

“I can’t live like that”: Reflections of caregiver distress from caring for an individual with problematic substance use

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Abstract

Background: The impact of addiction extends beyond the individual using a substance. Caring for an individual with addiction creates persistent stressful circumstances that cause worry, anger, depression, shame, guilt, anxiety, and behavioral problems within the family unit.

The aim of the study: The paper aims to explore the psychological impact when caring for individuals with active addictions and self-care strategies caregivers employ.

Methods: The study adopted an exploratory qualitative design and used purposeful sampling to recruit study participants through posters, word-of-mouth, and e-mail. Study participants were required to have a family member living with addiction and not be active substance users themselves. In-depth individual interviews were conducted among 21 participants to gather their experiences, meanings, and interpretation of how it feels to provide care for a family member suffering from addiction and substance use.

Results: Three themes, whose overarching focus is the pains that living and caring for a family with addiction caused the participants, are discussed. These included 1) caring experiences, 2) factors shaping caring experiences, and 3) self-care strategies.

Conclusion: The stress associated with caring for individuals with addictions impacts the caregiver's physical and mental health. Specific care modalities targeting caregivers need to be developed to address the health impact and to support self-care.

Introduction

Addiction to substances arises from a long-term and repeated misuse of high doses of substances that impede an individual's health and quality of life [1]. The impact of addiction extends beyond the individual using a substance to include family and community members [2]. Addiction impacts a family's everyday life, health, social relations, family relationships, roles, rituals, routines, and careers, as well as finances [3, 4]. As a result of addiction, people under the influence of substance use often shift their commitment to the substance and away from family and other obligations. The impact of problematic substance use and addiction can lead to marital disintegration, violence, and conflict, child neglect, and legal issues [5, 6].

Caring for an individual with addiction creates persistent stressful circumstances which can cause worry, anger, depression, shame, guilt, anxiety, and behavioral problems within the family [5, 7]. The stress associated with caring for a family member with an addiction can cause psychiatric disorders such as anxiety and depression, interpersonal problems, children's behavioral problems, and low self-esteem [8, 9].

In Canada, it is estimated that 660,000 children under the age of 18 live in households with at least one alcoholic parent. Although many children of parents with an addiction do not experience neglect or abuse,

they are at an increased risk for child maltreatment and different forms of abuse, which can contribute to psychological damage, and make them more vulnerable to their own substance misuse and addiction [1, 10, 11]. Children who are exposed to addictions are also predisposed to developing psychiatric issues such as anxiety or depression, and behavioral and cognitive difficulties that can affect their learning abilities [12].

The stress and crisis associated with caring for an individual with addiction can impede the family's functionality [13]. Chronic stress can cause an individual to adopt maladaptive behaviors and can also offset the natural balance of the body and have harmful physical effects [14, 15].

Self-care practices for families affected by addiction may include attending a personal counseling session, immersion in the individual's care and recovery, self-directed education on addiction, involvement in family treatment, and finding support [6]. Having social support is essential during stressful experiences, as positive support can reduce stress and its side effects while increasing resilience [16].

This manuscript is a result of a larger study set in a midsized city in a prairie province, where rampant substance use and addiction profoundly impact the community, including early exposure to children and youth [17, 18]. With the growing substance use crisis in the community, the need to understand how it affects families was expressed during a community engagement and knowledge exchange event where participants identified the lack of support for families affected by addiction as a significant gap in care [18]. The paper aims to explore the psychological impact of caring for an individual with addiction and how these families engage in self-care.

Methods

The study adopted an exploratory qualitative design to comprehend the experiences of families affected by addiction and imagine the resources needed to support them. We used purposeful sampling to recruit participants by placing posters in strategic locations such as the library and public notice boards, through word-of-mouth, and e-mail dissemination. Participants were required to have a family member living with addiction and themselves not to be active substance users. Preceding the commencement of the study, we obtained the participants' verbal and written consent and the University of Saskatchewan's Ethics Board approval.

Data was collected through in-depth structured interviews that were informed by a literature review. The interviews were conducted and performed by GM, a researcher with experience and expertise in qualitative research methods. The interviews focused on the participants' experiences of growing up, their experiences with substance use, their perceptions of the impact of addiction on them and their families, and the coping strategies they employed. Each interview lasted for an average of 28 minutes and was recorded with a digital voice recorder. Verbatim transcription ensued.

The research team included researchers, community members with lived experiences, and health care managers who came together to map the data exploration that led to the development of the preliminary

coding framework. We read and reflected individually and in groups on the concepts of interest and relational issues arising from two rich transcripts. The ideas were recorded and generated from this reflection on flip charts and grouped by similarity. In a subsequent meeting, four researchers read two different interviews and added to the list new issues that arose from the exploration phase. The items were then organized logically, designated as nodes, and formed into an analytical framework that structured the remainder of the interviews.

Two research assistants independently analyzed the interviews using NVIVO 12, a qualitative research data management software system. New nodes were created and added as the analysis progressed. The two project files were then merged, and the nodes were harmonized. Thereafter, three participants were invited to participate in a two-hour member checking exercise where the list of nodes and their meanings were presented. Any comments, questions, or concerns were addressed, and field notes emanating from these sessions were created. These field notes further clarified and enhanced the data analysis.

The research team finalized the data analysis by identifying and clustering nodes that had commonalities and designated them as themes. In this paper, we discuss the themes that accentuate the participants' psychological experiences of caring for individuals with addictions.

Results

Twenty-one individuals participated in the study who lived with addiction and or were exposed to environments where substances were used. These include four males and 17 females whose ages ranged from 27–72 years. Ethnically, six self-identified as Caucasian, 14 First Nation, and one Asian. The distribution of family members with addictions was as follows: three participants had sisters living with addiction, four had brothers, eight had parents, six had children, and one had grandchildren living with addiction. Overall, 13 of the participants grew up in homes where they were exposed to substances at an early age.

Three themes, whose overarching focus is on the psychological impact of caring for an individual with an addiction, are discussed: 1) caregiving experiences, 2) factors shaping caring experiences, and 3) self-care strategies.

Theme 1: Caregiving experiences

This theme focuses on families' diverse experiences of caring for an individual with an addiction. Caring for a person with addiction was described as a painful, agonizing, and dreadful endeavor. This feeling was precipitated by a sense of loss of a relationship and of hopelessness and helplessness at not being able to intervene in the life of the individual with the addiction. For others, it was characterized by the fear that the addiction would cause their loved one's death. This theme is constituted of three subthemes: 1) grieving the loss, 2) feeling of despair, and 3) living in perpetual crises.

Grieving the loss

The family member who suffers from the addiction is often unable to maintain the relationship dynamics needed to support sound and healthy co-existence with all members. For many participants, addiction robbed them of a relationship with the person using substances, which was akin to a loss of their relative. Even then, family members continued to expend their time, energy, and money into caring for the individual with the addiction to keep them safe or alive, with the hope that the lost relationship would be restored. After endless efforts did not yield the desired fruit, some participants signaled their loss of hope for recovery and actively grieved the loss of the relationship and the person:

I know it sounds cold, washed my hands of him because I have given so much to try and help him. So much of my life that there's nothing else I feel that I can do. I can't put more time and effort into helping him if he doesn't want to help himself. I've lost a brother because of drugs and substance use (38 years, sister).

The lack of agency by the person suffering addiction, as noted in the above quote, seems to further the loss of hope by caregivers. Grieving the loss of a relationship was sometimes accompanied by an intentional decision to sever the relationship with the family member with the addiction. Yet, the diminished connection did not permit the caregiver to move on with their life. Instead, it complicated the grief process:

It impacted me a lot, I've had a lot of grief, I had a lot of grief. I felt like I, I did lose my son [light sobbing], I lost the son I had, now there is this new man with this illness. (63 years, mother).

The severity of the loss relationship in this quote was significant since the person with the addiction is perceived as a different person and referred to as 'this new man.'

The degree to which participants elected to give up their previous relationship with the individual suffering from addiction, was to some extent, determined by their relationship closeness. Participants tended to have a loose association with adult siblings with addictions; this somehow eased their ability to admit the loss of personhood and relationship. Parents persisted in their hope of recovery, even when their child seemed to suffer from addiction.

Participants also grieved the consequences of living with an individual with an addiction. It was not uncommon for the participants to report a material loss when they allowed the individual with the addiction to cohabit with them. The company the individual kept also worried some participants. Living in such an environment took away the joy of home and, although participants were not living on the street, they felt unease due to the regular conflict and apprehension. Subsequently, they felt as though they had lost control of their dwelling and as a result, found comfort at workplaces or in public spaces:

So, there was always stuff going missing from my house. Finally, I said, "I'm not buying stuff anymore, I'm not buying any more electronics, I'm not buying nothing because everybody's stealing it anyways." It's just so frustrating. It just puts so much stress on me that, it's almost like I view coming to work as a getaway, it's, I'm always trying to get away from my house because they've almost taken it over you know

and it's just so stressful. Like, I can't even tell you how stressful it has been. Like living you know, two meth-addicted adult children, and I don't know where else to get help, like I'm at the end of my rope. And you know, I'm depressed because of it, I'm stressed out because of it, its affected my job, where literally I stay up, you know, 'til like three, four o'clock in the morning sometimes, you know, checking the garage, and having to kick people out, like constantly (54 years, father).

A sense of lack of security at home is assumed in the narrative and further evokes a feeling of community insecurity. Other family members moved out of their shared home to live in shelters or on the street because they felt their lives were threatened.

Participants who had parents with addictions also were forced to grieve the loss of their innocence when they were children. Due to the insecurity and neglect these children faced while growing up; they were placed in foster homes, where some of them were likely subjected to violence. One participant's grandchildren were placed in foster care because of her adult child's addiction. Not being able to intervene when the children were taken away to foster homes was a traumatic experience for her:

The children were taken away middle of the night by mobile crisis was scary even though they were being taken away due to domestic violence. They were taking care of each other, but now they got separated. I could see the fear on their face, and there is only so much comfort we can give the, for legal, to touch or to hug them (45 years, stepdaughter).

In the above narrative, the participant was not only grieving the loss of these children to foster homes, but also the bond and caring relationship between the children, and the fear of them being separated from each other. Most participants experienced a loss of relationship, and many, as children, suffered homelessness as a result of living with or caring for someone with an addiction. Despair was caused by the participants' lack of hope for recovery, for the person suffering from addiction, or to change their addictive behaviors.

Living in dread and despair

Many participants lived with the daily fear that their loved ones would die from overdoses or chronic substance use. While most accepted that their loved one's death from addiction-related causes was inevitable, they never felt fully prepared. One participant described the despair a father felt about his daughter's addiction:

Because of her [daughter], he laments, "every morning I wake up and I'm scared to get out of bed because I don't want to find my daughter dead." He'll go into her bedroom in the mornings and stand at the foot of her bed and watch to see if he can see her breathing. Like every morning when he gets up, he goes to check to see if his daughter's still alive or if she is dead, that's how bad she is. (44 years, sister)

The daily routine of checking on her and wondering whether she was alive or dead, as narrated above, seemed devastating enough to the participant. The fear that the addiction would cause their family member's death was compounded by the sense of helplessness in their endeavor to intervene and halt

the downward spiraling trend. The sorrow was even more poignant when family members became addicted at a young age as it was presumed that the addiction was robbing them of a productive life, noted below.

You almost must [be prepared for that eventuality], and that's sad. He's 34 years old and he's got a child. He's got so much to live for, but he probably can't see it, I guess. It really hurts, now, knowing Mom is gone. Myself being a parent, I can't imagine what that would feel like being your child. It hurts so bad being a sibling, just imagine it being your child (38 years, sister).

One participant feared that her brother's addiction to alcohol put the public at risk because he often drove under the influence of alcohol. While she was resigned to losing him, her inability to restrain him from driving under the influence tormented her:

Like I said he can kill himself, I'm okay with that. I can resign myself to that, I don't want him to kill anybody else and that's my concern is how we keep him from harming others, and I didn't want him harming his wife. And the fact that he had a loaded gun made me wonder if he was thinking about self-harm and I'm sure he is. I'm sure he's very depressed and thinks about self-harm often (56, years, sister).

In the above quote, the participant was not only worried about the person with an addiction, as he could harm himself or his wife, but also the risk he poses to others and the community at large.

Participants were wearied by the constant fear, worry, and dread that accompanied caring for an individual with an addiction. It was evident that most of them had reached the end of their tether, and without successful mechanisms for self-help, the participants often felt alone, and on the verge of breaking:

I was thinking to myself, "I can't live like that." And I can't help her, she doesn't want my help even though I work in the field of addiction and mental health. I've tried helping her but she doesn't want my help and I know I can't help her. I worry. I'm worried is she's alive, and I'm worried she has enough to eat, I worry where she's sleeping. It was like years and years and then I told myself, "I can't be doing that to myself 'cause I'm gonna get sick." I said, "I need to help myself." (62 years, mother).

It becomes apparent from the above narrative that the need for both self-care and caring for persons with addiction that many participants experienced conspire to weigh down many family caregivers. Despair drove family members to attempt interventions to save their loved ones from their addictions. The enormous financial investment in addiction treatment did not guarantee remission or recovery. Others put themselves in harm's way in desperate attempts to help their loved ones who were experiencing homelessness because of their addictions:

But me and my dad we went down there to go and talk to somebody about addictions because we were going crazy, we didn't know what to do. I just cried all the time because I didn't know what to do and I would drive around all night looking for him to make sure he was alive. At the addictions counseling, she

said, "you need to give him tough love," and they spent five minutes with us and that was all we got. And me and my dad we kind of thought well what is going on (22 years, sister).

Many participants felt that the actions and energy their families expended were ineffective because their family members continued to use, leaving them grasping for hope. Due to the chronicity of addictions, many lived in a perpetual crisis.

Living in perpetual crisis

Caregivers experienced a state of perpetual crisis caused by a chronic lack of necessities of life, abuse, neglect, and overwhelming demand for care. Addiction was intergenerational among families in environments where substances were present. Intergeneration substance use was a complex social issue to manage by those that did not use substances:

This intergenerational addictions and dysfunction it's like a train you can't stop it, you try, everything, like I put my kids through, we went to family treatment, and they all went to individual treatment when they were teenagers so, it's like you just can't stop it (57 years, mother).

Addiction also provided opportunity for violence and a need to escape a toxic environment, which led to family dysfunction and disintegration. Children especially were at significant risk of being caught in the fallout, including family breakdown, parental neglect, and diverse forms of child abuse:

Dad was a substance user and when I was three years old my mom left him because of his substance use and physical abuse. She then met a man who was a substance user and a drug addict who abused me in just about every way possible from the time I was three until the time I was about ten (45 years step-daughter).

The impact of addiction on fueling family crises was an extensive experience that almost every participant shared. In addition to child or spousal abuse, childhood exposure to substances, parents being both physically and emotionally absent, as well as divorce and marital separation, were noted.

Moreover, when more than one family member had an addiction, other members of the family were inadvertently neglected:

You will neglect the other part of your family because you're so consumed to what that child is doing. You're wondering, "Where are they? Are they safe? Are they sleeping? Are they eating? Are they alive?" Whatever it is. You're so consumed (57 years, mother).

Not giving up on the individual with the addiction meant that the care they provided became a full-time job. To the participants of the study, this meant taking responsibility for many aspects of their loved one's lives, including providing financial support, assuming the parental role to their grandchildren or grown children, providing necessities for living, and meeting health care expenses, such as treatment. In most instances, the long-term assumption of this role wore down the caregiver, impacting their own health in the process:

I have a chronic illness, I've been diagnosed with fibromyalgia back in 2008, so roughly for the past ten years, you know, I've had this, but it seems that stress brings on an attack almost, so if I get really stressed out I get angry and I'm yelling at my kids it's like the next day I'll be sick, like literally physically sick. And so yes, it's affected me physically, mentally, spiritually, emotionally. Every way, every way (48 years mother).

The perpetual need to care for individuals with addictions also affected participants' work-life balance. Understanding factors that shaped these experiences are vital to the development of self-care strategies.

Theme 2: Factors shaping family experiences

This theme focuses on factors that shaped families' experiences of caring for an individual with an addiction. These include a) inadequate knowledge of addiction and treatment resources and b) inadequate resources to support both the individual with the addiction and their family.

Inadequate knowledge of addiction and treatment resources

Participants expressed a lack of understanding of how addiction impacts families, which influences their appreciation for their need for self-care or identification of effective ways to provide support. This lack of understanding was most profound among participants who did not have prior lived experiences with substance use. Furthermore, their lack of knowledge about addiction and its trajectory to unrealistic expectations of the willingness of the individual with the addiction to enter treatment and recovery:

They [family members] don't understand the trigger points, they don't understand, when she's as bad as she is, it's not a choice that she's making; it's her survival cause she's so sick. They don't understand like even, even like when I say education, there needs to be something for people who can go and they can learn about what their loved one is going through, that it's not just a matter of "oh well I'm just going to wake up and I'm going to quit today" (44 years, sister).

In expressing the lack of knowledge about addiction as an illness and the recovery process, participants yearned for resources and education to support families. Such information would help them in early identification of substance use before addiction sets in:

It [information on signs of substance use by an individual] needs to be brought to someone's attention. The first resource needed is an early intervention or somehow, so that someone can catch the early signs [of substance use] you know. Not wait until it is so serious that the children are apprehended but that the earlier signs (63 years, mother).

Lack of knowledge about how addiction affects families was also found among healthcare professionals and community members. Some participants indicated that they did not find the support they needed when they sought care for the health and its impact of caring for an individual with an addiction. While some participants found that healthcare providers failed to recognize the symptoms of caregiving stress,

so they received suboptimal care. One participant described her observations of the effect of a man caring for his daughter with an addiction:

His doctor wants him to lose 10 pounds and cut out on carbs and sugar so that he is not tired all the time. Well he is so tired, his as no color, because he is mentally exhausted because of the environment you live in. It has nothing to do with having sugar in your coffee, but they don't know that, they don't, it's not. The system isn't, it's choppy, it's broken, the left-hand doesn't talk to the right and there's never a full picture (44, years sister).

The participant believes that the health care providers were unaware of the impact of addiction on families, and healthcare providers are not always informed. The lack of knowledge about addiction, including the early warning signs, treatment, recovery, and impact on both an individual and their family members, complicated the sense of helplessness and hopelessness that those affected by addiction felt. Helplessness also manifested as a tireless but futile endeavor to save the family member from being destroyed and ravaged by addiction. This vain undertaking occurred despite what many considered to be an unresponsive and unsupportive health care system that had no resources to help such families:

We tried phoning mental health groups, social services. I know she took my brother there too and there was nothing. The way my mom described it was, "there was just dead ends." You'd think that you were getting ahead and then you would open a door and that was it. It was a dead end. There was nothing else she could do (38, years, sister).

The apparent lack of understanding about the impact of addiction on families within the professional groups or the capacity within the healthcare system, captured in this quote as "dead ends," further complicate the fight of family members in caring for their relatives with addiction. Individuals with addictions whom caregivers deemed uncooperative, frustrated the caregivers. When family members entered treatment, caregivers had a glimmer of hope that recovery was possible and that the individual was doing their part. Relapse into the active phase of addiction, however, significantly strained the caregiver, some to the point of exasperation:

We're at a point where we don't know necessarily know how to approach it because she doesn't talk about anything, she gets defensive and she argues, then she takes off and goes out and uses (28 years, brother).

From the above quote, it appears that caregivers' helplessness, in part, was due to the silence, denial, and defensive attitudes that their relatives with addiction displayed. Most caregivers were not only confused about what to do but also seemed unaware of any resources to support them or enlighten them about addictions. Thus, they felt isolated and in the dark about their loved ones' options for recovery and, moreover, they displayed their lack of awareness of their need for treatment and recovery.

Inadequate resources to support both individuals with addictions and their families

Families yearned for resources that would help them make sense of their experiences and provide options for dealing with their heartache. Caregivers indicated that they could not find educational resources that would increase their knowledge about addiction, its impact, and treatment. The lack of available resources suggests that healthcare providers were not well informed about the impact of addiction on caregivers, how to support families or of resources available:

There's no education, there's nowhere for any of the families to turn, like, there's no, there is nothing, there's nothing. There's no support groups, there's no education, there's no clinics, there's no, people like my dad, there's no "let's look at the big picture, let's have some kind of a clinic and put everything together to treat you as an elderly man with all these conditions." That the direct link is my sister. None of that exists. There's a lot of work to be done (48 years, mother).

In addition to a lack of resources for self-care, most of the caregivers found that treatment options, like 30-day programs, were inadequate for those abusing substances. This limitation was one sign that comprehensive treatment for the individual with the addiction was not a realistic goal, as it also requires the full participation of the caregiver, including their care needs. Thus, the caregivers continued to feel chronic stress that came with supporting someone with addiction:

They all tell me the same thing, like, you need not 35 days of treatment. You need years, ongoing, like ongoing treatment, like and support like I mean, support not from 9 – 5 only, Monday to Friday, you know, is what addiction services, you know, they're not there on weekends, they're not there after 5 o'clock or whatever. They need people who are there all the time, 24/7, and ready to, you know, "what? you want to go to detox, let's go," like somebody's who's there who will care and will say "okay, you know you need help, let's go." (PA.003, mother of the persons of with addiction)

The participants also identified other gaps in care services. Given that most of the addiction services were decentralized, some caregivers felt that deciphering the services that were needed for their loved ones and navigating the system was a nightmare. They, therefore, wished for a system that would make care navigation seamless, especially at distressing times:

Having people trained like that and helping you link them to service and which path to take and then going from there. I know that a lot of times we don't wanna enable people, we don't wanna hold their hand and do it for them but sometimes I think you have to be that person to hold their hand and do it for them. But sometimes, I think you must be that person to hold their hand and take them through it. Because they won't go unless they have that person to hold their hand and take them through it. Because I guess I don't know rejection or how they've been treated in the health care system might've pushed them away. So, I think to have that person to talk for them and to advocate for them and show them this is what we need to do and kinda hold their hand and then till they get in there. I think that would be the way to go (35 years, sister).

The desire for services at the caregivers' doorstep was expressed in the narrative above to reduce the fear of rejection, stigma, and silence among both persons suffering from addiction and their family

caregivers. Silence, stigma, and shame often shaped caregivers' experiences. To help deal with addiction stigma, participants further expressed a need to interact with individuals and families with similar experiences and to find a safe space to offload the emotional burden that addiction in their family felt. Hearing positive stories of recovery and how family members have regained strength and hope may help them cope:

If there were groups, if there was places where people could talk to other family members and hear their experience, strength, and hope and they know what they've gone through. Like the isolation, I didn't say that, but the isolation of living with a partner with addiction, feeling shame and embarrassment, not wanting other people to know about it, trying to hide it, trying to cover up. You know all those pieces dissipated when I could sit and just be myself and be honest about what was really happening. So I think groups, I think places, I think counselors that specialize in the affects, how the family, family is eroded with addiction and how to recover, how to get their life back (50 years, Sister).

In the absence of formalized tailor-made resources by the health care system and support services for families affected by addiction, most participants used self-management strategies. Caregivers used Al-Anon, counseling services, and online resources to educate themselves on self-care strategies to mitigate the effects of addiction in the family.

Theme 3: Self-management strategies

Although some participants were not aware of the presence of self-help groups such as Alcoholics Anonymous (AA) or Al-Anon, those who did found them to be a supportive resource that helped them cope with caregiver fatigue. In these groups, they felt comfortable sharing their pain and concerns with others who truly understood what they were going through. For some, seeking counseling from a counselor without the lived experiences of being impacted by addiction was not deemed as valuable as attending AA meetings. Moreover, Al-Anon meetings were lauded because they were devoid of stigma and judgments about addiction, and members could relate to and learn from each other:

When I go there and I have the courage to start talking about what was happening in my house, all these other people in the room were doing this and nodding their heads like they knew. I was like, "how do you know what's going on?" Or when they would share before I even started talking and they would talk about what was going on, I was thinking, "were you looking in my kitchen window because you're talking, you're telling a story that I know." So, I immediately felt like they were my people; they weren't going to judge me, I felt safe, I could let it rip. I could cry, I could act crazy. I could yell I could call him names and they were okay with that because they had experienced that kind of pain. They knew my pain (50 years, Sister).

Given that many participants credited Al-Anon for supporting them, and a space to engage with shared experiences, it is imperative that families affected by addiction are provided the opportunity to learn about and locate Al-Anon groups. Such resources can help families cope with caregiver fatigue and foster an understanding of addiction as an illness. Hence, an understanding about treatment options and the recovery process can be forged.

Some participants used formalized counseling both as individuals and as a family. Counselors provided mental health support and were a source of knowledge on ways to cope with caregiver fatigue:

There was a time where I did go see professional help where I was seeing a psychologist for some of the stress. I keep in contact with him every so often; give him updates on how I'm doing. He gave me a lot of tools. He helped me a lot and gave me a lot of tools on how to deal with certain things (57 years mother).

Participants found that children benefited immensely from counseling sessions. Such benefits only accrued if the counselor was able to make a personal connection with the children and relate to them at their level. Then, they feel safe to discuss their experiences and concern. One participant described the experience of taking her grandchildren to counseling because their mother had an addiction:

When we went and met them, you would think that they knew her forever. They connected, they talked, they talk a lot about their mom, and everything they're dealing with. Other things, you know? She's been able to help them with things that I can't. For instance, the bullying and the biracial part with school. She really told it as it is. They really have that great connection. That's where we're off today at four. That part, they are being taken care of, mentally (57 years, mother).

Formal counseling was educative and helped both children and caregivers make sense of the complexities that addiction caused. Through counseling, the affected family were able to understand the need to focus on themselves, how to deal with guilt, and how to develop healthy boundaries:

And I'm, I'm a strong believer. I mean, I've used counseling over the years when I've had situations where I've just said, "I need an outside person to listen to this and give me some clarity because inside and talking to the wrong people is not helping," so I have sought counseling over the years, and it's always been a very positive thing for me. It always allows me to recognize my vulnerabilities and what's triggering my thoughts and how to channel them in a different direction (56 years, sister).

Seeking online information on addiction demonstrated the self-determination, ambition, and self-initiation. It helped caregivers not to be constrained by the resource limitations that formalized services had:

I have done lots of online 'cause I like to learn anyway, so I access a lot of information online. I've talked to a couple of places that are private rehabs and looked into resources from them where I've had some online counseling with them, so I've done some of it (56 years, sister).

Social media was also a resource for finding useful information on how to cope with caregiver fatigue. Participants noted Facebook as a repertoire where information about addiction and self-management strategies were shared by a network of people connected to it:

She [a friend] has a Facebook group on social media, so I thought, "I'll enter there," so I did. That's where I learned so much about what I'm going through, how I can help myself, what I need to do for self-care, all about the art of enabling, and what I was doing. (57 years, mother.)

Furthermore, a few participants, especially those who grew up in families that were affected by addiction, enrolled and completed an addiction counseling program partly to make sense of their own experiences and to support others in similar situations. They now use their formal and lived knowledge to relate with their clients.

I changed my whole life around and I have that experience. I can relate to others out there, so that's why I'm in this field today: to help others and to show others that there's a way out (57 years, mother).

Caregivers affected by addiction showed resilience in seeking self-care through seeking out and attending self-help groups, counselors, and online platforms. These support services helped them make sense of their experiences and lessen the pain caused by caring for an individual with an addiction.

Discussion

From this study, it was evident that family members were profoundly affected by caring for individuals with addictions. A significant impact of addiction was the loss of relationships with individuals with addiction and its effects on family stability and community life. The participants inability to have a meaningful relationship with their relatives who were suffering from addiction was grieved as a type of social death; some family members behaved as though the person with the addiction did not exist because of the person's inability to positively impact the family's social dimensions [19]. Socially dead individuals are deemed to have lost social identity, social connectedness, and bodily integration [19, 20]. In this study, addiction was described as adversity that stripped an individual of their personhood. Thus, addiction acquired both human and social agency, and acted as a social metaphor of a life-taker, as it causes social death in families.

Declaring that someone was socially dead was an ineffective coping mechanism that caregivers employed to communicate their irreconcilable inner turmoil and their sense of resignation at the destiny that awaited their loved ones as a result of unabated substance use [21, 22]. Rendering an individual socially dead made the grieving process possible and signaled acceptance, despite being painful and traumatic. Yet, social death's ambiguity could potentially overwhelm a caregiver's coping mechanism, which could impact their mental health [23, 24].

The caregiver's perceptions of their inability to mitigate the trajectory of addiction were expressed as helplessness and hopelessness, which appeared to be further exacerbated by their lack of knowledge of addiction. It conveyed exhaustion of the inner resources needed to mitigate distress and to engage in self-care. Although many caregivers retained the hope that recovery was possible, the painful cycle of relapse or reluctance of the individual with the addiction to enter treatment eventually stripped away any thread of hope [25], and the ensuing perception of the loss of control over the lives of people with problematic substance use, aggravated family suffering [26].

Addiction in a family can increase the family members vulnerability to maltreatment and instability, which can lead to violence, divorce, and the inability to provide for the dependents' needs [6]. Caregivers'

experiences of emotional burdens caused feelings of confusion, anger, frustration, anxiety, depression, abandonment, anxiety, fear, embarrassment, and guilt [6]. Stigma also creates barriers for individuals with addictions, their families, and health care providers and can diminish the ability to seek and provide resources and support [28].

Despite the obvious physical and mental health impact of addiction on a family, the findings from this research revealed that healthcare providers did not recognize the stress imposed by support needed to the family member. This research identified a need for specific resources to be developed for family members. Therefore, families may continue to live with unaddressed and unresolved health needs arising from the impact of caring for someone with an addiction. Supporting self-care for families affected by addiction requires a recognition of caregiver distress, which may enhance caregivers' ability to support their loved one's recovery [3].

Despite the limitations of addiction services focusing on families, participants exhibited resiliency and motivation in attempting to find support and resources for self-care and to deal with caregiver stress. Families' resourcefulness demonstrated their determination to find practical ways to meet theirs and their family's emotional and social needs [28]. These strategies provided encouragement and mutual learning opportunities for self-care. Al-Anon helped families become less vulnerable to addiction's impacts, and it gave them an environment where they could relate and learn from others who shared the same experience [29].

Families provide a source of attachment, nurturing, and association [3] to its members. Substance use and addiction are regarded as a family disease because of its impact on the family unit [30]. Families experience caregiver stress due to their support of an individual with an addiction [24, 31, 32]. A lack of support is a predictor for high caregiver burden. Interventions addressing substance use and addiction must recognize its impact on families in supporting an individual with an addiction [30–33]. To provide patient-centered care, health care providers need to screen for caregiver stress. Such an intervention will expand the awareness and understanding of how health care can better optimize support for family members in recovery.

Addiction treatment modalities need to be re-evaluated to ensure that families are fully integrated into their model of care. Along with screening, the dissemination of resources needs to be enhanced and readily available to support caregivers. Further research is required to develop evidence-based interventions focusing on family self-care modalities.

Conclusion

In this study, we explored the experiences of family members perceptions of caring for an individual with an addiction and how they engage in self-care. Our analysis of interview data gathered from 21 participants revealed that caregivers experienced a crisis caused by a lack of necessities of life, which contributed to abuse, neglect, and overwhelming demand for care. For many participants, addiction robbed them of a relationship with the person using substances, which was akin to a loss of their relative.

Several factors, including inadequate knowledge about the impact of addiction on families, and lack of resources to support family caregivers, compounded the caregivers' psychological stress. Furthermore, the participants lack knowledge about addiction and its trajectory led to unrealistic expectations of the individual with the addiction to enter treatment and recovery. We recommend further research on the impact of addiction on family caregivers. We further call for the development of intervention strategies to promote self-care among family caregivers.

Declarations

Ethics approval and consent to participate:

This study was approved by the Ethics Board of the University of Saskatchewan. Written consent was obtained from the participants before enrollment in the study.

Consent for publication:

Not applicable

Availability of data and material:

Not applicable

Competing interests:

The authors declare that there is no competing interest to declare

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Authors' contributions:

Geoffrey Maina was involved in all the phases of the research project including conceptualization of the project, data collection, analysis and manuscript development.

Marcella Ogenchuk was involved in the project conceptualization, data analysis, and manuscript development

Taryn Phaneuf was involved in the writing of the draft manuscript

Abukari Kwame was involved in the editing and review of the manuscript.

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