




Parents Caring for Adult Children With Co-Occurring Disorders: A Phenomenological Study

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Abstract

The purpose of this study was to explore and understand the lived experiences of parents caring for an adult child, aged 18 to 30 years, with a co-occurring mental health and substance use diagnosis, with attention to how caregiving intersects with trauma, resilience, and systemic challenges. To guide this exploration, the Resilience Trauma Negotiation (RTN) framework was introduced to examine how exposure, appraisal, coping responses, and systemic context intersect to shape the complex realities of caregiving. Using Moustakas's seven-step transcendental phenomenological approach, semi-directed interview questions were facilitated with 14 caregivers. Data were transcribed, coded, and analyzed to identify emerging themes that reflected how parents made sense of caregiving while also showcasing common patterns of experiences across participants. Results revealed nine subthemes distributed across the four domains of the RTN framework. In the exposure domain, parents reported persistent crises and hypervigilance. Within the appraisal domain, parents described role strain, constrained influence, and grief tied to ambiguous loss. Coping responses included emotional numbing, boundary setting, and advocacy through faith, while the systemic context revealed fragmented care, exclusion from treatment, and stigma that reinforced isolation and powerlessness. While this study contributes to the literature on family-centered and resilience-focused care, future research should examine how systemic supports, policy changes, and community-based resources shape caregiver well-being and sustain coping strategies across the long-term demands of caregiving for adult children with co-occurring disorders.

Keywords: *caregiver trauma, secondary traumatic stress, emotional numbing, Resilience Trauma Negotiation framework, co-occurring disorders*

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Introduction

Nearly one in five adults in the United States provides informal care for a loved one, and these caregivers consistently experience elevated psychological distress, poorer health outcomes, and greater emotional strain compared to non-caregivers (Kilmer et al., 2024). For parents of adult children with co-occurring disorders, caregiving becomes a continual balancing act between crisis management and daily support. Their responsibilities extend beyond providing emotional care to include financial oversight, ongoing advocacy, and coordination of fragmented services. Caregivers must also navigate systems characterized by recurring relapse, limited accessibility, and persistent stigma that often isolates them from supportive resources (Lawrence et al., 2021; Mardani et al., 2023).

Family caregiving is an underrecognized dimension of behavioral health, extending beyond professional treatment to include the unpaid, ongoing support parents provide for adult children with a co-occurring mental health and substance use diagnosis. This role often requires parents to assume substantial emotional and daily responsibilities at significant personal cost (Roth et al., 2015). Support may encompass both physical and psychological needs, including medication management and transportation to medical appointments alongside emotional regulation assistance, crisis monitoring, and reinforcement of coping strategies. Unlike many physical health conditions that follow more predictable trajectories, co-occurring disorders are marked by cycles of crisis, fragile stability, and relapse (Tyo & McCurry, 2023). These patterns sustain chronic vigilance, erode caregivers' physical well-being, disrupt routines, and intensify psychological strain, leaving parents emotionally depleted as responsibilities persist.

In addition to the relentless demands of crisis management, parents often report trauma-like symptoms. Research has identified intrusive thoughts, avoidance behaviors, hyperarousal, and emotional numbing among family members of individuals with co-occurring conditions (Forkey et al., 2023). These experiences mirror secondary traumatic stress, a concept initially developed to describe the emotional toll faced by professionals working with trauma survivors (Carmassi et al., 2021). Emotional numbing is particularly common; while it can serve as a protective mechanism that enables functioning in times of distress, it also introduces relational disconnection (Barutcu, 2025; Carmassi et al., 2021). Parents suppress their own emotions to maintain stability, only to find that such distancing weakens bonds with their child and isolates them from other sources of support (Barutcu, 2025).

Ambiguous loss adds another unique layer of complexity to caregiving for parents of adult children with co-occurring disorders. Ambiguous loss, as defined by Boss (1999), refers to grief experienced when a loved one is physically present but psychologically altered or distant. In a qualitative study exploring the ambiguity of parenting adult children with a substance use disorder, Wilburn et al. (2022) reported that parents described feeling as though they are caring for someone whose personality, behavior, and emotional presence appears lost. This unresolved loss perpetuates states of uncertainty and fuels cycles of hope and despair, making closure elusive. Parents often describe this experience as gradually "losing" their adult child, noticing small changes over time and feeling the emotional distance grow while continuing to shoulder daily caregiving responsibilities (Wilburn et al., 2022). These continuous shifts in presence and identity intensify emotional numbing and place additional strain on the parent–child relationship.

Systemic barriers amplify caregiver strain. Families must navigate a patchwork of disconnected services that rarely integrate substance use and mental health care. The transition from pediatric to adult systems at age 18 further destabilizes care, disrupting insurance coverage and continuity of services (Gray et al., 2018). Parents report frustration with systems that assume independence once children reach adulthood, even though their conditions often necessitate ongoing parental involvement (Gray et al., 2018). For families already living with trauma-like stress, these systemic disruptions exacerbate burdens and force caregivers into the role of care coordinators. Stigma further intensifies caregiver burden, as parents frequently report being blamed for their

child's difficulties, experiencing stigma by association, or encountering judgment from providers and community members (Kalhovde & Kitzmüller, 2024; Muralidharan et al., 2016). In an effort to protect themselves, many parents resort to self-silencing, choosing to withhold information to avoid adverse reactions. Although this silence can provide temporary protection from judgment, it simultaneously restricts access to supportive resources, deepens isolation, and intensifies the trauma of caregiving (Barutcu, 2025).

The developmental context of young adulthood creates another layer of difficulty. Emerging adulthood, defined as the period from ages 18 to 30, is typically characterized by exploration of identity, pursuit of autonomy, and entry into adult social and occupational roles (Arnett, 2015). Parents describe extended caregiving roles that feel more like case management than parenting (Arnett, 2015). The shift from nurturer to coordinator intensifies stress and disrupts the parent–child bond, generating guilt, frustration, and grief (Boss, 1999). The developmental misalignment between expectations of independence and realities of dependence contributes to ongoing strain in ways that are distinct to this stage of the life course.

Existing theoretical models account for some aspects of this reality but fail to provide a comprehensive explanation. Caregiver burden models reflect the weight of caregiving responsibilities, while stress-and-coping models address overload, but both approaches neglect the trauma-specific processes embedded in long-term caregiving (Lim et al., 2022). Further, these models do not adequately explain emotional numbing, ambiguous loss, or the extent to which caregivers experience trauma symptoms that parallel those of their children (Friedberg & Malefakis, 2018; Lim et al., 2022). To bridge this gap, the Resilience Trauma Negotiation (RTN) framework has been introduced as a conceptual model for understanding caregiver experiences and the impact of trauma.

The RTN framework situates caregiving as a process of ongoing negotiation between trauma exposure and resilience strategies. It organizes caregiver experiences into four interconnected domains: exposure, appraisal, coping responses, and systemic context. Exposure includes recurrent crises, stigma, and the ongoing uncertainty of relapse. Appraisal reflects caregivers' interpretations of ambiguous loss, constrained influence, and role strain. Coping responses include emotional withdrawal, strategic disengagement, boundary adjustments, and advocacy. Systemic context acknowledges fragmented health care, insurance transitions, and cultural stigma. Together, these domains provide a structure for examining how caregiver trauma occurs in families while also enlightening resilience strategies (McCleary & Figley, 2017). These domains are critical to address because caregivers are equally vulnerable to trauma and essential to the recovery process of their adult children. Without meaningful interventions, caregiver health deteriorates, and treatment outcomes for young adults are compromised.

Literature Review

Caregiving for relatives with behavioral health conditions is an overlooked aspect of the United States health landscape (Roth et al., 2015). According to a national report by the National Alliance for Caregiving (2021), more than 53 million Americans provide unpaid care, with nearly one-quarter supporting someone with a mental health condition. For parents of adult children living with co-occurring disorders, this role is especially complex, characterized by cycles of relapse, psychiatric hospitalization, and criminal justice involvement. These challenges are compounded by the need to navigate fragmented systems of care that rarely coordinate substance use and mental health treatment (Substance Abuse and Mental Health Services Administration, 2022). Research shows that U.S. caregivers experience significantly higher rates of depression, anxiety, and frequent mental distress than non-caregivers, with disparities widening between 2015 and 2016 and 2021 and 2022 (Kilmer et al., 2024). Despite growing recognition of caregiving as a public health issue, national surveys and reports seldom differentiate outcomes by caregiving context, leaving the experiences of parents supporting adult children with co-occurring conditions underexamined. These findings reflect the urgent need

to expand the literature to explore the intersection of trauma, resilience, and systemic barriers in caregiving for adult children with co-occurring disorders.

Ambiguous loss has emerged as a particularly relevant concept in this literature. Parents describe mourning the child they once knew, even as they continue to provide daily care for an adult whose emotional and behavioral presence has shifted (Boss, 1999; Wilburn et al., 2022). Qualitative findings reveal that this unresolved loss perpetuates cycles of hope and despair, erodes relational closeness, and amplifies caregiver distress (Wilburn et al., 2022). Nonetheless, ambiguous loss is rarely studied in tandem with trauma-related constructs, such as secondary traumatic stress, leaving important intersections unexamined.

Stigma is another critical, underexplored factor that shapes the caregiver experience. Parents often report being blamed for their child's struggles or experiencing stigma by association when disclosing their caregiving role (Muralidharan et al., 2016). This stigma discourages engagement in services, erodes trust in providers, and leads to self-silencing. While silence can serve as a temporary shield against judgment, it also reduces access to supportive networks and increases social isolation. Despite these challenges, many families turn to spiritual or faith-based communities as a source of emotional support and a sense of belonging.

In contrast, others encounter subtle forms of stigma within religious settings that reinforce shame and discourage open discussion of mental illness (Leavey et al., 2007). This tension reflects the need for culturally and spiritually sensitive approaches that recognize both the healing potential and the limitations of faith-based support for families affected by co-occurring disorders. Recent studies of stigma in the United States have shown that these dynamics magnify caregiver distress, but there remains little integration of stigma research into broader models of caregiver trauma (Goldberg et al., 2023).

Systemic barriers compound these individual and relational challenges. Families must navigate fragmented systems of care, with substance use and mental health services often operating in parallel and integrated. The transition from pediatric to adult systems introduces additional instability. Disruptions in insurance coverage, care coordination, and service continuity at age 18 create additional strain for parents who often remain the actual coordinators of care (Gray et al., 2018). These transitions are especially difficult for families supporting an adult child with co-occurring conditions, such as major depressive disorder and alcohol use disorder, bipolar disorder and stimulant misuse, or schizophrenia with cannabis dependence, because fragmented systems separate mental health and substance use treatment. The absence of coordinated, integrated care increases logistical demands, complicates treatment adherence, and places disproportionate emotional, financial, and advocacy burdens on caregivers (Gray et al., 2018). Despite national policy emphasis on integrated behavioral health and family engagement, implementation across service systems remains inconsistent (Substance Abuse and Mental Health Services Administration, 2022).

The developmental stage of emerging adulthood introduces unique dynamics that few studies adequately address. Typically defined as the period from ages 18 to 30, emerging adulthood is characterized by autonomy seeking, identity development, and transitions into occupational and relational roles (Arnett, 2015). For parents of adult children with co-occurring disorders, these normative milestones often remain out of reach, creating a misalignment between societal expectations and family realities. Research indicates that parents frequently shift from nurturers to case managers or advocates, experiencing guilt, frustration, and grief in the process (Lim et al., 2022). Only a few longitudinal studies have followed how this misalignment evolves across time or how families adapt to the prolonged caregiving role in this developmental period.

Theoretical work has struggled to keep pace with these complexities. Caregiver burden models capture the weight of responsibilities but rarely incorporate trauma-specific processes. Studies of resilience describe adaptive strategies but often minimize the coexistence of trauma and resilience within the same families. This fragmentation reflects the need for integrative frameworks. The RTN framework has been proposed as one such model, emphasizing four domains: exposure, appraisal, coping responses, and systemic context (Figure

1). It situates caregiving as an ongoing negotiation between trauma and resilience, offering a way to examine how parents endure and adapt within environments of chronic stress (McCleary & Figley, 2017).

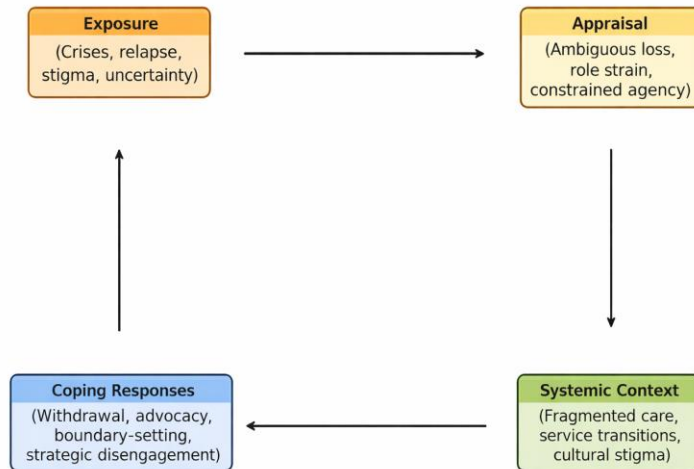
Further, few studies examine trauma and resilience together, despite evidence that both processes co-occur (McCleary & Figley, 2017). Longitudinal research that tracks caregiver trajectories over time is lacking, as is empirical work that integrates systemic, interpersonal, and intrapersonal factors. This study builds on existing literature by centering parental narratives, applying the RTN framework (Figure 1), and advancing a more comprehensive and multicultural understanding of caregiver experiences in the context of caring for an adult child with a dual diagnosis.

Purpose of the Study

The purpose of this study was to explore and understand the lived experiences of parents caring for young adult children with co-occurring disorders, with attention to how caregiving intersects with trauma, resilience, and systemic challenges. This study is grounded in the RTN framework, which situates caregiver trauma as a dynamic and cyclical process shaped by the interaction of repeated crises, parental appraisals, coping responses, and systemic context. Unlike linear models of caregiver burden or stress and coping, RTN acknowledges the negotiation between trauma exposure and resilience strategies within relational and systemic environments.

Caregiver trauma is conceptualized through four interdependent domains. Exposure refers to the ongoing crises that parents face, such as overdoses, psychiatric hospitalizations, arrests, and ambiguous loss (Boss, 1999; Wilburn et al., 2022). These crises sustain states of hypervigilance and create unresolved grief. Appraisal reflects how parents interpret their roles and circumstances, often marked by role strain, constrained influence, and feelings of helplessness. Coping responses encompass protective withdrawal strategies, such as emotional numbing and boundary renegotiation, as well as resilience-building strategies, including advocacy and persistence. Systemic context encompasses the fragmented and crisis-driven nature of behavioral health systems, stigma, and barriers associated with transitions into adult care, all of which intensify caregiver burden while shaping opportunities for adaptation (Figure 1).

Using a transcendental phenomenological approach, the study examined how parents experienced trauma-related responses such as emotional numbing and secondary stress, as well as the coping strategies and role adjustments that developed over time. The RTN framework was used as an interpretive lens to support understanding of these experiences across the domains of exposure, appraisal, coping responses, and systemic context (Figure 1) while maintaining focus on participants' lived realities. The findings aim to enhance understanding of caregiver experiences and support the development of trauma-informed, family-centered practices that address systemic barriers and strengthen caregiver resilience.

Figure 1. *Resilience Trauma Negotiation Framework*

Research Questions

RQ1. How do parents of young adults aged 18 to 30 years with co-occurring disorders describe their lived experiences of caregiving in relation to trauma, resilience, and ongoing systemic challenges?

RQ2. How do parents' lived caregiving experiences reflect the domains of the RTN framework, including exposure, appraisal, coping responses, and systemic context?

Sub-questions include:

SQ1. How do parents describe the ways they cope with stress, emotional numbing, and secondary traumatic stress within their caregiving role?

SQ2. How do parents experience and interpret systemic factors such as fragmented care, stigma, and service transitions while caring for their adult child?

Methods

This qualitative study employed a phenomenological design to examine caregiver trauma through the lens of the RTN framework. Phenomenology was selected because it provides a rigorous approach for exploring lived experiences and uncovering the meanings that individuals ascribe to them (Yin, 2018). In this study, caregiver trauma was defined as the presence of stress reactions and psychological symptoms in parents that parallel those of their adult children, including hypervigilance, avoidance, intrusive thoughts, and emotional withdrawal. Secondary traumatic stress and emotional numbing were considered interconnected processes that emerge in long-term caregiving, where relational closeness increases vulnerability to trauma contagion (Boss, 1999). The focal child was defined as an adult son or daughter aged 18 to 30 years with a co-occurring mental health and substance use diagnosis, such as major depressive disorder and alcohol use disorder.

Participants

The participants in this study included 14 caregivers ranging from age 31 to over 61, representing diverse caregiver roles such as biological, adoptive, step, foster, and kinship parents. Most participants were female, with varied marital statuses including single, partnered, divorced, married, and widowed. Educational backgrounds ranged from high school/GED to graduate or professional degrees, and employment statuses included full-time, part-time, retired, and unemployed individuals. The focal children, aged 18–30 years, represented multiple racial and ethnic backgrounds, including Black, White, Latina/o, Asian, multiracial, and Native American, and were experiencing different levels of crises requiring monitoring or acute intervention.

Recruitment was conducted through purposive sampling to ensure relevance to the study focus, and snowball sampling was used to expand outreach through peer referrals. Eligibility criteria required participants to be the primary caregiver of an adult child with a dual diagnosis, over age 21, and actively engaged in caregiving within the past 6 months. Fourteen parents participated in a one-time virtual interview conducted via Zoom and provided informed consent through Qualtrics prior to data collection. Institutional review board approval was obtained from Walden University (Approval No. 10-21-25-9455426), and all procedures adhered to established ethical standards to ensure the protection of participant confidentiality. Measures included the de-identification of transcripts, the use of pseudonyms for all participants, and the secure storage of data.

Data Collection

Participants completed an informed consent form, an eligibility screener, and a caregiver form that collected demographic and contextual information, such as caregiver age, gender, family composition, education, employment, and the age of their adult child, via Qualtrics. Once all the information was reviewed and eligibility was confirmed, interviews were scheduled. The interview guide (see Appendix A) was organized around the four domains of the RTN framework: exposure, appraisal, coping responses, and systemic context. The interview guide included semi-directed interview questions with optional prompts.

Semi-directed interview questions were conducted using the Zoom videoconferencing platform, with the participants' permission, and lasted between 45 and 60 minutes. The interviews were audio-recorded using the Zoom platform to protect the confidentiality of the participants and were later transcribed by the researcher. The data collected were anonymous and confidential. Participants were assigned a number in place of their real names to protect their identities. Member checking was conducted when clarification was needed to fill in any gaps in data, such as missing or unclear information, after the initial interview had been completed. To maintain content validity and avoid detracting from the interview, note-taking was kept to a minimum, and participants were allowed to express themselves freely. Participants were debriefed after the conclusion of the interview, and the debriefing process lasted between 10 and 15 minutes for each participant.

Data Analysis

Data saturation was achieved after 12 interviews, and two additional interviews were conducted to confirm the consistency of emerging themes, resulting in a total of 14 participants. This process aligned with established practices in qualitative research for determining adequate sample size (Guest et al., 2020). In alignment with the phenomenological design of this study, Moustakas's (1994) seven-step transcendental phenomenological analysis was employed to explore the trauma experienced by caregivers. This approach was selected because it provides a systematic process for distilling the essence of lived experiences while maintaining close attention to participants' voices. Using the proposed RTN framework as a lens, each step of Moustakas's method guided the analysis to capture how parents of young adults aged 18 to 30 years experienced emotional numbing, secondary traumatic stress, and role shifts in caregiving.

Prior to formal analysis, I engaged in epoché, intentionally bracketing personal and professional assumptions to approach the data with openness (Moustakas, 1994). Data analysis then followed Moustakas's (1994) seven-step transcendental phenomenological method. Analysis began with listing and preliminary grouping of all statements relevant to the phenomenon through horizontalization, in which each statement was initially treated as having equal value. These statements were then subjected to reduction and elimination to identify invariant meaning units that were essential to understanding the experience. The invariant meaning units were subsequently clustered into thematic groupings, which were validated by returning to the full transcripts to ensure that each theme was explicitly supported by participants' accounts and that no incompatible data were included. Following theme validation, individual textural descriptions were developed to describe what each participant experienced in relation to caregiving, trauma, loss, and systemic barriers. Individual structural descriptions were then constructed using imaginative variation to explain how these experiences occurred within relational, contextual, and systemic conditions. The analytic process concluded with the synthesis of individual textural and structural descriptions into a composite textural–structural description that expressed the shared meaning and essence of caregivers' lived experiences across participants (Moustakas, 1994).

The transcripts were reviewed multiple times to ensure accuracy and gain an understanding of the content and were then used to hand code the data manually. Initial codes were clustered into broader thematic categories and then aligned with the RTN domains of exposure, appraisal, coping responses, and systemic context. This process grounded findings in parents' sense-making of their caregiving roles. Pseudonyms were used to maintain privacy. NVivo software was used to manage and organize de-identified data.

Results

The purpose of this phenomenological study was to explore how parents of young adults aged 18 to 30 years with co-occurring substance use and mental health disorders experience caregiver trauma within the RTN framework. The data revealed interconnected processes that were examined within the four domains of the RTN model: exposure, appraisal, coping responses, and systemic context. Nine subthemes were embedded within these domains, reflecting the lived experiences of 14 parents (P01–P14) and organized in alignment with the study's primary research question, secondary research question, and two subquestions.

Primary Research Question

RQ1. How do parents of young adults aged 18 to 30 years with co-occurring disorders describe their lived experiences of caregiving in relation to trauma, resilience, and ongoing systemic challenges?

Analysis across the RTN domains revealed consistent patterns in how parents experienced and navigated caregiving for young adults aged 18 to 30 years. Within the exposure domain, all participants described ongoing crises and a pervasive sense of ambiguous loss, with most reporting sustained hypervigilance and anticipatory fear of relapse or hospitalization. Appraisal themes reflected pronounced role strain, diminished parental identity, constrained influence within treatment systems, and cumulative grief marked by repeated cycles of hope and disappointment. Coping responses included emotional numbing, strategic withdrawal, boundary renegotiation, and the use of advocacy and faith as mechanisms for endurance. Parents also described systemic challenges characterized by fragmented, crisis-driven care, stigma, social isolation, and increased barriers following transitions in insurance coverage and legal status at age 18. Collectively, these findings emphasize the chronic emotional burden and structural obstacles embedded in the caregiving experience.

Secondary Research Question

RQ2. How do parents' lived caregiving experiences reflect the domains of the RTN framework, including exposure, appraisal, coping responses, and systemic context?

Exposure Themes: Persistent Crises and Hypervigilance

All 14 parents (P01–P14) described caregiving as being defined by relentless instability, emotional exhaustion, and the constant anticipation of crisis. Their lives revolved around uncertainty, which entailed never knowing whether a call from the hospital, police, or treatment facility might come. P03 stated, *"I never know if today will be stable or another hospital call,"* while P09 added, *"My life is consumed by waiting for the next call, and every time the phone rings, I freeze."*

Participants repeatedly characterized their daily existence as "living in limbo," a life organized around the constant threat of disaster. P02 explained, *"I have not taken a vacation or even had dinner with friends without fear that something will go wrong. There is no escaping it."* Many parents noted that caregiving had become the central organizing structure of their lives. P10 shared, *"I wake up every day wondering if this will be the day I lose him or if we will make it one more night."*

Twelve parents described hypervigilance as a permanent state of being—an internalized alert system that never switched off. P07 admitted, *"I sleep with my phone on my chest every night, just in case something happens."* P12 echoed, *"Even when he is doing well, I cannot relax. I am always bracing for the relapse."* For some, vigilance felt both protective and sacred. P11 noted, *"I stay ready because if I let my guard down, that is when something happens. Watching him is how I love him."*

The emotional cost of this vigilance was profound, resulting in disrupted sleep, anxiety, and physical exhaustion. Parents also experienced ambiguous loss—the simultaneous presence and absence of their child. P05 reflected, *"I thought by now he would have a career, maybe start a family. Instead, I am still trying to keep him alive."* P12 expressed a haunting paradox: *"It feels like my child is gone, even though he is sitting right in front of me."* Ten parents used similar language of mourning a "living loss," describing themselves as grieving a child who was physically present but psychologically changed. These overlapping experiences of fear, grief, and exhaustion captured the exposure dimension of caregiver trauma within the RTN framework.

Appraisal Themes: Role Strain, Constrained Influence, and Ambiguous Loss

Thirteen parents described how caregiving redefined their parental identity, transforming them from nurturers into coordinators of care. P02 explained, *"I do not feel like a dad anymore. I am managing a case file."* Similarly, P08 elaborated, *"I never imagined parenting meant arguing with insurance companies and coordinating multiple providers. I spend more time on the phone with case managers than with my own son."* Parents lamented the loss of normalcy in family life, describing how they felt displaced by professionals and systems that now governed their child's well-being.

Ten participants discussed helplessness and the erosion of parental authority. P10 observed, *"No matter how hard I fight, I cannot control the outcome. It is like screaming into the wind."* P06 added, *"After the tenth time in rehab, you start to wonder if it will ever change."* P13 described the emotional wear: *"You start to lose yourself because you are always fixing someone else's mess. It is endless."*

Despite chronic disappointment, many parents held on to hope as an act of resistance. P11 reflected, *"You want to keep faith that your child can recover, but every relapse chips away at that hope until you are just trying to survive the day."* P01 added, *"Every time she comes home from treatment, even if it does not last, I see a glimpse of her true self. That gives me hope."* Parents described oscillating between hope and despair, often within the same day, revealing an emotional duality that reflected both trauma and resilience. As P09 summarized, *"You learn to live between faith and fear—they both sit at the same table."*

Sub-Question 1

SQ1. How do parents describe the ways they cope with stress, emotional numbing, and secondary traumatic stress within their caregiving role?

Coping Responses Themes: Emotional Numbing, Boundary Setting, and Advocacy

Eleven parents described emotional numbing as a necessary form of self-preservation developed through years of exposure to crisis. P04 explained, *“If I allowed myself to feel everything, I would break down completely. So, I turn it off.”* Similarly, P11 shared, *“I have learned to go cold; it is the only way I can survive the chaos.”* For many, emotional withdrawal was not seen as a loss of love but as a means of endurance. P06 stated, *“Shutting down does not mean I do not love him. It means I need to protect myself so I can still be here tomorrow.”* P10 summarized this paradox succinctly: *“You have to care enough to fight but not so much that it kills you.”*

Several participants linked their capacity for emotional regulation to faith and spiritual grounding. P03 described prayer as a daily act of emotional release, noting, *“When I feel myself going numb, I pray. It is how I hand over what I cannot carry.”* P12 said that trusting in God provided relief from guilt, explaining, *“I remind myself that I am not the only one responsible for his healing. God is part of that, too.”* Others reflected that spirituality offered permission to rest emotionally without abandoning care. As P07 expressed, *“Faith lets me step back and trust that he is in God’s hands when I cannot fix it.”* Across interviews, spirituality was often reframed as a means to transcend emotional numbing, instead of avoidance, which was described as a way to survive suffering without severing one’s connection.

Nine parents described boundary renegotiation as a painful yet vital act of self-preservation. P08 recalled, *“I had to tell him he could not live here if he were using...it broke my heart, but I knew I could not keep enabling it.”* P13 expressed the guilt inherent in such decisions: *“Every time I set a boundary, it feels like betrayal, but I know it is survival.”* For P02, this process brought profound relief: *“Drawing the line saved both of us. I could finally breathe again.”* Others connected boundary setting to their faith traditions, interpreting it as an act of stewardship. P09 explained, *“I asked God to give me the strength to say no with love.”* P05 shared, *“My pastor reminded me that boundaries are not punishment; they are protection. That changed everything.”* In this sense, boundary setting became not only a coping tool but also a spiritual practice that redefined compassion as accountability and care as balance.

Advocacy emerged as both a coping response and a moral calling rooted in personal values and, for some, religious conviction. Eight participants similarly described being their child’s “fighter” in systems that repeatedly failed to meet basic needs. P13 described, *“I became the one calling insurance every day, chasing down doctors, begging for appointments. It felt like I was the only one keeping the system accountable.”* For P09, advocacy became intertwined with purpose: *“Not giving up on him became my strength. Fighting for him gave me a reason to keep going.”* P14 described advocacy as identity restoration: *“Advocacy gave me purpose when everything else felt lost.”* P01 reflected that perseverance was spiritually anchored: *“Sometimes fighting for him is the only way I can live out my faith. It reminds me that I am still his mother and still have work to do.”*

For many parents, advocacy also intersected with communal faith and cultural support. Several participants from Latino and African American backgrounds mentioned that prayer groups, church elders, and culturally rooted spiritual communities provided both comfort and strength. P11 said, *“When my church prayed with me, it felt like they carried some of the weight.”* P02 added, *“Faith is not just belief; it is our community showing up when systems do not.”* Across experiences, advocacy transcended bureaucratic persistence and became a moral and spiritual form of resistance against despair. Collectively, these narratives revealed how parents redefined coping as both psychological adaptation and spiritual resilience, transforming suffering into purposeful action.

Sub-Question 2

SQ2. How do parents experience and interpret systemic factors such as fragmented care, stigma, and service transitions while caring for their adult child?

Systemic Context Themes: Fragmented Care, Exclusion, and Stigma

Seven parents described the behavioral health system as disjointed and not coordinated. P01 lamented, *“Every agency passes us along like no one owns the problem.”* P06 echoed, *“We restart from zero with every new provider.”* P11 added, *“I am the coordinator because the system will not be.”* Parents explained that fragmented communication between mental health, substance use, and medical systems left them acting as unpaid case managers, leading to burnout and distrust. P08 summarized, *“It feels like I am doing their jobs just to keep him alive.”*

Eight participants described exclusion from care once their children reached adulthood, citing confidentiality laws and payer transitions. P14 said, *“When my son turned 18, they stopped including me in treatment meetings. I felt like I was erased, even though I was the one keeping him alive.”* P07 added, *“Confidentiality laws made me invisible overnight.”* P12 emphasized how this shift complicated care coordination: *“Once she became an adult, everything got harder to navigate...Suddenly, I was a stranger in her treatment.”* P03 connected exclusion with emotional harm: *“They call it independence, but it feels like abandonment for both of us.”*

Six participants discussed the pervasive impact of stigma and social isolation. P09 shared, *“We stopped talking to neighbors because of the judgment.”* P03 said, *“Even my family blames me for his addiction.”* P05 added, *“People think I caused it, so it is easier to stay silent.”* Stigma not only silenced parents but also limited help-seeking behaviors. P10 explained, *“You learn to hide your pain because people do not understand it.”* However, several participants found solace in peer support and faith-based networks. P02 noted, *“I found a church group that did not judge, and that saved me.”*

Ultimately, parents agreed that systemic failures compounded the trauma of caregiving as much as their child’s illness. P06 concluded, *“The system breaks you down as much as the illness does.”* However, several participants reframed adversity as a source of resilience. P02 reflected, *“The system forces you to fight harder, and while it wears you out, it also teaches you how strong you can be.”* P13 echoed, *“You become an expert because you have no choice.”* These findings underscored that systemic fragmentation, exclusion, and stigma simultaneously deepened parents’ suffering and activated their capacity for advocacy and endurance.

Synthesis

The findings of this study showed that caregiver trauma develops through interconnected processes that reflect the four domains of the RTN framework. Repeated crises shaped parents’ appraisals of role strain and limited influence, which then informed coping responses such as emotional withdrawal, boundary setting, and advocacy, all of which were further intensified by systemic barriers, stigma, and fragmented care. Caregiver narratives revealed that trauma responses and resilience strategies were intertwined in ways that produced both survival and strain. The RTN framework provided a valuable structure for understanding caregiver experiences as a relational and systemic process, acknowledging the need for family-centered and trauma-informed interventions that address the experiences of caregivers alongside the clinical needs of young adults with co-occurring disorders.

Discussion

This phenomenological study explored how parents of young adults, aged 18 to 30 years, with co-occurring disorders experienced caregiving through the lens of the RTN framework. The findings revealed that caregiver trauma was not confined to isolated events but unfolded as a continual process of exposure, appraisal, coping, and systemic navigation. Across the four RTN domains, parents described caregiving as a cycle of emotional endurance marked by persistent crises, constrained influence, ambiguous loss, and fragmented support systems. These findings strengthened the understanding of how trauma and resilience evolve in families who care for young adults navigating complex behavioral health conditions.

Parents frequently referred to their lives as existing in “constant crisis mode,” an existence governed by unpredictability, vigilance, and emotional fatigue. Their narratives reflected a form of chronic trauma exposure consistent with contemporary literature that conceptualizes caregiver distress as cumulative and not episodic (Phillips et al., 2022). This pattern resembled the continuous threat perception described in trauma theory, where the absence of safety leads to physiological arousal and emotional exhaustion (Figley, 1995). However, parents in this study framed their vigilance as an act of love and cultural responsibility, particularly among participants from collectivist and faith-based backgrounds. Within some families, constant watchfulness was seen as part of the moral duty to preserve family unity and protect life. A theme echoed in research on caregiving in Latino and African American communities. Caregiving was often viewed as an extension of familial identity and moral obligation (Mehdipanah et al., 2025).

Ambiguous loss emerged as a defining emotional experience. Parents grieved the child they once knew while continuing to care for the adult their child had become, which was a process of mourning without closure (Boss, 1999). This loss was intensified by the developmental transition to adulthood, when confidentiality laws and service discontinuities limited parental access. Many participants described feeling dismissed or invisible once their child turned 18, which primarily emphasized ambiguous loss among parents of minors (Spencer et al., 2021). The present findings reveal that the adult transition adds a new layer of grief, as parents are legally sidelined despite their continued caregiving role. For families from collectivist cultures, this exclusion was particularly distressing because it conflicted with cultural values of interdependence and multigenerational caregiving (Yeh et al., 2003).

The redefinition of the parental role was another salient process. Parents reported shifting from nurturers to case managers, navigating bureaucratic systems, and managing crises, which mirrored earlier caregiver-burden models that identify emotional depletion, role strain, and identity dissonance (Applebaum & Sannes, 2025). Within the RTN framework, this shift revealed how constrained influence emerges not only from emotional exhaustion but also from systemic disempowerment. Parents repeatedly expressed that professionals dismissed their expertise about their own child, a finding consistent with recent studies documenting family exclusion in behavioral health systems (Carbonell et al., 2020). For participants from marginalized racial or socioeconomic groups, this exclusion intersected with experiences of bias and stigma, compounding their sense of invisibility. This intersectional perspective reinforces the need to view caregiver trauma as a culturally and structurally mediated process (Yeh et al., 2003).

Coping strategies represented endurance and adaptation. Emotional numbing was frequently described as a deliberate act of self-preservation. Parents acknowledged that detachment sometimes weakened their emotional connection but emphasized that it enabled them to function effectively. This interpretation aligns with research suggesting that selective disengagement can be adaptive under prolonged stress (Applebaum & Sannes, 2025). Advocacy became a culturally mediated expression of resilience, resonating with collectivist notions of family obligation and spiritual perseverance. This combination of withdrawal and engagement reflects the negotiation at the heart of the RTN framework, which involves a dynamic balance between survival and agency.

Systemic conditions were described as amplifiers of trauma. Participants detailed fragmented services, high staff turnover, and gaps in care during transitions to adult systems. These accounts parallel research identifying the lack of coordination between mental health and substance use systems as a key driver of caregiver stress (Mardani et al., 2023; Spencer et al., 2021). Parents from underrepresented racial and rural backgrounds emphasized additional barriers, such as limited access to culturally competent care, language obstacles, and transportation challenges. These findings correspond with work by Yeh et al. (2003), who documented that minority caregivers often face compounded systemic inequities that intensify distress. Stigma was also pervasive, manifesting as judgment from professionals and ostracism within faith or community circles. Several parents reported concealing their child's diagnosis to avoid shame, consistent with literature on stigma by association (Goldberg et al., 2023).

What distinguished this study from previous research was the degree to which parents conceptualized advocacy as both resistance and reparation. Many described advocacy as “the only way to survive the system,” reframing the act of fighting bureaucracy as a form of love and identity preservation. Advocacy became a culturally mediated expression of resilience, resonating with collectivist notions of family obligation and spiritual perseverance (Barutcu, 2025; Friedberg & Malefakis, 2018). Parents' descriptions of “keeping my child alive through paperwork” reflected the moral weight attached to advocacy as a burden and an empowerment.

The RTN framework proved valuable for organizing these experiences. The four domains provided a scaffold for understanding how caregiver experiences and trauma evolve within relational, emotional, and institutional spaces. The findings extend existing caregiver models by explicitly integrating secondary traumatic stress and ambiguous loss as cyclical, interdependent processes (Figley, 1995). The dual presence of emotional withdrawal and active advocacy reflects that resilience is not a fixed attribute but an evolving process shaped by context and culture. From a multicultural lens, this dynamic process aligns with culturally responsive models of resilience, which promote relational harmony, spirituality, and collective adaptation.

Limitations

Several limitations should be considered when reviewing these findings. The small sample size limits the breadth of perspectives represented, which makes it difficult to draw conclusions that extend across varied caregiver experiences and contexts (Vasileiou et al., 2018). The reliance on self-reported interviews may introduce recall bias and social desirability bias, as participants may frame their responses in more acceptable or favorable ways (Krumpal, 2013). Because this study captured only parental perspectives and omitted the perspectives of the young adults themselves, it limits the understanding of relational trauma experiences across family systems. Finally, conducting interviews virtually may influence rapport, disclosure, and participant privacy (Archibald et al., 2019).

Implications for Theory and Practice

Theoretically, this study expands the understanding of caregiver experiences within systemic and cultural contexts. The RTN framework provides an integrated approach for examining how trauma is navigated through exposure, meaning making, coping processes, and interactions with social systems. Future research should refine and empirically evaluate this framework across culturally diverse populations, utilizing longitudinal methods to track the development and change of trauma and resilience over time.

Clinically, practitioners should incorporate caregiver trauma screening into standard assessments, considering areas such as ambiguous loss, emotional numbing, and secondary traumatic stress, which are often neglected in traditional service delivery. Trauma-informed interventions should include structured opportunities for parents to explore chronic grief, validate protective coping strategies, and strengthen

advocacy skills. Peer support programs can reduce isolation and foster resilience by connecting parents with others who share similar caregiving experiences.

From a policy perspective, the findings reveal an urgent need to ensure continuity of care during the transition to adulthood. Policymakers should strike a balance between confidentiality and payer regulations that upholds young adults' autonomy while maintaining appropriate family involvement, especially when parents remain the primary caregivers (Phillips et al., 2022). Greater integration among mental health, substance use, and justice systems is necessary to reduce the service fragmentation identified by participants. In addition, anti-stigma initiatives should intentionally include caregiver perspectives to counteract the silence, shame, and invisibility many parents experience (Kalhovde & Kitzmüller, 2024). Future research should examine how systemic supports, policy changes, and community-based resources shape caregiver well-being and sustain coping strategies across the long-term demands of caregiving for adult children with co-occurring disorders.

Conclusion

This study explored the experiences of parents of young adults with co-occurring disorders, revealing lives marked by uncertainty, endurance, and unwavering care. Through the RTN framework, parents described balancing hope for recovery with the constant fear of relapse while navigating exhaustion and emotional strain. Many turned to faith, prayer, and cultural traditions for strength, finding comfort in community connections and a belief that their efforts carried meaning beyond the struggle itself. Their accounts reflected a love that persisted through pain and uncertainty, showing that resilience often grows through quiet acts of patience, courage, and care. These findings can help parents recognize that their pain and persistence are shared by others, reducing feelings of isolation and guilt. For professionals, this understanding fosters more compassionate, family-centered approaches that acknowledge the emotional and cultural complexities of caregiving while offering meaningful support to parents and their adult children.

References

- Applebaum, A. J., & Sannes, T. S. (2025). The importance of honoring family caregiver burden: Challenges in mental health care delivery. *Journal of Clinical Psychology in Medical Settings*, 32(2), 193–201. <https://doi.org/10.1007/s10880-024-10051-3>
- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, 18, 1–8. <https://doi.org/10.1177/1609406919874596>
- Arnett, J. J. (2015). *Emerging adulthood: The winding road from the late teens through the twenties* (2nd ed.). Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199795574.013.9>
- Barutcu, C. D. (2025). Secondary traumatic stress and coping strategies in family caregivers. *Psychology, Health & Medicine*, 30(7), 1437–1449. <https://doi.org/10.1080/13548506.2025.2479259>
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Harvard University Press.
- Carbonell, Á., Navarro-Pérez, J.-J., & Mestre, M.-V. (2020). Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review. *Health and Social Care in the Community*, 28, 1366–1379. <https://doi.org/10.1111/hsc.12968>
- Carmassi, C., Dell’Oste, V., Foghi, C., Bertelloni, C. A., Conti, E., Calderoni, S., Battini, R., & Dell’Osso, L. (2021). Post-traumatic stress reactions in caregivers of children and adolescents/young adults with severe diseases: A systematic review of risk and protective factors. *International Journal of Environmental Research and Public Health*, 18(1), 189. <https://doi.org/10.3390/ijerph18010189>
- Figley, C. R. (Ed.). (1995). *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*. Brunner/Mazel.
- Forkey, H. C., Schulte, E., & Thorndyke, L. (2023). Caring for caregivers experiencing secondary trauma: A call to action. *Clinical Pediatrics*, 62(6), 525–528. <https://doi.org/10.1177/00099228221140677>
- Friedberg, A., & Malefakis, D. (2018). Resilience, trauma, and coping. *Psychodynamic Psychiatry*, 46(1), 81–113. <https://doi.org/10.1521/pdps.2018.46.1.81>
- Goldberg, J. O., McKeag, S. A., Rose, A. L., Lumsden-Ruegg, H., & Flett, G. L. (2023). Too close for comfort: Stigma by association in family members who live with relatives with mental illness. *International Journal of Environmental Research and Public Health*, 20(6), 5209. <https://doi.org/10.3390/ijerph20065209>
- Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology*, 43(5), 488–502. <https://doi.org/10.1093/jpepsy/jsx142>
- Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLOS One*, 15(5), e0232076. <https://doi.org/10.1371/journal.pone.0232076>
- Kalhovde, A. M., & Kitzmüller, G. (2024). Family caregivers’ trajectories of distress while caring for a person with serious mental illness. *Qualitative Health Research*, 34(1–2), 154–165. <https://doi.org/10.1177/10497323231203627>
- Kilmer, G., Omura, J. D., Bouldin, E. D., Walker, J., Spears, K., Gore, J., Ali, A. R., & McGuire, L. C. (2024). Changes in health indicators among caregivers — United States, 2015–2016 to 2021–2022. *Morbidity and Mortality Weekly Report*, 73(34), 740–746. <https://doi.org/10.15585/mmwr.mm7334a2>
- Krumpal, I. (2013). Determinants of social desirability bias in sensitive surveys: A literature review. *Quality & Quantity*, 47(4), 2025–2047. <https://doi.org/10.1007/s11135-011-9640-9>

- Lawrence, P. J., Parkinson, M., Jasper, B., Creswell, C., & Halligan, S. L. (2021). Supporting the parents of children and young people with anxiety and depressive disorders is an opportunity not to be missed: A scoping review. *The Lancet Psychiatry*, *8*(10), 909–918. [https://doi.org/10.1016/S2215-0366\(20\)30315-1](https://doi.org/10.1016/S2215-0366(20)30315-1)
- Leavey, G., Loewenthal, K., & King, M. (2007). Challenges to sanctuary: The clergy as a resource for mental health care in the community. *Social Science & Medicine*, *65*(3), 548–559. <https://doi.org/10.1016/j.socscimed.2007.03.050>
- Lim, J. M., Barlas, J., & Kaur, D. (2022). Protocol for scoping review study to map out the existing research in relation to post-traumatic stress symptoms among caregivers of individuals with neurodevelopmental, psychiatric and neurocognitive disorders. *BMJ Open*, *12*(11), e058118. <https://doi.org/10.1136/bmjopen-2021-058118>
- Mardani, M., Alipour, F., Rafiey, H., Fallahi-Khoshknab, M., & Arshi, M. (2023). Challenges in addiction-affected families: A systematic review of qualitative studies. *BMC Psychiatry*, *23*(1), Article 439. <https://doi.org/10.1186/s12888-023-04927-1>
- McCleary, J., & Figley, C. (2017). Resilience and trauma: Expanding definitions, uses, and contexts. *Traumatology*, *23*(1), 1–3. <https://doi.org/10.1037/trm0000103>
- Mehdipanah, R., Briceño, E. M., Malvitz, M., Chang, W., Lewandowski-Romps, L., Heeringa, S. G., Levine, D. A., Zahuranec, D. B., Langa, K. M., Gonzales, X. F., Garcia, N., & Morgenstern, L. B. (2025). Exploring pathways to caregiver health: The roles of caregiver burden, familism, and ethnicity. *Journal of Aging and Health*, *37*(3–4), 148–155. <https://doi.org/10.1177/08982643241235970>
- Moustakas, C. (1994). *Phenomenological research methods*. Sage.
- Muralidharan, A., Lucksted, A., Medoff, D., Fang, L. J., & Dixon, L. (2016). Stigma: A unique source of distress for family members of individuals with mental illness. *The Journal of Behavioral Health Services & Research*, *43*(3), 484–493. <https://doi.org/10.1007/s11414-014-9437-4>
- National Alliance for Caregiving. (2021). *Caregiving in the United States 2020*. AARP. <https://doi.org/10.26419/ppi.00103.001>
- Phillips, R., Durkin, M., Engward, H., Cable, G., & Iancu, M. (2022). The impact of caring for family members with mental illnesses on the caregiver: A scoping review. *Health Promotion International*, *38*(3), daac049. <https://doi.org/10.1093/heapro/daac049>
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, *55*(2), 309–319. <https://doi.org/10.1093/geront/gnu177>
- Substance Abuse and Mental Health Services Administration. (2022). *Key substance use and mental health indicators in the United States: Results from the 2021 National Survey on Drug Use and Health* (HHS Publication No. PEP22-07-01-005, NSDUH Series H-57). U.S. Department of Health and Human Services. <https://www.samhsa.gov/data>
- Spencer, A. E., Valentine, S. E., Sikov, J., Yule, A. M., Hsu, H., Hallett, E., Xuan, Z., Silverstein, M., & Fortuna, L. (2021). Principles of care for young adults with co-occurring psychiatric and substance use disorders. *Pediatrics*, *147*(Suppl. 2), 229–239. <https://doi.org/10.1542/peds.2020-023523F>
- Tyo, M. B., & McCurry, M. K. (2023). Model of family caregiver resilience and burden in opioid use disorder: A theoretical framework. *Advances in Nursing Science*, *46*(2), 147–157. <https://doi.org/10.1097/ANS.000000000000448>

- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*, Article 148. <https://doi.org/10.1186/s12874-018-0594-7>
- Wilburn, V. G., Stoll, H. B., Rohr, A. C., & Moring, K. (2022). The ambiguity of parenting adult children with substance use disorder. *Canadian Journal of Occupational Therapy*, *89*(2), 127–134. <https://doi.org/10.1177/00084174211073260>
- Yeh, C. J., Arora, A. K., Inose, M., Okubo, Y., Li, R. H., & Greene, P. (2003). The cultural adjustment and mental health of Japanese immigrant youth. *Adolescence*, *38*(151), 481–500.
- Yin, R. K. (2018). *Case study research and applications: Design and methods* (6th ed.). Sage.

Appendix A: Interview Guide

1. Caregiving Over Time and First Recognition

- Can you walk me through your caregiving role over time, beginning with when you first noticed your child's substance use and mental health challenges interfering with their daily life?
 1. What stood out to you at that time?
 2. How did your involvement shift once these difficulties became more visible?
 3. What does a "typical" week look like?

2. Exposure to Crises and Acute Events

- Thinking about the past 6 months, how have ongoing crises or uncertainties affected your emotions day to day?
 1. Times you felt "shut down," "flat," or less responsive?
 2. What seemed to trigger or relieve that?
 3. How did it affect your connection with your child or others?
- In the past 6 months, has your child experienced any acute events related to substance use or mental health (such as an overdose, psychiatric decompensation, emergency department visit, or hospitalization)?
 1. How did you first become aware of the event?
 2. What immediate steps did you take?
 3. How did this event affect you emotionally, physically, and relationally in the short term?
- After such an event, what was the process of recovery or stabilization like for your family?
 1. Were you involved in crisis planning, discharge, or follow-up care?
 2. How did this shape your sense of safety and preparedness?

3. Trauma-Like Responses

- Some parents describe trauma-like reactions to repeated crises (e.g., intrusive memories, trouble sleeping, feeling on edge). Have you noticed anything like that?
 1. What does it look like for you (if at all)?
 2. What helps when it shows up?
 3. Has it changed over time?

4. Ambiguous Loss

- Many parents talk about a sense of "losing" parts of their child while they are still physically present. Does that idea resonate with you?
 1. Moments that capture this experience?
 2. Any practices that help you make meaning of this?

5. Safety and Vigilance

- How do you manage safety and uncertainty in everyday life?
 1. Monitoring or check-in routines?
 2. Thresholds for taking action (e.g., calling, visiting, emergency care)?
 3. How do you strike a balance between vigilance and your own rest?
- Can you describe any ongoing strategies you use to prevent or respond to acute incidents (such as crisis planning, overdose prevention, or safety check-ins)?
 1. What routines or precautions do you follow?
 2. Have these strategies changed in response to recent crises?

6. Stigma

- Have you encountered stigma or blame related to your child's substance use or mental health among family, friends, or professionals?
 1. How did those encounters affect what you share or seek?
 2. Any self-silencing or withdrawal?
 3. What was helpful or harmful in those moments?

7. Services and Systems

- Tell me about your experiences with services (addiction, mental health, emergency, insurance). What has helped and what has gotten in the way?
 1. Effects of confidentiality, age-related policies, or payer transitions?
 2. Coordination across providers?
- Thinking about the most recent acute incident, how did health care or emergency services respond?
 1. What helped in that moment?
 2. What barriers or frustrations did you encounter?
 3. How did confidentiality or age-related policies affect your involvement?

8. Supports and Needs

- Looking back on the last 6 months, what support would have made your caregiving easier or safer?
 1. What skills, information, or resources do you wish you had?
 2. Peer support or respite needs?
 3. How could services include you while respecting your adult child's autonomy?
 4. What is one message you would like clinicians or policymakers to hear?



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