his stepfather:

> He raped me, he raped my sister, and my mom didn't believe me. My mom didn't believe me. She didn't believe me at all, and, uh, I kind of felt bad because I felt like I could've helped—I felt like I could've done something to stop him, and I tried, I really did. I tried to stop him, um, I was kind of hurt, I was surprised because I never thought it would happen to me. But when my—my sister told me that it happened to her, I was, like, really, really upset. I was crying for, like, two months. Um, I tried to let it go, I tried to ignore it, I tried everything under the sun to put it away, but I could still think about it. I could still think about it to this day. And, like, honestly, I'm going to tell you, I feel like it's my fault.

Steve has a "severed" relationship with his stepfather ("severed" relationships are analyzed in the next section) and a "conflicted" relationship with his mother. Despite her apparent neglect, Steve has ongoing contact with his mother. It is noteworthy that Steve's description of his mother's response to

him reporting that he had been raped by her husband ("my mom didn't believe me") has a radically different tone from the "intact" comment he shared in the previous section ("I have a great relationship with my mother, um, my mother, she's been pretty much the mother and father of the relationship"). This is an example of how the stepfather's impaired self-regulation and the mother's inability to provide adequate supports fuel negative transactions that impact Steve's psychological functioning, behavioral control deficits, and quality of life.

Severed Relationships. These two excerpts describe the participants' perspectives about family members they no longer have contact with.

Gary

Gary, a Black male with mild ID, speaks in a quiet voice about his biological mother:

> And I was, like—I almost died when I was in my mom's belly because I came out too early, but, um, I just wanted to share to you guys that some parents are—aren't responsible, and sometimes, they don't think what they do when they're having a baby. And that really hurts when I talk about it because I wish I was, like, my brothers and sisters was out that—so, I just wanted to tell you, like, none of my other brothers and sisters have that problem except for me, and I wish I was like them, without that problem.

Gary brings attention to his in utero environment, describing emotions associated with his mother's irresponsibility. Gary attributes substance abuse, a preventable cause of ID (Barber, 2014; Habela & Hamosh, 2013; Mann et al., 2013), as the origin of his disability. The foundational transaction consists of (A) the mother's substance abuse and in utero victimization, resulting in (B) Gary developing biological vulnerabilities that intensify physical and emotional support needs. Unable to care for Gary, he is removed from his mother (C). Gary struggles with emotional regulation challenges, psychiatric issues, and CBs that lead to polarized interactions with residential providers (D).

Brent

In another group, Brent, a White male with moderate ID, describes a severed relationship he has with his stepmother as he responded to the prompt about complicated relationships:

> My stepmother, for example, gave me… Uh, she went to the grocery store and left with—with me—with foster—foster kids. And I was smokin' cigarettes and so forth. I was sneakin' them. Uh, she came back shoppin' and she could smell it on me. So she kinda—that kind of—but beat the livin' crap outta me—I mean, really bad—She beat me up so badly—that was not very nice—threw me down the stairs.

> My brother came home from the army and threw me out the door. And—and—there was stai—there was stairs. But they were cement stairs. And threw me down the stairs.

In this excerpt, Brent disclosed physical abuse by his stepmother and brother. Later in the group, responding to his perceptions about God, he describes his behaviors related to the stepmother's foster children that may have contributed to a negative family transaction which led to the severing of this relationship:

> And I used to—I used to do a lotta damage to her kids. And it hurt my feelings, when I done it. And I think what happened is God kinda watched over me, looked down on me, and said, "If you do these things, you're gonna go to hell, and really stay down there and never come back.

The transaction becomes increasingly complex as more information is available. Initially the stepmother and brother appear to be ruthless abusers throwing Brent down cement stairs for sneaking a cigarette. Brent describes his role in the larger transaction (doing "a lotta damage to her kids" in ways that he thinks God will send him to hell for). He and his family engaged in escalating behavioral problems that led to the severing of the relationship between Brent and his stepmother.

Discussion

Types of Relationships

There were four different types of family relationships described: siblings, mothers, extended family, and fathers. These data highlighted that it is important for clinicians to be aware of the important roles of primary carers, as well as siblings and extended family members, play in the lives of dually diagnosed people. These data highlighted the variability within family relationships, in that participants disclosed both positive and negative transactions with different family members.

Status of Family Relationships

The processes that were observed as happening within family relationships were coded into three subcategories of family relationship statuses: "intact," "conflicted," and "severed."

Intact

Although the disclosures about "intact" family relationship were outweighed by the "conflicted" and "severed," the impact of the positive bonds was salient. Positive transactions were noted in the "intact" relationships.

Generally speaking, the individual (A) interacted with the family member (B) and the outcome was a positive experience for both parties (C). It appeared that in these positive transactions both the individuals and the family members demonstrated qualities such as reciprocity, flexibility, affection, appreciation, accommodation, trust, responsibility, and acceptance. It may be beneficial for individual treatment providers to target interventions that help participants develop adaptive self-regulation and social skills that are foundational for these behaviors. Additionally, family therapy interventions that foster positive transactions may be valuable for all involved.

These positive relationships were not without issues, but there were bidirectional, adaptive rapports that reconciled differences. The synthesis of polarities (A and B) seemed to facilitate sustainable intact/in contact interactions (C). These data present some of the properties and processes that commonly occur between a dually diagnosed adult and family relationships; by heightening awareness, clinicians may be able to help individuals to cultivate realistic family relationships that add to their and the family members' quality of life.

Conflicted or Severed

Rather than reconciliation and collaboration that was common in the intact family relationships, conflicted and severed relationships appeared to include more negative transactions and polarization. Linehan (1993) describes dysfunctional family transactions as follows: "over time, children and caregivers shape and reinforce extreme and coercive behaviors in each other. In turn, these coercive behaviors further exacerbate the invalidating and coercive system, leading to more, not fewer, dysfunctional behaviors within the entire system" (p. 58).

This type of escalating transactional pattern appeared to be active within many of the conflicted and severed family relationships shared by the participants. In conflicted and severed relationships, the participants described more incidents of victimization/abuse and substance abuse perpetrated by family members and disclosed demonstrating more CBs related to those relationships. It seemed that in many cases both the individual and the family members experienced difficulties self-regulating.

Transactional Family Relationship Barriers

This qualitative study delves into the concept of bidirectionality and expands transactional patterns to include the family member's self-regulation status as part of dysfunctional situations. For example, a parent who experiences emotional regulation difficulties (A) interacts with a child with ID and intensified needs (B). The parent is unable to self-regulate behaviors and is unable to provide effective co-regulation to the vulnerable child (C). The

child, not receiving adequate supports, demonstrates emotional and behavioral dysregulation (D). These types of transactional patterns function as a vicious cycle of behavioral co-dysregulation that are fueled by the individuals' and the families' vulnerabilities.

Conceptualizing relationship problems through a bidirectional transactional lens aids in understanding the myriad of factors that are involved in complex social environments. Many of the stories disclosed by the participants were provocative and intense, a good reminder that relevant untold narratives may exist. It is essential to be cognizant of TFRBs that may have happened in the past and/or are ongoing in family relationships. These data demonstrate that participants may re-enter family relationships where there is unresolved, and potentially unreported, abuse that happened or is happening. Observing behaviors that happen prior to, during, and following family contacts may help the clinician evaluate the impact of family contacts if no overt disclosures are made.

CBs are common reasons for referrals to treatment (Tsiouris et al., 2011). Assessing how TFRBs and additional transactional relationship barriers influence CBs is an important aspect of treatment (Brown, Brown, & Dibiasio, 2013). This analysis showed that in positive transactions, family relationships appeared to co-regulate the people involved, while in negative transactions, evidence of co-dysregulation was reported. This means that both the participant's intrinsic emotion-regulation capacities and elements from the environment that elicit CBs may be relevant treatment targets. Environmental factors are believed to be associated with CBs (Matson & Boisjoli, 2007; Matson et al., 2011, 2012); therefore, understanding how environmental factors can co-create and co-maintain CBs is foundational for improving both personal and familial functioning.

Conclusion

The perceptions of family relationships from the perspective of the individual with ID is underrepresented in the literature. This is problematic because factors such as diagnostic overshadowing (Matson & Scior, 2004), biases/stigma (Ali et al., 2013; Ditchman et al., 2013; Jahoda & Markova, 2004), and a lack of alternative ID-specific information create the dominant discourse, obstructing clinical assessment and treatment. The aim of this analysis was to explore properties associated with family relationships to add to the literature associated with improving therapeutic supports for dually diagnosed individuals.

This analysis provides clinicians with empirical information that helps inform ID-specific practice. The intensity of many of the disclosures illuminate a few key areas that warrant treatment consideration. For example, these data highlight that the dually diagnosed participant with past or current CBs

(and potentially family members) may benefit from treatments that build self-regulation skills. DBT used in conjunction with the Emotion Regulation Skills System (Brown, 2011; 2016 [in press]), is a comprehensive treatment designed to help the individuals with ID improve emotion regulation capacities (Brown et al., 2013). Additionally, due to the abundance of provocative and intense disclosures of victimization/abuse, trauma-informed models, such as the ARC: Attachment, Regulation, and Competency model (Blaustein & Kinniburgh, 2010), may be clinically appropriate. The ARC model addresses the elements of attunement, self-regulation, and competency for the individuals and the environment.

Family-based treatment components should be considered for participants who want to address problematic family relationships. It is important to note that in any type of therapy setting, a participant's expressive and receptive language deficits may impact the balance of power and reduce collaboration; adequate accommodations are necessary to avoid disempowering the participant in a high-vulnerability situation (Jahoda et al., 2009). Additionally, cognitive dysregulation may hinder information processing in situations (e.g., family therapy the individual perceives as "conflicted") that elicit high emotion (Sweller, 2010). Combining treatments such as adapted DBT and family interventions may offer dually diagnosed participants ample scaffolding to support personal stability/growth and management of complex family relationships.

Limitations

Although this research provides relevant information related to a population whose perceptions are rarely studied, there are many limitations. Thirty participants is a small sample, and the transferability of the information to populations beyond this group is limited. It is also not optimal to study transactional relationships by only collecting data from one side of the relationship; there is a danger of over-interpreting the information without including data from family members.

Fortunately, empirical processes built into CGT, such as theoretical sampling and memoing, allow for foundational theory development despite the absence of a sample of family members. Other research decisions, the explicit transparency about CGT research methods, active management of reflexivity, use of NVivo software, inclusion of ample verbatim quotations, and extended excerpts showing context addressed issues of trustworthiness.

The fact that there was not a direct question about family relationships could be perceived to reduce trustworthiness. Conventionally in CGT, the question would have been added and the topic explored in-depth once it was clear that family relationships were a salient subject. A dialectical tension between the needs of CGT and the clinical needs of the population emerged. The research team resolved this conflict by (1) adapting

methodologies to accommodate vulnerable populations, (2) integrating clinical information into research decisions for dually diagnosed participants, and (3) being transparent about these accommodations. It could be argued that these processes are necessary when doing research with this vulnerable population.

This analysis is a starting point that hopefully will prompt exploration of these topics using different methods that will deepen the analysis. For example, examining gender differences related to perceptions about family relationships could be important. Exploring the differences in perceptions of family relationships for various age groups may be a contribution. Expanding the literature related to ID-specific therapeutic supports is an essential step toward helping increase adaptive functioning and quality of life for dually diagnosed individuals.

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