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ORIGINAL ARTICLE

“What if you listened to and involved the caregivers?” – Experiences and needs amongst caregivers involved with mentally disordered offenders and mental health services

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Abstract

Background and objectives: Over the past 20 years, the number of mentally disordered offenders (MDOs) has increased intensively in Denmark. Consequently, the number of caregivers, families and network involved with MDOs has also increased. Despite a heightened political focus on the involvement of caregivers as an important part of the patient pathway and recovery processes, knowledge of caregivers’ experiences is very limited. The aim of this study is to illuminate experiences and needs amongst caregivers taking care of MDOs in Denmark.

Methods: The study is based on semi-structured interviews with caregivers. The content of the interviews is analysed using content and textual analysis focusing on identifying patterns and themes.

Results: Caregivers involved with MDOs perform various roles and tasks from practical support to acting as case managers. These tasks tend to put a remarkable pressure and challenges on caregivers. Furthermore, caregivers experience emotional stress such as loneliness, shame, sorrow and feelings of inadequacy. Caregivers spend a lot of time establishing sustainable narratives about mental illness and offences, in order to reduce stigma and come to terms with chaotic and extraordinary incidents, and they play an important role as carriers of hope on behalf of the patients to support processes of personal recovery.

Conclusion: The majority of caregivers in this study share a fundamental experience of neither having achieved sufficient support in the trajectories leading up to the forensic debut nor being involved or receiving enough and dedicated information while the often long-term sentences to treatment or placement are ongoing.

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Introduction

During the past 10 years, the political focus on personal recovery, participation, involvement, empowerment, and user perspectives has increased in Danish mental health services. When looking at policy papers within this field, it becomes clear how they often address patients and caregivers simultaneously, aiming at increasing involvement and participation for patients as well as relatives and networks.[1–6] The reasons and rationale for increased involvement and participation is that it improves treatment outcomes and supports safe and improved pathways for the individual patient.[1,3–4] All regional strategies aim toward a patient-centered and coherent pathway to the greatest extent possible accommodating the needs, wishes, resources, and hopes expressed by patients and caregivers. According to the National Board of Health and the National Board of Social Services, the involvement of caregivers in mental health services reduces the risk of readmission by 22% and the risk of relapse by 45%.[7]

However, knowledge of the experiences and perspectives of caregivers is limited. Echardt, 2018 has shown how caregivers involved with pathways in general psychiatry are burdened with multiple roles and tasks, and how being a caregiver can affect health, economy, and social life.[8] Bonnesen, 2014 has described some of the challenges experienced by caregivers in general psychiatry regarding relations, roles, loneliness, and grief, how acting as a caregiver affects the whole family as well as the importance of taking care of oneself.[9] The frequent national questionnaire LUP focuses on pre-defined elements of user satisfaction as experienced by patients and caregivers within mental health services.[10]

Over the past 20 years, the number of mentally disordered offenders (MDOs) has increased intensively in Denmark, i.e. from 1,445 in 2001 to somewhere between 3,000 and 4,200 today[11]; the annual incidence of MDOs is between 600 and 750 individuals.[12] Consequently, the number of caregivers, families, and networks involved with mentally disordered offenders has also increased. The interest organizations representing patients and caregivers within the mental health area (for instance Det Sociale Netværk, SIND, Bedre Psykiatri, Skizofreniforeningen, etc.) pay relatively little if any attention to caregivers affected by forensic psychiatric issues. Unfortunately, the main focus and rhetoric tend to be on MDOs as a nuisance taking up beds in general psychiatry.[13–15] The variety in type and number of criminal offenses among the population of MDOs in Denmark, as well as diversity in psychopathology and level of social marginalization, is absent in the public debate.[16–17] It seems reasonable to assume that monstrous and stereotypical narratives about dangerous MDOs, exclusion of MDOs as not being worthy to receive treatment in general psychiatric services, and the interest organizations paying little interest in nuancing these representations, do not support or ease the burdens experienced by caregivers involved with MDOs.

To our knowledge, experiences from caregivers involved in long-term pathways for mentally disordered offenders with sentences to either placement or treatment have not been studied and documented in a Danish context. International research on experiences from caregivers involved with mentally disordered offenders is likewise very limited.[18–20] The aim of this paper is to illuminate experiences and needs amongst caregivers taking care of mentally disordered offenders in Denmark. New knowledge on caregivers' perspectives can hopefully be utilized to inform and develop future forensic psychiatric practices and to improve offers and efforts supporting caregivers involved with MDOs.

Methods and materials

The study is based on semi-structured interviews with caregivers exploring their experiences with being related to mentally disordered offenders.

This was part of a larger qualitative interview study focusing on long-term experiences before and after debuts as mentally disordered offenders and sentences to either treatment or placement.[21] The study was conducted within the mental health services in the Capital Region of Denmark. In total 38 interviews with 23 informants from 10 different clinical pathways were carried out. Both patients and caregivers were interviewed. This paper is focused on caregivers and is based on 21 interviews with 12 caregivers, representing experiences from 8 pathways. The caregivers represent various experiences and relations: parents, siblings, close friends, and ex-partners. Most of them were already familiar with mental health services before the offenses leading to forensic debuts, as most of the patients in the main study were already or had been in the previous contact with general psychiatry.

The interviews were based on an interview guide with open-ended questions. Some informants were interviewed only once, whereas others participated in several interviews.[1] The act of performing several interviews during 1-2 years strengthened the insight into various phases of the pathways, as well as insight into the different challenges experienced by the informants in the many phases. Some of the experienced informants who had lived with sentences to treatment or placement for several years looked back in the first interview and summed up several phases. If these narratives across time and phases were very rich and fulfilling, there was no reason to ask for another interview. In some of the pathways, it was not possible to perform re-interviews due to practical or ethical reasons, for instance, stress or current mental state.

Thematic analysis

The interviews were recorded, transcribed verbatim, and analyzed using content and textual analysis focusing on identifying patterns and themes.[22,23] The empirical material has been exposed to vertical as well as horizontal analysis to identify significant statements and phrases within each interview as well as across all interviews.[24,25] Several in vivo citations are used throughout the analysis. The specific citations have been chosen as illustrations and as telling statements representing a strong and remarkable theme identified in the analysis. Throughout the analysis, a chosen

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[1] Interviews were carried out by project manager, MPolSc. Liv Os Stølan, Competence Centre for Forensic Psychiatry.

in vivo quotation mainly covers sayings from several informants, expressing themselves in similar ways.

Results

Various roles

Most of the caregivers in this study were already familiar with mental health services and have previous experience as caregivers, as most of the patients in the pathways studied had been in contact with general psychiatric services before the offenses were committed.

Consequently, most of the caregivers were already familiar with a number of various roles and tasks varying from practical support (cleaning, tidying up, support shopping, or providing meals), financial support and help to ensure a place to live to act as case managers bridging and coordinating between mental health services and social services. Most caregivers describe their roles and tasks as demanding in terms of the energy and time required by the intensive levels of support. “It has been a full-time job”, a parent to a grown-up patient says. The intensity and number of tasks and roles vary over time depending on the level of illness and needs, whether there is a relapse eventually ending in admission, or the patient is in a more stable phase. After an intensive phase, it takes a long time to get back into everyday practices with reduced arousal. “It has taken about a year to regain a foothold”, a parent says.

It is demanding for caregivers to navigate and interact with a large number of professionals with each their logic and division of work and responsibilities. “We have been in contact [with an inpatient unit] for almost two years now, but I still can’t remember their names”, a caregiver says. “They are all nice and kind, but it is so hard to get to know them”, the informant continues. Consequently, due to the number of professionals needed to staff an inpatient unit 24/7, it can be difficult for caregivers to establish a sustainable and trustful relationship with members of staff. Several caregivers also describe how they are supposed to accommodate various opinions amongst professionals and changes in for example treatment plans depending on the consultant in charge. “Then again comes a new consultant who finds it necessary to reinvent the wheel”, as one caregiver puts it.

It is a general experience among the caregivers that mental illness with one member of the family affects the whole family and sometimes also the network: “It does not only affect the person being ill, but it also affects the whole network”, a sibling says. Illness seems to affect most aspects of family relations and dynamics. Especially in families with minor children, it can impact the other children in the family if one child requires intensified care and attention. It can also affect grandparents or other relatives. Along with practical support, the caregivers also represent a relational role as either mother, father, sibling, or friend. Several informants describe how this reciprocal relation is disturbed because of the illness, and the roles taken on by the caregivers can lead to displacements of relations. What used to be a reciprocal and equal relation changes into an unequal relationship between the helper and the person being helped. A sister describes the feeling of supporting and her nurturing the relationship with the ill brother, while “he gives nothing in return”. This becomes even more pronounced when caregivers experience a yo-yo dynamic. Several caregivers have been cut off for shorter or longer periods where the patient has refused to be in contact and then been invited back on board again. “Sometimes there is a crack and we can reach each other, but other times he is mean to me and tells me a lot of crap”, a caregiver explains. Most of the caregivers think of themselves as still available and not in a position to end relationships with the patient. Some of them also struggle with how to react and how to be patient and perseverant if the hiring and firing happen often. One informant describes how difficult it is to be given orders or shouted at, and that she has a bad conscience for sometimes reacting angrily toward her brother. This feels wrong because he is the one with an illness.

Several caregivers describe how they take over when the patient is discharged from an inpatient service. It is experienced as a massive responsibility when the caregiver fears self-harm, violent behavior, or even suicide attempts, and it leaves the caregiver with a huge responsibility and a 24/7 job in the days and nights after the patient has left the inpatient unit.

Loneliness, grief, feelings of inadequacy

Along with the strain due to the number of tasks and responsibilities, caregivers also describe tremendous loneliness and feelings of inadequacy. Several spend a lot of time pondering how they ought to have acted and whether the current situation might have been different if not prevented if they had done X or Y or Z. Caregivers also grieve for the loss of function and missed opportunities for the person being ill.

Very few of the caregivers in the study hold other significant and trustful relations with whom they can share their experiences and challenges. On the contrary, they often withhold information about their challenges of dealing with mental illness as well as offencesand their debut as caregivers for a mentally disordered offender. Some have lost friendships or actively cut ties with friends if they could not accommodate the stress and complexity experienced by the caregivers. “I have weeded out a some friends because if they will not listen to me, they are not my friends”, one informant says. Others describe how they have stopped sharing issues related to their role as caregivers and how they try to spare their friends: “We don’t want to burden them with a lot of things we are dealing with, so the relation changes, becomes more superficial”. A few of the informants have met peers in a group for caregivers. This encounter has been supportive, and they have kept in contact: “We met another couple in a caregiver group. So they are familiar with the circumstances. They are understanding and very good for us to talk to. In their company we can simply get things off our chests”, a couple of parents explain.

Carriers of hope

When asked what makes them capable of carrying on as caregivers several of the informant's point towards a specific strength and a large portion of resilience. “I was born with an extreme strength”, one says, whereas another points towards this as an active choice of action: “At some point I decided that I needed to be there as a caregiver". A third mention the response as a parent: "In the beginning, the only reason I was still in one piece was my children. They needed me to be around and to act". The specific and extraordinary strength described amongst several caregivers is often combined with virtues of patience and perseverance: "One simply has to be patient". Some caregivers see their role as carriers of hope whilst the patient cannot carry hope for themselves or has lost belief in change or improvement. One family has also experienced that they had to maintain hope and remind professionals about the philosophy of recovery: "Then I tell him [head of a unit] that the way for me to endure this is simply to hope for my son to recover. This is how I manage, and he simply did not understand". This caregiver expresses fundamental bafflement at the necessity to explain the importance of carrying hope to a head employed within hospital psychiatry.

Another caregiver explains that "all I want for him is to get alleviation, to reduce the burden, for him to get better and to improve his self-esteem. It is my hope for him that he over the next 5-10 years may be able to calm down a bit a family member summarises, "I live with this hope... he has so much potential, so I often think now is the turning point where he decides to live a life that is a little less messy."

Not all caregivers interviewed explicitly represented the role as carriers of hope and were not familiar with the intensified focus in mental health care on personal recovery processes or remarkable symptom reduction. A mother talks about her son benefitting from an intensified antipsychotic treatment: "I did not know he could get so well. I would have liked to know that this was possible, him being as healthy as he currently is. I did not know that this was possible. No one ever told me". Another caregiver is preoccupied with the importance of positive narratives and examples of successful pathways where patients and caregivers have experienced help and support within the mental health services. Positive narratives about successful treatment support hope, according to an informant, but "they often tend to be forgotten or they simply drown in the massive narratives about failures or less positive experiences within the mental health services".

Specific challenges for caregivers related to forensic patients

Several caregivers describe how they have had no previous contact with the police or criminal justice system and have moved along steep learning curves to understand new systems and their logic. A large number of the caregivers interviewed have found it demanding to adjust to practices and regulations applying to visits in secure settings, for instance, closed units in forensic psychiatric services or access to relatives in custody (eventually awaiting transfer to mental health services). "I don't know if one can get used to it, applying for permission to visit one's brother", a sibling wonders. Several parents of adult children have experienced difficulties getting information about whether their child was admitted or in custody due to rules and regulations of consent and transformation of information. They are all well aware of confidentiality and why consent from the patient must be secured, but especially for those previously deeply involved in practical support or more or less 24/7 assistance when needed, it has felt strange and inconsistent to be completely cut off. If the police have asked the court for control of correspondence and visits while the investigation is ongoing, this can also limit the opportunity to visit or even talk to the patient. "When I got there [to the unit] I was not allowed to enter. I could not see him, could not talk to him, I had to hand over his clothes to a member of staff at the doorstep. I broke down completely, I didn't know what had happened and I wasn't allowed to be informed", a caregiver remembers, being completely excluded from contact until the police had ended the investigation of the case.

Although security routines are well understood and accepted rationally, to be an object to them can still be experienced as an expression of suspicion when bags are being searched or when being asked which items one holds. Consequently, a visit to a mental health facility can be experienced as invasive and unpleasant. "It is closed, closed, closed", a caregiver says about visiting a relative in a closed psychiatric unit, and "the practices of controlling all visitors are hard for me to deal with. What on earth would I bring along? A saw? A gun or what?"

Sustainable narratives about offences and illness

The caregivers witnessing their relatives' forensic debuts have all spent considerable time establishing sustainable narratives and coming to terms with illness as well as offenses. "It has been a dilemma for me what I should tell the surrounding world", a sibling says. Prior, the sibling had struggled with how to come to terms with the offense himself: "I was so afraid that he [the brother] had done something which would permanently change my view of him".

For several caregivers it has been a shock to learn that the patients have committed violent crimes: "He has never acted in a violent way before", a caregiver says while looking for explanations and circumstances beyond the incident. In this case, the structure and organization at the social residential home are pointed out as crucial explanatory elements: "The number of staff, not the least a large group of unknown substitutes whom the residents interact with, it is demanding, and I am sure this has led him to the violent incident", a caregiver says.

In other cases, a reference to severe mental illness becomes the point of departure: "It is due to the illness. He would never have done such a thing if he was sane. He is not evil, this happened because of the illness. This was done by an ill human being". In some of the pathways in this study violent crimes affected members of staff or random victims. In two cases the violent crime was manslaughter in close family relations. In these cases, caregivers have to navigate a double role, since they are caregivers as well of victims suffering severe losses. In one of the cases, the family subscribes to the illness as a somewhat meaningful explanation of something profound without meaning: The loss of a family member. Furthermore, this family has established the explanation and logic that the deceased family member suffered and gave her life so that the patient could get help and get better.

In the majority of cases and pathways in this study, it has taken time and effort from patients as well as caregivers to come to terms with the fact that the patients were capable of committing serious offenses. This is a complex matter.

However, it seems to be easier for caregivers to come to terms with serious offences if the patient and caregiver share the same views and explanations, for instance, the reference to illness. Furthermore, it also seems to be important to caregivers whether or not the patient admits guilt: “He claims guilt. That’s good, I think. He does not deny. He stands up for it”, a caregiver points out.

Revising stigma

Most of the caregivers interviewed have found themselves omitting details and information about offenses and mental illness when telling friends or networks about the ill patient because they fear stigma or already have experienced stigma related to forensic psychiatric issues. A caregiver explains that she wonders if she can “get off that label again” if she shares information and details about the offense and forensic debut of a relative.

“There is a huge difference between being a parent of a child with a mental disorder and being a parent of a child with a mental disorder as well as a sentence to treatment or placement”, a caregiver says. When asked why, “it is much more difficult to talk about the latter”, the caregiver explains.

One family explains how other relatives distanced themselves from the MDO and stopped visiting: “They did not visit him. [...] He [the patient] also felt how their attitude towards him changed because of the offense and the verdict”. The caregiver sums up that one of the relatives “is educated within health sciences, and therefore I expected her to be capable of understanding that this had something to do with his illness, not him as a person. I don’t think they could see that. It has hurt him [the patient] a lot. And we were hurt as well”.

Not all informants have experienced stigma. One caregiver describes how she actively chose to inform the nursery and school and the parents about the severe and chaotic situation involving mental illness and a serious violent offense in her family: “Then I decided to be honest and open with them, and tell them exactly what we were going through”. The caregiver was worried about how this would be perceived and what people would think, but she had experienced nothing but support and understanding at the time of the interview.

Some have faced and identified assumptions or generalizations about forensic patients which they also previously had harboredthemselves, but now have been forced to revise. “When it’s your relative, you realize that there is a human being behind all this. Otherwise one tends to forget this dimension and consequently conclude that forensic patients should be locked up for good”, a relative explains. “One tends to forget the human dimension if it is not someone close to yourself”, another relative adds. These caregivers have realized how they have previously held monstrous or stereotypical assumptions about mentally disordered offenders: “I have now realized that I was part of this as well because I did not know any better”.

Being left without information, help and support

What stands out as the most profound experience among the caregivers in this study is the fundamental experience of not obtaining sufficient information or support in the pathways leading up to the forensic debut or during the often long-term sentences to treatment or placement.

Several relatives look back on pathways with a strong feeling that serious offenses could have been prevented. In several cases, caregivers have asked unsuccessfully for support and help from mental health services, psychosocial support, or substance use treatment from municipalities. This has left them with intense experiences of a remarkable lack of support despite their long-term attempts to get help. Consequently, some of them have lost confidence in the Scandinavian welfare model supporting a reduction of social and health-related inequality and have lost faith in social and health care authorities providing adequate assistance. A caregiver has fought in vain for social security benefits and social residential home for a homeless friend: “There wasn’t any support. It was a fight between us and the municipality. We went there [to the Social Services] three days in a row to see a social worker. “No, she has just left”, “no, she’s in a meeting”, “she is ill”, over and over, again and again. We were completely rejected. It was horrible”.

For some of the caregivers, this loss of confidence in helpful and accommodating authorities is combined with negative experiences or differential treatment by the police or in the courtroom during the legal proceedings, not least the lack of sufficient legal aid from a defense lawyer without knowledge of forensic mental health issues. For one caregiver the way the police exposed the patient has led to doubts about a professional and neutral approach: “I have always had great respect for the police authority, but after this, I have started thinking that it is not flawless. Maybe the Danish system is not so much..., maybe we should stop telling the world how good we are if we are not...”, a caregiver says. The way the police released a photo of the ill relative while being wanted by the police has completely changed her confidence in decency and neutrality in police matters because she felt that the patient was unnecessarily exposed.

For others, it was more the approach or the way the care or support was delivered that contributed to doubt or lack of confidence in the welfare institutions. A caregiver overheard a member of staff stating that “we don’t know how to react towards a criminal in an inpatient unit”. After that, she explained to the staff member “that she should never talk this way to me or my son”. This caregiver holds several similar experiences of overhearing a callous or dehumanizing tone amongst staff in inpatient units and sums up: “I will never come to love the mental health services. I have told them: You are extremely old-fashioned. You are 50 years behind. What if you listened to and involved the caregivers? I think you should try talking to the caregivers”.

Several caregivers now involved in long-term pathways with MDOs serving a sentence to treatment or placement feel that they lack fundamental information on the task as curator[26] or how to support the patient towards a lift of the sanction or at least a less invasive measure. The task of the curator can put caregivers in further dilemmas and conflicts of interest between the relation to the patient and the obligation to act if the risk of recidivism to crime is detected. The caregivers who have taken on the task as curators relate that they were not introduced to this function when they were appointed.

The unknown period and not knowing when the sentence can be lifted is tremendous stress for patients and certainly also for caregivers trying to support recovery processes and carrying hope on behalf of the patients. Some of the caregivers are frustrated if they cannot identify the purpose of the treatment plan and if they feel there is no change or progress. Not knowing the time horizon of the sentence to placement or treatment is experienced as a heavy burden amongst caregivers. “I have to deal with him just being there, I cannot make any difference, apart from visiting him”, a caregiver describes. To endure this pressure several caregivers ask for someone to talk to, someone knowledgeable about the specific challenges at stake in forensic pathways: “It is as if”, a caregiver points out, “the mental health services assume that everyone knows what it means to become a mentally disordered offender”.

Discussion

The main findings in this study seem to be in line with the few other European studies on caregiver perspectives and experiences related to mentally disordered offenders and their long-term pathways.

Roewert et al., 2017[19] also identified experiences of double stigmatization related to mental illness and offenses, as well as feelings of guilt and shame amongst the caregivers. Consequently, this in some cases led to social isolation or even discrimination in society. However, Askola et al., 2017 also, as seen in the present study, found cases where caregivers were met by understanding and support from neighbors and colleagues. Rowaert et al., 2017 found that when caregivers shared their experiences and stories with others this proved helpful and supported coping, which is in line with the experiences shared in our study.

Likewise, Rowaert et al., 2017 found that caregivers expressed ambivalence towards the judicial system, not trusting fair and equal legal proceedings for the patient, or lacking a solicitor with sufficient knowledge of mental illness and psychiatric measures. Although care for mentally disordered offenders varies between Denmark, Finland, and Belgium, caregivers across the studies are left with the impression that patients had to commit before adequate treatment or measures were established. Many risk factors were not addressed sufficiently or at all before the offenses committed by the patients, according to the caregivers in this study, which has also been pointed out by Rowaert et al., 2017.[19] Crucial risk and protective factors such as housing, economy, dual diagnoses treatment, or antipsychotic medication identified by caregivers have also previously been described in case studies and retrospective studies of files and trajectories as well as by the MDOs themselves.[27–34]

According to Askola et al., 2017[20] caregivers felt that they were seen as a burden by members of staff in mental health services and that their views and experiences were not taken seriously. A review by Rowaert et al., 2016[18] confirms that caregivers involved with mentally disordered offenders experience more stress and various burdens than families or networks involved in pathways without offenses and forensic issues and that they need increased information and support. Some challenges reported by caregivers involved with MDOs in this study are similar to experiences of caregivers in general psychiatry in a Danish context.[8,9] However, when a patient also commits offenses and debuts as a mentally disordered offender, caregivers experience an increasing number of challenges and complexities. As a large number of caregivers have previous experience in general psychiatric services, the similarities in experiences and challenges are not that surprising. However, the identification of specific challenges, when involved with MDOs as documented in this study, calls for dedicated interventions aimed at caregivers involved in forensic pathways. What seems urgently in need is the dissemination of specific information, addressing stigma, and establishing formal caregiver groups.

Some of the caregivers describe how they have lacked an introduction to the task as curator. Various practices and information gaps have also recently been described in a governmental report, a report from the Danish Institute for Human Rights as well as in a recent interview study.[11,34,35] One of many tasks for the curator is to overlook that sentences to treatment or placement do not go on longer than necessary. If curators are not well informed or not appointed at all this can be a legal certainty issue and increase the risk of discrimination.

The strain caused by visits to mental health services described by the caregivers is similar to the experiences previously described concerning prison populations. It is well documented how institutionalizationaffects contact and frequency of contact between parents, children, and siblings. Furthermore, it involves a demanding job for caregivers coming to terms with and processing remarkable and chaotic events such as admission, imprisonment, or police contacts.[36]

The experiences with stigma explained by the caregivers in this study reflect what is also described in the Danish research literature on stigma, namely that stigma is added and enhanced when several complex issues are present, for instance, offenses or substance use disorders as well as mental illness.[37] Consequently, efforts to reduce stigma related to MDOs must address such tendencies to double or triple stigma.

Caregivers are often referred to as important carriers of hope and supporters of individual recovery processes according to recovery literature as well as policy papers.[1–7] When asking patients about the roles of the caregivers, there is also no doubt as to the crucial role as carriers of hope consistently performed by caregivers.[31,38] As demonstrated in this study, some caregivers are self-aware and explicitly take on this role, whereas to others it seems less obvious. Although this study has documented numerous burdens and challenges experienced by caregivers, it is worth considering whether this focus may overshadow the strengths and resources also held by caregivers. This could negatively impact the caregivers' perception of themselves as performing a significant role as carriers of hope and supporters of personal recovery processes for their relatives coming to terms with severe mental illnesses and offenses. This risk seems relevant to bear in mind for future research as well as in the development of future forensic psychiatric practices towards caregivers in this field.

Limitations and strengths of the study

The use of individual in-depth semi-structured interviews enables unique access to personal experiences. The caregivers included in this study represent a variety of pathways and experiences.

Several interviews/points of impact with most of the informants have helped towards a deeper understanding of challenges and experiences over time as well as insight into the various stages and phases of the forensic pathways and trajectories they are involved in as caregivers. Furthermore, the caregivers represent various relational roles as siblings, parents, friends, or partners. This is considered a strength of the chosen study design.

Most of the caregivers in this study were already experienced caregivers before the forensic debut, as most patients had been followed in general psychiatry before the offenses were committed. It could be argued that the study lacks representation of caregivers newly debuted or caregivers related to MDOs solely. However, as a substantial part of the MDOs in a Danish context have previously been in contact with mental health services,[32] the included caregivers in this study therefore, match a more general pattern.

The involvementof caregivers can be crucial for the patient and a successful pathway. However, not all patients have sustainable relations with caregivers and not all patients want caregivers involved. In this study, the relations between the majority of caregivers and patients were sustainable and intact, although they in some cases were temporarily substituted with intermittent periods of “hiring and firing”. However, it is important to bear in mind that sustainable relations are not always the case. Some caregivers burn out, some choose to stop being in contact with the patient, or the patient cuts off relations with caregivers. However, this kind of worn-out relationship is not represented in this study.

Conclusion

Caregivers involved with MDOs perform various roles and tasks from practical support to acting as case managers or taking on the responsibility to watch and assess an unstable patient in relapse. Although the tasks are marked by various intensities, they tend to put remarkable pressure and challenges on caregivers. Furthermore, caregivers experience emotional stress such as loneliness, shame, sorrow, and feelings of inadequacy. Caregivers spend a lot of time establishing sustainable narratives about mental illness and offenses to reduce stigma and come to terms with chaotic and significant incidents, and they play an important role as carriers of hope on behalf of the patients to support processes of personal recovery.

The majority of caregivers in this study share a fundamental experience of neither having obtained sufficient support in the pathways leading up to the forensic debut nor being involved or receiving enough and dedicated information while the often long-term sentences to treatment or placement are ongoing. Consequently, caregivers have a hard time supporting MDOs seeking to reduce the risk of recidivism and helping the MDOs leave their involuntary interaction with mental health services behind. There seems to be a remarkable distance between the ideal level of involvement outlined in policy papers and what caregivers experience in practice.

This study has revealed an urgent need to develop and extend support and dedicated efforts aimed at caregivers involved with MDOs.

Declaration of Competing Interest

The author declares no conflict of interest.

Ethics

The study was approved by Datatilsynet (j.nr. 2012-58-004) according to Danish law. All informants received oral and written information about the study before signing a consent form. In vivo citations are used in ways that secure anonymous representations of the informants.

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References

1. Region Midtylland. Politik for samarbejde mellem patienter, pårørende og medarbejdere i Region Midtjylland. Psykiatri og Social [Internet]. 2015 [cited 2022 Jan 14]. Available from: https://www.psykiatrien.rm.dk/siteassets/patient/nar-du-er-parorende/nar-du-er-parorende-til-en-voksen-18/politik-for-samarbejde-mellem-patienter-parorende-og-medarbejdere-i-psykiatrien-i-region-midtjyllland.pdf
2. Region Sjælland. Politik for recovery. Psykiatrien. Region Sjælland [Internet]. 2014 [cited 2021 Nov 14]. Available from: https://www.regionsjaelland.dk/sundhed/geo/psykiatrien/om_psykiatrien/nogletal-politikker-og-planer/politikker/Sider/Recoverypolitik.aspx
3. Region Nordjylland. Politik for inddragelse af patienter og pårørende i Region Nordjylland. Region Nordjylland [Internet]. 2016 [cited 2021 Nov 14]. Available from: https://rn.dk/-/media/Rn_dk/Om-Region-Nordjylland/Strategier-og-politikker/Politik-for-inddragelse-af-patienter-og-paaroerende-i-Region-Nordjylland.ashx?la=da
4. Region Syddanmark. Patient- og pårørendepolitik for Psykiatrien i Region Syddanmark. Psykiatrien i Region Syddanmark [Internet]. 2015 [cited 2022 Jan 14]. Available from: http://www.psykiatrienisyddanmark.dk/wm512572
5. Region Hovedstadens Psykiatri. Handleplan for udvikling og forankring af en recovery-kultur i Region Hovedstadens Psykiatri. Copenhagen: Region Hovedstadens Psykiatri [Internet]. 2019 [cited 2022 Jan 14]. Available from: https://www.psykiatri-regionh.dk/centre-og-social-tilbud/kompetencecentre/Rehabilitering-og-recovery/Publikationer/Docu-ments/FINAL%20-%20Handleplan%20-

%20Udvikling%20og%20forankring%20af%20en%20recovery-kultur%20i%20RHP_WEB.pdf

6. Møllerhøj, J. Recovery, rehabilitering og retspsykiatri — begrebsafklaring og dilemmaer. KFR Arbejdspapir nr. 3. Roskilde: Kompetencecenter for Retspsykiatri, Region Hovedstadens Psykiatri [Internet]. 2019 [cited 2022 Jan 14]. Available from: https://www.psykiatri-regionh.dk/centre-og-social-tilbud/kompetencecentre/kfr/Forskning-og-udvikling/Sider/KFR-arbejdspapirer.aspx
7. Socialstyrelsen & Sundhedsstyrelsen. Koncept for systematisk inddragelse af pårørende. Copenhagen: Socialstyrelsen & Sundhedsstyrelsen. [Internet] 2018 [cited 2022 Jan 14]. Available from: https://socialstyrelsen.dk/udgivelser/koncept-for-systematisk-inddragelse-af-parorende
8. Eckhardt, JP. Belastende livsvilkår: Pejlemærker for personalets møde med pårørende i psykiatrien. Nordisk Tidsskrift for Helseforskning. 2018;14 (2): unpaginated.
9. Bonnesen, K. Pårørende til psykisk syge. Copenhagen: Dansk Psykologisk Forlag; 2014.
10. DEFACTUM. LUP Psykiatri 2018 — Landsdækkende undersøgelse af patient- og pårørendeoplevelser. Aarhus: Defactum; 2019.
11. Rigsrevisionen. Beretning om retspsykiatriske patienters forløb. Copenhagen: Rigsrevisionen [Internet]. 2021 [cited 2022 Jan 14]. Available from: https://rigsrevisionen.dk/revisionssager-arkiv/2021/apr/beretning-om-retspsykiatriske-patienters-forloeb
12. Justitsministeriets Forskningskontor. Nye foranstaltningsdomme i 2019. Copenhagen: Justitsministeriet; 2020.
13. Møllerhøj, J. & Johansen, KS. Kronik: Inklusion gælder ikke for de alvorligt psykisk syge. Altinget; 2017, 5 April [cited 2022 Jan14]. Available from: https://www.altinget.dk/sundhed/artikel/kronik-inklusion-gaelder-ikke-for-de-alvorligt-psykisk-syge
14. https://www.tv2ostjylland.dk/region-midtjylland/sind-kriminelle-far-den-bedste-behandling-i-psykiatrien [cited 2022 Jan14].
15. https://www.tv2east.dk/vordingborg/kvinde-blev-draebt-inde-paa-lukket-afdeling-saadan-noget-maa-ikke-ske-paa-et-psykiatrisk-hospital [cited 2022 Jan 14]
16. Stølan, L.O., Raben, H., Sørensen, L., Brandt-Christensen, M. & Møllerhøj, J.. Kriminalitetsprofiler i en dansk retspsykiatrisk population — udfordringer for psykiatriens kriminalitetsforebyggende opgave? Nordisk Tidsskrift for Kriminalvidenskab; 2016;103 (3): 245-270. Available from: https://tidsskrift.dk/NTfK/issue/view/6949
17. Møllerhøj J, Os Stølan L. 'First and foremost a human being...': user perspectives on mental health services from 50 mentally disordered offenders. Nord. J. Psychiatry. 2018;72(8):593—8. https://doi.org/10.1080/08039488.2018.1502352. Nov 17.
18. Rowaert S, Vandevelde S, Lemmens G, Vanderplasschen W, vander Beken T, vander Laenen F, et al. The role and experiences of family members during the rehabilitation of mentally ill offenders. Int. J. Rehabil. Res. 2016;39(1):11—9. https://doi.org/10.1097/mrr.0000000000000152. Mar.
19. Rowaert S, Vandevelde S, Lemmens G, Audenaert K. How family members of mentally ill offenders experience the internment measure and (forensic) psychiatric treatment in Belgium: a qualitative study. Int. J. Law Psychiatry. 2017;54:76—82. https://doi.org/10.1016/j.ijlp.2017.05.003. Sep.
20. Askola R, Louheranta O, Soininen P, Putkonen H, Åstedt-Kurki P, Paavilainen E. The offense as perceived by the parents of forensic psychiatric patients. Issues in Ment. Health Nurs. 2017;38 (9):705—11. https://doi.org/10.1080/01612840.2017.1326993. Sep 2.
21. Møllerhøj, J. & Stølan, LO. Vendepunkter. Patienters og pårørendes fortællinger og erfaringer med forløb før og efter dom. KFR Arbejdspapir nr. 6. Roskilde: Kompetencecenter for Retspsykiatri, Region Hovedstadens Psykiatri. [Internet]. 2021 [cited 2022 Jan14]. Available from: https://www.psykiatri-regionh.dk/centre-og-social-tilbud/kompetencecentre/kfr/Forskning-og-udvikling/Sider/KFR-arbejdspapirer.aspx
22. Kvale, S. & Brinkmann, S. Interview. Det kvalitative forskningsinterview som håndværk. Copenhagen: Hans Reitzels Forlag; 2015.
23. Malterud, K. Kvalitative forskningsmetoder for medisin og helsefag. Oslo: Universitetsforlaget; 2017.
24. Johannessen, H. På sporet af sammenhænge. In Gildberg, F.A. & Hounsgaard, L., editors. Kvalitative analysemetoder i sundhedsforskning. Aarhus: Klim: 2018. p. 167-179.
25. Skilbrei, M.L. Kvalitative metoder. Planlegging, gjennomføring og etisk refleksjon. Bergen: Fagbokforlaget; 2019.
26. Retsinformation. Bekendtgørelse om bistandsværger nr. 947 af 24/09/2009 [cited 2022 Jan 14]. Available from: www.retsinformation.dk/eli/lta/2009/947
27. Sundhedsstyrelsen. Psykisk syge kriminelles forløb 2005 —2009. Copenhagen: Sundhedsstyrelsen [Internet]. 2011 [cited 2022 Jan 14]. Available from: https://www.sst.dk/-/media/Udgivelser/2011/Publ2011/EFT/Psykiatri/Psykisk-syge-kriminelles-forl%C3%B8b-2005-2009.ashx
28. Region Midtjylland. Kritisk hændelse i psykiatrien i Region Midtjylland 2012. Rapport afgivet af en ekstern undersøgelseskommission. Aarhus: CFK — Folkesundhed og Kvalitetsudvikling, Region Midtjylland [Internet]. [cited 2022" Jan 14]. Available from: https://www.social.rm.dk/siteassets/nyheder/2017/blakargard-2017/rapport_2012_kritisk_haendelse.pdf
29. Region Midtjylland. Redegørelse for "Blåkærgård-sagen". Aarhus: Psykiatri- og socialledelsen, Region Midtjylland [Internet]. [cited 2022 Jan 14]. Available from: https://www.social.rm.dk/siteassets/nyheder/2017/blakargard-2017/redegorelse—blakargard.pdf
30. DEFACTUM. Vold på botilbud og forsorgshjem — Tværgående analyse af 10 cases om voldsepisoder. Aarhus: Defactum [Internet]. 2016 [cited 2022 Jan 14]. Available from: https://www.defactum.dk/publikationer/showPublication?publicationId=596&pageId=309986
31. Stølan, L.O. & Møllerhøj, J. Drømme og muligheder. Hvad er betydningsfuldt i retspsykiatriske pleje-, behandlings- og rehabiliteringsforløb? Hvad har værdi for patienterne? Rapport fra et forskningsprojekt baseret på interviews med 50 retspsykiatriske patienter. Roskilde: Kompetencecenter for Retspsykiatri, Region Hovedstaden Psykiatri [Internet]. 2017 [cited 2022 Jan 14]. Available from: https://www.psykiatri-regionh.dk/centre-og-social-tilbud/kompetencecentre/kfr/Forskning-og-udvikling/Documents/Dr%C3%B8mme%20og%20muligheder%202017.pdf
32. Danske Regioner. Er der en sammenhæng mellem behandling/støtte af psykisk syge og kriminalitet — En analyse med henblik på forebyggende tiltag. Copenhagen: Danske Regioner [Internet]. 2019 a [cited 2022 Jan 14]. Available from: https://www.regioner.dk/media/12261/rapporten-sammenhaeng-mellem-behandling-stoette-og-kriminalitet-30-01-2019.pdf
33. Danske Regioner. Anbefalinger til kriminalitetsforebyggende indsatser målrettet mennesker med psykisk sygdom. Anbefalinger fra arbejdsgruppe til regionernes psykiatridirektører. Copenhagen: Danske Regioner [Internet]. 2019 b [cited 2022 Jan 14]. Available from: https://www.regioner.dk/media/12260/anbefalinger-til-kriminalitetsforebyggende-indsatser-maalrettet-mennesker-med-psykisk-sygdom.pdf
34. Moltke, A. & Lehn-Christiansen, S.. "Jeg satte ild på, fordi jeg tænkte: Nu må de da høre mig, nu må de sgu da hjælpe mig". Erfaringer med psykiatrisk foranstaltningsdom i et recovery-perspektiv. Roskilde: Roskilde Universitet, Institut for Mennesker og Teknologi, Center for Sundhedsfremmeforskning; 2020.
35. Steffensen, T., Frandsen, M.G. & Nielsen, N. Retspsykiatri i et menneskeretligt perspektiv. Copenhagen: Institut for Menneskerettigheder [Internet]. 2019 [cited 2022 Jan 14]. Available

from: https://menneskeret.dk/udgivelser/retspsykiatri-menneskeretligt-perspektiv

36. Scharff Smith, P. & Jacobsen, J.. Når straffen rammer uskyldige. Børn af fængslede i Danmark. Copenhagen: Gyldendal; 2010.
37. Jacobsen, C.B., Martin, H.M., Nøhr, R. & Bengtsson, S.. Stigma og psykiske lidelser — som det opleves og opfattes af mennesker med psykiske lidelser og borgere i Danmark. Copenhagen: Danske Regioner, Danske Sundhedsinstitut and SFI — Det Nationale Forskningscenter for Velfærd; 2010.
38. Møllerhøj J. Offender Recovery. Forensic patient perspectives on long-term personal recovery processes. Int. J. Environ. Res. Public Health. 2021;18(12):6260. https://doi.org/10.3390/ijerph18126260. Jun 9.