

The relatives of people with depression: A systematic review and methodological critique of qualitative studies

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Abstract

Being a close relative of a person with depression can take a heavy toll on the former, but these relatives are increasingly made responsible for taking on extensive carer roles. Research on relatives of people with depression is currently dominated by a focus on “carer burden” and although such a focus can explain many relatives' experiences and daily lives, it provides very limited insight into the everyday life of a person living with someone with depression. Therefore, we scoped qualitative research on people who are relatives of people living with depression and identified knowledge gaps caused by explicit or implicit theoretical or methodological assumptions. We conducted an exhaustive literature search in CINAHL, PubMed, PsycINFO, Sociological Abstracts, and Eric. In total, 34 publications were included, their quality evaluated and their findings mapped and summarized. We identified four interrelated and overlapping themes that dominated the findings of the publications: (a) recognition of “depression”, (b) emotional responses, (c) interruptions of relationships, and (d) a staged psychosocial process. The vast majority of studies presented de-contextualized and underinterpreted analyses assuming a homogeneity of (illness) experiences and disregarded the important influence of social contributors to social relationships, connectedness, and mental health problems.

KEYWORDS

depression, family relationships, qualitative research, relatives, scoping literature review, sociology, theory and method development

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INTRODUCTION

Changing treatment philosophies and healthcare policies have contributed to a significant transformation of the positioning and roles of relatives of people living with depression and other serious mental illnesses (throughout this article, we use “people with depression” in line with UN’s Disability Inclusive Language Guidelines). The de-institutionalizing and mainstreaming of mental health services have made relatives of people with depression increasingly responsible for taking on carer roles and responding to the ongoing mental health concerns and distress of their loved ones (McPherson & Hansen, 2021; Teghtsoonian, 2009). These “responsibilization” processes have been augmented by the adoption of neoliberal healthcare policies, goals, and orientations, which, due to a greater emphasis on staff accountability and economically efficient use of time, place further responsibility on family members to be active contributors to the recovery of their relatives (McPherson & Hansen, 2021; Teghtsoonian, 2009). Being a close relative of a person with depression can take a heavy toll on the former’s health and well-being (Jeglic et al., 2005; van Wijngaarden et al., 2004; Yu et al., 2020). Yet, little is known about the everyday experiences of these people. In the effort to address this lacuna, the current paper reports the findings from a scoping review undertaken to identify key themes in this area of research as well as the findings from a concomitant critical research evaluation designed to identify potential knowledge gaps.

The toll on relatives of people with depression can be exacerbated by the dominating sociocultural perspectives on depression and other mental illnesses. From an interactionist perspective, the meaning of people’s experience of their own or others’ depression is mediated and negotiated through sociocultural healthcare practices (Bröer & Besseling, 2017; McPherson & Armstrong, 2009). For example, present-day meanings of depression are informed by an increased and widespread favoring of individualism and individualist values of personal responsibility, self-realization, and initiative. This makes people with depression stand out as the direct opposite, namely as “inadequate” and “deflated” (Ehrenberg, 2010). In addition, there is a blurred line between “depression” and expected and transient “normal sadness,” which can result in contested interpretations with consequences for relatives and the ill person’s day-to-day privileges and responsibilities. For example, in contexts with high levels of social adversity, symptoms of depression can be normalized, and depressive disorders may remain undiagnosed, which often happens without the necessary awareness of health policymakers (Patel et al., 2016). In contrast, such a position has been criticized for medicalizing and pathologizing “normal sorrow”; processes that were accelerated by the de-contextualized approach to mental health diagnoses introduced with the DSM-III diagnostic system (Horwitz & Wakefield, 2007). Consequently, relatives of people with depression must negotiate the contrasting meanings and subsequent questions of the legitimacy of their relative’s behavior.

Research on relatives of people with depression is dominated by an emphasis on “burden” (Kokanovic et al., 2006), which to a large extent grew out of an interest in understanding the social costs of de-institutionalization (Greenberg et al., 1994). Although this research highlights important implications of the carer burden, it ignores the nuances and reciprocity in committed relationships. For example, a focus on burden ignores the potentially rewarding experiences of caring (Greenberg et al., 1994; Henderson & Forbat, 2002). Furthermore, the language and labeling of “relatives” and “relationships” is not neutral and may miss the subtleties within these relationships. For instance, “caregiver,” “family member,” “friend,” “loved one,” “offspring,” “parent,” “partner,” or “spouse” suggest diverse relationships with different relational expectations regarding obligations and commitment. Some people may identify with and accept the normative expectations associated with some of these descriptors and reject others. Carer experiences and relationships are thus diverse and varied beyond a limited focus on the burden.

There is an incremental growth in the number of qualitative studies of relatives of people living with depression, including two published syntheses. Hansen et al. (2011) evaluated eight papers using the COREQ checklist (Buus & Perron, 2020), synthesized the findings, and suggested that relatives go through a cyclic psychosocial process of adapting to their relative's depressive illness. Inspired by Karp's (1994) notion of "identity turning points," Hansen et al. (2011) described three distinct phases in this process that were separated by major junctures in the relatives' recognition of their situation: searching for help and explanation, the debilitating period, and recovery. In addition, through meta-ethnography, Priestley and McPherson (2016) evaluated 15 papers (including the eight reviewed by Hansen et al., 2011) using an adapted version of the CASP checklist (Critical Appraisal Skills Programme, 2018), synthesized the findings and described a similar cyclical psychosocial process with four phases: making sense of depression, changes in family dynamics, overcoming challenges, and moving forward, which relatives move through as they come to terms with caring for a person with depression. The results of the two syntheses are similar and depict relatives' psychosocial trajectories as parallel to those of the individuals who are experiencing episodic psychological difficulties characteristic of depression.

In summary, quantitative research on relatives of people with depression is dominated by a focus on the burden on the relative, and qualitative research on relatives' psychosocial responses following the persistent and fluctuating relapsing–remitting pattern of affective illnesses. Although such a focus can explain many relatives' experiences and daily lives, they provide very limited insight into the everyday life of a person living with someone with depression outside periods of clear symptoms of clinical illness. It also limits researchers' abilities to focus on other, less conspicuous dimensions of relatives' experiences and concerns in everyday life (Kokanovic et al., 2006). The reviews by Hansen et al. (2011) and Priestley and McPherson (2016) included brief descriptions of quality assessments focusing on standard methodological strengths and limitations. We believe that there is now scope for a more robust critical evaluation of this growing body of research with a greater emphasis on analyzing and challenging trends in the explicit and implicit theory and methodology underpinning this research. Therefore, the aims of this scoping review were to identify the scope of qualitative research on people who are relatives of people living with depression and to identify knowledge gaps caused by dominating theories and methodologies used by researchers in the field.

METHODS

We conducted a scoping review (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2020) of peer-reviewed articles and PhD dissertations reporting qualitative research on relatives of people with depression.

The first part of the systematic and exhaustive literature search was a "building block" database search (CINAHL, PubMed, PsycINFO, Sociological Abstracts, and Eric) using synonyms of "relatives" AND "mental health" AND "qualitative research." Where possible, we utilized controlled search terms from the databases' thesauruses. We imported 5974 references into Covidence (www.covidence.org) and removed 868 duplicates. Two independent reviewers (NB and BO) screened the references against the inclusion criterion: Qualitative research on relatives of people with depression was published in English. Our scoping approach included journal articles and PhD dissertations where the depressed person was formally diagnosed with depression as well as studies where participants believed that they had depression without being formally diagnosed (and papers where the presence of formal diagnosis was not reported). Our exclusion criteria were: (a) research with mixed samples, for example, relatives and professionals or depression and other mental health illness, as it was impossible to discern whether they met the inclusion criteria and which group

of participants the findings were concerned with; (b) program or treatment evaluations, as these focused on very specific issues, e.g. electroconvulsive therapy, and not wider concerns of living with depression; (c) studies of post-partum depression, as this situation triggers particular clinical and social responses; (d) publications where relatives and the persons with depression were studied separately, but reported together in the same publication, as the relevant parts of these reports were very limited in size; and (e) literature reviews. We screened out 4799 references reading titles and abstracts, evaluated 307 full-text papers, and identified 14 relevant studies. The second part of the search was a systematic “chain” search of the relevant studies' ancestry references (reference lists) and the descendancy references (citing articles) in the SCOPUS citation index. This procedure identified 20 additional relevant references. The search protocol was published in the Figshare research repository (Buus et al., 2022).

Although it is debated whether scoping reviews should include an assessment of the quality of studies (Munn et al., 2018; Peters et al., 2020), we critically assessed the 34 included references using the British Medical Sociology Group's “Criteria for the evaluation of qualitative research papers” (Blaxter, 2013), which incorporates the knowledge development objectives and traditions of a broad community of qualitative researchers from a wide range of academic and practice disciplines (Buus & Perron, 2020). The 20 items of the guideline inquire into evidence of the researcher's positioning with regards to the topic and the cases/participants; justification for the approach to data collection and evidence of a systematic, nonselective sample; justification for the approach to data analysis, evidence of a systematic and nonselective presentation of results, and evidence of systematic testing of findings; sufficient contextualization of setting, cases/participants and data; and adequate ethical considerations. We chose this guideline because it is deliberately flexible and nonexhaustive and draws on assessors' “taste” (Sandelowski, 2015) and skills as they inquire into methodological justification, coherence, and context regardless of the specific research methods used. The criteria were not designed to exclude poorly reported studies, and we used them to provide structure to our reading of the papers. Two independent reviewers evaluated each paper (NB and BO) using the criteria and they discussed similarities and differences in their evaluations. In the findings section, we will focus on a lack of description of context, which was an issue in all papers.

In addition to this evaluation of the studies, the two reviewers collectively rated the papers according to Sandelowski and Barosso's (2003) typology of descriptive versus interpretative qualitative studies. This is concerned with the level of interpretation of data with studies' results sections classified as no finding (reporting raw data), topical survey (reporting groups or lists of manifest topics), thematic survey (reporting latent themes), conceptual/thematic description (reporting theoretical interpretations), or interpretive explanation (reporting extensive theoretical interpretations). The reviewers independently rated each study and disagreement was resolved through consensus-seeking discussion.

The included publications were charted in a table according to year of publication, publication type (i.e., article or dissertation), the discipline of the publication outlet, country of origin, aim, definition of depression, relationship of participants to the depressed person, number of participants, study design, data collection methods, data analysis/interpretation, summary of findings, and level of interpretation (see an abbreviated version of the chart in [Table SI](#) in the supplementary online material).

Mapping and summarizing the papers' findings was supported by the use of NVivo. After the import of studies (as PDFs) into NVivo, the first author coded the findings of the papers using an open coding process. Codes were gradually aggregated and the whole group of authors discussed the significance of key themes against the backdrop of the quality assessment and the mapping. The following findings section includes a description of the scope of findings and methods in current research on relatives of people with depression.

FINDINGS

The 34 publications included 32 articles and two PhD dissertations reporting from 27 studies in total. They included the 15 publications included in Priestley and McPherson's synthesis (2016). In terms of academic disciplines, 16 of the publications were classified as “nursing,” 10 as “psychology,” five as “medicine,” and three as “sociology of health.” The number of publications from this field of research has grown incrementally since the mid-1990s (when there were only 2 publications), with 20 publications found in the period 2000–2009, and 21 publications after 2010. Although the area was dominated (85% of publications) by nursing and medicine up to and including 2009, after 2010 more than half (52%) of the publications originated in psychology and sociology of health. The majority of publications ($n=27$, 85%) were from developed countries and five (15%) from developing countries.

Depression was defined in several ways. More than half (59%) referred to a clinical (formal) diagnosis of depression, which was either researcher-recorded or participant-reported. In 26% of studies, depression was researcher-defined through both formal (standardized tools) and informal assessments based on either direct assessment of the person with depression or indirect assessments of the relative's accounts of the person with depression's symptomatology. In a further 26% of publications, depression was self-reported by participants but not formally diagnosed. Studies only very rarely reported clinical details regarding the character of depression, including severity, duration, number of depressive episodes, age at first onset, co-morbidity, etc., which added to an image of depression as a homogeneous illness. The studies thus emphasized providing a justified diagnosis of depression but provided only little information about the unique situation of the participants or the study context in general.

About half of the publications (53%), included a single type of relative, for instance, intimate partners, mothers, offspring, and the other half (47%) included a mixture of relatives. The median number of participants was 15, ranging from 3 to 52.

Interviewing was used to collect data in all studies, with one (González et al., 2010) also utilizing observation. Individual interviews were used in 30 publications (88%), while eight papers (25%) reported using couples, family, or group interviews or focus groups, and 10 (29%) included a type of follow-up data collection. In 12% of the publications, relatives were interviewed alongside the person with depression. Two publications stood out by making use of markedly different approaches to data collection and analysis. First, a publication by Van Parys and Rober (2013) combined a thematic analysis of interview data with an analysis of how offspring interactionally accomplish “care” of the parent with depression. Interactional data linked to the theme “trying to comfort the parent,” which was identified in the thematic analysis, were examined and presented as the performative dimensions of children's comforting practices. Second, an Interpretive Phenomenological Analysis by Yap et al. (2020) included photo elicitation to explore participants' experience of “feeling at home” in places with a cohabitant relative with depression. This was reflected in findings highlighting the significance of “place,” for example, dangerous, hopeful, painful, or (un)safe places, which had not been evident in prior research in this area.

Half of the publications ($n=17$) described using a thematic/content analysis. Eighteen percent ($n=6$) of the publications described a Grounded Theory approach, which was a methodology favored in nursing publications before 2010. Twenty-one percent ($n=5$) of the publications used a phenomenological approach, with Interpretive Phenomenological Analysis particularly prevalent in psychology publications after 2010. Three (9%) of the publications reported making use of interpretive/hermeneutic analysis. One of the studies used a Weber-inspired ideal type analysis, one study described a generic “qualitative analysis” and one publication did not explicitly refer to any method of analysis.

Dominating themes

All publications considered the impacts of depression and how relatives responded to the situation. The mapping and summarizing process identified four interrelated and overlapping themes that dominated the findings of the publications. Although some publications emphasized a single theme, most publications emphasized or touched on several themes. The themes were (a) recognition of “depression,” (b) emotional responses, (c) interruptions of relationships, and (d) a staged psychosocial process.

Recognition of depression

Many studies included descriptions of how participants had come to recognize their relatives' situation as depression (Ahlström et al., 2007; Baik & Bowers, 2005; González et al., 2010; Highet et al., 2005; Kaimal & Beardslee, 2010; Kleebthong et al., 2020; Muhwezi et al., 2008; Priestley et al., 2018; Stapley et al., 2017). This included descriptions of intense experiences during a period of uncertainty and frustrated help-seeking before recognizing and accepting depression as a name for the core issue. For some, this happened when a healthcare specialist suggested a formal diagnosis, which could create a sense of hope given that their problem now had a name and indicated treatment. It also included accounts of relatives' flexible explanatory models about the causes and timing of their relatives' depression with participants initially thinking of the difficulties as something like stress, personality, or “just” a developmental phase. A number of these publications hinted at a normative evaluation of participants' explanations by assuming that participants lacked medical knowledge about depression and therefore recommended more training for health staff and psychoeducation for the community on depression (González et al., 2010; Highet et al., 2005; Kleebthong et al., 2020; Muhwezi et al., 2008).

In the process of identifying the difficulties of depression, families were frequently introduced to a variety of diagnostic practices as they engaged with mental health services. For instance, as part of a larger trial comparing the effectiveness of three manualized treatments for adolescent depression, Stapley et al. (2017) conducted 85 semi-structured interviews with parents of 28 adolescents at three time points over a 2-year period from first referral. The comparative analysis of parents' experiences over time identified three patterns of how the parents made use of professionals' knowledge and interventions. The patterns were summarized as Weber-inspired ideal types (perfect examples): “the learning curve parents” (parents finding the professionals' perspectives and help useful), “the finding my own solutions parents” (parents initially finding the professionals' help useful, but later finding their own solutions to problems), and “the stuck parents” (parents not finding the professionals' help useful and being in an unresolved situation). In this study, the authors concluded that parents' recognition of their offspring's depression was not static and that it was intrinsically linked to their use of the service. If parents did not share the professionals' perspectives on depression, they were inclined to stop attending the program.

Emotional responses

The emotional impacts or strain of relatives of people living with depression was described as intense and pervasive and distributed across many areas of life, which could overwhelm relatives to the point of collapse (e.g., Nosek, 2003). Emotional responses had an overwhelmingly negative valence and typically included worry, depression and hopelessness, and, depending on immediate levels of risk, an all-consuming concern or panic. Several publications highlighted

relatives' frustration and helplessness in response to their loved one with depression rejecting ideas or initiatives to mitigate or resolve the situation, such as seeing a psychotherapist or taking anti-depressant medication (Hansen & Buus, 2013; Logan, 2011). Others emphasized respondents feeling a sense of isolation and a loss of self as their sole focus was on the other person's needs rather than their own (Armitage et al., 2020; Camilleri et al., 2017; Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). Several publications described participants being dismissive and resentful toward their relative with depression (Brawer-Sherb et al., 2020; Hansen & Buus, 2013; Oliffe et al., 2011). Only very few publications included mention of intensified caring feelings or personal growth arising from going through this type of adversity (e.g., Logan, 2011; Muscroft & Bowl, 2000).

Although the majority of studies focused on reporting the individual emotional experience of carers, the emotional impact also had social dimensions with some publications reporting participants feeling shame about their relatives' problems and behaviors (Muhwezi et al., 2008). In Hansen and Buus's study (2013) of cohabitant partners' identities, stigma made participants publicly refer to more socially acceptable explanations of their partners' situations, such as "stress" or "somatic illness," rather than depression, which led to a sense of further isolation.

Interruptions of relationships

Several publications highlighted how depression interrupted interpersonal relationships and how participants and their relatives negotiated and managed such interruptions. Descriptions of relationship interruptions varied significantly depending on which type of relationship was affected; with, for example, offspring lamenting the lasting negative effects of growing up in a household with parental depression (Brawer-Sherb et al., 2020; Kaimal & Beardslee, 2010) and parents describing a sense of loss of how they expected their son or daughter to be (Armitage et al., 2020). Interruptions led to conflicts and uncertain renegotiations of roles in families and relationships, for instance, finding a balance between care and protection and coercive intervening (Badger, 1996a) or romantic roles versus caring roles (Glenn et al., 2013). Several publications described relatives as "walking on eggshells," trying not to upset or anger the relative with depression (Armitage et al., 2020; Highet et al., 2004; Mechling, 2016; Oliffe et al., 2011; Skundberg-Kletthagen et al., 2014; Stapley et al., 2016). Other publications described relational identity changes among participants: from fused caring relationships toward more differentiation and self-preservation by the family member (Bottorff et al., 2014; Glenn et al., 2013; Hansen & Buus, 2013; Priestley et al., 2018).

Publications generally emphasized interruptions of the most immediate relationships with less emphasis on the potential compounding effects of social and financial pressures on families and partners. These included issues relating to social problems and disadvantages such as financial strain, barriers to accessing health care, and poverty (Oliffe et al., 2011; Radfar et al., 2014), which were not analyzed in their own right. In one exception, Kaimal and Beardslee (2010) compared emerging adults from low-adversity and high-adversity families. They identified three types of perception toward parental depression (self-oriented, ambivalent, and other-oriented). Kaimal et al. (2010) then analyzed 16 participants' perceptions of their parents' depression over a 2-year period. Comparisons were made between participants from low-adversity and high-adversity families. The analysis identified changing perceptions in high-adversity participants, hinting at improved family relationships, but not in low-adversity participants. Surprisingly, Kaimal et al. (2010) did not draw any firm conclusions on how levels of adversity were linked to participants' reflections on parental depression.

Three publications, with two from the same study, explored how gender relationships in heterosexual and same-sex relationships affected illness experiences when a partner had depression (Bottorff et al., 2014; Oliffe et al., 2011; Thomeer et al., 2015). In particular, these

analyses focused on situations where typical gender norms were interrupted by the effects of depression. For example, Oliffe et al. (2011) published an interpretive analysis exploring gender relationships in heterosexual couples where the man had a clinical diagnosis or self-identified as having depression. They conducted individual interviews with a convenience sample of 26 couples from three different parts of Canada. The study identified three interactional patterns that differed in the way the men and women in couples accept or break with typical gender norms: trading places, business as usual, and edgy tensions (Oliffe et al., 2011). These patterns compensated or concealed the men's depression-induced deficits or led to increased tensions in the couples. Most significantly, the study identified and discussed the limits of the woman partners' resilience and caregiving within the couples' gendered relationship, not as an individual burden on the woman.

A staged psychosocial process

This theme was first articulated and most comprehensively demonstrated in Grounded Theory nursing studies, where participants' psychosocial processes were described as parallel to the trajectory of the ill relatives' episodes of clinical depression. This theme often subsumed elements of the other themes as the process included cognitive (recognition of depression and identity changes) and behavioral (management of situation) dimensions. The descriptions of the process did not offer consistent explanations of movements between stages beyond the beginning and end of the depressive illness episode (Badger, 1996a, 1996b; Hansen & Buus, 2013; Harris et al., 2006; Muscroft & Bowl, 2000; Nosek, 2003, 2008; Priestley et al., 2018; Stjernsward & Östman, 2008).

For example, Badger (1996a, 1996b) published two papers from a Grounded Theory study of a convenience sample of 11 spouses and parents of persons with depression in the United States of America. Exploring participants' experiences of living with a relative with depression, Badger identified a three-staged basic social psychological process: acknowledging the stranger within, fighting the battle, and gaining a new perspective. The descriptions of the process were complex as they included both cognitive (recognition of the situation) and behavioral (coping strategies) dimensions. Although Badger did not specify what created movement between stages, they followed a clinical trajectory from initial symptoms and crisis, to treatment and remission.

Studies identified different numbers of stages and elements and/or placed more emphasis on one or other phase/element. Nevertheless, this recurrent idea of there being a process of sorts apparent within several primary studies is also reflected in the two systematic reviews (Hansen & Buus, 2013; Priestley & McPherson, 2016) noted earlier which both also conclude with an increasingly comprehensive idea of there being a typical process or time-contingent flow through stages of thought and emotion.

Quality of research reporting: Contextualization and level of interpretation

The publications varied substantially with regard to explicit and implicit (following the procedures of the selected methodologies) justification of methodological decisions and the level of coherent presentation of results. Here, we will highlight two general, interrelated, and prominent issues across the included studies: contextualization and level of interpretation.

Poorly or noncontextualized research was an issue of concern in the evaluation of all the papers and a major problem in many papers, which ultimately hampered comparisons between studies and reduced case-to-case transferability of findings. First, as mentioned previously,

studies varied in the way they classified depression (e.g., clinical diagnosis, researcher diagnosis, participant-defined depression) and rarely included details on the severity and duration of depression, eventually repeated depression or if the person was depressed during data-collection or in remission. Second, most studies identified the type of relatives that were included but rarely provided information on the length and character of the relationship, including whether people were intimate partners, parents of children, or cohabitants. Third, very rarely was there a description of participants' socioeconomic or (mental) health status or comorbidities that might add depth to explaining their experiences. Comprehensive contextualization allows researchers to *demonstrate* their interpretations to readers rather than simply *grouping or listing* them. As words and utterances get their particular meaning from contexts (Manilowsky, 2002 [1922]), poorly contextualized analyses make it impossible for readers to confidently evaluate the validity of the researchers' interpretations, including, ultimately, the coherence of overall conclusions/themes.

In the classification of the interpretive level of the analysis, the two evaluators had 59% agreement before reaching a consensus regarding final scores. In the final scores, half of the findings were classified as no finding or topical survey, 3% and 47%, respectively. This classification represented studies that included a low level of analytic interpretation and involved a direct reporting of what participants said or a basic grouping of responses into main topics. Twenty-nine percent were classified as thematic surveys, 18% as conceptual/thematic descriptions, and 3% as interpretive explanations (see Table S1). These ratings indicated that the findings in the papers were severely underinterpreted and the deeper meaning of data were left underexplored. Finally, although this indicated a relatively low level of conceptual interpretation, the ratings were very similar to the scores reported by Sandelowski and Barosso (2003), which could indicate a general pattern in qualitative health research.

DISCUSSION

This scoping review identified four overlapping themes in the research on relatives of people living with depression, *recognition of depression* often including initial interactions with healthcare services and putting concerns into words, *emotional responses* often including negative feelings of frustration and hopelessness as well as experiences of stigma and shame, *interruptions of relationships* including changes to existing relationships, thwarting of expectations, and some acknowledgement of economic and gender influences, and *a staged psychosocial process* that followed the pattern of recurring illness. We will discuss the findings as indicative of a relatively narrow research paradigm primarily focused on episodic clinical depression and largely ignoring the socially situated aspects of what life is like for relatives of people living with depression.

Although previous syntheses (Hansen et al., 2011; Priestley & McPherson, 2016) have privileged the notion of an overarching, staged psychosocial process, we question the trustworthiness and helpfulness of this notion. First, the studies originally identifying a staged process were conducted by healthcare researchers (with an orientation toward clinical illness) working with Grounded Theory (with an inherent focus on “discovering” basic social processes) and the research findings could be affected by these influences. These studies were published in the 1990s and 2000s and have lost their prominence as the number and influence of studies from competing perspectives from nonhealth disciplines have grown in the 2000s and 2010s. Second, as stated earlier, the notion of a staged process parallels the cyclic pattern of a relapsing–remitting mood disorder, and although illness and social processes will overlap, the psychosocial aspects were overshadowed by a focus on the most acute clinical processes. Third, the staged process implies a trajectory toward recovery and

resolution, which we believe is problematic as this was only very rarely clearly identified in any of the original studies reporting these processes. So, while this research has contributed to a broader understanding of depression by extending the focus beyond only the individual with depression, it reflects assumptions consistent with a medicalized view of depression. More longitudinal research systematically exploring different parts of life with a relative with depression is needed to determine the existence and character of the psychosocial process espoused by prior syntheses.

The research area is further complicated by research participants being identified by a psychosocial state attributed to one of their close relatives, and by depression being a term that is contested (Kokanovic et al., 2013) and flexible (Buus et al., 2012). The approaches to participant selection varied significantly in terms of how and who identified depression. The use of researcher-defined diagnosis generally offers a relatively high level of certainty regarding the presence of clinical depression and can to some extent ease comparisons between studies. In the review, research diagnoses were almost exclusively provided as part of substudies of clinical cohort studies of young people with depression. From such a perspective of diagnostic certainty, there could be diagnostic bias in the relatively large proportion of studies reporting clinical or participant-reported depression. However, although self-reported depression does not provide the same certainty for study inclusion criteria, it is experientially real in the study participants' socially negotiated meaning of depression (Rønneberg, 2017). If participants are concerned about depression then the accuracy of the diagnosis can be considered of less importance in studies of participants' everyday life with depression. Finally, any diagnostic category—correct or not—is influential in participants' negotiated understanding of depression. Therefore, the examples of researchers actively introducing diagnostic categories to participants could be regarded as actively skewing their experiences toward a more medicalized perspective.

An emphasis on recruiting relatives of people with clinical depression may reduce researchers' opportunities to explore wider social meanings of the term. The “Black Women's Perceptions of Black Men's Depression study” (Watkins et al., 2013) was designed with less emphasis on recruiting relatives of people with clinical depression (although many participants were) and the study identified community meanings of depression that were not identified in the more conventional, clinically oriented studies. This included issues of gender, race, intergenerational differences between men with depression, and the need for cultural change. Future studies aiming at generating a fuller understanding of what life is like in communities with depression may therefore need to detach themselves from a primary focus on clinical diagnosis.

All the included studies used interviews or focus groups as data collection methods, and this had constitutive effects on the review findings. There were, for instance, frequent inquiries into “how it all began?” which emphasized how participants had come to understand the situation as depression. Also, numerous studies reported first-person accounts of emotional responses and interruptions of social relationships. However, the first-person accounts were generally poorly contextualized and thematically grouped together without interpretive depth. Accounts were often taken at face value and presented as evidence of concerns rather than analyzed in terms of its situated psychosocial impact. Stigma, for instance, was mentioned in several studies as an interpretation of participants' experience of embarrassment caused by having a depressed relative. However, this was never followed up by systematic explorations of spoiled identities and how participants managed instances of discrimination that they might attribute to the stigma. Future research could profit from including extensive observational data potentially providing insights into interactional patterns between study participants, their relatives with depression, and the wider communities.

Although a small number of studies provided nuanced accounts of how factors such as gender and socioeconomic status can contribute to the unique experiences of carers, the

vast majority of studies presented de-contextualized and underinterpreted analyses assuming a de-contextualized homogeneity of (illness) experiences and disregarded the important influence of social contributors to social relationships, connectedness, and mental health problems.

Epidemiological research finds that depression is inextricably interrelated with social determinants of health, such as people's socioeconomic status (Freeman et al., 2016; Kessler & Bromet, 2013). However, clinical healthcare intervention has historically focused on the individual suffering from depression with treatment centered on antidepressant medication and individual psychotherapy. The problem is that antidepressant treatment remains ineffective for a significant proportion of those affected (Cipriani et al., 2018; Moncrieff, 2018) and individual psychotherapy, in Australia at least, often being out of reach. An overreliance on antidepressant treatment may reduce spontaneous self-help strategies and have iatrogenic influences on the course of illness (Meadows et al., 2019). Such an individualist conception includes overlooking how the condition affects, and is affected by, a person's psychosocial relationships and changing social conditions (Ridge, 2018; Thomeer et al., 2013). The review suggested a similar individualist perspective has been applied to studying the experiences of relatives of people with depression.

Limitations

We aimed to conduct an exhaustive review, and we were surprised by a low level of precision and a low level of recall in the initial building block database searches, which indicated that there are not yet effectively controlled search terms available for researchers in this area of research. The extensive chain searching increased the level of recall, and the use of Covidence software was introduced to reduce potential mistakes in identifying and handling relevant publications. A key challenge was related to applying the exclusion criteria, where we relied on consensus discussions following independent reviews. Moreover, our decision not to exclude the 50% underinterpreted, descriptive studies most probably had a significant influence on these review findings. However, we believe that this decision was correctly given that the introduction of a cutoff on the basis of the character of the findings would be controversial (Buus & Perron, 2020) and because there was not a substantial corpus of highly contextualized and highly interpreted studies to draw on.

Our decision to use the "Criteria for the evaluation of qualitative research papers" made certain problems stand out from a social science perspective, most notably the lack of contextualization, which would not have been as apparent if we had used the public health checklists in the previous reviews. Further, Sandelowski and Barosso's (2003) typology highlights issues of underinterpretation, but it does not take into account that some approaches, for example, phenomenological approaches, are deliberately descriptive. Some of our classifications may therefore categorize descriptive studies as "underinterpreted."

The study was conducted by an interdisciplinary team (clinicians and nonclinicians) of critical researchers with expertise in problematizing knowledge and power relationships. In hindsight, our position is probably reflected in sensitivity toward dominating truths in the interface between everyday life living with depression, clinical practices, and research practices. Our approach, including the decisions regarding the use of the abovementioned evaluation tools, was encouraged by our specific interests in theoretical assumptions and research methods, which on the one hand, created a relatively bleak image of the existing research, but, on the other, made our review stand out from the previous reviews and offer a critical perspective on the current research practices and their epistemologies.

CONCLUSION

In the current social and clinical context of increased responsabilization of relatives of people with depression, we found individualizing qualitative research that confirmed the location of the problem in the individual with depression. This occurred by identifying the individual with depression as the burden and the relatives and family members as the ones “dealing” with it. This was further augmented by an emphasis on first-person perspectives, which overshadowed fundamental sociological questions relating to the social determinants of mental health and the consequences of social inequalities. Researchers with clinical training unwittingly may have brought clinical and individualist conceptions of depression into the establishment of this area of study, which dominated the area and limited the scope of research. Future qualitative research now needs to re-focus and include a more socially contextualized and nuanced understanding of relatives of people living with depression.

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CONFLICT OF INTEREST STATEMENT

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