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Paper:

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Title: Taking parents seriously: the experiences of parents with a son or daughter in adult medium secure forensic mental health care.

<u>**Running head:**</u> Taking parents seriously

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Abstract

Adult forensic mental health services provide care and treatment to individuals with complex offending and mental health histories. However little attention has been paid to the parents of those receiving care within them. This research explored the experiences of parents with an adult son or daughter with mental illness in a medium secure mental health unit. Transcripts from semi-structured interviews were analysed using Interpretative Phenomenological Analysis. This led to the identification of three superordinate themes: "Something's not right" - onset of mental distress; "It's a terrible battle'- relating with professionals; and 'A very sad fact of life'- caring with no end in sight were identified which together contained nine subordinate themes. The onset of the mental distress was narrated as overwhelming, frightening and confusing with experiences of violence. Services were seen as invalidating, and interactions with them characterised as a battle. Poor information and involvement was a common experience. Whilst diagnosis was a relief to some, the on-going sense of loss and burden was clear. Staying connected and hopes for the future were also described. It is clear from this study that mental health services need to do more to engage and foster trust with parents from the outset and to offer support for this group. If secure services were to view parents as 'forensic carers' this may help improve respect and engagement between services and carers. Services and policy makers should strive to foster high quality family involvement as part of developing social inclusion.

The need to acknowledge and include family members in mental health care has been documented, encouraged and even enshrined in law by governments in several countries (e.g. Australia; see McMahon & Hardy 2010; Scotland; see Mental Health (Care and Treatment) (Scotland), 2003 Act). As well as forming the foundation for family inclusion by services, some government reports specifically recognise the needs of carers when they have been the victim of their family member (e.g. Department of Health, 1999). This is important, as research suggests assaults on family members are common; around half of the relatives of a sample of patients admitted to an acute psychiatric unit reported verbal abuse and/or threats, with up to a third sustaining physical injuries (Vaddadi, Gilleard & Fryer, 2002; Vaddadi, Soosai, Gilleard & Adlard, 1997).

Over the last thirty years, a number of studies (predominantly from the UK) have examined the role and experience of the families of those with a mental health problem. These have described parents' initial explanations for their child's difficulties and the time lag between seeking help and diagnosis (Tuck, du Mont, Evans and Shupe, 1997) as well as difficulties with accessing support, information and assistance from professionals which can often be experienced as of limited help once received (e.g. Ferriter & Huband, 2003; Jankovic et al, 2011). Interviews with family members have examined knowledge, perceptions and beliefs about schizophrenia and sources of stress for this group (McCann et al, 1996). Models such as 'redefining parental identity' highlight the on-going changes experienced by parents in response to the 'lengthy' and 'unpredictable course' of their adult child's severe mental distress (Milliken, 2001). Such changes can be associated with fluctuations in their levels of hope and despair (Tuck, du Mont, Evans and Shupe, 1997) and the burden and guilt that families experience (e.g. MacInnes & Watson, 2002; Ferriter & Huband, 2003). Whilst inpatient admission of their family member has been reported as a

source of relief (Jankovic et al, 2011), caregivers can still feel responsible for helping the relative move forward (Rose, 1998).

Drawing on policy and evidence, a number of approaches to carer involvement have been developed. These include the Triangle of Care (Worthington et al., 2013), the recovery agenda for informal carers (Machin & Repper, 2013) and the Pyramid of Family Care (Mottaghipour, & Bickerton, 2005). Within secure mental health services in the UK, surveys have identified ways in which support to carers can be provided and have made recommendations for minimum standards in such settings (Canning et al, 2009). These include providing information, carer support groups and family therapy. Whilst secure hospital carer groups have been developed and evaluated (e.g. McCann, 1993), a survey of secure services in the UK revealed that the availability of structured family interventions is limited (Geelan & Nickford, 1999). Despite some progress in family inclusion and support, Ridley et al. (2013), found that both provision of carer support and the extent to which it may be accessed were inconsistent whilst Canning et al (2009) note that support for carers "has not yet become a consistent or widespread part of forensic services practice" (p877). In order to develop family support and inclusion for those with members in adult secure mental health care, research is needed to better understand their experiences.

Aims of the study

This study aimed to undertake a detailed examination of the experience of parents who have an adult child[1] diagnosed with a mental illness receiving compulsory treatment and support in a forensic mental health unit.

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[1] The term adult child is used to denote an individual who is over the age of 18, living within a secure mental health setting and the son / daughter of a study participant.

Methodology

Design

A qualitative design using Interpretative Phenomenological Analysis (IPA) (e.g. Smith, 1996; Smith & Osborn, 2003; 2008) was employed. Qualitative methods lend themselves to indepth analysis of interview data from small numbers of participants. IPA is suited to a detailed exploration of how participants make sense of their world (Smith & Osborn, 2003; 2008) and has been widely used where there are unexplored areas of psychological interest, and in answering questions about personal meanings (see Knudson & Coyle, 2002; Rhodes & Jakes, 2000). The researcher tries to make sense of the participant trying to make sense of their world, resulting in a double hermeneutic process (Smith & Osborn, 2003; 2008). IPA's idiographic nature enables detailed consideration of participants rather than making premature general claims for the larger population (Smith & Osborn, 2003; 2008) although analysis aims to highlight generic themes allowing researchers to get closer to the universal and the 'essence' of experiences (Smith, 2004). Interviews were guided by a semi-structured interview framework available from the authors.

Setting

The study took place in conjunction with a 34 bedded regional medium secure unit within the UK, which provides secure, therapeutic in-patient treatment and care to male and female patients over the age of 18 years. The majority of individuals within the service are subject to compulsory detention under mental health legislation. Patients are admitted from various sources including the courts, prison, other inpatient facilities and the community.

Procedure

Potential participants were identified using a purposive sampling strategy in a two step process. In step one, inpatients meeting the following inclusion criteria were identified by staff in the unit: (a) a functional psychiatric diagnosis of psychosis – schizophrenia, schizoaffective or other psychotic disorder for a minimum of six months established by a Consultant Psychiatrist; (b) 18 years or older; (c) stable with regard to their mental state as determined by a Consultant Psychiatrist; (d) resident in the unit for at least six months; (e) capacity to provide informed consent and (f) in regular contact with a parent or guardian. Eligible service users were given oral and written information by the clinical team and asked if they would be willing for the local study collaborator to meet with them to discuss the project. At least 24 hours later, those who were willing met the local collaborator (final author) who sought consent to contact the individual's parents in writing about the study. Where granted, step 2 involved a letter signed by the Consultant Psychiatrist for the patient being sent to the parents introducing the research and providing a participant information sheet. Parents were asked to telephone the researcher if they were willing to participate. During this call the first author checked to ensure the participant inclusion criteria were met (willing to communicate their experiences to the researcher and able to speak and read English), verbal consent to participate was sought, and interview arrangements were made. This approach to recruitment was a requirement of the ethical committee's approval along with the requirement that there could be no follow up or researcher precipitated contact with potential participants unless they had telephoned the researcher in step 2. Written consent was obtained prior to commencing the interview. The Consultant Psychiatrists sending the invite letters did not know which individuals gave consent to participate.

Two of the five interviews were carried out in Health and Social Care premises and the remaining three took place in the parent's home. Interviews varied from 50 minutes to 90

minutes. Four of the participants were interviewed on a one to one basis with one couple requesting to be interviewed together.

Participants

Two patients (one male and one female) consented for their mother only (n=2); five patients (four males and one female) consented for both parents (n=10) to be sent study information. One male patient, later withdrew his consent, and thus his parents were withdrawn from possible inclusion. Of the ten parents contacted, seven made contact with the first author.   All parents met the inclusion criteria and agreed to an interview, however, one individual later withdrew. Four participants were married, and two (one male, one female) were divorced. All interviewees were over 50 years of age; five identified their ethnicity as White British, one as White Irish. All had other children and all had experienced verbal aggression and/or physical violence from their adult child, although never reported this formally. Three of the parents had witnessed their son or daughter's direct violence towards themselves (self-mutilation) and all were aware of their son or daughter's aggressive and violent behaviour outside of the family. Table 1 displays basic information for each parent participant.

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Insert table 1

About here

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Ethical considerations

This study was reviewed and given favourable opinion by the local NHS Research Ethics Committee (ref 12/NI/0028) with research governance provided by the host care trust (sponsorship ref: RGS 12014).

Written informed consent was obtained and all participants were informed of their right to withdraw at any time. Information about available support and guidance was provided to participants. In order to ensure anonymity, pseudonyms have been used throughout and identifying information has been removed.

Data analysis

Interview transcripts were analysed using IPA, as detailed by Smith (Smith, 1996; Smith & Osborn, 2003; 2008). Transcripts were read and re-read a number of times whilst listening to the audio recording. Initial thoughts and comments relating to aspects of the transcript were noted in the left-hand margin. Subsequently, emerging themes were noted in the right-hand margin. Commonality and difference were noted and connections between themes were made to produce larger, superordinate categories. Themes were produced for each individual set of data, patterns were then established across cases to form a master set of themes for the group.

Rigor and quality checks

A reflective journal was kept throughout the research which documented the first author's pre-conceptions, thoughts, feelings and impressions generated by the research and the potential impact of these. Two of the transcripts were audited in detail by the second author to ensure initial themes and ideas were evidenced and grounded in the data. The second author also checked that each of the final themes could be directly linked to individual participant data.

Characteristics of the first author

IPA assumes that interpretations arise from an interactional process between interviewer and interviewee (Smith, 1996). Providing information about researcher characteristics allows transparency about how these may have influenced the study (Stiles, 1993). The lead researcher was a 30 year old female undertaking the research as part of her training in Forensic Psychology. She had little experience of working with family members of individuals diagnosed with mental illness, but had five years of experience working with people with complex offending and mental health histories, including conducting interviews.

Results

Participants described their experiences as unanticipated and for which they had little knowledge. Their experiences of realization, violence and battling for support culminated in accepting of loss and ongoing responsibilities. Their stories are contained within the super-ordinate and sub-ordinate themes depicted in figure 1.

Insert figure 1

About here

Theme 1: "Something's not right"; the onset of mental distress

Parents had a strong sense that something was 'wrong' with their child before help was sought and/or a diagnosis was made. Their words point to the often-overwhelming feeling of 'knowing-but-not-knowing':

    Realising.

Some participants provided vivid memories of their child showing distress. However, without prior knowledge and understanding of mental ill health, participants described the difficulty in interpreting what they now perceive as early warning signs.

> *he didn't say at the time he heard voices. . . . he kept saying "There is somebody in here". He was in the built-in wardrobe. He was up in the loft. He had broke all his walls, broke everything (tearful). . . . "There is nobody in this house [son]".*
> *(Kate)*

Participants noted that their child's behaviours could interfere with his or her ability to engage with the family, work and recreational activities. They also recalled mood fluctuations and physically aggressive behavior.

> *She lived with a boyfriend that was a sergeant in the police . . . [she] wrecked his house and cut his face . . . and that's when I started, here's me, something's not right (Tessa)*

Trying to make sense of uncertainty.

Uncertainty seemed to envelop parent's understanding.   Accounts were littered with '*You're not sure*', '*I don't really know*' and '*I can't figure it out'* in their attempts to find an explanation for what was happening.

> *I sometimes wonder, . . . are they voices or are they thoughts? You know, are they just angry thoughts? . . . Is it just sheer anger or frustration, or you know, I don't really know. (Alice)*

Whilst the specific content of their causal explanations differed, all included drug use as a factor. Some incorporated vulnerability factors and psychosocial triggers, whilst others remained unsure.

I didn't know whether it was something she was born with, something that would have happened anyway . . . whether it was just too many drugs that had actually damaged her brain or whatever, no idea. (Tessa)

There is nights I lie awake thinking about it . . . But I can come to no conclusion. (Thomas)

Some tried to find explanations online or from other sources, whilst others questioned their role and skills as parents in the development of their child's difficulties.

"Going through hell"; experiences of violence and risk.

Abuse, aggression and violence permeated the lives of all the participants. They spoke of the risks their child posed to themselves as well as to others and acknowledged feelings of anxiety, powerlessness, and vulnerability. Despite facing abuse and assaults all persisted in their role as a caregiver attempting to manage increasing difficulties.

[her] dad thought that she was going to hit me . . . we used to hide knives and stuff in the house, just in case (Tessa)

Participants described police being called to assist them and feeling terrified during repeated crises and risk behaviours.

> *I was out there four and five o'clock in the morning . . . looking for him, . . . when the phone rung or the door wrapped or anything? He's dead! . . . that's what I have been living through for years and years and years. . . . We have been going through this absolute fucking hell, for years. (Adrian)*

Theme 2: "It's a terrible battle"; relating with professionals

This theme describes the relationships between parent caregivers and mental health professionals before and after admission to forensic mental health services. The majority of parents described a strained and invalidating relationship with professionals.

Ignoring the parents.

The process of searching for professional support was stressful with all reporting a tendency among professionals to negate their concerns. Consequently, participants sense of helplessness and hopelessness escalated, together with feelings of anger and disempowerment.

> *It took me two years to fight with the hospital [before I] finally won through that they accepted that she did have a mental problem. Well, it was a terrible battle and I know an awful lot of people who still sort of have that battle. (Tessa)*

Most were told at some stage that they were overreacting leading to a sense of outrage.

the Doctor says 'til 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 says, "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'. (Chris)

Participants reported that their experiences were not validated and that the professionals didn't listen to and believe the family's side of the story especially if the individual presented 'well' on the day. Some felt that entering forensic mental health services sooner would have prevented further deterioration whilst others described desperation in their contact with professionals

Jen's self-harming was just, just awful . . . He (Doctor) sat there and he said to me

"Your daughter doesn't have a mental illness" . . . I says, "Who in their right

mind would do what she has done to her arms and legs?" . . . I mean it was just

horrific, . . . the injuries were just really terrible. (Alice)

The majority of parents did not portray interactions with care services as effective partnerships. The language chosen to describe these interactions: 'a fight', 'a struggle', 'a battle' graphically illustrates the way these interactions were experienced. For these 'battling' parents, services appeared to contribute to strain in their parenting roles. Many of the parents perceived that services could not be trusted to ensure an optimal outcome; thus they needed to be vigilant in ensuring the system worked for their son or daughter.

Getting into services.

The process of getting assistance followed a period of hypervigilance in which participants felt they were living on high alert; watching what was happening and trying to cope. Participants talked about how much onus was on them as parents despite struggling to know what services were available and when and how to access them. Getting assistance and accessing mental health treatment was often a multistep process. For some this involved the police as well as health care providers.

> *we couldn't get help from anybody or anyone. . . . he was actually trying to cut the wire out of the back of his head [with a Stanley knife]. . . . we coaxed him to go down to the Doctors and . . . do you know what he give my Patrick? Antibiotics! . . . [a week later] Patrick come in here and he says "I need help" and . . . the Police came out . . . we brought him up to [secure unit] right away, and then the girl that we were talking to told him that he was being detained under the Mental Health Act. (Adrian)*

A sense of immediate relief was experienced by most families at the time of admission. Recuperation of physical and emotional 'strength' was also described at this time.

> *He's safe. . . . I know I can go to bed at night, I don't have to wait on a phone call coming saying, you know, he's lying somewhere, I feel content that he's in the unit. A lot of pressure [is] off. (Thomas)*

Of note was the absence of stigma reported by all.

I don't feel that I have anything to be ashamed of, I would never deny where

Claire is . . . My daughter is ill, if she broke her leg you would be saying to

everybody aye, she has got a plaster on, she broke her leg . . . Her mind is broken,

simple as that. (Chris)

Lack of information and involvement.

Although the distance to the unit contributed to feelings of exclusion, a lack of information

reinforced parent caregivers' feelings of isolation and left them feeling detached.

we are like outsiders, you're not kept in the loop, . . . you're not involved in

anything, you're not kept really up to date with what's going on. (Kate)

Parents wished to be able to talk to someone who understood what their life was like and

wanted a more integrated approach with good communication between the professionals and

themselves. Parents raised issues about the way mental health professionals interacted with

them, commonly interpreting the responses of professionals as uncaring, creating a 'them'

and 'us' perspective.   Instead parents wanted to be treated as a resource and described

recognizing patterns of emotions and behaviours. They hoped that by sharing these with

health professionals they would make better and more informed treatment decisions.

I don't know if they [unit staff] see it . . . she'll sit on a visit and use foul language

talk about things that she can visibly see is upsetting me. . . I'll say to the wife

"We went through this here before do you remember?", "Next week she's going

to be such and such" . . . if we notice anything strange we would say to the staff . .

. [make them] aware of the situation, that's as far as we can take it. (Chris)

Theme 3: "A very sad fact of life", caring with no end in sight

Although the diagnosis of a mental health problem confirmed parental intuition that something wasn't 'right', the diagnosis also brought grief and sorrow. The future was viewed with a combination of hope, uncertainty and as 'never ending' with parents deeply committed to looking after their child and doing whatever was necessary.

Getting a diagnosis.

After living for years in a kind of emotional limbo, it was comforting for some parents to have a name for their child's difficulties. The diagnosis explained the troubling behaviour and also gave hope that Doctors could provide help and support.

> *I was actually relieved that someone could say to me this is what is wrong with*
>
> *your daughter, and you know, this is the reasons why your daughter is doing what*
>
> *she is doing. (Alice)*

For other parents, knowledge that their child was suffering from a mental health problem was a shock, accompanied with feelings of confusion and leading to more questions.

> *I hadn't a clue what it was, and when I heard paranoid schizophrenia ... Is this*
>
> *curable? Will he be through this all his life? Will he be alright? . . . I didn't know*
>
> *'coz I never went through anything like that before. (Adrian)*

For some, feelings of grief and a sense of helplessness were evident. Distress was the most frequently expressed emotion reported by the carers. The distress encompassed mixed feelings including anger, disappointment, and frustration.

> *I'm terrified when I, when I read it . . . I got the report and my first reaction was I*
>
> *cried, my second reaction was, I was angry. Because I had fought so long for*
>
> *help and nobody, NOBODY was listening. [tearful] (Kate)*

Facing change and loss whilst staying connected.

Parents' perceived that their adult child's mental health problems had resulted in the loss of positive aspects of their character and to their sense of connection with the family member.

> *There is times I go down there I think John is numb . . . your talking 'til him and*
>
> *he's not there . . . there is no feeling there. (Thomas)*

Parents compared their adult children now to their former selves to assess how much change had occurred.

> *She has changed so completely . . . she had a brilliant life and maybe that's why*
>
> *you notice it so much . . . she had a lovely lot of friends, she had a lovely*
>
> *personality, she was never nasty, she was just a nice person to know. (Tessa)*

Parents also spoke of the strong bond with their child and a sense of reciprocity within this relationship. Care-giving meant understanding the importance of staying connected to their son or daughter and not losing sight of the basic essence or identity of the individual.

To me it's the same . . . When Claire was at school and a child, she was my

daughter . . . When she took ill she was still my daughter, and needed more

attention than previous to that. Now she's even more ill, we are still there . . .

Claire is still Claire. (Chris)

The future: bearing the burden while hoping for a better life.

Dealing with feelings of responsibility and uncertainty about the future for their son or daughter included realizing that the relative was unlikely to return to their former self. This brought new worries in relation to the perceived permanency of caregiving.

In the last five years or so I've realised it's over. Claire is going to be a patient

for the rest of her life. It's a very sad fact of life, but it is a fact of life. The dream

has ended. [tearful] (Chris)

Fears of uncertainty about the future were exacerbated by the unpredictability of the illness and a perceived fear that their adult child will have difficulty managing without their support:

We are both ill and none of us 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 up and

looking after her. (Tessa)

However, hope was seen as essential to coping with the many challenges and struggles they faced and as motivation for the recovery process. The sense of hope motivated caregiving and created a sense of purpose:

So you have hope for him. That's the only reason I go down and see him. If I

started to feel pity and sorry for him, I would not go down and see him. (Thomas)

Whilst the narratives displayed hope as a sustaining force to seek ways to improve life for the son or daughter, they also revealed the struggle to remain hopeful and the risk of disappointment.

People should be made aware [you] don't build your hopes too high with this

illness, in some cases this illness will go on for a life time. (Chris)

Discussion

This study has addressed an important clinical forensic issue that has rarely been explored in research namely the experiences of parents supporting adult children prior to and whilst receiving compulsory treatment in a medium secure forensic unit. Participants reported these experiences as demanding and frustrating with multiple challenges faced in relation to professional services. This included difficulties getting support from services and ensuring they were meaningfully involved in their son / daughter's care. Understanding these experiences is critical as parents often continue caring for their adult children suffering from severe mental illness (Absalom et al., 2010; Ridley et al., 2010), beyond what would normally be expected in the lifecycle (Schene et al., 1998; Lefley, 1997).

The onset of mental health difficulties was narrated as a fateful event with parents not knowing whom to contact to ask for help when their child was becoming unwell. Such a lack of knowledge about schizophrenia and how to get help has been documented previously (Carter, 2011; Jankovic et al, 2011; McCann et al, 1996) with research suggesting that the importance of this has been underestimated by mental health services (Wane et al., 2009).

Being directed from one service to another, without being given effective guidance added to the stress of looking after their child whilst trying to find help.

Participants believed that their child needed more help than judged by the clinicians and many felt the delay in the service response contributed to their child's deterioration. Services were perceived as reactive rather than proactive with little support being offered. Many family caregivers did not feel valued, with their view of their child's mental state not heard by the professionals. Sadly this experience has been documented numerous times (Askey et al., 2009; Carter, 2011; Gray et al., 2010; MacInnes, 2000; Tuck et al., 1997; Wane et al., 2009; Wynaden, 2007). Clearly this is an issue that requires immediate action.

Being a 'forensic carer' demanded resilience and the ability to cope with complex legal and medical rules and regulations. Similar to the findings from general mental health settings (Tuck et al., 1997; Milliken, 2001), participants experienced devastation, uncertainty, and periods of hope and despair. They also reported feelings of grief and loss (Ferriter & Huband, 2003). What was clear was their level of care and concern for their son or daughter. As with the 'engaged carers' described by Chesla (1991), participants were actively involved with their child, trying to understand their child's world, fostering their child's self-esteem and affirming their child's strengths. They persevered in the informal caregiving role with no thought of abdicating this or letting professionals assume total responsibility for total care.

In this study, the practices of some health professionals contributed to the distress experienced by caregivers. Participants respected the need for confidentiality however they felt more could be done to share information, respect their views and to foster a collaborative partnership between the family and the professionals. However, the lack of perceived progress in this area despite UK government guidance (Department of Health, 2008; Health Offender Partnership, 2007) and previous research (Cormac & Tihanyi, 2006; Drapalski et al., 2009; McCann et al, 1996; Winefield et al., 1998) suggests that much work is still to be

achieved in this area. To promote inclusion and to support families in their role as 'forensic carers', services could adopt checklists designed to facilitate communication (e.g.

http://www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/checklistforpsychiatrists.aspx accessed 14/8/17) and consider practical initiatives such as carer groups (McCann, 1993) and family psychoeducation and inclusion (e.g. Nagi & Davies, 2015). Implementing the 'Triangle of Care' (Worthington, Rooney & Hannan, 2013) across services would also support this ambition as would creating specialist roles or link workers within services to lead this work. However, the most effective approach may be for services to enact a co-production agenda with both service users and carers (Freeman et al, 2016).

Suggestions for future research

Three avenues for future research are evident from this study. First, little is known about the many parents who do not remain in contact with their children. An examination of these parents could shed important light on reasons for maintaining or severing contact and highlight any specific needs they might have from services. Whilst this poses some ethical challenges the findings could be very helpful. Second, understanding the experiences of other family members (e.g. siblings) could help develop broader family supports and interventions. Finally, investigating the impact of implementing service changes such as those suggested is essential.

Study limitations

The main limitation of this study is the lack of racial and cultural diversity amongst participants. Data shows that individuals from Black and Minority Ethnic backgrounds are over-represented in forensic services (Saltus, Downes, Jarvis, & Duval, 2013) and it is possible that such groups might appraise the caregiving situation differently. Further work to

examine the cultural and ethnic differences in experience is needed. Additionally, the selection processes may have impacted inclusion in two ways. First, seeking consent from the individual within secure services to contact their parent(s) is likely to have excluded parents who were estranged or had poor relationships with their son / daughter. Second, the phone opt in requirement may have limited the sample to those who were more motivated and potentially more involved in (and concerned about / dissatisfied with) their child's care. Future studies should explore alternative mays to identify and approach family members that respects confidentiality and is acceptable to the relevant ethics panel.

Conclusions

The findings from this study demonstrate that being a parent carer to a son / daughter living in a forensic mental health setting is complex and challenging.   Parents welcomed the opportunity to talk about their experiences, and reported not having has the chance to speak about and consider their experiences through informal conversations or in a more therapeutic relationship.   Their lived experiences were characterised by strained relationships with mental health services. Caregivers felt that their needs and views were often ignored leaving them to care for their distressed and often behaviourally challenging loved one.   This research suggests there remains a sizeable gulf between policy, intent / guidance and actual service delivery. This must be addressed if parents are to be properly supported and are to have meaningful and productive relationships with secure mental health services.

Relevance for practice

Finding from this study highlight a number of actions for services. From the parents' perspective, staff and services need to become more 'carer aware'. This includes acknowledging the needs of the parents and forging warm, respectful and constructive

relationships with family members. Reaching out to parents through taking their views seriously, providing them with information and establishing spaces where forensic carers can support one another could prove useful. Such tasks could fit well with mental health nursing roles within inpatient care. Adopting a co-production approach may also be of benefit.

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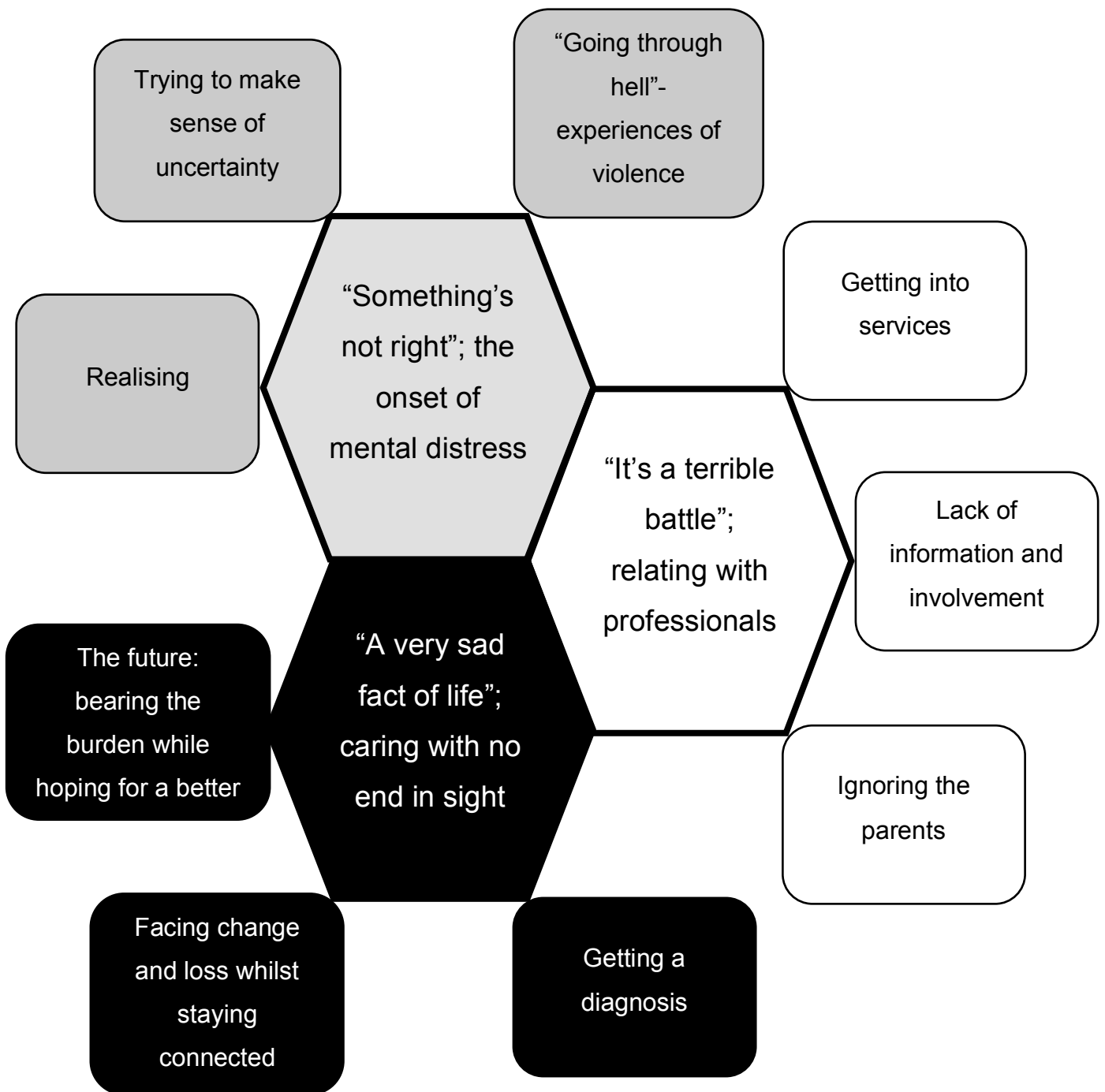
Figure 1: Representation of the three superordinate themes and the nine subordinate themes.

Table 1. Characteristics of family caregivers

Pseudonym*	Marital Status of participant	Relationship to patient in medium secure unit	Caregiver living with patient at time of admission	Length of time caring
Tessa	Married	Mother	No	>15 years
Chris	Married	Father	No	>15 years
Kate	Married	Mother	Yes	>5 years
Adrian	Married	Father	Yes	>5 years
Alice	Divorced	Mother	No	>10 years
Thomas	Divorced	Father	No	>5 years

* Tessa and Chris and Kate and Adrian were married couples. However only Tessa and Chris were interviewed together