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REVIEW ARTICLE



WILEY

Experiences of family caregivers in forensic mental health care—A qualitative evidence synthesis

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Accessible Summary

What is known on the subject?

- Internationally, research and policy agendas recommend that family caregivers of service users in mental health care be involved in care and treatment, to support the service user's recovery process.
- Family caregivers of service users in mental health care are often highly burdened.
- There is a lack of research-based knowledge about the experiences of family caregivers of service users in forensic mental health care (FMHC) and their involvement in care and treatment.

What this paper adds to existing knowledge?

- This study indicates a persistent caregiver presence and/or caregiver advocacy in regard to care and treatment of the service user in FMHC.
- This study indicates that health care professionals (HCPs) might play a role in eliciting a persistent caregiver presence and/or caregiver advocacy.

What are the implications for practice?

- HCPs need to develop their collaborative skills and be more willing to listen to and understand caregivers' persistent presence and/or advocacy.
- HCPs need to be more skilled to understand caregivers' and families' living with the complexities of mental illness and offence.
- HCPs are encouraged to adjust the involvement of family caregivers in care and treatment to FMHC.

Abstract

Introduction: There is a lack of research about experiences of family caregivers of service users in forensic mental health care (FMHC) and their involvement in care and treatment. Research shows that caregivers are burdened. Further knowledge is required, to provide a foundation for improving clinical practice.

Aim: To review research literature, to investigate existing knowledge about caregiver experiences and, secondly, caregivers' experiences of facilitators and barriers related to their involvement in care and treatment.

Method: Qualitative evidence synthesis undertaken in a thematic synthesis of thirteen peer-reviewed studies.

Results: The analysis identified three descriptive themes: violence against family; a great burden of responsibility; and difficult collaboration, together with an additional three analytical themes: bearing witness; persistent presence; and advocacy becomes necessary.

Discussion: Persistent caregiver presence and/or caregiver advocacy may be elicited by health care professionals' (HCPs') exclusion of caregivers from care and treatment. Caregivers' feelings of guilt in relation to the service user's offence may play an additional role in persistent presence and advocacy and, therefore, in HCPs' exclusion of them.

Implications for Practice: HCPs need to develop their collaboration with caregivers by their willingness to listen to caregivers to understand emotional complexities within families experiencing mental illness and offence.

KEYWORD

Family caregiver experiences; forensic mental health care; qualitative evidence synthesis,

1 | INTRODUCTION

This study presents a qualitative evidence synthesis (QES) of family caregiver experiences in forensic mental health care (FMHC). Research has reported on caregivers' experiences in general mental health care (Abou Seif et al., 2022; Cleary et al., 2020); however, little is known about their experiences in FMHC.

Caregiver involvement in care and treatment represents a political objective for the mental health care (National Institute for Health and Care Excellence, 2020). Studies show that caregiver involvement in care and treatment of a person with mental health issues (service user) can have a beneficial effect on service users' medication compliance and can prevent or reduce the length of hospitalization (Ashcroft et al., 2018; Haselden et al., 2019; Javed & Herrman, 2017; Svendsen et al., 2021). Therefore, family caregivers are considered to be an important resource in the care and support of service users (Paradis-Gagne & Holmes, 2021). Empirical studies reveal that, although many caregivers want to support the service user, they experience a burden to the extent that it has a negative effect on their own health (Abou Seif et al., 2022; Lavoie, 2018). The concept of caregiver burden has recently been defined as "... the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020, p. 442). Studies show that caregiver burden in mental health care is linked to several caring responsibilities, high levels of stress, anxiety and depression (Happell et al., 2017; Lavoie, 2018; Shiraishi & Reilly, 2018). Additionally, studies reveal that caregivers' experiences of powerlessness and stigma are exacerbated by a perceived lack of involvement and support from health care professionals (HCPs) (Cleary et al., 2020; Doody et al., 2017; Happell et al., 2017; Lavoie, 2018; Shiraishi & Reilly, 2018). Consequently, caring for a service user can

have negative consequences on the caregiver's state of physical, social and mental health and thereby on their ability to support the service user (Cleary et al., 2020; Lavoie, 2018; Liebherz et al., 2017; Paradis-Gagne & Holmes, 2021; Skundberg-Kletthagen et al., 2014).

Research shows that FMHC caregivers experience similar feelings and burdens to those in general mental health care (Askola et al., 2017; Finlay-Carruthers et al., 2018; Robinson et al., 2017). However, it has been suggested that there is higher caregiver burden among FMHC caregivers, related to the service user's severe mental illness, criminal offence(s) and legal proceedings (Askola et al., 2017; MacInnes & Watson, 2002; Rowaert et al., 2016, 2017; Tsang et al., 2002). Approximately 60%–70% of FMHC service users are diagnosed with schizophrenia and have committed a serious crime (de Tribolet-Hardy & Habermeyer, 2016; Gatherer et al., 2020). Caregivers of a service user with schizophrenia are usually first-degree family members, such as parents. Their roles include helping the service user to access services and providing financial support (Cleary et al., 2020; Gatherer et al., 2020). Supporting a service user can be complex because some service users attempt to or succeed in exerting violence (Gatherer et al., 2020; Hörberg et al., 2015; Kumar et al., 2015), which creates additional emotional distress and burden (Amaresha & Venkatasubramanian, 2012; Cleary et al., 2020; Kumar et al., 2015). Internationally, FMHC represents an intersection of criminal justice, health and social systems. Care and treatment of service users are provided in inpatient and outpatient facilities and in prisons (Barr et al., 2019; Every-Palmer et al., 2014; Sampson et al., 2016). For security reasons, FMHC takes place in a secure environment, with restrictive procedures, such as: limitations on visits or restricted visiting hours. These restrictions have been identified as factors that burden and complicate the relationship between caregiver and inpatient service user. In outpatient facilities, the caregiver

may be burdened by the responsibility for medication, finances and behavioural challenges (Cleary et al., 2020; Gatherer et al., 2020).

In the current study, only one literature review, by Rowaert et al. (2016), was identified with the aim of investigating family caregivers' experiences in FMHC. The review shows that caregivers are socially, psychologically and physically impacted by complex caring roles and lack of help from the health care system. However, the review is limited by a lack of a systematic and comprehensive literature search, critical appraisal and in-depth analysis of the studies included.

To improve support for caregivers and service users and to optimize collaboration between caregivers and HCPs, it is important to increase knowledge about caregivers' experiences in FMHC. We, therefore, considered that an updated systematic review of literature was required. The QES reported in this study systematically investigated caregivers' experiences, in a broad, explorative and analytical manner.

1.1 | Aim

To identify and review existing research literature and investigate both the characteristics of existing knowledge of caregivers' experiences in FMHC and their experiences of facilitators and barriers related to involvement in care and treatment.

2 | METHOD

The current QES, followed the methodological recommendations, as described by Booth (2022), for the application of focused review questions, and a critical appraisal to systematically identify, select, extract and synthesize relevant research literature. Further, the PRISMA Statement recommendations for reporting were followed (Page et al., 2021; Sarkis-Onofre et al., 2021). A review protocol was published in PROSPERO (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021251680).

2.1 | Focused review questions and literature search

The qualitative model of conceptualization PICO (Population, phenomenon of Interest and Context) was chosen to guide the development of the research questions (Aromataris, 2020; Munn et al., 2018). PICO elements are defined as follows:

P (Population) refers to a caregiver/carer/family member/relative/informal caregiver who cares for a family member or significant other (non-family member) (Liu et al., 2020) and is over 18 years of age. I (phenomenon of Interest) refers to experiences, used in broad and explorative terms in the current study, in an attempt to understand health issues broadly, from the experiences and perspectives of the caregiver. Co (Context) refers to all inpatient facilities

(including low, medium and high security levels) and outpatient facilities in FMHC. The research questions were:

1. *What characterizes caregivers' (P) experiences (I) in FMHC?(Co)?*
2. *What characterizes caregivers' (P) experiences of facilitators and barriers (I) related to involvement in the care and treatment of a service user in FMHC?(Co)?*

The PICO elements were used as inspiration in developing a systematic block search (Aromataris, 2020; Munn et al., 2018), which was completed in the databases CINAHL, Medline, PsycINFO and Scopus on March 11 and 12, 2021 and further updated on May 26, 2022, with no further inclusion of studies. The timeline of 2014–2022 was chosen, to follow up on Rowaert et al. (2016). The systematic block search strategy used subject headings (SH), free-text keywords (FT), truncation = * and phrase search and was combined with the Boolean operators OR/AND (De Brún & Pearce-Smith, 2014), as illustrated in Table 1.

2.2 | Study selection

The systematic literature search resulted in 3766 studies. Of these, 1094 duplicates were removed in the EndNote reference management program, followed by an additional removal of 32 duplicates using the data extraction tool Covidence (Covidence, 2020). Title and abstract were screened for 2640 studies, based on the following criteria. Inclusion criteria were: peer-reviewed literature, qualitative and mixed methods studies, studies investigating the experiences and perceptions of adult caregivers over 18 years of age, and caregivers of inpatients and outpatients in FMHC. Exclusion criteria were as follows: quantitative research, reviews, protocols, editorials, comments on papers, and caregivers of service users with intellectual or learning disabilities. In all, 2579 studies were excluded; 61 studies were assessed for eligibility, whereof 48 studies were excluded based on the full-text reading. The selection process resulted in the inclusion of 13 studies. The first and last authors conducted the selection process and the second author was consulted in case of disagreement. The selection process is illustrated in a flowchart, inspired by Page et al. (2021), in Figure 1, and the 13 included studies are presented and reported in a literature matrix (Garrard, 2020) (Table 2).

2.3 | Critical appraisal

The CASP (Critical Appraisal Skills Programme, 2018) tool, for the critical appraisal of qualitative studies, was used to appraise the 13 studies. Based on the inclusion and exclusion criteria, the first author critically appraised all the studies and the second and last authors critically appraised six and seven studies, respectively. The decision to include or exclude studies was discussed among the entire author group. No further studies were removed, as it was possible to

TABLE 1 Systematic block search in databases.

	Block 1	Block 2	Results
CINAHL (EBSCO)	SH: "forensic psychiatry," FT: Forensic psychiat*, SH: "mentally ill offenders," FT: mentally ill offender*, criminal* insan*, FT: "state patient*", FT: forensic mental health, FT: forensic n3 unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital, FT: secure n3 unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital, FT: violent* n3 mental	SH: "family," SH: "extended family," SH: "family relation," SH: "patient-family relation," SH: caregivers, FT: relative* or caregiver* or carer* or "family caregiver*" or "family member*" or "social network*" or "personal network" or "extended famil*" or famil* or "next of kin" or "famil* relation*" or "patient-family relation*," or parent* or spouse* or friend	630
Medline (Ovid)	SH: Forensic Psychiatry, FT: forensic psychiat*, FT: mentally ill offender*, FT: criminal* insan*, state patient*, FT: forensic mental health, FT: (forensic adj3 (unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital)), FT: (secure adj3 (unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital)), FT: violent* adj3 mental	SH: caregivers, SH: Family, SH: family relations, FT: (relative* or caregiver* or carer* or family caregiver* or family member* or social network* or personal network or extended famil* or famil* or next of kin or famil* relation* or patient-familyrelation* or parent* or spouse* or friend*).mp.	1581
PsycINFO (Ovid)	SH: forensic psychiatry, SH: mentally ill offenders, FT: forensic psychiat*, FT: mentally ill offender*, FT: criminal* insan*, state patient*, FT: forensic mental health, FT: (forensic adj3 (unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital)), FT: (secure adj3 (unit* or ward* or department* or setting* or facilit* or care or service* or institution or hospital)), FT: violent*adj3 mental	exp family/ or exp extended family/exp family members/ or exp caregivers/exp family relations/ exp social networks/, FT: (relative* or caregiver* or carer* or family caregiver* or family member* or social network* or personal network or extended famil* or famil* or next of kin or famil* relation* or patient-family-relation* or parent* or spouse* or friend*).mp.	927
Scopus	FT: "forensic psychiat*", FT: "mentally ill offender," FT: "forensic mental health," FT: criminal* insan*, state patient*, FT: "forensic W/3 unit*" or "forensic ward*" or "forensic department*" or "forensic setting*" or "forensic facilit*" or "forensic care" or "forensic service*" or "forensic institution" or "forensic hospital," FT: "secure W/3 unit*" or "secure ward*" or "secure department*" or "secure setting*" or "secure facilit*" or "secure care" or "secure service*" or "secure institution" or "secure hospital," FT: TITLE-ABS-KEY(violence W/3 mental)	FT: relative* or caregiver* or carer* or "family caregiver*" or "family member*" or "social network*" or "personal network" or "extended famil*" or famil* or "next of kin" or "famil* relation*" or "patient-family relation*" or parent* or spouse* or friend*	628
Total result			3766

answer "yes" to the first two questions in CASP, as recommended by Booth (2022) and Butler et al. (2016) for the inclusion of studies. Integrated score results were integrated into the matrix in the right-hand column (Table 2), to illustrate a generally high score of the studies included in the current QES.

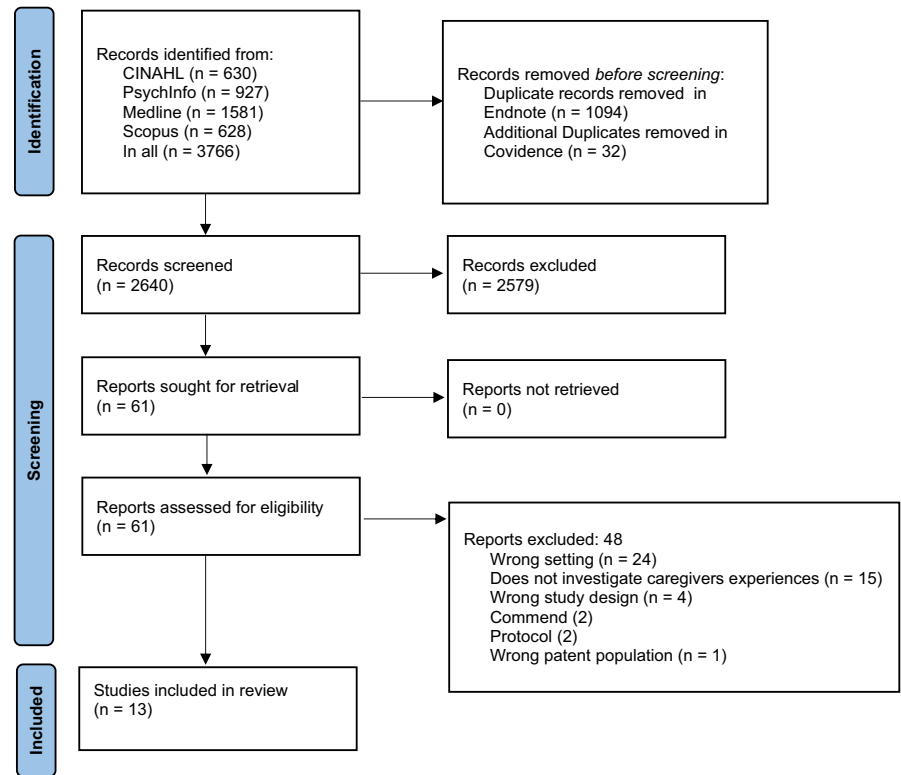
2.4 | Thematic synthesis of selected studies.

A thematic synthesis, as described by Thomas and Harden (2008), was applied, in three steps:

In step 1, a "line-by-line coding" of the results of the included studies was carried out, and at least one definition code was applied to each paragraph. The above process developed into step 2, in which interrelated "descriptive themes" were developed, using the descriptions similar to those of the Results sections of the included studies. In step 2, the descriptive themes answered the first research question—"What characterizes caregivers' experiences in FMHC?" In step 3, interrelated "analytical themes" were derived

from the descriptive themes, thus also answering the first research question. Further, as a key aspect of QES, step 3 went: "...beyond the findings of the primary studies to generate additional concepts, understandings or hypotheses" (Thomas & Harden, 2008, p. 7). QES was chosen as a method, to arrive at a new and enhanced understanding about the phenomenon under investigation, which is crucial in the development of clinical interventions (Booth, 2022; Thomas & Harden, 2008). In answering the research questions, we extracted the essential elements from the descriptive themes, which then shaped the analytical themes. The analytical themes thus represented additional understandings of caregivers' experiences, based on the descriptive themes and underlined by results from the studies included in the current QES. In line with Thomas & Harden, this third step is an interpretive step, and the value of its outcome depends on the reviewers' judgement and insights. Subsequently, to answer the second research question—"What characterizes caregivers' experiences of facilitators and barriers related to involvement in the care and treatment of a service user in FMHC?"—focus was additionally placed on facilitators and barriers regarding involvement in care

FIGURE 1 PRISMA Flow Diagram of the study selection process.



and treatment in the analytical themes, based on the caregivers' experiences.

3 | FINDINGS

The international studies included in the current QES are presented in the literature matrix (Table 2), by country, aim, methods, sample and population, findings and CASP scores. In total, 131 caregivers were included across 13 studies. These were mothers and fathers (parents), siblings, sisters, brothers, grandparents, uncles and aunts (non-parents). The study by Livingston et al. (2016) did not report the informants' gender ($n = 13$) (unspecified gender). Siblings ($n = 4$) were also reported without specifying gender (Rowaert et al., 2017). The majority of the informants were female family caregivers ($n = 78$), with mothers ($n = 51$) representing the single largest uniform group of informants. Of the male caregivers ($n = 36$), fathers represented ($n = 26$). Because the two studies, by Paradis-Gagné, Holmes, and Jacob (2020); Paradis-Gagné, Holmes, and Perron (2020), used the same informants twice, they were counted only once. The composition of caregiver informants by gender and relation to service user is illustrated in Figure 2.

3.1 | Thematic synthesis

The analysis resulted in three interrelated descriptive themes: *violence against family*; *a great burden of responsibility*; and *difficult*

collaboration, together with three interrelated analytical themes: *bearing witness*; *persistent presence*; and *advocacy becomes necessary*.

Caregivers were included from both inpatient and outpatient facilities in the studies included in this QES, and generally no distinction was made between inpatient and outpatient facilities in the findings in the studies.

3.1.1 | Descriptive theme: violence against family

The characteristic of this theme was that violence had become a "normal" condition of life for many caregivers and their families.

The majority of caregivers and families had been exposed to mental and physical violence by the service user over many years (Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Lavhelani et al., 2020; Livingston et al., 2016; Mothwa et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). In many cases, the criminal offence(s) had been directly targeted at the family (Lavhelani et al., 2020; Livingston et al., 2016; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020; Tingleff et al., 2019). The following example illustrated violence against a mother: "I am afraid of his bad conduct, that if he comes back, he will raise trouble. He also hit me with his fist and two of my teeth fell out" (Lavhelani et al., 2020 p. 5). Violence was also characterized by service users' episodes of strangulation attempts on siblings, or threats to burn the house down with family members inside. This led to a heightened security behaviour of storing or hiding knives or putting locks on doors for protection (Chemerynska et al., 2020;

TABLE 2 Matrix of studies included ($n = 13$). The content in the italics refers to elements that are not included in the current QES.

Authoris, year, country & journal	Aim	Methods	Sample and study population	Findings	Casp score
Askola et al., 2017, Finland Issues in Mental Health Nursing	To describe the views of forensic psychiatric patient's parents, and especially how they feel about the patient's offence	Interviews Inductive content analysis	7 caregivers; 6 mothers +1 father	The findings suggest that the offence committed has a significant effect on the lives of parents of forensic psychiatric patients and in many ways these people felt like a marginalized group even though they were frequently a mayor resource for their child who had been taken into forensic psychiatric care.	19
Chemerynska et al., 2020, England Journal of Forensic Psychology Research and Practice	To examine the experiences of carers and ascertain their needs	Focus group interviews and individual interviews Thematic analysis	6 caregivers; 5 females +1 male	Findings suggest that some improvements have occurred over the past years in support of carers and in service provision for their loved one's treatment. However, more improvements are urgently needed because carers continue to experience emotional burden, feeling excluded by services, and strain from their caring responsibilities.	16
Finlay-Carruthers et al., 2018, UK International Journal of Mental Health Nursing	To undertake a detailed examination of the experience of parents who have an adult child diagnosed with a mental illness receiving compulsory treatment and support in a forensic mental health unit	Semi-structured interviews Interpretative Phenomenological analysis	6 caregivers; 3 mothers +3 fathers	The onset of the mental distress narrated as overwhelming, frightening and confusing with experiences of violence. Services were seen as invalidating, and interactions with them characterized as a battle. Poor information and involvement were a common experience. Whilst diagnosis was a relief to some, the ongoing sense of loss and burden were clear. Staying connected and hopes for the future were described. Mental health services need to engage and foster trust and support for this group.	18
Goodman et al., 2020, UK International Journal of Mental Health Systems	To explore the perceived barriers and facilitators to effective de-escalation from a high-secure patient, carer and staff viewpoint	Semi-structured Interviews (by phone or face-to-face) Framework analysis	4 caregivers; 4 females +12 patients, +25 staff	Strong staff-patient therapeutic relationships underpinned by trust, fairness, consistency and an awareness of the trauma-aggression link were considered key to successful de-escalation. Specific psychological and interpersonal skills including empathy, respect, reassurance, sincerity, genuine concern and validation of the patient perspective are needed to achieve this. Barriers related to the physical environment; organizational resources, practices and systems; staff traumatization; hierarchical and punitive attitudes towards patient care, and an insufficient understanding of psychiatric diagnoses, especially personality disorder. It was apparent across themes that fear, which was experienced by both staff and patients, was a driver for many behaviours.	15
Lavhelani et al., 2020, South Africa South African Journal of Psychiatry	To determine the perceptions of family members regarding reintegration of male state patients into their families	In-depth interviews Thematically analysed using Tech Open Coding Method	10 caregivers; 3 mothers +2 sisters +2 daughters +1 grandmother +1 uncle +1 brother	Data revealed that family members have varied perceptions regarding reintegration. These perceptions were based on the behaviour displayed or an offence committed by the mental healthcare user before admission and how participants experienced it.	16



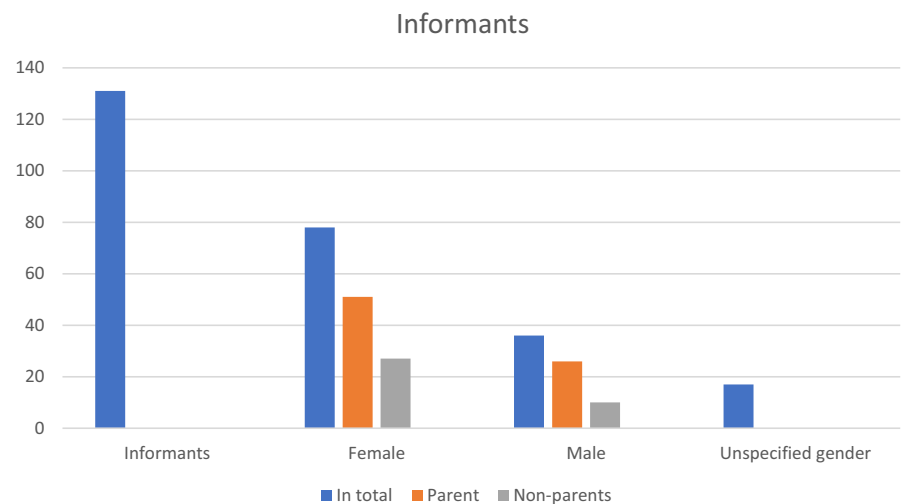
TABLE 2 (Continued)

Authoris, year, country & journal	Aim	Methods	Sample and study population	Findings	Casp score
Livingston et al., 2016, Canada Psychology, Public policy, and Law	To examine the experiences and perceptions about RB (Criminal Code Review Boards) processes from the perspectives of people found NCRMD, their family members, and legal or mental health professionals	Interviews Thematic analysis	13 family caregivers +26 NCRMD: people found "not criminally responsible on account of mental disorder," +16 professionals	Although, people found NCRMD and others were generally perceived to be treated respectfully and fairly during RB hearings, the participants also identified opportunities for strengthening procedural justice.	17
Mothwa et al., 2020, South Africa South Africa Journal of Psychiatry	To explore and describe the challenges experienced by families caring for mental state patients who are on leave of absence	Unstructured in-depth interviews Thematic analysis	9 caregivers; 5 males +4 females	Challenges related to state patient's behaviour like emotional challenges and social challenges and mental healthcare professionals may use these results to design therapeutic interventions for family members of state patients who focus on empathetic understanding and the mobilization of effective coping skills and social support.	18
Paradis-Gagné, Holmes, & Jacob, 2020, Canada (a) Journal of Research in Nursing	To explore the experience of families dealing with the complex reality	Semi-structured interviews Grounded theory	14 caregivers; 5 mothers +1 sister +1 daughter +1 niece +1 grandmother +4 fathers +1 uncle	Families are governed through specific mechanisms, including instrumentalization of the family's role and transfer of the violent person's care to the family. Obstacles preventing families from being included in their relative's care were also raised.	18
Paradis-Gagné, Holmes, & Perron, 2020, Canada (b) Journal of Forensic Nursing	To investigate experiences of family violence committed by a relative with severe mental illness	Semi-structured interviews Grounded theory	14 caregivers; 5 mothers +1 sister +1 daughter +1 niece +1 grandmother +4 fathers +1 uncle	Families are encouraged (and sometimes forced) to assume greater responsibility for taking care of their sick relative without necessarily receiving the required support or resources. This instrumentalization of the family has significant iatrogenic effects, including an increased burden and psychological distress. A conflict within the roles of participants, who act as agents of both care and social control within the family, was identified. These opposing mandates create emotional ambivalence and significant moral distress.	18

TABLE 2 (Continued)

Authoris, year, country & journal	Aim	Methods	Sample and study population	Findings	Casp score
Robinson et al., 2017, UK Journal of Forensic Psychology Research and Practice	To explore carer experiences of forensic mental health services, in terms of their relationship and engagement with the service	Semi-structured interviews Interpretative phenomenological analysis	6 caregivers; 3 fathers +2 mothers +1 sister	The role of carers in the forensic mental health service is complex with competing demands. These results are a step towards understanding the views of this carer group.	20
Rowaert et al., 2017, Belgium International Journal of Law and Psychiatry	To investigate how family members experience the mental illness, the internment measure, and the (forensic) psychiatric treatment of their relatives	Semi-structured interviews Thematic analysis (Braun & Clarke, 2006)	27 caregivers; 13 mothers +6 fathers +4 siblings +2 daughters +1 uncle +1 aunt	The experiences of family members indicate the need for improved treatment guidelines that allow earlier compulsory interventions to prevent crime and preferential admission to (forensic) psychiatric facilities rather than prisons. In addition, family members expressed the need for better communication from mental health professionals and the judicial system during the process and greater availability of peer support.	18
Sampson et al., 2019, United Kingdom International Journal of Forensic Mental Health	To explore the experiences of carers of longstay patients in low- to high-secure forensic care	Focus group interviews and written responses Thematic analysis (Braun & Clarke, 2006)	14 caregivers; 9 mothers +4 fathers +1 grandmother	Focus groups identified importance of communication, and improving carer knowledge of services as methods of meaningful inclusion in treatment and recovery.	18
Tingleff et al., 2019, Denmark Journal of Forensic Nursing	To investigate the perceptions held by forensic psychiatric patient's relatives of MR (medical restraint) and what they perceive as factors impacting the use and duration of MR	Semi-structured interviews Thematic analysis	15 caregivers; 10 mothers +5 fathers	Some parents considered that staff used MR as a necessary protection of their son/ daughter. However, most parents held strong negative perceptions regarding the use of MR, and quality and safety of care provision. It is apparent that parents believed that should be involved in the care in situations associated with the use of MR, because they considered this could reduce its use.	16

FIGURE 2 Composition of caregiver informants by gender and relation to service user.



Finlay-Carruthers et al., 2018; Lavhelani et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). Because of their experiences, the caregivers reported anxiety, fear, hypervigilance and exhaustion (Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Jacob, 2020). One caregiver referred to the impact on a sibling of the actions of a service user, described as: “(Violence), it stays for life, afterwards. Those images never go away” (Paradis-Gagné, Holmes, & Perron, 2020, p. 113).

Some caregivers had called the police because of threats and violence. Nevertheless, the service user was discharged shortly after hospitalization and this meant that the family was left to wait for the next violent escalation (Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Perron, 2020). If the service user was an outpatient, it was up to the family to prove the violence. One caregiver described this caregiver position of helplessness by giving an example of a police officer's response to them as a family: “Sort it out for yourselves. You are all to blame when you have a fight” (Askola et al., 2017, p. 706). As described in the studies by Paradis-Gagné, Holmes, and Perron (2020) and Finlay-Carruthers et al. (2018), danger became a somewhat “normal,” ongoing risk condition, leaving the caregivers and families feeling powerless and vulnerable.

3.1.2 | Descriptive theme: a great burden of responsibility

This theme represented characteristics of caregivers' sense of responsibility and burden in relation to the service user.

Many caregivers reported having practical roles, such as looking after the service user's finances, administering medication and seeking help from the mental health system or legal aid on behalf of the service user (Askola et al., 2017; Finlay-Carruthers et al., 2018; Mothwa et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). Paradis-Gagné, Holmes, and Jacob (2020) described that, sometimes, if an inpatient had an exit permit, HCPs planned a home visit for the service user. This pressured the caregiver to feel responsible for caring for the service

user, regardless of the fact that they lacked sufficient energy to do so. In Chemerynska et al. (2020) and Rowaert et al. (2017), caregivers described that the magnitude of practical and psychological obligations were burdensome for them.

Many caregivers' sense of responsibility was also linked to the service user's future. In this regard, they worried about a further offence (Chemerynska et al., 2020; Mothwa et al., 2020; Rowaert et al., 2017; Tingleff et al., 2019), and about who would take care of the service user, if they were no longer able to do so, due to old age or death (Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Jacob, 2020; Robinson et al., 2017). This example illustrated one caregiver's concern:

“We are both ill and neither of us (parents) know the minute we are not going to be here, and there's going to be a big change because we can't see anybody going there and looking after her” (Finlay-Carruthers et al., 2018, p. 1540).

In Finlay-Carruthers et al. (2018), caregivers described how struggling to get support from the HCPs led to caregiver acceptance of ongoing responsibilities for the service user. This current theme connected to the theme “violence against family.” For example, if the service user refused to take medication or felt pressured to do so, while at home on a visit, it could become very burdensome for the caregiver and the rest of the family, if the service user reacted in a violent manner, as a result of not taking their prescribed antipsychotics or sedative medication (Lavhelani et al., 2020; Mothwa et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). Thus, caregivers seemed to be faced with a dilemma: not only did they have the responsibility to provide care, they were also a controller and, at the same time, had to consider the care and safety of themselves and other family members (Paradis-Gagné, Holmes, & Perron, 2020).

3.1.3 | Descriptive theme: difficult collaboration

Caregivers' experiences of feeling excluded from the service user's care and treatment characterized this theme.

Overall, caregivers reported that they usually found collaboration with HCPs to be difficult, as illustrated in the following example:

"They work in their towers, they could not care less about the family...the doctors don't care about us, they don't talk to us, they don't ask us anything..." (Paradis-Gagné, Holmes, & Perron, 2020, p. 114).

Caregivers had the perception that they were considered to be outsiders, and or not taken seriously in their opinions and knowledge regarding the service user's health, and this led to them feeling ignored and excluded from the care and treatment (Askola et al., 2017; Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Perron, 2020; Robinson et al., 2017; Rowaert et al., 2017; Sampson et al., 2019). Several caregivers pointed out that HCPs often gave their "duty of confidentiality" as the reason for not responding to caregivers' questions or concern regarding (the service user's) health and treatment, and this led to caregivers feeling excluded (Chemerynska et al., 2020; Paradis-Gagné, Holmes, & Perron, 2020; Sampson et al., 2019; Tingleff et al., 2019).

Many caregivers experienced immediate relief from burdens and monitoring while the service user was admitted (Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Livingston et al., 2016; Paradis-Gagné, Holmes, & Perron, 2020; Robinson et al., 2017). However, when caregivers felt they were ignored and excluded by HCPs, they lost trust in the care and support of the service user provided by HCPs (Askola et al., 2017; Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Goodman et al., 2020; Rowaert et al., 2017; Sampson et al., 2019; Tingleff et al., 2019). This theme connected to the theme "a great burden of responsibility," in the sense that, when caregivers struggled to be involved and supported in regard to care and treatment, they took more responsibilities upon themselves.

3.1.4 | Analytical theme: bearing witness

This analytical theme "bearing witness" was derived from the descriptive themes "violence against family," "a great burden of responsibility" and "difficult collaboration," supported by lines of arguments from the included studies.

The theme was characterized by caregivers' comprehensive knowledge of service users' emotional, social and behavioural patterns. As close observers over several years, in communication and relationship with the service user, witnessing was the basis for observing and becoming knowledgeable about changes in those patterns.

The service user's behavioural patterns could change either gradually or suddenly, and could include tiredness or confusion, chuckling or talking to oneself, fear, isolation, being delusional, having psychotic episodes or an escalation in the level of aggression (Askola et al., 2017; Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020; Rowaert et al., 2017; Sampson et al., 2019). Askola et al. (2017) and Finlay-Carruthers et al. (2018) showed that change of behaviour in the service user could also relate to taking intoxicants, such as drugs and alcohol. Caregivers often experienced that

HCPs ignored caregivers' comprehensive knowledge of the service user, such as warning signs or in situations where caregivers could help predict or prevent escalation of violence, based on their knowledge of the service user's trigger points (Askola et al., 2017; Chemerynska et al., 2020; Goodman et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Rowaert et al., 2017; Tingleff et al., 2019). The following quotation is an example that illustrated the above point:

"I have warned, and warned and warned the hospital, I warned his (staff) carer, the social worker, how bad things were. I almost feel like (son) had to get as bad as he did, before I got help for him" (Chemerynska et al., 2020, p. 6).

Caregivers experienced and perceived that their comprehensive knowledge of the service user was a potential facilitator in their involvement in care and treatment. However, when the caregiver felt ignored, despite such knowledge, and excluded by HCPs from care and treatment, this could lead to feelings of anger, disempowerment and distrust (Askola et al., 2017; Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Sampson et al., 2019). To a very high degree, caregivers were found to perceive this exclusion of their knowledge as a barrier to their involvement.

3.1.5 | Analytical theme: persistent presence

This theme was characterized by most caregivers being very persistent in taking care of the service user, to a point where they lived their lives with an almost constant focus on their ill family member.

The current theme "persistent presence" connected to the theme "bearing witness" and was derived from "violence against family," "a great burden of responsibility" and "difficult collaboration." On witnessing a change in the service user's behaviour, they became and remained alert and vigilant (Finlay-Carruthers et al., 2018; Mothwa et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). Staying alert was induced by caregivers' need to protect family members/others or themselves, or to protect the service user from her/himself (Mothwa et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020). Caregiver hypervigilance resulted in a behaviour that meant that they wanted to be constantly present at the service user's side. They adapted their lives so that everything revolved around the service user and minimized time spent with other family members, partners, friends or at work (Askola et al., 2017; Chemerynska et al., 2020; Paradis-Gagné, Holmes, & Jacob, 2020; Paradis-Gagné, Holmes, & Perron, 2020; Robinson et al., 2017). A mother described this involvement in the following quotation: *"...He used 80% of my strength. My other son used 20%..."* (Paradis-Gagné, Holmes, & Jacob, 2020, p. 669). Additionally, some caregivers indicated that the needs of the service user came above all others' needs. In the following example, a service user's mother accepted her brother's choice not to let his children be around the service user. However, she referred to her brother's concern and protection of his children with

the statement that "he is entitled to his fears." Further, she did not approve of the brother's choice, because she said the service user loved the children, indicating that the service user and the children would not have been kept apart, if it had been up to her.

"My brother didn't want (my son; service user) to be there at all when he's there, with his kids...I didn't approve, but I understood. But it is too bad, because (my son) loved his kids...My brother is entitled to his fears..." (Paradis-Gagné, Holmes, & Perron, 2020, p. 113).

The fact that caregivers' lives revolved entirely around the service user could illustrate a facilitating factor, in the sense that the caregivers gave of themselves unconditionally and were persistent in their support and thereby showed resourcefulness and willingness to be involved in care and treatment. Nevertheless, they expended a lot of energy in maintaining this persistence.

3.1.6 | Analytical theme: advocacy becomes necessary

Characteristics of this theme was that some caregivers were of the perception that the service user was unfairly treated and/or victimized by the healthcare system or by HCPs, which could create the foundation for, what may be described as caregivers advocating for the protection and rights of the service user.

This current theme connected to the theme "persistent presence" and was derived mainly from the descriptive themes "difficult collaboration" and "violence against family." This was because the theme illustrated how, by their persistent presence and advocacy, caregivers tried to protect the service user from her/himself, or to protect others from the service user.

Maintaining the service user's identity and fighting for better conditions for the service user (Finlay-Carruthers et al., 2018) seemed to be the intention in caregiver advocacy. For example, some caregivers fought for better treatment conditions for the service user because they experienced that the service user gained weight, smoked too much and were too sedated in the care of the HCPs (Livingston et al., 2016; Tingleff et al., 2019). Advocacy may be regarded as a strength and a facilitating factor, when it comes to persistently standing up for the patient's wellbeing and recovery process.

In Rowaert et al. (2017), a third of the caregivers had hired legal aid counsellors to support the service user in court, to be "one step ahead" of the HCPs. Caregiver perceptions of the service user as sometimes being victimized seemed to "fuel" advocacy. Overall, caregivers felt guilt or blamed themselves, or others, instead of blaming the service user for the criminal offence(s), potential criminal offences and/or the service user's diagnosis (Askola et al., 2017; Chemerynska et al., 2020; Finlay-Carruthers et al., 2018; Paradis-Gagné, Holmes, & Perron, 2020; Rowaert et al., 2017; Tingleff et al., 2019). In the following example, a caregiver described how a doctor was considered to be responsible for the service user's potential harm to herself or someone else. The service user was not considered to be the responsible party. Rather, the caregiver

regarded the service user as a potential victim of the doctor's lack of responsibility, should harm had come to the service user or someone else:

"The doctor says, 'to her' 'Ach you'll be alright, I'll give you a couple of pain killers, go away on home there, you'll be okay'. I say, I want you to repeat what you just said in front of a witness, because when she goes outa here and harms herself or somebody else, I'm taking you to court" (Finlay-Carruthers et al., 2018, p. 1539).

Other indications of victimization included situations where a caregiver did not believe there had been a crime, or believed that the patient had been falsely accused (Mothwa et al., 2020). In the study by Askola et al. (2017), some caregivers directly described the service user as a victim or that they could not be held accountable for the offence, because, for example, it was committed in connection with a psychotic episode or other states of mental illness (Askola et al., 2017; Lavhelani et al., 2020). In Tingleff et al. (2019), caregivers considered that the service user had been unfairly treated or was a victim, due to lack of professional care. Caregivers believed that the service user's subsequent disruptive behaviour and/or the use of mechanical restraint could have been avoided, had the HCPs been more tolerant of disruptive behaviour (Goodman et al., 2020; Tingleff et al., 2019). Caregivers may have higher tolerance for threats, because of prolonged exposure to them and they have been to some extent "normalized," and therefore, expectations that are different to those of the HCPs. Another example of distrust, related to victimization of the service user, was illustrated by a caregiver reflecting on the service user's recovery chances in FMHC:

"If my son is ill, can we focus on treating his illness and not on the custodial side of things and therefore, more freedom? Why are we concentrating on freedom when we are talking about recovery and treatment?" (Sampson et al., 2019, p. 310).

Caregivers were not sure whether it was more appropriate to describe the HCPs as prison guards, custodians or professionals with focus on quality of care for the service user (Sampson et al., 2019). The above statement illustrated a distance between the caregiver and HCP, and could be a further reason why caregivers believed that they needed to advocate for the service user. In their perception, advocacy seemed to be a facilitating position in their effort to be involved in care and treatment.

4 | DISCUSSION

This QES indicates that caregivers feel excluded from care and treatment and experience a lack of collaboration with the HCPs in managing the service user's challenges in FMHC. These barriers may lay the foundation for caregivers' "persistent presence" and "advocacy becomes necessary."

Similar findings of caregiver exclusion and lack of collaboration are reported in a systematic review of informal caregiver experiences in general mental health care, by Abou Seif et al. (2022). In their study, caregivers described that they did not have collaboration



with HCPs and had concerns about the quality of care for the service user. In this current study, in FMHC, caregivers take upon themselves a persistent presence and/or advocacy in the attempt to protect, not only the service user but also other people, in an effort to prevent the service user committing a new offence, as described in the analytical themes “persistent presence” and “advocacy becomes necessary.” Further, these two themes also reflect that caregivers are concerned about whether the HCPs have focus on quality of care for the service user. In this regard, in comparison to general mental care, service users in FMHC have been identified to have more health problems related to weight gain, medication, smoking and inactivity (Pedersen et al., 2021, 2022). Additionally, for service users in FMHC, there is a greater risk that sanctions last much longer compared to people without mental health issues who commit criminal offences (The Danish institute for human rights, 2019). All these things considered, and with caregivers having restricted access to service users in inpatient facilities, caregivers may be concerned about the service user's health in the care of HCPs. The fact that caregivers are restricted when visiting inpatient facilities, for example regarding visiting hours, locked doors, etc., may underline their perception of HCPs as prison guards instead of professionals with focus on quality of care.

Studies indicate that exclusion of caregivers in FMHC are not only represented by caregivers' experiences and perceptions but also by HCPs' attitudes towards caregivers (Gatherer et al., 2020). According to the interview study by Hörberg et al. (2015), about HCPs' engagement with families in FMHC, the HCPs considered that most caregiver behaviours constituted a barrier to their own involvement in care. Their study show that caregivers did not want to collaborate with HCPs and tried to take control of the service user's care and treatment (Hörberg et al., 2015). Therefore, the HCPs found it necessary to maintain control over the family, so that caregiver involvement was conducted on terms set by the professionals. The fact that, in Hörberg et al.'s study, HCPs were of the opinion that caregivers' involvement should be on HCPs' terms could perhaps contribute to caregivers maintaining a persistent presence and turning to advocacy because the HCPs' opinions “fuel” lack of collaboration, disempowerment, anger and distrust in the caregivers. Consequently, it can be that HCPs, perhaps inadvertently, elicit caregivers' persistent presence and/or that advocacy becomes necessary. If so, HCPs may actively co-create what they themselves consider to be the problem regarding the involvement of caregivers in care and treatment, that is that some caregivers may become or seem manipulative and troublesome as described by Hörberg. It appears that these exact caregiver attitudes are those that may arise when caregivers are ignored, disempowered and excluded from care and treatment.

According to our current study and other research studies (Finlay-Carruthers et al., 2018; Gatherer et al., 2020; Robinson et al., 2017; Rowaert et al., 2017; Sampson et al., 2019), the above descriptions of caregiver exclusion exemplify the inconsistency between the political objective to involve caregivers in service users' care and treatment (National Institute for Health

and Care Excellence, 2020) and applied practice. This is further documented in a recent study by McPherson and Oute (2020) that explores numerous guideline papers concerning political requirements for “caregiver involvement” in care and treatment related to depression, in Denmark and the UK, between 2004–2020. Their analysis shows that there is a risk of placing responsibility—and thereby burden—on caregivers regarding caregiving, because the guidelines are too simplistic and do not account for the complexity within an individual family context concerning the service user's specific diagnosis, illness trajectory and treatment and interactions among family members. Our current study shows that, in outpatient facilities, caregivers may feel pressured by home visits and having responsibility for medication and finances. In addition, caregivers and families may be exposed to violence, for example, if they are ignored by HCPs when they ask for help. This indicates that burdensome responsibilities are placed on caregivers and that they need support from HCPs to reduce their level of responsibility.

HCPs may inadvertently elicit caregivers' persistent presence and/or advocacy, by excluding them. However, it could be argued that this factor cannot be determined solely by caregivers being excluded and/or feeling excluded. In taking on caring responsibilities, caregivers may experience feelings of guilt. “Persistent presence” and “advocacy becomes necessary” reflect the fact that, for some caregivers, most of their time, focus and efforts revolve around the service user, and this may indicate feelings of guilt. In this regard, caregiver guilt feelings are precisely characterized in research by constant and persistent help-giving behaviours, which reflect a need to compensate for the disease, or challenges for which caregivers consider themselves responsible in relation to the service user (Cherry et al., 2017; Hatfield, 1981). In our analytical themes, it was described that caregivers try to compensate for lack of professional caregiving if they do not trust HCPs' care and treatment, and/or if they blame themselves for the criminal offence(s) or diagnosis. In relation to the service user's diagnosis, experiences of guilt are reported in the study by Cherry et al. (2017), which explores the links between guilt, shame, emotional over-involvement (EOI) and critical components (CC)/hostility in caregivers of people with long-term mental health difficulties in general mental health care. Cherry et al. (2017) confirm that guilt seems to be associated with EOI, and describe how EOI is one of the components in expressed emotions (EE), that is caregivers' attitudes and emotions towards a family member with mental illness and the behavioural patterns within the family. EOI towards family members with schizophrenia and borderline personality disorder are the respective focal points in the research studies by Amaresha and Venkatasubramanian (2012) and Bailey and Grenyer (2015). In their studies, EOI is characterized as self-blame, and involves sacrificing almost everything other than the needs of the service user, including one's own and others' needs. It can include extreme and exaggerated overprotectiveness of the service user, which can cause reduced self-confidence in service users and delay recovery. These descriptions of EOI are highly

reflected in the themes "persistent presence" and "advocacy becomes necessary."

In the current study, it cannot be ascertained if caregiver guilt feelings and/or EOI increase in relation to HCPs' exclusion of caregivers in FMHC. It, therefore, remains unclear if caregiver guilt feelings and/or EOI are more significant in FMHC, and whether there is a difference between inpatient or outpatient facilities, in comparison to general mental health care. Neither can it be ascertained if caregiver guilt feelings and/or EOI might complicate HCPs' support of caregiver involvement in the care and treatment. In the latter circumstance, caregiver guilt feelings and/or EOI could become a barrier in the collaboration between caregivers and HCPs in FMHC and may partly explain why HCPs would find it difficult to involve caregivers in care and treatment.

4.1 | Strengths and limitations

CASP is the most commonly applied appraisal tool in assessing quality in qualitative research within health sciences (Long et al., 2020); all the studies included in the current QES were assessed to be of high quality in CASP (Table 2).

A total of 10 out of the 13 (Table 2) studies did not have a focal point quite in line with the current study's research questions. This can illustrate that most of the studies are of a less explorative character than desired. An example is Askola et al. (2017), which had a specific focus on how the parents felt about the service user's criminal offence(s). However, the parents also described their experiences broadly. In two studies, caregivers were one type of informant among other groups of informants (Goodman et al., 2020; Livingston et al., 2016); only the perspectives of the caregivers were included in our study. Further, the research questions in the latter mentioned two studies were not primarily aimed at caregivers' experiences, nor was an explorative approach taken. Rather, the focus was mainly on their experiences concerning, for example, implementation processes. Nevertheless, the caregivers described experiences regarding collaboration with HCPs or knowledge concerning care and treatment. Consequently, those studies' findings were included to a lesser degree in the analysis, than those of the other studies.

In regard to the thematic synthesis method, which was guided by Thomas and Harden (2008), caregivers in the included studies were not directly interviewed about their experiences of barriers and facilitators in relation to their involvement in care and treatment. However, it was possible to identify and interpret from caregiver descriptions what could act as a barrier or a facilitator, by conducting the analytical, third step of the method.

4.2 | Implications for practice and research

The current QES, set in FMHC, helps to form an understanding that some family caregivers' development of persistent presence

and/or advocacy may indicate at one and the same time both a resourcefulness and a reaction that is burdensome to family caregivers of the service user. Therefore, an important implication arising from the current QES is a need for HCPs to develop an acknowledging and caring attitude towards caregivers' complex reasons for their persistent presence and advocacy, and thereby improve their support of and collaboration with caregivers. In this regard, nurses both have a duty and skills to support caregivers (The International Council of Nurses, 2022; Völlm, 2019), for example with reference to the concept of attentiveness as described in Halldorsdottir's (2012) nursing theory. Attentiveness is in Halldorsdottir (2012) defined as paying close attention to the comfort and wishes of the patient and family and thereby empower them to express themselves, by listening and responding in dialogue (Kagan, 2008); for example, listening to caregivers' suggestions regarding their comprehensive knowledge about the service user. In order for HCPs, including nurses, to be attentive and thus to include families in care and treatment, they could usefully address their interpretation of "duty of confidentiality." For example, if shared consent between the caregiver and the service user has not been obtained, it is still possible and legitimate for HCPs to listen and respond to the caregiver, in more general terms, regarding the caregiver's concerns and questions.

More research is needed to uncover the characteristics of caregivers' "persistent presence" and "advocacy" in care and treatment and in collaboration with HCPs. Additionally, the part that caregiver feelings of guilt and/or EOI may play in the development of persistent presence and advocacy should be explored, along with how these feelings and behaviours relate to HCPs' exclusion of caregivers. In this regard, differences between inpatient and outpatient facilities may be unfolded.

Based on the finding of this QES, that siblings of service users may experience different kinds of neglect in regard to service users' mental challenges, it is important to investigate the experiences and needs of siblings, which may contribute to research knowledge regarding support interventions for siblings of service users in FMHC.

There is a lack of knowledge about why up to 40% of caregivers are not present in the lives of the service user (Finlay-Carruthers et al., 2018; Rowaert et al., 2016). This absent group of caregivers may contribute to knowledge about reasons as to why they are not involved in the service user's life. Our current study suggests that caregivers seem to be greatly burdened by the struggle to receive support, which may play a role in the lack of contact with the service user. Further research is recommended that would investigate the reasons for lack of contact.

5 | CONCLUSION

This QES investigated family caregiver experiences in FMHC and confirms that caregivers are burdened by emotional challenges and practical responsibilities in relation to the service user. The entire family is burdened. Moreover, new knowledge is that HCPs may

inadvertently elicit persistent caregiver presence and/or advocacy, by excluding them from care and treatment out of a preconception that caregivers are difficult to work with. In this regard, caregiver feelings of guilt and/or EOI may play an additional role in the development of persistent presence and advocacy, and in HCPs' exclusion of caregivers in FMHC.

Caregivers who remain in contact with their ill family member want to support the service user to the utmost of their ability. They may be the only ones that the service user has left in their lives, so it would be beneficial for HCPs to support caregivers (and their families) optimally, by developing their skills in understanding the emotional complexities within families that have experienced mental illness and criminal offence.

6 | RELEVANCE STATEMENT

Family caregivers of service users in forensic mental health care are burdened by the service user's mental state, offence(s) and difficult collaboration with health care professionals, including nurses. Research about caregiver experiences, as well as facilitators and barriers regarding their involvement in the care and treatment of the service user, is needed for caregivers to maintain their support of the service user.

AUTHOR CONTRIBUTIONS

Tina Kirstine Vestphal, Frederik Alkier Gildberg, Rikke Jørgensen, Sara Rowaert and Ellen Boldrup Tingleff involved in conception and design, **data collection, Critical revision of the article content and Final approval of the version to be published.** Tina Kirstine Vestphal involved in data analysis and interpretation.

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CONFLICT OF INTEREST STATEMENT

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available at DOI reference number and URL reference number.

ETHICAL APPROVAL

Ethical guidelines for nursing research in the Nordic countries (Northern Nurses' Federation, 2003), The Nuremberg Code (2005), The Regional Scientific Ethical Committees (2012) and the Declaration of Helsinki (2002) shall be adhered throughout the study.

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