

# A proverbial double-edged sword

*A qualitative metasynthesis of family involvement in depression from the perspective of people with depression*

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*The notion of family and carer involvement appears throughout European mental health policy and guidelines. However, it has been noted that carer involvement policy may derive from a responsibilization agenda rather than from evidence that it genuinely supports recovery. We review qualitative research on family life with depression from the perspective of people with depression. Studies were included if they elicited accounts from adults with a professional diagnosis of depression. Nineteen studies were included which incorporated the experiences of 493 adults with depression. A metasynthesis of findings from these studies is discussed within three themes: family issues and depression interact; family support*

*as a double-edged sword; benefits and limitations of psychosocial interventions. Findings reveal a complex inter-relationship between family roles, relationship dynamics, gender, culture and attitudes towards depression. Family involvement in primary care and medical settings can be a double-edged sword and the perceived benefit may depend on the extent to which family perspectives on treatment fit with the depressed person's understanding of their depression as medical or psychosocial. Psychosocial interventions for individual clients have several limitations in terms of improving family relationships while family-based group interventions may be more beneficial, depending on the engagement of the family and the partner in particular. The review findings emphasise the complexity of family life with depression indicating that the requirement for 'carer involvement' as simplified in current policies and guidelines is naïve policy at best and that family or couple psychosocial interventions may often be more appropriate.*

## Introduction

For over a decade, international mental health policy has emphasized the involvement of family members in mental health care to support recovery outcomes. Reference to family or carer involvement can be found in national guidelines and policies across Europe relating to mental health generally and depression specifically. In Scandinavian policy, for example, the Danish Health Authority (DHA) depression guidance indicates that "the involvement of patients' relatives must be actively sought during all phases of treatment" (DHA, 2016, 7). A DHA booklet about establishing systematic nationwide involvement of relatives in mental health care (NBSS & DHA, 2014) sets out this policy in detail and includes a range of strategies, guidelines and examples of regional and municipal programmes which variously serve to enable relatives to be involved in identification, classification and regulation of the diagnosed person (Glasdam and Oute, 2019; McPherson and Oute, 2020). Similarly, the UK guideline for depression (NICE, 2009), which informed the current Danish guideline (DHA, 2016, 75) makes references throughout to the need for carer involvement (McPherson and Oute, 2020). Examples can also be found in the policies of Australian, Canadian and other industrialized neoliberal states (Teghtsoonian, 2009).

The policy of carer involvement has been critiqued in terms of the way in which it contributes to the responsibilization of informal caregivers who come to be held personally responsible for overseeing and conducting labour that was previously the duty of welfare institutions (Vreugdenhil, 2017). This has resulted in the co-

opting of voluntary and informal care into the mental health workforce (Fullagar and Gattuso, 2002; Teghtsoonian, 2009). Such forms of responsibilization have occurred increasingly over the decade, during which time many neoliberal mental health systems have also undergone reforms driven in part by austerity politics (McPherson and Oute, 2020). The drive for family involvement in Danish and UK depression guidelines has been shown not to be based on any particular body of evidence demonstrating its added value in terms of recovery or treatment outcomes (McPherson and Oute, 2020). For example, the DHA guideline workgroup included two lay people; the development process involved a consultation with three service users; representatives from patient organisations were included in a reference group; and members of the public were invited to provide feedback on a draft of the guideline (DHA, 2016, 9). However, the involvement of a small number of lay people and service users in development or feedback processes does not constitute a formal review of research which has systematically collected and analysed numerous accounts of service user experiences. McPherson and Beresford (2019) note a similar ambiguity in the work of the UK guideline committee for depression in which lay involvement on the committee is considered an adequate replacement for a systematic synthesis of qualitative research. In excluding formal evidence and relying on scarce patient involvement in the development process alone, national guidelines which recommend family involvement effectively sideline users' and relatives' perspectives through the exclusion of significant bodies of qualitative research. In the absence of a review of evidence, the carer involvement policy itself is instead informed by top-down policy promoting patient and public involvement in health care generally as well as recycling of previous policy as evidence (McPherson and Oute, 2020).

Metasyntheses of qualitative studies examining family caregivers' experiences of living with a depressed person (Hansen et al., 2011; Priestley and McPherson, 2016) indicate that family caregivers experience complex burdens and emotions living with a family member with depression. This impacts on their capacity or willingness to be 'involved' in both formal and informal caring. Caregivers appear to move through phases in attempting to come to terms with their loved one's depression: 'making sense of depression'; 'changes in family dynamics'; 'overcoming challenges' and 'moving forward'. Cohabitant carers experience transformations in sense of self and their view of their relationship with the depressed person. The extent to which carers can adapt within the family context can relate to the survival or otherwise of couple relationships in particular (Priestley et al., 2018). While useful for understanding family caregiver perspectives, no metasynthesis

of patients' own views on family involvement has been identified. To address this gap, this review aims to identify and synthesise qualitative research concerning patients' experiences of family involvement in depression, which, coupled with evidence on caregiver perspectives, could inform policies and guidelines on depression management.

## Method

The review approach used in this article is informed by Sandelowski and Barroso (2006) who outline principles for qualitative metasynthesis. The approach to study identification and selection, quality appraisal and synthesis of findings is outlined below.

### Databases and Search strategy

Databases CINAHL, MEDLINE, PsycArticles and PsycInfo were searched in February 2020. The search aimed to identify qualitative peer reviewed research in which people with direct experiences of depression were interviewed or took part in focus groups or interviews and in which themes emerged relating to the role or impact of family members or family relationships. The search terms used were:

1. TI depress\* AND
2. TI (»ethnographic stud\*« OR »qualitative« OR »phenomenolog\*« OR »grounded theory« OR »purposive sampl\*« OR »content analysis« OR »thematic analysis« OR »constant compar\*« OR »field stud\*« OR »theoretical sampl\*« OR »discourse analy\*« OR »focus group\*« OR »ethnograph\*« OR »hermeneutic\*« OR »narrative analy\*«) AND
3. AB (famil\* OR parent\* OR caregiver\* OR child\* OR carer\* OR partner\* OR spouse\* OR couple\*) NOT TI (postpartum OR postnatal)

### Study selection and eligibility criteria

The search identified 202 articles. The titles and abstracts of citations were screened to assess potential eligibility. Of the 202 articles, 29 were reviewed in full against the eligibility criteria. In addition, studies that had been included in a qualitative metasynthesis (McPherson et al. 2020) concerning the experiences of

psychological treatments for depression were also screened for eligibility and as a result, 10 further studies were reviewed in full. Of the 39 articles reviewed in full, 19 met the inclusion criteria and were included in the review.

Studies were included if they elicited accounts from adults who had experiences of depression (not including bipolar disorder, psychotic depression, postnatal or postadoption depression). Participants had to have a professional diagnosis of depression, either using a validated depression screening questionnaire or a diagnostic interview. Studies could be included if depression was comorbid with another diagnosis (physical or psychological). Where studies collected data from patients as well as professionals and/or caregivers, they were included if it was possible to identify themes which were exclusively based on the data elicited from patients. In order to be included, studies had to report at least one theme or three 'findings' (see Data extraction and Synthesis below) which related to ways in which family members or family relationships related to patients' experiences of depression. Studies in which the focus of family support was in relation to a physical condition rather than depression were excluded. Studies in which the depressed individuals were children or adolescents were excluded.

## Included studies

Table 1 summarises key features of the 19 studies. Studies incorporated the experiences of 493 adults with depression. Some studies were evaluating interventions for depression while other studies were more exploratory, seeking to develop an intervention or to understand more about how people conceptualised depression. Some studies had specifically asked participants about the role of the family while others revealed findings about the role of the family without having specifically aimed to explore this. Studies had been carried out in the UK, Australia, USA, India, Germany, Belgium and Hong Kong. Most of the studies did not recruit any particular age range but two targeted young adults and two targeted older adults, meaning that overall the studies represent a very broad age range including both men and women as well as good representation of economically disadvantaged groups.

## Quality Appraisal

Articles eligible for inclusion were assessed using the Critical Appraisal Skill Programme (CASP, 2018) tool. This tool considers clarity of aims, appropriateness of

methods, design, recruitment methods, suitability of data collection, researcher reflexivity, ethics, analytic rigour and clarity of findings. In terms of study aims, design and suitability of methods, the studies were of broadly similar quality given that they had been selected to meet certain criteria relating to aims and method.

Qualitative methods used among the studies all followed a broadly thematic approach. A significant proportion described a generic form of content or thematic analysis while five specified grounded theory, two specified IPA, one specified framework and one described ‘consensual qualitative research’ which also involved identifying and describing themes. While there was variability in depth of analysis, this was not necessarily linked to the analytic method chosen. Broadly speaking, some studies provided a more descriptive level of analysis than others regardless of analytic approach. However, all studies were deemed to provide a minimum degree of insight in the form of at least three ‘findings’ or one theme on the topic of the role of family and were included.

*Table 1: Included Studies*

Authors	Country	Sample (women)	Definition of depression	Additional sample features	Study focus	Methodology
Azar et al (2010)	Australia	20 (20)	CES-D 10+ (another 20 were not depressed)	aged 18-30	Physical activity among depressed women	Thematic analysis
Battle et al (2010)	USA	26 (17)	DSM-IV interview and MHRSD 14+		Treatment goals of depressed patients	Content analysis
Bhat et al (2020)	India	69 (69)	Diagnosed by professional	Rural women receiving community mental health treatment	Feasibility and acceptability of mobile mental health interventions	Grounded theory
Boyd et al (2006a)	USA	18 (18)	Diagnosis based on clinic records	Mostly low income or ethnic minority	Developing a <u>family based prevention programme</u>	Content and thematic analysis
Burnett-Ziegler et al (2019)	USA	27 (27)	QIDS-C 6-24 or IDS-C 15-69	Mostly low income or ethnic minority	Feasibility and acceptability of <u>mindfulness based group intervention</u>	Inductive content analysis
Claus et al (2019)	Germany	17	DSM-IV-TR interview	parents	Experience of <u>family group based CBT</u>	Deductive content analysis
Donnelly et al (2019)	Qatar	55 (25)	BDI-II 17+ (indicated in Donnelly 2016)	Arabic cardiovascular patients	Conceptualisations of depression	Thematic analysis
Finucane and Mercer (2006)	UK	13 (10)	BDI 14+	Recurrent depression	Experience of MBCT	Framework approach
Glasman et al (2004)	UK	9 (4)	DSM-IV or BDI 20+		Experiences of CBT	IPA
Heilemann et al (2016)	USA	8 (8)	DSM-IV		Experiences of schema therapy	Constructivist grounded theory

Hellemans et al (2011)	Belgium	24	DSM-IV diagnosis	Inpatients	Experiences of multi-family therapy group	IPA
Hinton et al (2015)	USA	77 (0)	DSM-IV interview	Men over 60 with chronic depression	Perceived role of family members in treatment	Thematic analysis
Izquierdo et al (2014)	USA	47 (34)	CIDI (in past); currently reporting depression symptoms and/or taking medication	Latinos over 50	Experiences of primary care visits	Grounded theory
Krause et al (2018)	Chile/Columbia	24 (19)	Professional judgement; receiving treatment	Economically disadvantaged	Experiences of psychotherapy	Grounded theory
Kuwabara et al (2007)	USA	15 (10)	DSM-IV interview	aged 18-25	Experiences of depression in emerging adulthood	Grounded theory/thematic analysis
Liang and George (2012)	South India	9 (0)	PHQ12 5+	Employed community sample	Experience of depression and role of family	Consensual qualitative research (thematic)
Nikendei et al (2016)	Germany	35	DSM-IV		Experiences of day/inpatient treatment	Thematic analysis
Tam and Wong (2007)	Hong Kong	20 (15)	DSM-IV diagnosis	Chinese	Explore dysfunctional attitudes	Content analysis
Teychenne et al (2011)	Australia	18 (18)	CES-D 10+	Disadvantaged neighbourhoods	Explore influences of sedentary behaviour	Thematic analysis

*BDI Beck Depression Inventory; CBT Cognitive Behavioural Therapy; CES-D Center for Epidemiological Studies-Depression; CIDI Composite International Diagnostic Interview; DSM-IV Diagnostic and Statistical Manual Fourth Edition; IDS-C Inventory of Depressive Symptoms Clinician version; IPA Interpretative Phenomenological Analysis; MHRSD Modified Hamilton Rating Scale for Depression; MBCT Mindfulness Based Cognitive Therapy; PHQ Patient Health Questionnaire; QIDS-C Quick Inventory of Depressive Symptoms Clinician version*

## Data extraction and synthesis

From each study, information was collated concerning study participants including sample size, gender mix (where provided), country of study, any distinguishing features of the sample and how participants were diagnosed. Articles were entered into NVIVO for analysis. The approach to analysis was broadly in line with the principles of thematic analysis (Braun and Clarke, 2006) in which codes are allocated to segments of textual data. When applied to metasynthesis of qualitative material, Sandelowski and Barroso (2006) propose that the raw data (quotes) presented in the studies do not constitute data; rather, the study findings are considered as the data and are coded accordingly. "Findings consist of the databased and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation. Findings are researchers' interpretations of the data they collected or generated in their studies." (Sandelowski and Barroso, 2006, 142). Therefore, no direct participant

quotes were coded as data for the purposes of the review; the material coded consisted of author interpretations. This definition of a finding was applied when considering articles eligible for inclusion as noted above.

Author interpretations were coded where they concerned the role or impact of family in any aspect of depression. This could include the role of family in causing or maintaining depression as well as in treatment and recovery. Initial labelling of codes aimed to stay as close to the content and wording of the author interpretation as possible. When all articles had been fully coded in this way, similar codes were merged and labels further abstracted. The codes were then grouped into themes which reflected a broader pattern in the data. The codes within each theme were checked for consistency and accuracy and reviewed in order that they could provide content for each theme.

## Results

Three main themes are detailed below: Family issues and depression interact; Family support as a double-edged sword; and Benefits and limitations of psychosocial interventions. While the themes overlap to an extent and are not necessarily presented in a strict chronological form, there is a degree to which the ordering of themes broadly reflects a temporal dimension. The first relates in part to the how depression can come about within a family; the second relates to initial interactions with health services, which tends to be in medical settings; the third relates to psychosocial interventions which tend to be offered after interaction with medical care.

### Family issues and depression interact

A core feature of this body of research is that issues within both early family life as well as current family life are reported to interact with depression in a number of ways, making it very difficult to disentangle family life from depression. For example, people with depression appear to relate their current emotional difficulties to elements of their early family life such as loss or adversity (e.g. Boyd et al., 2006a); and it has been reported that dysfunctional families or conflictual relationships in the family can be perceived as a source of current emotional distress:

*Participants in this study also believed that growing up in a dysfunctional family and experiencing emotional distress during childhood could have a serious impact on the*

*person's psyche, personality and mental wellbeing that extend into adulthood. This can negatively affect how people think and feel about themselves, their personal identity, and self-esteem that may be the cause of depression. (Donnelly et al., 2019, 1108)*

As well as loss, conflict or communication difficulties, studies also report that family habits relating to poor self-care such as sedentary behaviour or low physical activity can be felt to have impacted on participants' adult lifestyles and might contribute to adult depression (Azar et al., 2010; Teychenne et al., 2011).

Whether or not certain patterns of relating stem from early family life, some studies report that participants tended to interact with their current families in ways that can reinforce depression such as needing regular approval from others, avoidance of conflict, tending to conform to social expectations of gender or role; and not seeking out or making use of support available within the family.

*They would also avoid conflicts by leaving alone situations in which conflicts might occur, forbearing on others, or withdrawing from social interactions that might lead to disharmony. For instance, they tended to avoid disagreement among family members; this entailed having appropriate social manner or skills, and being generous to others. (Tam and Wong, 2007, 111)*

Studies also reported a range of ways in which people with depression could be left feeling alone or abandoned even within their family, because of or leading to depression. This included families conceiving of the person's behaviour as 'laziness', 'self-indulgence' (Boyd et al., 2006) or blaming them for it:

*...one man expressed distress because his family viewed his depression as a personal moral failing while another complained about how his family viewed depression as "craziness." These negative perceptions contributed to men's feelings of being useless or worthless and worsened their depression. (Hinton et al., 2015, 520)*

Other ways that people with depression were reported to feel alone within their family included concerns about not finding a partner and not having children because of the stigma of depression; feeling unsupported in the family, exacerbating loneliness and depression; feeling depressed because of separation from family by life circumstances; feelings of shame preventing people talking to their family about depression. Single parents were reported to feel alone without the support of their child's father (Boyd et al., 2006) and young adults felt estranged or alienated from their family in their transition to adulthood:

*Stigma was both perceived by the depressed individual ("shame") and from others, in terms of being judged by authority figures and announcing a sense of failure to friends and family. (Kuwabara et al., 2007, 3)*

In spite of an overall sense of abandonment by the family, people with depression also appeared to express a range of deep concerns for their family members. Reporting on participants in areas of conflict (the Middle East), Donnelly et al (2019a) found participants' worry about their families' safety could cause depression. In a Western context, Boyd et al (2006) found that mothers were concerned about life stresses impacting on their family (such as financial, housing problems, violence) and were particularly concerned their children might acquire depression by witnessing their own depression. They worried about their parenting being inadequate (although the mothers did not personally see a link between parenting ability and their depression). In an Eastern context, Tam and Wong (2007) reported that depressed people were concerned about their family losing respect ('losing face') because of the individual's depression.

There were also a range of ways in which responsibility to the family appeared to prevent people with depression looking after themselves or getting other support. Among ethnic minority groups in the USA, Burnett Ziegler et al (2019) and Izquierdo et al (2014) reported that child care, caregiving and other family responsibilities as well as negative experiences of help-seeking of a relative prevented seeking or attending mental health care. Both Azar et al (2010) and Teychenne et al (2011), reporting on participants in Australia, found that family responsibilities prevented self-care activities such as physical activity.

*Among women with depressive symptoms, family/household responsibilities and distance to university/work were also cited as a cause for lack of time for physical activity participation. (Azar et al., 2010, 6)*

Heavy family responsibilities could also exacerbate depression (Donnelly et al., 2019) and among Qatari and Indian men, worry about financial responsibility to the family appeared to contribute to depression (Donnelly et al., 2019; Liang and George, 2012). In contrast, young adults in the USA who remained financially dependent on their parents were found to be unable to access mental health care because their parents were unable to fund treatment (Kuwabara et al., 2007).

## Family support as a double edged sword

Whilst the research reviewed reveals a complex inter-relationship between family roles, relationship dynamics, gender, culture and attitudes towards depression, the research also reveals a number of ways in which families have the potential to be a supportive component in the lives of people experiencing depression. This may sometimes be a double edged sword, however, particularly in a context in which there is no uncontested, correct way to manage or treat depression or even an agreed upon definition or causal theory. Moreover, family support has been reported to be explicitly problematic.

*...involvement of family members is like the proverbial “double-edged sword” in the sense that it has the potential to promote and/or to impede depression treatment and “outcomes.” (Hinton et al., 2015, 520)*

Hinton et al. report that because of the complexity in families and potential for the family to be contributing to depression, involving families in care is an important opportunity to “address the negative impact of family members on men’s depression” (p521). This is supported by various findings concerning the ways that depressed people express the wish for family support. Depressed individuals in Australia have been reported to need family support and encouragement in order to enable more self-care such as physical activity (Teychenne et al., 2011). Family support has been reported to be practical or emotional, for example it “may consist of having a confidante, people to check in on them, and assistance with childrearing and housework” (Boyd et al., 2006, 193). Similarly:

*Family members buffered men’s depression by supporting them emotionally, assisting men in coping with depressive symptoms or providing moral encouragement. Several men, for example, described how their wives would counter their feelings of being worthless or useless by emphasizing to men their intrinsic value. ... men described family as emotionally supportive because they were simply “there,” providing companionship and attention that alleviated men’s sense of being isolated, lonely or disvalued.(Hinton et al., 2015, 519)*

There were also ways in which family involvement may appear supportive but where other interpretations are also possible. For example, whilst mothers have been reported to wish for more support with childcare as noted earlier, Boyd et al. (2006, 193) also report that “sometimes these parenting difficulties result in extended family taking over the care of the children” which could be interpreted

as more of a punishment than a support. Likewise, Hinton et al. (2015, 520) report that “during primary care visits, family members sometimes disclosed information to providers about the man’s depressive symptoms,” which might be seen as a supportive role but this would depend on whether the depressed person wanted the information reported or not. Both Hinton et al (2015) and Izquierdo et al (2014) report on the ways in which families encouraged participants to seek medical treatment or adhere to medical treatment and management; yet whether this is regarded as positive support or not may depend on whether the individual considers their distress to be a medical problem or whether they might prefer to address their issues from a more social or psychological stance.

*The family role in illness management included assistance with organization, advice and persuasion, and drawing men’s attention to their depressive symptoms. For example, family members organized antidepressants and encouraged or reminded men to take them. When men ignored or minimized depressive symptoms, family members told men their symptoms were serious and encouraged them to talk to their doctors. (Hinton et al., 2015, 520)*

It is unclear the extent to which this author interpretation has moved beyond the data offered by patient participants or what participants’ views of this persuasion and encouragement were. Hinton et al (2015) conclude that

*Decisions about family involvement in depression interventions and services should be based on men’s preferences as well as the availability, role(s), preferences, and skills of family members. (Hinton et al., 2015, 521)*

Yet, as noted by Krause et al (2018), the degree and nature of family support will depend on family members’ perception of mental illness and its treatments. If this is not in line with the perceptions of the depressed person then support could potentially cross the line into coercion. Studies report a number of ways in which family support could be explicitly problematic in this sense. For example, family presence at visits in India were reported to sometimes prevent certain disclosures:

*...when family members do accompany women to the clinic, interpersonal conflict and barriers related to low autonomy may not be disclosed during the clinical encounter. (Bhat et al., 2020, 472)*

Similarly, Hinton et al. (2015, 520) reported that disclosure of depression among older men in the USA could be hindered by the presence of family members because of privacy concerns or “because they did not want to worry their family mem-

bers". Moreover, the authors reported that some families were disinterested in supporting their relative, had no time, would discourage treatment or, where they did attend visits,

*...family members were perceived as being disruptive during the clinic visits because they were too controlling, critical, or because their relationships with older men were simply too dysfunctional. (Hinton et al., 2015, 520)*

## Benefits and limitations of psychosocial interventions

Findings concerning family support reviewed above have tended to relate to depression management in primary care or medical settings. An alternative way families may be involved in the care of depressed people is through psychosocial or psychological therapies. This theme explores the ways in which both individual, group or family-based psychological or psychosocial interventions can impact on family relationships from the perspective of depressed individuals.

Studies included in the current review and which concern patient experiences of individual psychological treatments for depression include Cognitive Behavioural Therapy (CBT) (Battle et al., 2010; Glasman et al., 2004), Mindfulness Based Cognitive Therapy (MBCT) (Finucane and Mercer, 2006), schema therapy (Heilemann et al., 2016), Chilean or Columbian state psychotherapy using various modalities (Krause et al., 2018) and a multi-modal day and inpatient clinic in Germany (Nikendei et al., 2016).

Exploring the treatment goals of depressed people beginning a course of CBT, Battle et al (2010) found that improvements in family function was frequently stated as a key treatment goal for a majority of participants. However, a common finding among studies is that individual therapies appear to leave family problems unresolved, sometimes as consequence of individualizing the mental health problems. For example, Finucane and Mercer (2006) reported on participants who, following MBCT, found both past and current family problems unresolved (such as unresolved trauma, current domestic violence) and that family burdens prevented practicing techniques learnt in therapy. Following CBT, Glasman et al (2004) also reported that family burdens and contexts prevented implementing and practicing cognitive strategies and that,

*Emotional closeness or intimacy was a barrier for a number of people, who described the difficulty they had using thinking strategies when faced with their immediate*

*family. Participants described not being able to break familiar well-rehearsed patterns and responses with family members. Terry talked about always in the past finding his family too smart for him, and even now when he went home he was immediately drawn into the familiar role of being ‘pushed aside’.* (Glasman et al., 2004, 345)

Similarly, while Nikendei et al (2016) found that inpatient care could be a significant relief to individuals from their family chores and burdens, on returning to family life afterwards, participants could feel overwhelmed by family demands and return to conflict situations with some relapsing as a result. Thus, Nikendei et al (2016) note that the level of conflict in the home should be taken into account when considering the potential value of day versus inpatient treatment. In Chile and Columbia, outpatient psychotherapy was reported to help improve communication and relationships within the family (Krause et al., 2018) and schema therapy appeared to provide a wide range of benefits in terms of improving ways of relating within the family, for example,

*Through the interactive work of understanding why things happened in the past, seeing patterns, and becoming more accepting of themselves, participants realized they had options for different ways of dealing with their families that they never saw before. Women expressed how important it was to be able to change old patterns that hurt them, but to do so without completely rejecting their families. The ability to make such changes was valuable because it opened up the possibility that they could choose to be emotionally healthy without having to completely abandon cultural values for prioritizing the family unit. Secure that they could stay close and honor their family ties even if they saw unhealthy patterns, women valued how therapy gave them the opportunity to seek the best ways to relate to their families* (Heilemann et al., 2016, 1359).

A range of other findings also highlight ways in which interventions for individuals with depression could be improved to take account of family issues. Azar et al (2010) reported that interventions could usefully be tailored and might include skills to engage more family support. Boyd et al (2006, 199) note that interventions could seek to teach mothers “to be advocates for themselves and their families” given that “many of the women seemed to feel too powerless and overwhelmed by the tasks to get them and their children the services that they required”. Similarly, reporting on depressed women in India, Bhat et al (2020, 473) noted the need “to tailor interventions to those that empower women within the household”, specifically indicating that mobile or telehealth interventions may not be suitable becau-

se women tended to share the family phone and women worried their husbands would disapprove or be suspicious. It was also reported that educating family members about depression and treatment would be useful to enable individual therapies to be practiced or implemented:

*...the intrapsychic focus of CBT, which precluded direct involvement of his wider social system, placed limitations on it. For him, it would have helped if his wife understood and experienced the therapy. (Glasman et al., 2004, 345)*

Given the limitations of individually focused treatments for helping with difficulties relating to the family and given that improving family relationships is a key treatment goal for many, Battle et al (2010) suggest that:

*Given that it can be difficult to adequately address certain types of relationship issues in individual treatment, it may be worthwhile to refer patients for adjunctive family or marital treatment. Alternatively, it could be useful to incorporate a family or marital component within a course of individual psychotherapy. Even if the primary treatment modality is individual treatment, conjoint sessions with the patient's spouse or other family members can provide a critical adjunct to the treatment process in many cases. (Battle et al., 2010, 428)*

Two studies reported on experiences of group family interventions, one based on systemic approaches (Hellemans et al., 2011) and the other on CBT approaches (Claus et al., 2019), the latter designed to prevent difficulties developing in children of depressed parents. Both reported that discussion of depression with children in the household had been uncommon prior to the intervention. Talking about depression with the children had been experienced as beneficial; children learnt about depression from other children in the group and discovered that they were not alone in their experiences of having a parent with depression. This helped to relieve some guilt among depressed parents:

*...it was a particular relief to have someone else tell their children that their parents' depression was not their fault... parents felt relieved that the topic was now "out in the open" and no longer a source of discomfort or guilt (Claus et al., 2019, 7).*

This format was reported to be experienced as a "valuable first step in starting a conversation" in the family, making it easier to continue discussing it (Claus et al., 2019, 5). Discussing depression with other families was reported to be particularly useful, enabling exchange of experiences, gaining insights from other families, learning about different ways of coping and feeling less alone. The involvement

of the partner was reported to be particularly important to depressed individuals who “found it helpful to experience cohesion, support and understanding from their partner” (Hellemans et al., 2011, 229).

It has been noted that family interventions may not always be practicable because, for example, “time constraints with school schedules, older children refusing to attend, embarrassment, and juggling many demands” (Boyd et al., 2006, 195). However, findings highlighted various other potential benefits of family based interventions such as helping depressed individuals learn how to foster more support within the family (Boyd et al., 2006), help develop parenting skills (Claus et al., 2019) and help encourage adherence to the process (Krause et al., 2018).

## Discussion

Three main themes emerged from this metasynthesis. One theme concerned the interaction between family issues and depression including experiences of early family impacting on depressed adults’ current emotional life; as well as current family dynamics contributing to or maintaining depression. This is in line with research in the field of family process, attachment styles and marital discord which finds support for theoretical concepts that relate attachment insecurity to depression as well as marital distress (e.g. Heene et al., 2005; Oute and Huniche, 2017). A wide range of theoretical and empirical literature reviewed by Heene et al (2005) indicates that depression and marital discord are correlated but that they interact in complex ways with the addition of other factors such as conflict communication, attachment style, problem solving behaviour, self-blame, early family life and so on. The addition of children to the family dynamic can complicate this further and pose challenges for families where one or more adults have depression.

Secondly, findings considered family involvement as a double edged sword in the sense that whilst depressed adults expressed a wish for understanding and support from their partners and families, this could sometimes be problematic within medical and primary care settings. Potential difficulties included the reinforcement or playing out of conflictual or controlling relationships which then prevented the individual receiving appropriate care from the health professional. Difficulties also included the potential for families becoming (sometimes inadvertently) complicit in potentially coercive care such as persuading their family members to adhere to a medical framing and treatment approach. Concerns about coercion and restraint in psychiatry have tended to focus on physical restraint and

inpatient settings and have been amplified since the 2006 Convention of the Rights of Persons with Disabilities, which conferred new rights on people with psycho-social disabilities (Rose et al., 2017). However, coercion can also apply to chemical treatments and ways of framing emotional distress. In considering the fuzzy boundaries between patient education to improve adherence to medicines versus manipulation and ‘nudge’, Reach (2016) considers the ways in which patient education can sometimes appear benign while retaining elements of paternalism and manipulation. In a similar sense, ‘family involvement’ implemented with a view to improving adherence and monitoring the patient may likewise reflect a paternalistic agenda rather than a genuinely patient-centred approach.

Finally the findings highlighted the impact of various psychosocial interventions, both individual and group based, on family life. Since improved family functioning and better relationships are often the things that depressed people would like to change, interventions which help with this may be most suitable for delivering patient-centred outcomes. The findings reviewed here suggest that individual psychotherapies may not be particularly useful for improving family functioning or even individual patterns of relating with the exception of schema therapy. Conversely, family difficulties left unaddressed potentially limit the impact of individual therapies even on individual functioning. It appeared that group based family interventions did seem to deliver positive outcomes from the patient perspective. These interventions therefore seem most promising and can also potentially deliver benefits for the whole family and couples in particular which would help to address the sorts of difficulties identified by caregivers and partners in the literature (discussed above) and is also supported by theoretical and empirical work discussed above concerning depression and family function, attachment and marital discord (Heene et al., 2005).

These findings should be viewed in the context of evidence based medicine (EBM) in neoliberal states which invariably prioritises Randomized Controlled Trials (RCTs) over other forms of evidence. Findings from meta-analyses of RCTs are then grafted onto cost utility approaches to healthcare rationing either implicitly or explicitly as in the UK and Denmark (Hughes and Doheny, 2019; Speight and Reaney, 2009). Guideline developers view qualitative research as lacking validity and claim that an appropriate way to ascertain patient perspectives is simply to involve a small number of individuals in the development process, as noted earlier. The UK guideline body has explicitly stated, “we do not believe questions of effectiveness should be addressed by qualitative reviews as it lacks external validity” (NICE, 2018, 53). It has been argued that EBM can be and is now being

reformed from its ‘modernist roots’; is now embracing more pluralistic forms of knowledge and subjectivity; and that patient and public involvement is one illustration of this ‘new’ EBM (Wieringa et al., 2017). An alternative view is that RCTs and EBM cannot be reformed, since to attempt to do so falls into a trap of ‘strategic ignorance’; that an alternative paradigm in which subjectivity is central rather than peripheral is needed to genuinely take account of subjective experience and improve care for individuals (McPherson et al., 2018). The metasynthesis presented here reveals findings which could not have emanated from an RCT; we argue that this illustrates why RCTs and cost utility analyses are conspicuously inadequate to address questions about the value, feasibility and appropriateness of family involvement in depression care. Moreover, artificially separating efficacy of specific interventions from the broader context of patients’ everyday lives produces a narrow medical-political gaze on family life with depression. RCTs, even the ‘pragmatic’ variety, are designed primarily to remove context rather than incorporate it.

The current metasynthesis has taken account of the experiences of 493 diverse individuals with depression and represents a wide range of populations in terms of age, gender, national settings and majority versus minority ethnicities. Whilst there are inevitably statistical limitations of qualitative research, the evidence reviewed here when synthesised contributes transferrable experiential knowledge that could be used to inform patient-centred policies for depression. The NBSS & DHA pamphlet on family involvement in mental health states that, “in situations where the patient does not want the relatives involved, the relatives may still need to get involved” (NBSS & DHA, 2014, 10). Our analysis suggests the contrary and emphasises that it is of primary importance for people with depression to maintain choice and control over their care at all times and that this should apply to professionals’ as well as relatives’ preferences for treatment and management approaches. Our analysis also reiterates the importance of early life experiences and points to the potential value of trauma-informed approaches which could help to identify any relevant family issues (past and present) prior to introducing the patient to options such as family based interventions (Sweeney and Taggart, 2018). Finally our findings suggest that after exploring family background, family and social context and patient preferences in general, family based interventions should be made widely available as an option for people with depression. There are however certain practical barriers to family interventions given the need to identify a time, venue and mode of working that suits everybody. Psychological professions should prioritise consulting with patients and relatives to identify va-

rious ways to overcome practical barriers which also points to a further need to overcome the widespread paternalism in mental health care systems. In line with the political emphasis on community health and strengthened ties between the state and civil society in Scandinavia and Europe (McPherson and Oute, 2020), this may take the form of more outreach, linking in with community initiatives and working with colleagues and provider organisations to identify more flexible working practices which seek to accommodate the needs of patients and their families.

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