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Understanding and Communication about an Adult's Mental Health Problem by their Adult Relatives: A Systematic Review

Abstract

Introduction: Relatives are profoundly affected by an adult family member's severe and enduring mental health problem (MHP). The burdens of caring impact on adult relatives' emotional, physical and social wellbeing. How relatives make meaning and communicate about the MHP is thought to affect family talk about mental health and this can impact family coping and wellbeing.

Aim: No review has yet drawn together research about how adult relatives of people with severe and enduring MHP make meaning and communicate about their relatives' difficulties. We aimed to address this gap.

Method: We conducted a systematic review of peer-reviewed primary research. SCOPUS, Pubmed, Psychnet, SCIE, Cochrane and CINAHL+ databases were searched.

Results: Nineteen papers qualified for inclusion. Findings are organised under four themes: making meaning about the MHP and affected individual; conceptualising the self in the presence of the MHP; meaning making processes underlying relatives' wellbeing outcomes; and relatives' perspectives on family talk about the MHP.

Discussion: Historical relationships, caregiver identity and mental health literacy moderate relatives' understanding and talk about the MHP.

Implications for Practice: Psychoeducation and communication support for relatives should be provided by mental health practitioners. Future research should address familial communication about MHP, including with children.

Accessible Summary

What is known on the subject?

- Adults who support an adult family member with a severe and enduring mental health problem often experience carer burden. Over time this often negatively affects their mental and physical health and social wellbeing.
- Understanding and communicating about mental health problems in families can help to improve resilience and coping among both adults and children.

What the paper adds to existing knowledge

- We conducted a review of studies looking at how adult relatives understand and communicate about an adult family member's mental health problem.
- The findings highlight that how relatives make sense of MHP is related to historical family relationships, their mental health literacy and whether they see themselves as a 'carer' or not.
- The findings also show that little research to date has explored how adult relatives talk with children about their parent's difficulties, and how the adults' understanding might affect what children learn about the MHP.

What are the implications for practice?

- There is a research gap to be addressed regarding family communication with children about parental mental health problems. This knowledge gap likely impacts family-focused mental health nursing and therapy provision.
- Mental health nursing, therapeutic and support workers and advocates are ideally positioned to assist relatives with improving their mental health literacy and confidence communicating about mental health, and to promote inclusion of relatives and children in interventions.

Relevance Statement

This review evaluates research about how relatives make meaning and communicate about an adult family member's severe and enduring mental health problem. Relatives are key supporters of their family member (including children), yet their contributions to family meaning-making and communication about the mental health problems remains poorly understood. Relatives' mental health literacy and carer identity appear to moderate their communication patterns. Mental health nurses, therapeutic and support workers and their colleagues in psychiatric and social care play a vital role in supporting affected families. These professionals and volunteers are ideally positioned to advance family-focused work, psychoeducation and communication support.

Introduction

Increasing emphasis on community-based care for adults with mental health problems (MHP) in the UK has intensified the supporting role of the family (Magliano, Mcdaid, Kirkwood, & Berzins, 2007). Mental health and third sector service closures due to healthcare funding challenges coupled with poor rebalancing through investment in community resources during the last decade have intensified this pressure (Thornicroft & Tansella, 2013). In families where an adult has a severe and enduring MHP (British Psychological Society, 2002), their adult relatives often support them, and their children if they are a parent (Nicholson, Sweeney, & Geller, 1998).

A key strategy of UK health and social care policy is to shift the focus from the person with MHP to the family (Department of Health, 2011; Department of Health, 2013). The 2008 public health Carers Strategy, *Carers at the heart of 21st century families and communities* (Department of Health) addressed the increasing care burden on relatives and informal caregivers. Policy updates have additionally attended to adult relatives' own parenting and work statuses, systemic factors that can increase the complexities of caregiving (Department of Health: 2010, 2014). A common challenge for relatives is finding time for respite and self-care, and it appears that many are unaware of carer legislation and support services (Adcock, et al., 2017). Consequently, their needs frequently go unrecognised (Afzelius, Plantin, & Ostman, 2018).

Patterns of deteriorating mental and physical health are seen uniformly amongst unpaid adult carers across all economic levels, increasing with weekly hours of caregiving (Adcock, et al., 2017). The shock of a mental health diagnosis can yield initial fear and confusion (Outram, et al., 2015). Subsequently, psychosocial challenges and reductions in quality of life are common, including disruption of leisure activities and career, increased isolation, emotional distress, parenting stress, financial burden, grief and burnout (Ostman, 2007; Rudder, Riebschleger, & Anderson, 2014; Gallagher & Mechanic, 1996). Many adult relatives supporting a family member with severe and enduring MHP describe loss of hope for the future (Rose, 1983) and stigmatisation by peers, professionals and strangers (Bruland, Lenz, & Wahl, 2017). Adjusting to role change can be a unique challenge, particularly for those who take on childcare responsibilities (Ziminski, 2007). While the literature documenting these caregiver burdens largely emphasises negative correlates it also documents that many adult relatives also experience a sense of purpose through caregiving and want to support their families (Hayslip & Kaminski, 2005). Furthermore, differences in wellbeing outcomes for adult relatives across different ethnic populations point to the relevance of cultural expectations about caregiving upon perceived burden (Goodman & Silverstein, 2006).

Mental health literacy, the ability to understand mental health information and problems, is associated with recognising health difficulties, seeking help, reducing stigma and maintaining good personal mental health (Jorm, Korten, Jacomb, Christensen, Rodgers, & Pollitt, 1997). For adult relatives, acquiring mental health knowledge equips them to deal with issues, both practically and emotionally, and sustains them within the family environment (Cohen, Ferguson, Harms, Pooley, & Tomlinson, 2011). Where there are children in the family, their mental health literacy is often powerfully influenced by the adults around them (Nolte & Wren, 2014). Increased mental health literacy in children with a parent with MHP is thought to help improve coping and mental health outcomes for these children (Pikhala, Sandlund, & Cederstrom, 2011). Children with better mental health literacy show greater emotional resilience and are more likely to seek help from adults (Riebschleger, Grove, Cavanaugh, & Costello, 2017). A coherent understanding of parental behaviour and maintaining a distance between parent and self appears to reduce internalisation of blame and over-identification with the MHP, and consequently better long-term mental health outcomes

(Cooklin, 2013; Focht & Beardslee, 1996). Where mental health literacy is developed in families, a deeper level of interpretation of the MHP is acquired, going beyond diagnostic and biological descriptions to emotional, behavioural and self-reflective understanding (Focht & Beardslee, 1996). Open discussion is more likely with increased mental health literacy, and is associated with reductions in adverse outcomes for all family members (Imber-Black, 2014).

Communication has been evidenced as the most influential factor in shared family adaptation and coping with severe and enduring MHP (Jonker & Greeff, 2009). It is underpinned by meaning making, defined as the understandings and attributions held by an individual that influence how they construe a social object or concept (i.e. the meanings that are held about a topic). Inclusion of family members in adult mental health interventions supports development of such knowledge and communication. Interventions addressing family system and subsystem interactions (e.g. Beardslee, Gladstone, Wright, & Forbes, 2007; Margolis & Fernandes, 2017; Wolpert, Hoffman, Martin, Fagin, & Cookin, 2015; Yates & Lina, 2017) are indicated by meta-analytic evidence as particularly effective (Thanhauser, Lemmer, de Girolamo, & Christiansen, 2017). Despite this, adult mental health interventions tend to be individually focused. Austerity and individualism appear to impede systemic approaches due to under-resourcing and the lack of availability of suitably trained clinicians presents an organisational barrier (Maybery & Reupert, 2006). Furthermore, relatives may work during the daytime when appointments are offered and be ineligible for time off to attend. These limitations in family-focused adult mental health care present constraints to the support available to adult relatives and likely impact how they make sense of their caregiving experiences.

Relatives' meaning making and communication are therefore likely shaped primarily by the lay knowledge and social representations of MHP they are exposed to (including stigmatising ones), prior life events, lived experience of MHP and individual thinking and coping style.

Growing awareness of the impact of severe and enduring MHP on families is seen in the research described above, and the commonality of burdens and challenges for children and adult relatives. Most existing reviews have focused on children and parents with MHP, including prevalence, risks to children, practical and emotional needs and analysis of interventions (Marston, et al., 2015; Reupert & Maybery, 2016; Wahl, Bruland, Bauer, & Okan, 2017). Riebschelger et al (2017) analysed literature on children's mental health literacy needs. With regards to meaning making and communication, children's accounts of their experience of their unwell parent have been examined (Dam & Hall, 2016; Drost, van der Krieke, Sytema, & Schippers, 2015; Gladstone, Boydell, Seeman, & McKeever, 2011). Examining general communication with children about mental health (not specifically relating to a family member), Mueller, Callanan and Greenwood (2016) identified a tendency towards stigma and silence by peers, schools and the media. Regarding relatives, burdens and support needs have been reviewed (Wirsén, Akerlund, Ingvarsdotter, Hjarthag, Ostman, & Persson, 2017), including specifically for family members affected by schizophrenia (Brady & McCain, 2004; Saunders, 2003). We did not identify any existing review of relatives' meaning making and communication.

Indeed, there have been calls to develop better understanding about how adult relatives understand their family member's MHP and how this shapes family functioning (Nolte & Wren, 2016; Reupert & Maybery, 2016; Saunders, 2009). Better understanding how adult relatives make sense of their family member's MHP and how (or if) they communicate about this within the family would inform practices within family-focused psychiatric services, mental health nursing and social care and guide future research.

Aims

The aim in this paper is to summarise and evaluate existing peer-reviewed primary research pertaining to adult relatives' meaning making and communication experiences regarding their family member's severe and enduring MHP.

Methods

Search strategy

The search aimed to find peer-reviewed primary research pertaining to the meaning making and communication experiences of the adult relatives of any adult with a severe and enduring MHP. The search terms are provided in Table 1. Searches were conducted of the SCOPUS (818), Pubmed (747), Psychnet (183), Social Care Institute for Excellence (589), CINAHL+ (223) and Cochrane (66) databases. Search outputs from each database are provided in brackets. No publication date limits were applied. Reviewing reference lists of key papers and journals led to consideration of additional articles.

Study eligibility

Relevant articles were identified through a staged process of duplicate removal, abstract screening and full text screening according to inclusion and exclusion criteria. The criteria can be found in Table 2. No restrictions were placed on study design and quantitative, qualitative and mixed methods studies were assessed. The final set comprised qualitative papers only, which was understood to result from the focus on meaning making and communication.

Data abstraction and evaluation

The systematic review process described by Siddaway, Wood and Hedges (2019) and PRISMA guidelines were followed. Articles were read with particular attention to the method and results, and methodological data and results extracted from each paper. Recurring concepts and themes were recorded and compared across papers. From these, thematic categories were developed and applied back to the articles to ensure a representative evaluation of the studies' findings. The intention was to establish what is already known, seek relationships between study findings and identify contradictions, to develop an overarching conceptualisation of the topic area (Cooper, Hedges, & Valentine, 2009). Contrasting and inconsistent findings are reported alongside the main themes below.

Quality assessment

Tracey’s (2010) ‘Big-Tent’ framework was used to evaluate study quality. Tracey’s (2010) eight criteria assess ‘common markers of goodness’ across qualitative approaches in a way that allows for paradigmatic differences: this broad structure provides the ‘big tent’ framework (Denzin, 2008). The extent that studies met the criteria is shown in Table 3. Following this process, all papers were found to be of sufficient quality for inclusion.

Findings

Initial searches yielded 1215 articles after duplicates were removed. Forty papers were identified for full-text review of which 19 were eligible for inclusion (see PRISMA flowchart in Figure 1). A summary of the characteristics of each study is provided Table 4, including: qualitative analysis method; study design; country where research was conducted; caregiver type; sample size averages; and parenting status of person with MHP.

Four themes pertinent to relatives' understanding and communication experiences were identified: (1) Making meaning about the MHP and affected individual; (2) Contextual social and emotional factors underlying relatives' meaning making; (3) Conceptualising the self in the presence of the MHP; and (4) Relatives' perspectives on family talk about mental health. Findings will be presented under these themes.

Making meaning about the MHP and affected individual

A primary consideration within the literature was how relatives individually made sense of their family member's MHP. Their meanings were often constructed in relation to caregiving, which many family members undertook. An important process was the evolution of relatives' meaning frameworks over time as they tried to make sense of their family member's emotional and behavioural presentation. Jonsson, Skarsater, Wijk and Danielson (2011) refer to a process of letting the 'abnormal become normal'. Karp and Tanarugsachock (2000) described having a family member with MHP as inhabiting a 'different phenomenological world'. Rose's (1998) grounded theory (GT) also emphasised how meaning frameworks guided relatives' understanding. Rose's (1998) central theme of 'essence of person' showed how relatives stayed connected with the person rather than the 'illness', often using definitions not provided or shared with professionals. This helped them make sense of distressing behaviours in ways that others could not, define their caring role and decide how to communicate about the MHP with others. Such meaning frameworks appear to help relatives retain a sense of control and assimilate new knowledge about the MHP, despite unpredictability in their family member's presentation. Rose (1998) emphasises the clinical role of promoting individuals' diverse sense-making processes while addressing their common concerns, for example via psychoeducation from a biopsychosocial perspective. Finding an acceptable way to talk about the MHP with non-relatives was a crucial stage in being able to communicate about the mental health difficulties. Talking appeared central to relatives' ability to develop meaningful understandings of the difficulties and to settle questions they held internally. In a thematic content analysis with 17 relatives with a family member with bipolar disorder Jonsson, Skarsater, Wijk and Danielson (2011) found that participants were careful about who they talked to about their family member's mental health, but described relief after opening up. Considering the effects of a failure to make meaning, Stern, Doolan, Staples, Szmukler and Eisler (1999) explored how seven relatives constructed accounts of caring for a family member with MHP. They described two dominant and differing narratives: 'restitution and reparation' and 'chaotic and frozen'. In 'restitution and reparation', disruption due to the MHP was followed by reconstructive processes that yielded meaning and contextualised the difficulties in the carer's life. Such clarifying processes had not occurred in 'chaotic and frozen' narratives, where carers communicated was incoherently and repetitively about the MHP. These findings implicate how supporting relatives to structure their understanding and 'scaffold' their actions can provide a 'platform' for coherent meaning (Stern et al, 1999). The authors suggest that high expressed emotion at times of crisis might hinder the cognitive flexibility, that is the cognitive ability to consider multiple construct or perspectives simultaneously, and narrative reconstruction, that is developing new meanings and understandings, that could aid the development of understanding. They suggest that it is likely that relatives' understanding and coping are shaped by opportunities to verbalise their experiences.

Two studies focused on meaning making about MHP in migrant communities and highlighted the relevance of culturally held meanings about mental health not only in individuals' understanding, but also their behaviour. In studies with Egyptian families in Australia (Endrawes, O'Brien, & Wilkes, 2007) and Chinese families in England (Yeung, Irvine, Ng, & Tsang, 2017), cultural stigma was found to hamper relatives' understanding because of the belief that MHP should not be discussed outside the family. In combination with religious traditions and language barriers, family obligations were found to perpetuate silence (Endrawes et al, 2007). It is likely that this reduces opportunities for relatives to make sense of what is happening at home. Cultural factors relating to immigrant status, gender, age and religion were also reported to play a role in relatives' mental health conceptualisations. Endrawes et al (2007) found that older, first-generation immigrants tended to be more sceptical of medication and hospital treatment. Yeung and colleagues (2017) reported that male relatives in Chinese families took longer than women to label their partner's unusual behaviours as 'mental health' rather than 'personality'. In both studies, relatives drew upon both medical and religious conceptualisations to support their sense-making.

Similarly, a focus group with eight female relatives in Jamaica reported simultaneous use of medical and spiritual conceptualisations (Pusey-Murray & Miller, 2013). Nonetheless, participants unanimously described medication as the means to control MHP. Caregivers were described as "somewhat confused about what mental illness is" (p.116). Descriptions like "brain not functioning well" and "excess talking" were reminiscent of Stern et al's (1999) 'chaotic and frozen' narratives. Difficulty accessing psychiatric interventions and lack of access to information about MHP from a range of sources were suggested to be contributing factors (Pusey-Murray & Miller, 2013).

Contextual social and emotional factors underlying relatives' meaning making

Several studies explored the context in which relatives made meaning about mental health, focusing specifically on their social milieus and emotional processes. Patterns of coping with emotions and the tone of family relationships appeared to be important factors that shaped mental health talk and shared meanings in families.

Several studies (see e.g. Karp & Tanarugsachock, 2000; Tranvag & Kristoffersen, 2008) highlighted interconnections between historical family relationships and mental health understandings. These studies stated that relatives engaged in a developmental process as they attempted to understand their family member's MHP, and that it was shaped by the relational family context. Karp and Tanarugsachock (2000) described an 'oscillating emotional journey' for relatives that corresponded with developments in their relationship with the person with MHP. They conducted a grounded theory with 50 participants, the largest study identified. A progression from 'pre-diagnosis' and 'diagnosis' to 'realisation of permanence' to 'acceptance' was described, founded on the ebb and flow of emotion between the person with MHP and their relative. Relatives had to make arduous efforts at interpreting their family member's needs. Similarly, Tranvag and Kristoffersen (2008) emphasised how past relationships impacted present emotional states. Their model of cumulative adjustment described how the nature of past emotional experiences between the person with MHP and their relative (e.g. or relational burden or satisfaction) was likely to be echoed in future emotional experiences, and could lead to relatives becoming 'stuck' in a certain stage. Similarly to other authors, Tranvag and Kristoffersen (2008) highlight mental health education, emotional awareness and family talk as vital for progression through each stage.

In a rigorous longitudinal design, Rose, Mallinson and Walton-Moss (2002) investigated contextual factors that affected relatives' emotional responses to the MHP. Rose and colleagues (2002) reported a basic social problem for relatives of 'living with ambiguity', which they responded to by ‘pursuing normalcy’. Relatives’ ability to do this was affected by their historical knowledge and age-related expectations of their family member. Relatives who could update their view of ‘normal’ to account for the MHP experienced less grief and anger. Others pushed the person with MHP to conform to social ideals of ‘normalcy’ and ‘happiness’, seemingly with less positive outcomes for their own emotional wellbeing and their interpersonal relationship.

Using stigma-by-association, that is experiences of being stigmatised by others due to association with a stigmatised person (here a person with MHP), as a metric for social and emotional coping, Van der Sanden, Bos, Stutterheim, Pryor and Kok (2015) found that the relatives most likely to feel stigmatised by ideals of normalcy were females, cohabitants, parents, and spouses of the person with MHP. High stigma-by-association was underpinned by the most acute beliefs about blame and responsibility for the MHP. This was associated with increased avoidance of non-family members, which potentially limited helpful opportunities to process and verbalise MHP-related experiences. This social isolation and lack of mental health talk was suggested to contribute to negative patterns of relating to the self.

While the challenging and negative emotions made up the bulk of the findings, some positive emotional aspects of having a family member with MHP were noted, including life lessons, love and caring. Veltman, Cameron and Stewart’s (2002) participants described feeling pride and gratification towards their family member with MHP, increasing in patience and strength on a personal level and finding greater depth of meaning from their ‘unconventional lives’. They believed, however, that others would not expect this to be the case (Rose, Mallinson, & Walton-Moss, 2002). By ‘finding normality in chaos’ (Rose, Mallinson, & Walton-Moss, 2002), relatives may cope better with the uncertainty of MHP.

Conceptualising the self in the presence of the MHP

Related to emotional coping, several studies reported on identity disruption and rebuilding for relatives. Positioning the self in relation to the family member and to the MHP itself appeared as a key process. Conceptualising the self in the presence of the MHP required relatives to 'scaffold' (e.g. Stern et al, 1999) meanings about the MHP and their role in line with their broader worldview and beliefs. Social and cultural factors were linked to whether relatives primarily identified as a 'carer' or a 'relative' (e.g. lover, partner or parent).

Forming an identity as a relative of someone with a severe and enduring MHP was associated with incorporating meanings about the MHP into the self-concept (Rusner, Carlsson, Brunt, & Nystrom, 2012; Wynaden, 2007). Rusner et al (2012) used Interpretative Phenomenological Analysis (IPA) to examine meanings about being related to someone with bipolar disorder. Twelve relatives (including four co-parents) described paradoxical experiences of being needed and rejected. Developing mastery over internal conflicts (e.g. desire to protect) and external challenges (e.g. stigma) was seen as central to healthy self-concept as a relative. Nonetheless, relatives described tension due to a sense of living across two 'worlds'. Many took responsibility for their family member's stress at the expense of their own emotional wellbeing; for example, protecting their family member from isolation by intensifying their support, but in doing so paradoxically becoming socially isolated themselves. How interpersonal processes influenced relatives' experiences - and what was communicated within the family - was not addressed.

Comparably, Wynaden (2007) interviewed 27 family caregivers, mostly females and parents, reporting a grounded theory with two key psychosocial processes: 'being consumed' by the MHP and 'seeking balance'. Acceptance of the MHP was associated with how effectively relatives could process feelings of grief. The participants described learning "tricks of the trade" (p.385), which included acquiring mental health knowledge and refining their communication strategies, giving shape to a new sense of self in relation to the MHP. These findings highlight that developing assertiveness, present-moment focus and positivity are core coping and adjustment processes. Similarly to Rose (1998), Veltman, Cameron and Stewart (2002), Wynaden (2007) and Lawn and McMahon (2014) found dominant narratives of loyalty and love. For many spouses, the term ‘carer’ may be uncomfortable due to their primary self-conceptualisation as a spouse, a partner and a lover. As one participant noted: “You have to value who you are, not as what you do” (Lawn & McMahon, 2014, p.261).

Twenty-one of Lawn and McMahon’s (2014) participants had children with the person with MHP. Many described feeling like both mother and father, shouldering the emotional side of parenting and balancing care of their spouse and offspring. Mizuno, Iwasaki and Sakai (2011) reported similar findings in their TCA with 12 husbands of women with schizophrenia in Japan. For the 9 couples with children, husbands frequently described fulfilling the role of both mother and father. This suggested a cross-cultural similarity in the experiences of the ‘well’ parent. However, Lawn and McMahon (2014) reported that spouses expected their partners with MHP to co-parent whenever possible, whilst Mizuno et al’s (2011) fathers prioritised nurturing the child-mother relationship and encouraging children to take responsibility. In both studies, fathers varied in whether they talked to their child about the MHP or not. Nonetheless, children were reported to comment occasionally about their mother’s behaviour. How fathers decided to talk (or not) was not examined.

These results indicate a mediating role for relatives in protecting children’s attachments and assuming parenting roles. Mizuno, Iwasaki and Sakai (2011) position their findings within the Japanese context; strong cultural values about children binding a marriage and husbands protecting wives dominated participant discourse. ‘Excessive’ attachment in children is cited as a common challenge of maternal schizophrenia, comparably with attachment ‘disorder’ or ‘disturbance’ (Reupert, Maybery, & Kowalenko, 2013). Several children looked after by Lawn and McMahon's (2014) participants were also reported to have mental health problems. Relatives did not, however, tend to question what impact growing up with a parent with MHP may have had (Lawn & McMahon, 2014).

Fraser and Warr (2009) also studied the experiences of males in a particular cultural context. Five fathers and five spouses in rural Australia were interviewed about their caregiving roles. A 'partnering' versus 'parenting' dichotomy was seen across the groups. Like Lawn and McMahon's (2014) participants, husbands reported marked dissonance when trying to be both husband and carer. They tended to be reactive caregivers who focused less on the MHP itself and more on creating a low-stress environment by reducing housework and managing childcare. Fathers, however, were described as proactive caregivers who focused more on illness management, often taking a "quasi-professional" (Fraser & Warr, 2009, p.46) role that would likely expose children to more medicalised dialogue and 'well/ill' comparisons. In accordance with socially held views of parenting, fathers were reported to use a narrative of "limitless responsibility" (Fraser & Warr, 2009, p.46). The authors did not report on how the MHP was talked about with the children.

Relatives' perspectives on family talk about mental health

Finally, three recent papers examined the relatives' perspective on family communication about MHP. As part of a larger stigma-reduction study, Karnieli-Miller et al (2013) asked 14 relatives about deciding when, how much and what to communicate about the MHP. The authors termed this 'the art of selective disclosure'. Family social rules, family history, and relatives' beliefs about what the person with MHP would want them to say were key determinants of disclosure with non-family members. Relatives described weighing up the pros and cons of preserving emotional energy versus educating others, and their identity as either 'relative' or 'caregiver' was important. As Karnieli-Miller et al's (2013) findings relate to communication with people outside the family, conclusions are not drawn about within-family talk.

Directly addressing communication, Maenhout, Rober and Greeff (2014) conducted an IPA of spouse interaction in families where one partner had depression. Six spouses participated and five couples had children. Two communication styles were reported by the study: talkative couples (many conversations, easy communication) and taciturn couples (silence dominates, talking difficult). Increased spousal communication was linked with better mental health literacy, higher empathy and spouses feeling valued. Talking was seen to strengthen family resilience: “Yes, I think if we did not talk about [the depression], things would have been worse” (Maenhout, Rober & Greef, 2014, p.6). Nonetheless, the need to pick the ‘right’ moment to talk was highlighted, evidencing the widely cited clinical need to promote mental health talk in families. Nonetheless, one participant reported avoiding mental health talk in front of the children. Across the sample, spouses minimised talk if their partner felt silence was protective to maintain harmony in the spousal relationship.

Finally, Ballal and Navaneetham (2018) explored ‘well’ parents’ experiences of talking to children about their other parent’s MHP. Their findings emphasised a number of dilemmas that ‘well’ parents face when communicating with children about a parent’s MHP. A gender-balanced sample of ten ‘well’ parents participated. Again, participants were found to limit children’s exposure to mental health talk and information with the aim of reassuring and protecting children from age-inappropriate information or roles, or to reduce the likelihood of talk outside the family. As also reported by Mizuno, Iwasaku and Sakai (2011), relatives shouldered the burden of sharing information about the MHP with the children. Similarly to Maenhout et al (2014), ‘well’ parents sometimes found discussion with the children necessary, although it was unclear whether talk was maintained over time. The findings indicated that parents with MHP were generally not involved in conversations with children (Ballal & Navaneetham, 2018).

Discussion

This review has drawn together literature in a relatively sparse area of mental health research where adult relatives' meaning making and communication experiences are the focus. In line with the family carer literature (Ostman, 2007; Rudder, Riebschleger, & Anderson, 2014; Gallagher & Mechanic, 1996), this review highlighted the profound practical, emotional and social impact for relatives of people with a severe and enduring MHP. Burden, stigma, shame, financial difficulties and isolation were commonly cited, indicating the universality of these experiences across populations, genders and cultures. These challenges manifested in accordance with relatives' gender, culture, relationship to and cohabitation with the person with MHP, mental health literacy and access to healthcare and carer support. While often associated with caregiver burden, these challenges appeared to also affect non-caregiving relatives. There was variation amongst the studies with regards to whether relatives identified as caregivers for the person with MHP or not. It is likely that the varied aims and methods of the studies identified also contributed to whether this was reported or not.

Across the reviewed studies, increased mental health literacy was associated with improvements in understanding, coping and stigma reduction for relatives (Maenhout, Rober, & Greeff, 2014). 'Scaffolding' of mental health knowledge over time (Stern, Doolan, Staples, Szmukler, & Eisler, 1999), that is allowing new understandings to form and take hold, via experience and psychoeducation appeared to be a key process for supporting relatives' coping and identity. It seems that they make attempts to integrate historical understanding of their family member with a new and often changeable presentation due to the MHP.

Successful integration appeared to be associated with better outcomes for relatives, children and parents. The review indicated that relatives with more ‘scaffolded’ understanding of the MHP, e.g. through psychoeducation or their lived experience, report better quality of life, better communication and familial relationships (Karp & Tanarugsachock, 2000; Tranvag & Kristoffersen, 2008). This points to a clear role for mental health practitioners, including nurses, psychologists, social workers, and others, to offer contexts to relatives of persons experiencing MHP where the MHP can be discussed, experiences processed and made sense of and psychoeducation provided.

Where relatives focused on their personal relationship (rather than caregiving relationship) to their family member with MHP, narratives of personhood emerged more readily. This appeared more prevalent among spouses and cohabiting relatives, indicating that the nature of the relationship with the person with MHP may have a significant impact on the understanding their relatives and caregivers develop about their difficulties and their favoured approaches to support. It is possible that relatives’ emphasis on the person rather than the MHP represents a transferable value that shapes how they label MHP-related emotions and behaviours. This supports the relevance of early psychoeducation for relatives relevant to their relationship and family context. The meaningful inclusion of relatives in family approaches such as Beardslee’s Family Intervention (Focht & Beardslee, 1996; Pikhala et al, 2011) may be beneficial for sharing such narratives within the family. Variation in a relative’s personal relationship to the person with MHP also includes gender. Fraser and Warr’s (2009) finding that fathers and spouses took more proactive or reactive approaches to managing the MHP and focused on giving different types of support further indicates that gender plays a substantial role in relatives’ identity development. For example, dominant societal discourses about masculinity and traditional gender norms around caregiving likely shape the experiences of male and female relatives, with the potential for greater role confusion for men. Not enough studies exist of single-sex relative groups to draw firm conclusions, but there are implications for tailoring support differently for spouses and fathers. Across countries, cultures and ethnicities, the papers reviewed emphasised a clinical need for earlier, family-focused education and communication interventions that recognise relatives' pivotal roles in family meanings and talk.

Where failure to make meaning about the MHP and feelings of disruption persist over time, relatives appear to experience poorer emotional wellbeing. They report more difficulties caring for themselves and others and fewer opportunities to talk to friends and relatives about their experiences. Relatives appear to manage uncertainty, avoid emotional distress and preserve stability at times by holding back from speaking or acting. Similar findings have been reported in studies examining perceptions of talk between adults with MHP and their children as a strategy to exert control and protection in confusing or risky situations (Nolte & Wren, 2016). It may additionally reflect a lack of shared language to discuss what is happening. In line with Nolte and Wren's (2016) findings, Ballal and Navaneetham's (2018) findings indicate that relatives were often left to discuss the MHP with children even when the parent was around, but that relatives often chose silence over talk with children.

Three studies were identified that addressed relatives' talk and communication about the MHP, of which one had a family focus (Maenhout, Rober, & Greeff, 2014). These studies emphasised that relatives often experience a conflicted relationship with family talk about MHP. Complex decision-making appears to underlie relatives' choices to talk or stay silent in a given moment and they largely appeared to make these decisions independently. This is consistent with knowledge that caregiving relatives shoulder a considerable burden of responsibility and safeguarding without professional support (Afzelius, Plantin, & Ostman, 2018). Taking the perspective that meaning creation occurs between people (van Parys &

Rober, 2012), it is probable that the frequency of talk (or silence) within families contributes to the development of internalised rules about the acceptability and helpfulness of discussing the MHP. Nonetheless, relatives who talked generally reported finding it beneficial. Given the benefits of mental health literacy upon individual wellbeing outcomes, helping relatives to increase mental health talk at home may contribute to better wellbeing outcomes for all family members. Mental health professionals working with parents, relatives and children in social and psychiatric settings are well placed to support these unmet needs.

It was a notable finding that only one paper in the review examined talk between children and relatives (Ballal & Navaneetham, 2018), particularly in comparison to the many studies that address talk between children and parents with MHP. Children were rarely mentioned in the discussions and implications, yet sample descriptions commonly stated that relatives or their family members with MHP were parents and several results sections contained references to children in the family. This indicates how reported divisions between adult, child and carer services are mirrored within the literature base. How and what relatives convey to children about MHP may be particularly relevant to children's own meaning-making and experience of mental health-related behaviours witnessed at home. When adults wish to minimise talk, even for protective reasons, a barrier to children developing a coherent understanding of their parent's MHP is likely to arise. Addressing such partitions in the research base is likely an important step in promoting integration in real-world service provision. Such research evidence is vital for mental health nurses, psychologists, therapists and other mental health professionals and volunteers who wish to develop and deliver family-focused interventions. This might include developing understanding about how adult relatives and children share meanings and talk about MHP and how psychoeducation is passed to children relative to their developmental stage. This is a key area for future research.

Limitations

Several limitations should be acknowledged. First, only literature published in English was included. Also, the focus on peer-reviewed primary research meant that grey and non-peer-reviewed literature was excluded.

Within the reviewed studies, there was inconsistent reporting of participant demographics. A number of experiences within the context of MHP which may potentially significantly family meaning-making were not explicitly or consistently considered within the literature. These include the culture and ethnicity of participants and the impact of experiences related to culture (e.g. structural discrimination and lack of equity in access to mental health services) on family wellbeing and meaning-making. Furthermore, periods of hospitalisation of the person with MHP (and involuntary commitment in particular) and the impact on the family's experiences were also not consistently considered. In particular, it was often unclear whether participants looked after the children of their family member with MHP or not. Mental health diagnoses in the reviewed literature were also ascertained via self-report.

Finally, the lack of direct research into how relatives make meaning and communicate with children about parental MHP means that the findings relating to children are based on small samples.

Conclusion

This review contributes a timely and novel summary of existing work within a neglected area. The review supports the triangulation of research findings with children, parents with MHP and their supporting relatives. It is a step toward a more detailed picture of families living with MHP from the relative's perspective and aiding mental health nurses, psychologists, psychiatrists and social workers in the delivery of effective interventions.

Policymakers and clinicians emphasise the need to include relatives in family-focused adult mental health interventions. It is known that they frequently support children when a parent has a severe and enduring MHP. Yet, there is a striking paucity of research from the relatives' perspective on how they talk about and understand the MHP together. Future studies should address this knowledge gap. Clinically, the findings of this review support the use of approaches to build confidence and identity development among adult relatives, and to promote mental health literacy and communication in the wider family system. Mental health practitioners are ideally positioned to address these needs.

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