



I had to Take Care of My Herd to Not Die Myself: A Retrospective, Qualitative Study of Siblings' Experience of Family Relations Before Their Siblings' Drug-Related Death

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Abstract

This study explores siblings' experiences of family relations before their siblings' drug-related death. A qualitative approach inspired by reflexive thematic analysis was chosen for the analysis. Four men and ten women, aged 23–61 and representing all regions of Norway, were interviewed. Three themes were identified: (1) *A changed view of both their sibling and personal relationship*, (2) *Changed patterns of communication in the family* and (3) *Coping strategies*. The results are discussed through the lens of family systems theory and salutogenesis.

Keywords Siblings · Family relations · Drug-related death · Family systems theory · Reflexive thematic analysis · Salutogenesis

Introduction

Health authorities recognise drug-related deaths (DRD), the situation of persons whose lives are dominated by drug use, and their relatives' living situations as serious public health concerns (European Monitoring Centre for Drugs and Drug Addiction, 2021). This article is written in a Norwegian context—characterised as a Scandinavian welfare state with well-established public services. Nevertheless, there were still 324 overdose deaths in 2020 in Norway, placing Norway among the highest recorded incidences of drug-related deaths per capita in Europe (Norwegian Institute of Public Health, 2020). Figures relating to DRD are also high in the statistics for several other countries. For example, in 2019, there were 70,630 fatal overdoses in the USA and 5769 in the European Union (The European Monitoring Centre for Drugs and Drug Addiction, 2021). In Norway, both in the

National Overdose Strategy 2019–2022 (National Directorate of Health, 2019) and in the Escalation Plan for the Field of Drugs and Addiction 2016–2020 (Prop. 15 S) the objective is to *'improve the provision of help offered to the relatives and others who may need assistance following an overdose death'*. Nevertheless, we still hear little from and about group understood as the next of kin. Internationally, the substance-use policy also seems to favour individual-oriented perspectives, and family-oriented perspectives are rarely included (Adams, 2008; Copello et al., 2010).

Problematic Substance Use

PSU has been acknowledged as the harmful use of psychoactive substances (WHO, 2019). However, bereaved siblings' experiences of living with their siblings' problematic substance use (PSU) have received little attention in the literature (Løberg et al., 2021). This is especially the case for adult siblings (Schmid et al., 2009; Smith-Genthôs et al., 2017). Family dynamics and relationships are often impacted when a child in a family develops a chronic illness. The parents' focus, time and resources are directed at the struggling sibling, something that often lasts well into adulthood (Gabriel, 2017; Tsamparli & Frrokaj, 2016).

The often-close relationships between siblings can prove to be particularly important to the substance-using brother or sister (Mikkelsen et al., 2011). However, the level of stress

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that can exist around this situation can lead to ambivalence and resistance for the siblings, as the extent of the difficulties may affect several areas of their lives, such as the sibling's relationships, finances, energy, and overall quality of life (Greif & Woolley, 2015). To cope with difficulties, resilience is crucial. Resilience refers to both the process and the outcome of successfully adapting to difficult or challenging life experiences (APA, 2022).

Impacts of Problematic Substance Use on Family Relations

PSU is particularly demanding for families (Orford et al., 2010). Such a change that starts in youth may continue and become a long-term struggle, with the potential to greatly impact family life and continue doing so for a long time thereafter (Lindeman et al., 2021). This can be described as a process with an unpredictable course—one that could either result in recovery or a life-threatening and long-lasting battle with PSU (Nesvåg, 2012). Thus, PSU challenges all types of close relationships within the family unit (Lindeman et al., 2021; Orford et al., 2010; Orr et al., 2012; Ray et al., 2007). The bereaved left behind by those who died from a drug-related death will therefore likely have experienced a long-term level of stress before their family member's death. DRDs, especially overdose deaths, tend to happen abruptly and can be compounded by strong emotional expressions (Yule & Levin, 2019).

On the other hand, some drug-related deaths may also have, to a certain extent, been expected, especially following on from many years of drug use. There is a high risk of prolonged and severe grief and adverse reactions to the trauma among the bereaved, leading to a reduced quality of life and ability to function, both because of the circumstances surrounding the death but also because of the great pressure the family members had been subjected to before the DRD (Jordan et al., 2012; Li et al., 2003; Titlestad et al., 2020a, 2020b, 2021). The relatives perform a significant and demanding job and make up a major component of the societal efforts that go into helping individuals with PSU while they are alive. A recent study of experiences among bereaved parents following the DRD highlights how these efforts can contribute to an overload of stress, mainly caused by a state of constant parenthood preparedness (Titlestad et al., 2020a, 2020b, 2021). This was, of course, exacerbated by their experiences in the time leading up to the death, such as dedicating so much of their life to dealing with a child's PSU. Meaning, that when the parent does then experience a DRD, they may be less capable of managing the grief process (Titlestad et al., 2020a, 2020b, 2021). However, we know less about these consequences when it comes to the bereaved siblings.

Drug Death Bereavement and Recovery Project (the END Project)

This study is part of a Norwegian study entitled the Drug Death Bereavement and Recovery Project (the END Project). The purpose of the END Project is to contribute to a greater understanding of the consequences of DRD for the deceased person's close relatives and friends, their situations and needs, and to enhance the quality and competencies of social and healthcare services (ResearchGate, 2019). The current article specifically focuses on the siblings' experiences of family relations before the death of their sibling. The study was guided by the following research question: What are siblings' experiences of family relations prior to their siblings' deaths?

Methodology

Qualitative methods of research are concerned with how or in what way something occurs and aim to shed light on human experiences (Brinkmann & Tanggaard, 2015). Thus, a qualitative approach was selected for this study to explore the siblings' experiences of family relations prior to their sibling's death. Reflexive thematic analysis, as described by Braun and Clarke (2019), was chosen to generate a phenomenological and hermeneutical understanding of the participants' experiences. Our focus therefore lies on the experience the interviewees have of the world, the interplay between them and the people around them, and the contexts in which their experiences occur (Langdrige, 2007). Hermeneutics promotes the importance of interpreting people's actions by focusing on deeper content meaning than is immediately apparent (Thagaard, 2018).

Recruitment and Details of the Participants

From March 2018 to the end of December 2018, bereaved family members and friends were enrolled on the main END project and invited to fill in a questionnaire. The interview sample for this study was drawn specifically from siblings who agreed to fill out the questionnaire and who were eligible to be interviewed. We wanted both sexes to be represented. We also made sure that the participants represented all regions (mid, north, west, and eastern) of Norway. All participants are bereaved whose late siblings used illegal drugs, such as amphetamines and opiates. Four men and ten women, aged 23–61 and who represented all regions of Norway, were interviewed. Two persons that were asked to participate declined or didn't respond to

our request. No siblings from the same family were interviewed. The time that had passed since losing their sibling varied from 3 to 360 months.

Data Collection: Semi-structured Individual Interviews

Qualitative semi-structured individual interviews were used for the data collection. The semi-structured interview examines themes that are largely decided beforehand, which allow for the process and dynamics of the interview to determine how strictly the interviewer follows the script (Burck, 2005). The interview questions were co-constructed within the original research project's project group (PG). The PG consists of 16 people with broad interdisciplinary experience from research on substance use, welfare services and family therapy, as well as personal experiences of loss. The interviews had an overarching retrospective focus, in which the participants were asked to look back on the time leading up to the death of their sibling. The interviews were conducted by the three authors of this article between 24 June and 4 December 2019. The interviews lasted between 45 and 120 min. The wide variation in interview length is related to the variety of participants and their different styles of replying to the questions. In example, participants who had experienced years of involvement in their siblings' problematic substance use prior to their drug-related death, usually had a longer story to tell than participants who had been less involved during a shorter period. The difference in interview length could also be connected to the fact that three different researchers conducted the interviews. Two of the researchers emphasized follow-up questions and comments to a wider degree than the third researcher. The place for the interviews was chosen by the interviewees themselves, such as their own homes, their workplaces or a hotel room rented by the interviewers. The interviews were audio recorded and transcribed verbatim. All interviews were conducted in Norwegian.

Reflexive Thematic Analysis

We have used an adapted version of reflexive thematic analysis (RTA) described by Braun and Clarke (2019, 2022) to analyse the data material. The process of analysis helped identifying patterned themes and to report the findings. Reflexivity in TA involves the practice of critical reflection on your role as researcher, and the research practice and process (Braun & Clarke, 2022, p. 5). Thus, as researchers we were critiquing our biases throughout the research process to avoid that our own experiences and prejudices dominated (Finlay, 2003). The authors have various backgrounds that were drawn upon to make sure that a multiverse of perspectives was included in all part of the work. LL and

SKL are both social workers and family therapists. LL has long experience in mental health and SKL has more than twenty years of experience within substance use treatment and rehabilitation. AHL is social worker and sociologist. AHL has long experience in social work, mental health, recovery and individual supported employment.

RTA provides systematic but not rigid procedures for coding and identifying the themes of qualitative data (Braun & Clarke, 2006). We therefore made a number of individual adjustments. The following RTA phases described how we used reflexivity to guide our process of analysis:

Step 1 Familiarization with the data. In this phase, LL read and re-read all the transcripts, to be more familiar with the data material. LL noted 'tentative' ideas regarding potential themes in the material.

Step 2 Coding. This was a back-and-forth process, suggesting codes, re-reading the interviews, changing/adjusting codes after discussions with the co-authors. In this way, all the transcripts were thoroughly reviewed by three of the researchers.

Step 3 Identifying and classifying themes. Themes are defined as patterns of shared meanings (Braun & Clarke, 2019). The first round of thematization was carried out by LL, and then discussed with AHL and SL. The finalization of themes was a collaborative process involving all authors before an informative name of the themes was decided on: (1) *A changed view of both their sibling and personal relationship*, (2) *Changed patterns of communication in the family* and (3) *Coping strategies*.

Step 4 Writing up. This phase involved the preparation of the written report, understood in this case as the current article. The writing process was carried out in a circular method in which the authors sent drafts of the different sections for feedback and insight from the other authors. As qualitative researchers, we acknowledge that you are never neutral. Thus, it is necessary to be reflexive of your role as a researcher (Braun & Clarke, 2022). Thus, we discussed experiences from both the interview and the analysis process in order to increase our reflexive awareness of the interpersonal processes that have unfolded in the process. We were therefore aware of how our contribution could affect the construction of themes and discussed this throughout the analysis process. To prevent our assumptions from becoming too intrusive, we have tried to be as transparent as possible throughout this article.

Research Ethics

All procedures were conducted in accordance with the Declaration of Helsinki (The World Medical Association, 9th July 2018). This study was approved in February 2018 by

the Norwegian Regional Committees for Medical and Health Research Ethics (reference number 2017/2486/REK vest). All participants signed a consent form and received copies of the ethical approval for the research project. All participants were informed about their right to withdraw from the research project at any stage without the need for an explanation. All transcripts were anonymised and stored on an encrypted server owned by the regional health authority. Care was provided to the participants according to Dyregrov's (2004) recommendations for conducting research on vulnerable populations. Thus, all participants were made aware of the option of talking to someone after the interview.

Results

Three themes were identified: (1) *A changed view of both their sibling and personal relationship*, (2) *Changed patterns of communication in the family*, and (3) *Coping strategies*.

A Changed View of Both Their Sibling and Personal Relationship

The realisation that a sibling was dealing with PSU resulted in the participants' changing of how they saw their sibling, such as an older brother, in that they no longer perceived them as a role model and an example to follow. With new information shedding light on the challenges their sibling was facing, their understanding of that person changed significantly. A sibling whose existence, experiences, and perhaps even life advice had previously provided them with a feeling of security 'disappeared' and the participant thus lost important resources they needed in their own lives. This was described by Participant 1 as: 'My sibling was yanked down from their pedestal. He deprived me of a role model, and I lost someone I looked up to. That is something I miss'. In this respect, several of the participants described similar experiences, in that they felt that they had lost a sibling, even before that sibling had died.

PSU also caused the person's behaviour and demeanour to change. This altered behaviour was described as irrational, selfish and occasionally extremely difficult to be around, all the while being a result of the sibling's PSU. A relationship that had previously been defined as close and positive had become distressing, and destructive. The relationships and their roles towards each other's had therefore changed dramatically. An important change was that siblings could no longer rely on their brother or sister to take care of their own health. In this vein, all participants described having major concerns for their sibling. The concerns were, to a great extent, expressed as being constant—essentially that of always worrying about where the siblings were, their condition, and whether they were still alive. Participant 7

verbalised this as: 'It was arduous and frustrating being related to a brother with PSU. I felt like I'd lost him even before he died'. This resulted in fatigue, sadness, anger, loneliness, guilt, shame, and troubled conscience. As Participant 5 explained: 'When it got particularly intense, I basically lost a part of my own life'. This intensity was maintained in that both their siblings (as well as the siblings without PSU) and their parents would use them as a discussion partner for their various needs. Everyone involved therefore had varying different needs, but with the common denominator being that the participants ended up being the recipients of everything, with all the consequent strain that entailed. This constant feeling of negativity was hard to bear, while at the same time, they felt like they couldn't just give up. By giving up, they risked their whole family system collapsing, including themselves. As Participant 4 said: 'I had to take care of my herd, to avoid dying myself'. Thus, it wasn't possible to just be a sibling anymore, it was necessary to have a 'social control function' as well to ensure the safety for his own family. Even though the participants felt that their efforts were appreciated and necessary for the family's survival, the 'work' could also be so all-consuming, that they felt that they lost themselves in the process.

Changed Patterns of Communication in the Family

Issues related to the siblings' PSU impacted all members of the family system. The family members therefore made different accommodations to take care of the sibling with PSU and to uphold the family unit. As participant 11 said: 'I often felt a responsibility to invite him to things with my friends, and with my partner at the time, and he appreciated this, at the same time as he probably found it painful'. It was a common theme among the participants that some information regarding how serious the situation had gotten had to be kept secret. This was understood as a choice they made to avoid overloading the family system. By overloading the system, we mean that any new details, information, changed behaviour etc., from family members could be enough to overload a system which was already burdened to the extreme. Nevertheless, most of the family were aware of the severity of the situation anyway. Several of the participants described how their sibling seemed to be aware of what information they chose to share and to whom they told what within the family. This was again understood as an attempt to not overload the family system. At the same time, this was also seen as a choice that the person chose to make based on the different relationships between family members, and the various skills each family member had to offer the situation. The siblings regularly experienced that they were the ones who had a 'clear picture' of reality. For example, their sibling may call to borrow money, but also to share information that they didn't want their parents to know about—namely, as the

substance-using sibling may have felt that they wanted to spare their parents from the worst descriptions of their situation. The parents were therefore more often involved in the more practical side of things, such as helping them move, their finances, and contacting services that could help them. The family members could therefore be left with vastly different information of the reality of the troubles.

The lack of having a full overview of the situation, thus prohibited the family from having a shared understanding of the issues they were facing. It was therefore difficult to confront these challenges with a unified point of view. Participant 1 explained how this turned them into a dysfunctional family: 'Our family became dysfunctional and reacted differently to the things that happened'. A shared understanding was further complicated as a result of the loyalty and promises made to the substance-using sibling, in addition to the constant anxiety of overwhelming the family system. Participant 14 described this issue as follows: 'My brother wouldn't let me tell our parents that he had been in a major crash as a result of PSU'. The many secrets and different roles the family members were forced to take on and/or took on themselves resulted in the emergence of 'unwritten rules' regarding what one could and could not talk about within the family. This then also impacted the relationships between all family members. For example, it would become difficult to talk about positive events, such as christenings, engagements and so on. Positive events within the family could almost be considered as if they had forgotten the difficulties or would be overridden by a fear that the sibling with PSU would feel even more like a failure and further away from the expectations of where they should be in life. This then made the participants feel that their siblings' problems were all-consuming, and that their own life events and experiences were given little attention.

Coping Strategies

The demanding family situation made it necessary to find strategies to survive, both on the individual and on the family level. One clear, common feature was that the siblings' PSU was rarely talked about without trying to cover up the issue, as well as the unwritten rules of silence and concealment. These experiences were shared by all participants, regardless of whether they were living at home or not at the time. As participant 9 described: 'I think it is too tough for my parents about what my brother is exposed to and his drug abuse'. Instead, the participants described it as a form of 'pseudo-harmony' where they would talk of other, safer topics. They would therefore put a kind of 'shield' around the situation. A 'shield' that helped them manage in dealing with their everyday lives. Even though they employed this 'shield', the participants still experienced that the severity was actually common knowledge

among all family members, regardless of the fact they had different access to said knowledge. Participant 5 explained it as: 'Mum's a smart woman who understands a lot, but she chooses not to take everything in, when it becomes too much for her'. Another common theme among the participants was that the problem was not spoken about to people outside of the family but was solely kept within the core family unit.

The participants described the various, individual strategies they used to deal with the situation. For example, 'being the perfect child' was one such strategy that came up repeatedly among the participants. Even though they were often tired and occasionally struggled with difficulties concentrating, they would still attempt to personally 'ease the pressure' on their family by performing at their absolute best. This could include at school and/or their job, but also to generally appear strong in all aspects of their life. Others distanced themselves both physically and mentally, from the family as a whole as well as from the substance-using sibling specifically. Mentally, this was achieved through the active decision to not think of the problem as something that they themselves should feel any blame for, recognising that they had a limited influence when it came to solving the problem, thus putting themselves and their own family first, and setting boundaries for contact. Regarding the concrete, physical measures, examples of this included moving far enough away that, in practice, they were unable to physically meet up, and for when they did meet up, the setting of clear boundaries for the interaction (such that their siblings could not turn up intoxicated or the like).

Yet, even if it was necessary to set boundaries to take care of themselves, this was a difficult decision to make. As expressed by Participant 10: 'I missed my brother when he had good periods, but I couldn't bring myself to have anything to do with him when he was intoxicated'. Setting boundaries included doing so with the rest of the family. By being in 'the middle' of all the information, several of the participants felt that they were used as a kind of advisor to their parents. Even though the parents had the best intentions, these advice-giving situations would result in a significant role reversal, which then also resulted in the relationship between the participants and their parents having to change. Having to be 'strong' was no longer a choice, but something they were forced to be. Some of the participants further described this advisory role as being futile anyway, as the parents would, in any case, not seem to follow the advice they were being given. Participant 5 explained: 'I needed to set some boundaries for myself, as I was always asked for advice, even if they rarely followed them'. The advisor function' was therefore more of a burden than it was help. Thus, the participants widely opposed such a role. Nevertheless, in absence of better strategies, even unhelpful strategies were adhered to over time.

Discussion

Siblings PSU impacted various aspects of family life and changed their relationships and the family systems. Based in general system theory, a family system can be understood as being unique, with their own rules and decision-making processes that distinguish them from all other systems (von Bertalanffy, 1950). Over time, well-functioning family systems thus develop patterns of interaction that allow the family life to work and appear stable. For example, if one member of the family is in trouble, somebody ‘doubles’ for them and fills their role as best they can (Messer, 1971, p. 380). When a major change impacts family life the balance of the family is knocked off kilter. This understanding is grounded in family systems theory and the two hypotheses that make it up: (1) *the family is an autonomous system* and (2) *the family is an adaptable system* (Priest, 2021). In this context “autonomous” mean the processes that serve to generate and maintain the family system. ‘Adaptable system’ means that any system has to be able to adjust to ongoing changes to exist. In response to changes within the system, families thus need to react. However, families end up facing issues when those processes become either too rigid or too adaptable, or when so much pressure is put on one of the two processes, that the system eventually ends up being overwhelmed (Priest, 2021). The participants in the study described how the demanding circumstances meant that they were forced to make major changes. To survive as a family, they had no choice but to adapt. However, the challenges relating to the PSU meant that the changes that occurred regarding the roles and relationships of each family member happened to such an extent and at such a pace the family system was not prepared for. Thus, based on family systems theory (Priest, 2021, p. 10), too much of the responsibility for keeping their family’s autonomy was put on needing to adapt. This brought about a ‘role reversal’ (Maysel et al., 2004). Even though the participants who took part in the study were young adults or adults, all of them could be considered as family members who had been forced to take on major care-giving roles ‘overnight’, that they hadn’t been prepared for.

Role reversal affects patterns of communication, but is not necessarily negative, and it usually becomes necessary through changes and adjustments in the roles within the family over the course of a life cycle (McGoldrich et al., 2014). For instance, evident in the young adult trying to distinguish themselves from their original family unit and developing adult-to-adult relationships with the parents is an important part of one’s life cycle (Carr, 2012). Role reversal can be a turning point in the development of a family’s resilience, as it can help increase the family’s

capacity to adapt when dealing with a particularly stressful situation. However, for many families, these changes happen so fast and were of such a serious nature that the family system was then negatively impacted. Titlestad et al., (2020a, 2020b) describe how DRD-bereaved parents had often, for a long time, taken over the responsibilities which would normally, depending on the child’s age, have been handled by the child themselves. Other scholars refer to this tendency as ‘extended parenthood’ (Tysnes & Kiik, 2019), which reflects the consequences that this extension of duties often have for parents of children who need this continued support (Titlestad et al., 2020a, 2020b). Extended parenthood for one of the adult children in the family affects siblings’ relationship with their parents in a long-term perspective and combined with a role reversal, it may mean long-term repercussions for the family system and siblings’ position. The different information family members had then made it difficult for the family members to deal with the challenges with a common understanding. So instead of having a unified plan to try and solve and tackle the challenges head on, almost everyone would end up having to take their own measures.

The participants’ experiences of these measures they set in motion themselves, or were given responsibility for, were extensive and described as having impacted them on both a personal and relational level. This aligns with much of the previous research (Gabriel, 2017; Tsampanli & Frrokaj, 2016). To protect themselves, they had to try and shield themselves for periods of time, for example, by moving further away, not picking up the phone, not meeting up with their sibling. Many of the participants expressed this as being necessary, but that it also gave them a troubled conscience. The participants therefore found themselves in a double-bind situation, as each choice had negative consequences: for themselves, for their sibling, or for other members of the family (Bateson, 1972).

Having a sibling with PSU is a stressful situation, both physically and psychologically and makes everyday situations hard to cope. People living in demanding and stressful life situations can, however, still experience their lives as being positive. This also applied to the participants in our study. On that occasion, salutogenesis is relevant. Salutogenesis is the focus of looking at the resources available to a person, Berg et al., (1996). Finding out what it is that helped the siblings live with the stress and challenges of PSU in the family are key issues we must research when it comes to figuring out how to cope and deal with the situation. As a response to this salutogenic question, Antonovsky developed the concept *sense of coherence* (SOC). The concept consists of three factors that, when combined, can help provide a high level of SOC. The three factors include: comprehensibility, manageability, and meaningfulness. With these, Antonovsky claimed that a SOC can help us better deal with

the stressors in our lives (Thybo, 2004). A high attainment of SOC is thought to provide an individual with stability when forced to face stressful situations. The theory describes all the fundamental factors required to master one's stress in any context (Berg et al., 1996; Ekblad & Wennström, 1997).

Comprehensibility ensures that the strain and stress one is put under in any given situation is cognitively understandable, sequential, and coherent. The individual must therefore be able to understand what they are being exposed to, in a way that makes the world appear rational and predictable (Antonovsky, 2000). If we transfer this comprehensibility to the siblings' experiences of living in a family with a substance-using brother or sister, this could, for instance, include the siblings seeking out more knowledge about PSU, as well as being there for suffering family members. Psychoeducation is often used when working with relatives in this kind of situation, through the employment of professional help, such as family therapists, or through disseminating research-based knowledge on what it means to be a relative of someone with PSU. Psychoeducation can thus expand one's opportunities to act in such an arduous situation, as it could provide an enhanced insight into, and new perspectives of the situation (Christiansen, 2015).

Manageability—can be understood as the feeling that the resources the individual has at their disposal are adequate to cover their needs and are the right resources to use in this particularly stressful situation (Antonovsky, 2000; Ekblad & Wennström, 1997; Thybo, 2004). Resources can be seen as specific, physical resources that can be externally sourced too, such as other people who can help. Many of the siblings in the study had spent a lot of time and energy coming to terms with the services they could use, to find the right organisation that could help their brother or sister with whatever they needed, from financial aid to treatment. Resources relating to the siblings' own functionality and life situations were also mentioned by several of the participants as being vital when it came to negotiating their demanding family situation.

Antonovsky (2000) describes *meaningfulness* as the individual's experience that it is worth investing energy in trying to solve the challenges they are dealing with. In this context, then, a sense of coherence can be understood as central to the development and maintenance of the family's resilience, as it contributes to both strengthening the family unit, as well as the individual family members' perseverance and abilities to master the ongoing stressful life situation. Thus, the concept of family resilience is especially timely, as our world continues to grow increasingly more complex and unpredictable, with families now facing unprecedented challenges (Walsh, 1996). Or, as Participant 3 put it: 'I helped him because he was my brother, and because I loved him'.

Patterson et al. have conducted several studies about families living with different long-term, chronic illnesses

(Patterson & Garwick, 1994). The researchers claim that a family's adjustment to long-term stress is a process that evolves over time, during which meaning, behaviours, and emotions all reciprocally influence one another in the social context of the specific family (Patterson & Garwick, 1994). New routines and roles are needed to be able to manage the tasks related to dealing with the illness, and the family's former, structural organisation may no longer be enough to meet the new challenges (Patterson, 1988). How the family restructures itself as it adjusts to the demands the illness has placed on their lives may impact the identity of the family and their overall sense of purpose in life. For some families, this may mean that the focus of their resources is channelled into dealing with the illness, such that other needs in the family are given less space (Patterson & Garwick, 1994).

Patterson and Garwick (1994) point out that understanding this family adaptation in relation to long-term family struggles involves paying more attention to their meaning-making process. Family members' understanding of the reasons and consequences of said illness often sets a course as to how the family will respond as time goes on. According to the authors, working with families to develop shared situational meanings—that reduce guilt and blame and include shared responsibility for managing the condition—can be perceived as an adaptive response (Patterson & Garwick, 1994, p. 297).

Concluding Comments and Implications for Practice

The findings of this study can be seen as a contribution to more knowledge about the major strains put on family life after a DRD, particularly for those who have lost their sibling as a result. Well-functioning family systems are flexible and capable of dealing with change well. PSU, however, may be of such a nature that the changes that those problems force into existence are more severe and happen at a much faster rate than what most family systems will be able to cope with, without their having to deal with major personal and relational challenges. Any relevant measures that can be taken to help should therefore not overestimate the strengths of the family system, specifically when faced with such extensive challenges. Patterson and Garwick pointed out as early as 1994 that one way in which practitioners can facilitate better family adaptation to a chronic illness is to pay more attention to the family's meaning-making process and to support families in making these processes more explicit and more adaptive. The value of people talking about their experiences to each other and to the attentive listening professionals is highlighted in several central systemic ways of working (Lorås & Ness, 2019; Lorås et al., 2017). To facilitate family conversations, practitioners need basic and central systemic psychotherapy knowledge and skills, which give a structure to the conversations in which several persons and perspectives are presented,

and with a central systemic focus on understanding psychological difficulties in the context of social relationships and culture (Boston, 2000).

It is therefore essential that professionals have this understanding of the family's long term-perspectives and the consequences for the siblings in particular, both while their siblings are still alive and after they have died. However, several earlier studies (Adams, 2008; Copello et al., 2010; Selseng & Ulvik, 2019) also reported how the dominant trends in substance-use policies provide limited opportunities to implement any integrated work with families. This study, on the other hand, clearly shows how important it is to offer families the opportunity to enter joint conversations so that they can receive the help and support they need for the ongoing challenges they are subjected to, and to prevent a breakdown of the family unit in the future.

Limitations of the Study

As qualitative researchers, we acknowledge that the analysis process used in this study draws heavily on the researcher's ability to be critically aware of our own 'built in' assumptions and preconceptions, as well as the participants' cultures. We have strived to be transparent and rigorous in our work by presenting each step of the analysis and showing examples of the participants' quotations. A purposefully designed sampled group of participants shared their experience of family relations prior to their siblings' deaths. The time that had passed since the loss of their siblings varied from three to 360 months. Thus, their memories of the time before their siblings' death differed greatly. A potential strength of this is that the participants have had enough 'distance' from their families' struggles prior to their siblings' deaths to talk about the situation openly. Perspective for life experiences is probably different when siblings look at it with distance to ongoing overload, they earlier experienced, but precisely because of the distance, it can also give more and other nuances to siblings' life situation. However, this can also be seen as a limitation, as it was such a long time ago since they had this experience, that they may now only remember certain aspects. A possible limitation is also that it is often possible that participation in this type of study appeals especially to those participants who are particularly engaged and involved, and, thus, for example, do not present the experiences to those siblings who have distanced themselves early or who took on different roles within the family.

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Declarations

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