The lived experience of working with people with eating disorders: A meta-ethnography

Meghan R. Graham[a], Stephanie Tierney[b], Amy Chisholm[c], John R.E. Fox[d*]

[a] Department of Psychology, Royal Holloway, University of London, Egham, England

[b] Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, England

[c] Vincent Square Eating Disorders Service, London, England

[d] School of Psychology, Cardiff University, Cardiff, Wales

* Corresponding author: John R.E. Fox, South Wales Clinical Psychology Doctoral Programme, School of Psychology, Cardiff University, Cardiff, CF10 3AT, UK

E-mail address: foxj10@cardiff.ac.uk

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Abstract

Objective: Working with people with eating disorders (EDs) is known to elicit strong emotional reactions, and the therapeutic alliance has been shown to affect outcomes with this clinical population. As a consequence, it is important to understand healthcare professionals' (HCPs') experiences of working with this client group.

Method: A meta-synthesis was conducted of qualitative research on HCPs' lived experiences of working with people with EDs. The results from the identified studies were analyzed using Noblit and Hare's meta-ethnographic method. Data were synthesized using reciprocal translation, and a line of argument was developed.

Results: Thirty-seven studies met the inclusion criteria. Reciprocal translation resulted in a key concept: "Coping with caring without curing." This was underpinned by the following third-order concepts: (a) "The dissonance and discomfort of being a helper struggling to help," (b) "Defending against the dissonance," and (c) "Accepting the dissonance to provide safe and compassionate care." These concepts were used to develop a line-of-argument synthesis, which was expressed as a new model for understanding HCPs' experiences of working with people who have an ED.

Discussion: While the conflict associated with being a helper struggling to help led some HCPs to avoid and blame people with EDs, others adopted a compassionate stance characterized by humanity, humility, balance, and awareness.

Key words:

Systematic review

Meta-ethnography

Eating disorders

Healthcare professionals

Qualitative research

Introduction

Eating disorders (EDs) have a reputation for being challenging to treat (Startup, Mountford, Lavender, & Schmidt, 2015) in the context of high levels of risk, relapse and resistance (Jansen, 2016; Reilly, Anderson, Gorrell, Schaumberg, & Anderson, 2017; Zaitsoff, Pullmer, Cyr, & Aime, 2015). Anorexia nervosa (AN) and bulimia nervosa (BN) are associated with many medical complications, some of which can be fatal (Westmoreland, Krantz, & Mehler, 2016), which means that healthcare professionals (HCPs) working with this client group are required to manage high levels of physical and psychiatric risk concurrently (Le, Barendregt, Hay, & Mihalopoulos, 2017). Managing significant risk is linked to emotional exhaustion, particularly where HCPs have unrealistic self-expectations (Kleespies & Dettmer, 2000). Recovery is often elusive, with only 31% of people with AN and 68% of those with BN recovering within nine years (Eddy et al., 2017). A further challenge of the work is many clients value aspects of their ED (Fassino & Abbate-Dage, 2013) and therefore regard HCPs as a threat, which fosters inaccurate self-report and disengagement (Gregertsen, Mandy, & Serpell, 2017). Moreover, there are few evidence-based treatments for EDs, particularly AN (Lock, 2015). Given that thinness can elicit envy in societies in which it is culturally endorsed (Beggan, & DeAngelis, 2015), HCPs may have mixed feelings towards underweight clients, which can further complicate the work. Concerns have been raised that the training of HCPs working with ED clients is inadequate (e.g., Hay, Darby, & Mond, 2007; Jones, Saeidi, & Morgan, 2013).

HCPs caring for people with EDs frequently report feelings of anxiety, distress, anger, and exasperation (Golan, Yaroslavski, & Stein, 2009; Land, 2004), and often have stigmatizing views of these clients (Raveneau, Feinstein, Rosen, & Fisher, 2014). Lower functioning and higher levels of dysregulation among service users (Satir et al., 2009),

clinician inexperience, larger caseloads and a diagnosis of AN are independently associated with more negative reactions among HCPs (Franko & Rolfe, 1996). Managing negative reactions via externalization of EDs, self-monitoring and discussion in supervision can reduce staff burnout (Golan et al., 2009). There is evidence that acceptance-based interventions are helpful for staff working with other potentially challenging populations, such as people with intellectual disabilities (Noone & Hastings, 2009).

Understanding the lived experiences of staff in ED services is important given that the clinician-client alliance has been shown to affect treatment outcomes (Graves et al., 2017). Several existing reviews have examined this topic. In a mixed-methods review of knowledge, attitudes and perceived challenges among HCPs working with people with EDs, Seah et al. (2017) identified issues of limited knowledge and confidence, negative attitudes, service-user non-adherence, high workloads, miscommunication among teams, and being personally affected by the work. Thompson-Brenner, Satir, Franko, and Herzog (2012) conducted a mixed-methods review on HCPs' reactions to people with EDs and highlighted feelings of worry, frustration, hopelessness and incompetence. Employing thematic synthesis, Sibeoni, Orri, Lachal, Moro and Revah-Levy (2017) explored views of the treatment of adolescent AN and found that HCPs reported focusing on weight gain and behaviors, removing control to maintain physical safety, and struggling to develop therapeutic relationships due to mistrust, perceived manipulation, and a battle for control.

Given that these reviews lacked detail, all but one were aggregative, and the interpretative synthesis by Sibeoni et al. (2017) focused on one ED and age group, a meta-ethnography was planned on the lived experiences of diverse HCPs caring for service users of all ages with different EDs. Whereas aggregative reviews summarize existing literature in an additive manner, meta-ethnography goes beyond the original data to develop new understandings (Barnett-Page & Thomas, 2009) by building an explanatory theory or model

(Bondas & Hall, 2007[a]; Walsh & Downe, 2005). All EDs were incorporated in the search terms because they are often grouped in the literature; this grouping accords with the transdiagnostic model of AN, BN and most Other Specified Feeding and Eating Disorders and Unspecified Feeding and Eating Disorders as sharing a core psychopathology of over-evaluation of the importance of eating, shape and weight, and their control (Fairburn, 2008). The definition of lived experience that guided study selection was: "The detailed, nuanced, and subjective experience, including individual perceptions, meanings, understandings, descriptions, and felt somatic sense of an experience from the first-hand point of view of a particular person" (Mertens, 2005, as cited in Palmer, 2015, p.123).

The meta-ethnography aimed to generate a model of the processes involved in working with people with EDs, drawn from the lived experiences of HCPs, to improve clinical practice and inform service development.

Method

Systematic literature search

The following databases were systematically searched in March 2018: PsycINFO, PubMed, and Web of Science. Three categories of search terms – eating disorders, experiences and professionals – were combined using Boolean operators. No date restriction was employed. Reference lists of relevant studies were manually searched for additional papers.

Selecting studies

Inclusion and exclusion criteria were applied by the lead author (MG) to identify relevant studies. The inclusion criteria were: (a) peer-reviewed empirical studies; (b) studies employing a qualitative or mixed-methods design (provided the qualitative results were reported separately); (c) studies focusing on EDs; (d) studies whose participants included HCPs (i.e., any worker in a healthcare setting involved in the direct care and/or treatment of

service users), and (e) studies focusing on the lived experience of working with people with EDs. The exclusion criteria were: (a) studies in languages other than English, and (b) book chapters, books, book reviews, dissertations, opinion pieces, conference presentations, and meeting abstracts.

Figure 1 illustrates the search strategy and process for selecting studies. The lead author looked at all references (during the screening of titles and abstracts, and by reading full texts where applicable), and thirty per cent of articles selected to be read in full were independently screened by other members of the research team. Two discrepancies in decisions were resolved via discussion and re-reading articles, leading to the exclusion of an additional article.

Figure 1 to go about here

Quality appraisal

To provide a guide regarding their relative rigor, the methodological quality of the included studies was assessed by MG using the Critical Appraisal Skills Programme (CASP; 2010) checklist for qualitative research, a tool employed in previous syntheses of qualitative ED studies (e.g., Espindola & Blay, 2009; Fox, Dean, & Whittlesea, 2015). The checklist has 10 criteria, so each study was awarded a score out of 10, with half-points granted if a criterion were partially fulfilled. In the absence of standard protocols for mixed-methods studies, the qualitative components of studies of this type were evaluated using the CASP checklist for qualitative studies. This review followed Fox et al. (2015) in classifying studies from A to C, with A denoting studies scoring 8.5 or above and carrying a low likelihood of methodological flaws; B signifying studies scoring five to eight with a moderate likelihood of

methodological flaws, and C indicating a score of less than five and a high likelihood of methodological flaws. Twenty per cent of included studies were independently rated by other members of the research team using the CASP checklist. There was unanimous agreement regarding five studies and there were minor discrepancies with two; discrepancies were resolved via discussion. Table 1 shows the CASP ratings.

Table 1 to go about here

Data synthesis

Noblit and Hare's (1988) meta-ethnographic method was employed because we sought to develop a new conceptual understanding of the topic by configuring existing data. Meta-ethnography is well-established (Bondas & Hall, 2007[b]) and entails the following phases:

1. Getting started: An area of intellectual interest was identified (i.e., the lived experiences of HCPs working with people with EDs).
2. Deciding which studies to include: Inclusion and exclusion criteria were applied, and relevant search terms employed in a range of databases (Figure 1).
3. Reading the studies: Included articles were read multiple times to identify and extract methodological features, demographic information, and key concepts.
4. Determining how the studies are related: The key concepts in each study were closely compared to decide relationships between them. At this stage, accounts are either deemed directly comparable and capable of being "reciprocally translated" into one another; in opposition to each other and suited to "refutational translation", and/or cumulatively representative of a "line of argument" that "puts any similarities and dissimilarities into a new interpretive context" (Noblit & Hare, 1988, p.64).

5. Translating the studies into one another: Reciprocal translation was used to identify third-order concepts (our interpretations of the original authors' interpretations) that captured similarities across studies. As there were no contradictions between findings, refutational translation was not necessary.
6. Synthesizing translations: Following reciprocal translation, the concepts were organized into a conceptual framework, which represented a new interpretation and line of argument.
7. Expressing the synthesis: The synthesis was elaborated via narrative and diagram (Figure 2).

Throughout, the meta-ethnography was regularly discussed among the research team. An inductive approach was employed, allowing findings to emerge from the data rather than be determined by an a priori theoretical framework (Dillaway, Lysack, & Luborsky, 2017).

Results

Quality assessment

All studies were classified as A or B, with an average rating of 7.74. The primary reasons for losing points were not stating/justifying the research design; not providing a rationale for the method of data collection; lack of reflexivity, and presenting insufficient data to support findings; this may reflect limited word-counts rather than deficiencies in execution (Walsh & Downe, 2006). The overall score and classification for each study are included in Table 2. Given that all studies were rated B or above, and in line with other meta-syntheses in the field (Espindola & Blay, 2009; Sibeoni et al., 2017), no studies were excluded on the basis of the quality ratings.

Characteristics of the included studies

Across the 37 studies, data were collected from 769 HCPs. They included nurses, psychologists, psychiatrists, occupational therapists, dietitians, general practitioners, and

medical providers such as gynecologists. Nurses were well represented in studies with mixed samples and there were nine studies with solely nurse participants. Two studies exclusively involved HCPs with a history of an ED. Across the studies that did not specify personal experience as an inclusion criterion and reported the number of participants who disclosed such experience, 43.6% of HCPs were stated to have a personal history of an ED. Across the studies in which the gender composition of participants was discernible, 91.4% were female. Twenty-six studies centered on experiences of working with people with EDs; the remaining 11 focused on experiences of working with AN. Eight studies related specifically to work with adolescents. Sixteen studies recruited exclusively from an inpatient setting. Included studies were undertaken in Australia, Canada, New Zealand, Norway, Singapore, Tasmania, the UK, and the USA. Most data collection proceeded via interview (generally semi-structured). Authors commonly employed thematic analysis. Key characteristics of included studies are shown in Table 2. Despite variety in the methodologies of included studies, and the range of disciplines, settings and locations represented, there was considerable concordance across accounts. However, as will be outlined below, some differences were apparent according to experience level, setting, and professional background.

Table 2 to go about here

Meta-ethnography findings

The stages of analysis outlined above led to the development of a key concept to depict the lived experience of working with people with EDs: "Coping with caring without curing." This described how a combination of treatment refusal, chronicity, systemic challenges and/or personal factors confronted HCPs with the fact that the help they offer

people with EDs may be unwanted and/or insufficient. It resulted in a sense of dissonance – a mismatch between their aspiration to help, and the reality. HCPs could either defend against this dissonance, or face it with courage and humanity. This key concept was underpinned by the three concepts that will now be presented. The number of studies that endorsed each concept and sub-theme is represented in Table 3.

Concept 1: The dissonance and discomfort of being a helper struggling to help

This concept, identified in 33 studies, describes the frustration, helplessness and distress that often resulted from efforts to assist people with EDs, alongside a sense of scrutiny in the helping role linked to the watchfulness of service users. Together, these experiences represented a painful dissonance between the expectation and reality of caregiving.

Emotionally draining work.

In 29 studies, participants reported that their work with individuals with EDs was "emotionally draining" (treatment provider; Warren et al., 2012, p.183) in the context of high levels of resistance and relapse, the shock of emaciation, feeling manipulated by service users, and difficulties with other professionals and families. Many clinicians described experiencing frustration, and some reported anger, in response to service users' rejection of treatment, denial, and relapse: "I looked after a girl who used to rip out the naso gastric feeding] tube….After some time, you would get feelings of immense anger and frustration" (health professional; Walker & Lloyd, 2011, p.142). Cameron et al. (1997) noted that "the frustration appeared to be linked to the inability of HCPs to control the progress of the illness, about 'not being able to do enough'" (p.28). The emaciation of service users elicited fear: "I can be scared and sad for not only their quality of life but the risk of a patient dying" (treatment provider; Warren et al., 2008, p.39). Some participants felt manipulated and/or

attacked by service users, creating a difficult dynamic: “It’s the manipulation. You think it’s a personal attack against you” (nurse; Carter et al., 2012, p.551).

Interactions with service users’ families could be stressful if, for example, they were in denial about the ED (Harken et al., 2017). Difficulties with colleagues were also reported to add to the emotional demands: “We are forcing kids to do things that we do not understand. The doctors are making these decisions” (nurse; Micevski & McCann, 2005, p.110). Perceived lack of understanding among peers caused frustration: “The most uncomfortable thing for me is the lack of education of other people around me….in particular the physicians” (dietitian nutritionist; Trammell et al., 2016, p.79). One participant described the emotional toll of “caring without curing” (King & Turner, 2000, p.145) as follows: “Medicine is easy when you can just prescribe something and then they are better…but difficult sometimes when you have to put a lot of emotion into looking after them and sometimes you don’t seem to get anywhere” (general practitioner; Reid, Williams, & Hammersley, 2010, p.6).

Feeling helpless and deskilled.

Linked to high levels of relapse and resistance, HCPs in 21 studies described feeling deskilled and ill-equipped to help service users: “When I got to my internship and I did see EDs, it sort of scared me. I didn’t know what to do” (dietitian nutritionist; Trammell et al., 2016, p.78). A sense of helplessness was more apparent in studies involving HCPs without specialist ED experience. One participant described the dissonance of feeling helpless within a helping role as follows: “We are fixers and doers by our nature, that’s why we get into the profession that we do, so to not have an immediate answer is difficult” (medical provider; Linville et al., 2010, p.119). For a minority of HCPs, feeling helpless led to self-judgment: “Most of the time you feel you are going round and round in circles so it makes you feel like a useless therapist” (health professional; Walker & Lloyd, 2011, p.386). The data suggested

that organizational and sociocultural factors contributed to participants' sense of limited power to help. Lack of time, the most common systemic problem, particularly affected those in primary care: "You can't even scratch the surface" (general practitioner; Reid, Williams, & Hammersley, 2010, p.7). At a macro-level, sociocultural pressure compounded HCPs' sense of helplessness to effect change: "We often feel like we are fighting a losing battle when they are exposed much more consistently to messages that contradict what we promote" (treatment provider; Warren et al., 2012, p.188).

Watching and being watched.

In 13 studies, the necessity of close observation of service users – particularly in inpatient environments (Akgül et al., 2016) – and a sense of being observed in turn, resulted in interpersonal mistrust amid a culture of surveillance. Participants described feeling awkward about intently monitoring service users to prevent ED behaviors: "They have to have somebody sitting in their room all day long with them….I feel uncomfortable for them" (nurse; Harken et al., 2017, p.e38). Some noted that this entailed a lot of work: "General psychiatric is easier…there's [fewer things] to look out for…Compared to the eating disorder is how you eat, what you eat, what you drink, how much you drink, where are you, what you doing…everything" (nurse; Seah et al., 2018, p.141). Participants articulated a feeling that their behaviors and/or appearance were scrutinized by service users, resulting in fear about saying or doing the wrong thing, particularly when inexperienced. For a minority of HCPs, the sense of scrutiny led to self-consciousness: "I feel like they are really watching me; I was trying to drink really normal" (staff member of ED unit; Long et al., 2012, p.244). Those with a personal history of an ED reported an additional layer of scrutiny, from other professionals; some of Williams and Haverkamp's (2015) participants described unhelpful interactions with colleagues, such as being questioned about weight loss.

Moral distress.

Feeling unable to help and in conflict with service users generated "dissonance" (ED therapist; Williams & Haverkamp, 2015, p.405) for HCPs accustomed to providing valuable and valued care, across 10 studies**.** This could lead to self-judgment for the perceived violation of their core values, as illustrated in the following quotation: "My heart just doesn't warm to them any more…Disgusting – sad you know, that's not a nurse" (nurse; King & Turner, 2000, p.142). In some cases, disempowering service users – to preserve their physical safety – led to self-questioning: "I didn't want this role, I've always fancied myself as being quite therapeutic and collaborative" (nurse; Snell et al., 2010, p.354). Moral distress was most prevalent among, but not unique to, nurses.

Concept 2: Defending against the dissonance

This concept, evident in 23 studies, conveyed the experience of some HCPs of avoiding, blaming, and battling service users. These coping strategies could defend against the dissonance of caring without curing by blocking it out or attributing "the problem" to service users, but simultaneously could exacerbate moral distress due to the loss of unconditional positive regard.

Avoiding and distancing.

Across 17 studies, there was a tendency among some HCPs, particularly nurses, to unconsciously or consciously avoid negative emotions, conflict, and/or association with service users. For example, Ramjan (2004) reported that some nurses requested not to work with adolescents with AN to distance themselves from difficult interactions. "Shutting off" and being task-oriented was another strategy employed by HCPs: "You just close off everything else and just take that fixed view that yes, you're going to eat" (clinical nurse specialist; Jarman et al., 1997, p.148). This could reduce frustration and distress temporarily, but sometimes led to dehumanization of service users: "They become a set of symptoms and things to monitor and measure" (nurse; Davey et al., 2014, p.63). Some clinicians reported

binge eating to evade burnout (Warren et al., 2012), which can be understood as avoidance of emotional pain. Others used their diet to distance themselves from service users: "I find myself going to an extreme, at times, of eating whatever I want and thinking it is bad to 'eat healthy.' I feel like I try to compensate for my clients' eating-disordered views" (treatment provider; Warren et al., 2008, p.37). Cameron et al. (1997) noted that participants construed people with EDs as "other" to "exclude them from the domain of socially acceptable eating patterns, in which most participants located themselves" (p.27). Similarly, some HCPs with a personal history of ED emphasized the "normality" of their relationship with food and their bodies (Rance et al., 2010; Trammell et al., 2017), in what was interpreted by Rance et al. (2010) as a binary view of recovery that entailed avoidance of shared humanity with service users. One therapist described how non-disclosure at work of her personal history of ED created "dissonance" due to the mismatch between her secrecy and her anti-stigma message to service users (Williams & Haverkamp, 2015, p.405).

Battle and blame.

In 11 studies, there was evidence of HCPs blaming clients and/or regarding themselves as waging battle with "rebellious and dominating" service users (Long et al., 2012, p.244). Comparisons of clinicians to figures of authority jarred with the notion of collaborative care: "We were just like sergeant majors, we thought we were. Standing over them telling them what to do" (nurse; King & Turner, 2000, p.142). King and Turner (2000) remarked that HCPs pathologized typical adolescent behaviors, and service users were dismissed as "vain" by a participant in Walker and Lloyd (2011). Ramjan (2004) noted a tendency to judge service users as responsible for their distress, reflected in the prison metaphor the participants employed, which cast clients as criminals. Cameron et al. (1997) highlighted that the "moralizing discourse" employed by participants constructed individuals with EDs as "difficult people, rather than as people with a difficult illness" (p.29). While a

minority of clinicians were unperturbed by this dynamic, for many it was inimical to their view of themselves as caring professionals.

Concept 3: Accepting the dissonance to provide safe and compassionate care

This concept, depicted in 34 studies, described some HCPs' efforts to face the reality of caring without curing, without blaming or avoiding service users. This entailed adopting a balanced and flexible approach that was responsive to service users' needs, and their own. It also required tolerating negative emotions, uncertainty and fallibility to provide compassionate care in the knowledge that it may not be perceived by service users as helpful, and may be rejected altogether.

Balance and flexibility.

Participants in 17 studies stressed the importance of balance and flexibility. Brinchmann et al. (2017) described therapists in their study as navigating a "golden middle way" between extremes to create a safe environment for service users that promoted development. Balance was also evident in the depiction of effective HCPs as "having one arm around the client while kicking them in the butt" (therapist; Oyer et al., 2016, p.128-9). This approach involved taking control where necessary and then "gradually giving service users bits of control back, as and when we think [they] can cope with that" (social worker; Jarman et al., 1997, p.145). While participants saw rules as important to preserve safety, they emphasized the therapeutic value of flexibility, for example in adapting ethical codes to suit the cultural context (Tan et al., 2013). However, flexibility was anxiety-provoking because it meant clinicians could not "hide behind a method which can provide them with the safety and security of being in control" (Jarman et al., 1997, p.147).

Balance was evident in HCPs remaining motivated to support change without succumbing to rescue fantasies, and in their appreciation of the multifactorial influences on their experiences (Reid, Williams, & Burr, 2010). Some HCPs recognized they did not bear

sole responsibility for outcomes while continuing to work hard for service users, but this was highlighted as difficult: "It's a constant challenge to find the balance between appropriate attention to my clients/doing everything I should and can for them, and letting go/bearing in mind that I can't control what they do/what happens to them" (treatment provider; Warren et al., 2012, p.184).

Mindful awareness, acceptance and self-observation.

A balanced approach was facilitated by a mindful stance, which was articulated in 10 studies. This manifested in HCPs taking an objective and non-judgmental perspective; facing and responding to reality, and trying to monitor, tolerate, reflect on and regulate their own behaviors, reactions and relationships: "At the end of the session, I reflected and realized that 70% of the session was me talking AT them [the client]. I am a model of relationships, and if I am doing that….that is not therapeutic" (therapist; Oyer et al., 2016, p.132). Some HCPs mindfully observed and positively framed the watchfulness of service users as an opportunity to model a healthy relationship with one's body (Palmer, 2015; Seah et al., 2018). Meanwhile, certain HCPs with a personal history of ED emphasized the need for self-awareness, including knowing one's residual symptoms (Williams & Haverkamp, 2015). Supervision, team meetings and personal therapy were presented as fora that could promote a mindful stance.

Connecting with common humanity.

Many HCPs, across 24 studies, described connecting with their own humanity and that of service users in their work, as opposed to an us/them mentality. Connecting with common humanity comprised a recognition of the individuality of clients and HCPs; attuned responses; self-care; considered self-disclosure; a maternal stance, and finding reward in service users' steps towards recovery. Humanity was evident in attuned responses to service users' body language, facial expressions, and words: "I'll just carry on walking beside

them…that's helped me slow down and have that sort of metaphor of sort of walking alongside at their pace and using their language and just try to get into their life world" (nurse; Snell et al., 2010, p.354). Discussing topics other than their ED afforded a means of acknowledging the individuality of service users, and developing relationships founded on respect.

This respect was echoed in clinician accounts of battling alongside, rather than against, service users via externalizing the ED and viewing it as separate from the client. Meanwhile, self-care encompassed respect for one's own humanity, and awareness of the need to preserve wellbeing in order to show humanity to service users. HCPs saw limited self-disclosure as normalizing and facilitating relational safety: "I have talked about things going on in my life….it….puts them on your level" (nurse; Micevski & McCann, 2005, p.107). For some HCPs, predominantly nurses, maternalism – a protective and nurturing stance underpinned by genuine care for service users (Wright, 2015) – facilitated unconditional positive regard and reconciled the need for both empathetic support and boundaries. However, these aspects of maternalism were acknowledged to be "potentially conflictual," and it was suggested that nurses be supported to navigate this through supervision and training (Ryan et al., 2006, p.132).

Humbly open to learning and support.

Awareness of their own fallibility promoted efforts by HCPs in 22 studies to self-improve and engage with service users as equals. Humility was demonstrated by HCPs acknowledging their limitations and valuing support: "I couldn't imagine just doing it on my own….You need support" (healthcare professional; Macdonald et al., 2018, p.229). Humility was also apparent in HCPs demonstrating a desire for more training; providing a rationale for decisions; collaborating with service users and their families, and being open to learning from conflict and mistakes: "[Conflict] gives me the opportunity for self-reflection. I always

appreciate it when the dietitian that I work with, challenges my thinking" (mental health professional; Dejesse & Zelman, 2013, p.198). Having personal history of ED was portrayed as facilitating humility and guarding against "an us/them kind of perspective" (therapist; Williams & Haverkamp, 2015, p.404).

Line of argument

Synthesizing the studies and reflecting on the resulting concepts generated a line of argument, which is illustrated in Figure 2. The central premise is that the lived experience of working with people with EDs is characterized by feeling drained, demoralized and on edge due to the subversion of HCPs' usual role as helpers against a backdrop of complexity, chronicity, and treatment refusal. This foregrounds the limits of clinicians' power to help, given that what they offer may not match the needs and/or wishes of service users. Problems may be beyond their power to resolve due to intrapersonal factors such as their level of experience; interpersonal factors such as relationships within the team; systemic factors such as the time available and cultural context, and/or the client's readiness to change. For "fixers and doers," a painful dissonance can result from the sense of powerlessness and subversion of role. One response is to defend against this by avoiding, battling, and blaming service users. While this may provide temporary relief, it can exacerbate the dissonance by violating the principle of unconditional positive regard, and is unlikely to be conducive to productive alliances with service users. Another response is to mindfully face the dissonance with humanity and humility, and seek balance. This involves remaining emotionally present and compassionate while acknowledging that ideal care is illusory, and at times actions that may make HCPs seem, and feel, like prison guards are necessary to preserve service users' safety. This approach entails tolerance of uncertainty, and of not always being perceived as helpful by service users. However, it also facilitates the connection with clients that was the source

of many HCPs' enjoyment of the work, and overcomes the inhumane rigidity of avoidance and blame.

Figure 2 to go about here

Discussion

This is the first meta-ethnography to focus exclusively on HCPs' lived experiences of working with people with EDs. As well as supporting the findings of previous reviews (Salzmann-Erikson & Dahlén, 2017; Seah et al., 2017; Sibeoni et al., 2017; Thompson-Brenner et al., 2012), it yields new insights regarding the experiences of this work, and approaches to managing challenges in clinical practice. Findings from 37 studies, which spanned 21 years and were of moderate to high quality, were synthesized to produce a key concept of "Coping with caring without curing." The meta-ethnography describes how those working in ED services are limited in their capacity to help, which creates a painful dissonance that can impact on enjoyment of the job, perceptions of service users, and working alliances. This key and novel finding captures the tension inherent in being a professional helper and not knowing how to help, or having your offer of help rejected. Inherent in the key concept is a sense that, compared with many service users, people with EDs are harder to assist because they present with both physical and psychological risks (Seah et al., 2017; Walker & Lloyd, 2011), as well as high levels of complexity and treatment refusal (Franko & Rolfe, 1996; Golan et al., 2009; Kaplan & Garfinkel, 1999).

HCPs reported experiencing work with this client group as emotionally draining, which could lead to negative judgments of service users and themselves. This finding echoes Thompson-Brenner et al.'s (2012) review, with feelings of frustration and helplessness reported as common even among highly experienced therapists in this field (Franko & Rolfe,

1996). A contributor to the emotional demands was the "culture of surveillance" that some HCPs, particularly those based in inpatient environments, encountered in their work. This sense of being scrutinized by clients, and in some cases colleagues, was a novel finding of this synthesis; it could lead to hostility and anxiety, thereby fueling negative attributions (Cromby & Harper, 2009).

The pull towards avoidance, battle and blame identified in this meta-ethnography echoes results from quantitative research showing that many HCPs have stigmatized views of people with EDs (Raveneau et al., 2014). According to the model of helping behavior proposed by Weiner (1986, as cited in Fox, Woodrow, & Leonard, 2012), negative attributions of service users' actions render helpful interventions less likely. Our meta-ethnography showed how such attributions can also lead to moral distress due to the conflict with HCPs' belief in the importance of unconditional positive regard. This is consistent with previous research showing that moral distress is correlated with lack of respect for patients (Lamiani, Borghi, & Argentero, 2017). Individuals with EDs value empathy from and collaboration with HCPs (Bezance & Holliday, 2013); however, as in Sibeoni et al. (2017), the data suggested that some clinicians struggle to maintain empathy and respect in their interactions with service users, and/or seek to avoid them. As well as compromising relationships with clients, engaging in avoidant behaviors is a risk factor for burnout (Fearon & Nicol, 2011).

Another contributor to the dissonance and discomfort of the work was feeling unable to help, which is also a risk factor for burnout (Fearon & Nicol, 2011) and is particularly challenging for HCPs with 'rescue fantasies' who may identify with the role of ideal carer (Golan et al., 2009). Such identification is arguably understandable in the context of a popular press that tends to depict HCPs as either selfless heroes or heartless villains (Barker, Cornwell, & Gishen, 2016). Moreover, people with EDs commonly seek ideal care (Bell,

1999; DeLucia-Waack, 1999) and family members are frequently desperate for a "cure" (Fox et al., 2012). The perfectionism inherent in striving to be an ideal carer, and HCPs' avoidance of painful emotions, mirror the experiences of many people with EDs (DeLucia-Waack, 1999). It is possible that this parallel is linked to the high prevalence of personal history of ED among HCPs in the studies.

Our meta-ethnography highlighted coping strategies which appear conducive to HCP and service-user wellbeing. The emphasis on connecting with common humanity, and being humbly open to learning and support, are similar to the findings of Salzmann-Erikson and Dahlén (2017), and Seah et al. (2017). What is novel is the notion of mindfully drawing on this humanity and humility to adopt a compassionate approach that eschews the rigidity of avoidance or blame. The importance of connecting with common humanity is underlined by research showing that service users appreciate being treated as individuals (Gulliksen et al., 2012). The attunement that characterizes common humanity is valuable given that people with EDs have high levels of insecure attachment (Zachrisson & Skårderud, 2010) and the negative effects of this can be mitigated by healthy, attuned therapeutic relationships (Ardovini, 2002). Mindful awareness, acceptance and self-observation involved HCPs accepting clients and themselves as human, and as and where they are. This aligns with evidence that acceptance-based interventions are helpful when working with challenging populations (Noone & Hastings, 2009).

A related healthy practice was taking a balanced and flexible approach, constituting imperfect but responsive care that allows for fallibility and humanity in oneself and others. This stance evokes the position of safe-uncertainty outlined by Mason (1993). According to his model, teams are motivated to remain in the safe-certain position. Correspondingly, the pressure to provide "ideal care" among HCPs working with people with EDs could push the team towards approaches seen as safe and certain (e.g., standardized protocols). However,

Mason (1993) advocated a position of safe-uncertainty, "which is always in a state of flow" (p.35) and facilitates new ideas. It has been suggested that this position can free HCPs from the bind of needing to know the "final answer," while supervision and consultation keep them safe in their practice (Fox et al., 2012). Tolerating imperfection is important given that self-expectations of staff have been identified as a critical factor in burnout (Scully, 1983; Freudenberger, 1980, as cited in Kleespies & Dettmer, 2000).

The findings of this meta-ethnography are consistent with a multifactorial view of HCPs' experiences as reflecting an interaction between behaviors of individual clients and colleagues, systemic factors (Franko & Rolfe, 1996), and clinicians' own practices and internal conflicts (Walker & Lloyd, 2011). Organizational pressures, such as inadequate staffing, contributed to the discrepancy between HCPs' desire to provide valued care, and feeling they were unable to do so; lack of time is correlated with moral distress among HCPs (Lamiani et al., 2017). It is likely that staff with insufficient resources will seek a safe-certain position, rather than tolerate safe-uncertainty. Furthermore, it has been established that higher caseloads are associated with more negative staff reactions towards people with EDs (Franko & Rolfe, 1996). On a personal level, the capacity of HCPs to be attuned and provide relational safety depends, in part, on their own attachment security (Goodwin, 2003).

There were some differences in the data according to experience level, professional background, and setting. In the included studies, less experienced staff were portrayed as more fearful of saying the wrong thing, and helplessness was more prevalent among generalist as opposed to specialist practitioners. Inexperience has been linked to more negative reactions to service users with EDs in previous research (Franko & Rolfe, 1996). It has been suggested that the difficulties generalist staff experience in identifying and responding to EDs reflect the reluctance of clients to report them, and lack of knowledge about treatment options (Waller, Micali, & James, 2014). The systemic pressure of lack of

time seemed to be felt most keenly in primary care, while the surveillance culture and frustrations around communication were predominantly reported in inpatient settings. The greater likelihood that nurses would engage in avoidance and blame, and adopt a maternal stance, may reflect their high level of contact with people with EDs and their involvement in implementing treatment protocols, positioning them both for intimacy with service users and becoming the object of their anger (Ryan et al., 2006; Zugai et al., 2018[a]; Zugai et al., 2018[b]).

Fox et al. (2012) highlighted the irony that it is generally the least experienced HCPs who spend most time with service users and receive the least containment in the form of space to formulate, process, and reflect. The need for reflective spaces in which to process moral distress in healthcare settings has been highlighted (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004). It has been suggested that psychologists have an important role in helping ED teams to manage distress and frustration via facilitating reflective spaces; foregrounding the individuality and humanity of clients, and providing training to enhance clinical practice (Fox et al., 2012).

Given that the clinician-client relationship is known to affect treatment outcome (Graves et al., 2017) in this field, and low levels of wellbeing among HCPs are associated with poor safety outcomes (Hall, Johnson, Watt, Tsipa, & O'Connor, 2016), staff experiences of the work are a vital consideration for ED services. The findings of this meta-ethnography suggest that HCPs can make a valuable contribution and find reward if they pursue a balanced and humane approach, rather than unrealistically aspiring to be an ideal carer or embracing the punitive role of a prison guard. However, they are likely to need support and reflective space to tolerate the resulting uncertainty and ongoing internal conflict (Halton, 2003).

Limitations

As almost one-third of the included studies focused exclusively on AN, findings may be most pertinent to those working with this condition (Hage et al., 2017[a]; Ryan et al., 2006). Exclusion of unpublished studies may have led to the loss of information (Petticrew et al., 2008).

The fact that 11 of the included studies were identified from manual searching of reference lists, or by chance via background reading, raised concerns regarding the breadth of our search. It was identified that nine of these 11 studies would have been located by the original database searches if the 'professionals' category of search terms had been applied to study abstracts as well as titles. As a confirmatory check, the search was rerun in the databases with this update. Seven articles that were not identified by the previous search were deemed suitable for full screening; none of these met the inclusion criteria. Difficulty with locating qualitative papers through traditional databases (Booth, 2016), due to issues with MESH terms and filters, has led to a suggestion that other means of accessing them (e.g., hand searching and citation tracking) should be employed (Harris et al., 2018). Reviewers have been warned to extend searches beyond well-known databases to avoid missing journals with relevant information that are not referenced on them (Booth, 2016).

While critical appraisal has come to be an expected element of qualitative-evidence synthesis, it is contentious because of the epistemological variety of qualitative research, the diversity of appraisal tools, the variability in ratings within as well as between tools (Carroll & Booth, 2015; Dixon-Woods et al., 2007), and the fact that such tools do not measure conceptual quality (Toye et al., 2014). Applying the CASP checklist for qualitative studies to mixed-methods studies is problematic because the latter should be evaluated as a whole, given that the strengths of one strand can compensate for deficiencies of the other (Heyvaert, Hannes, Maes, & Onghena, 2013).

The prevalence of convenience and purposive sampling among the included studies may have led to bias within individual papers. With convenience sampling, the researcher may not know how the sample characteristics compare with those of the population of interest, and thus there is a risk of inattention to sampling bias and its potential impact on findings (Etikan, Musa, & Alkassim, 2016). Unlike convenience sampling, purposive sampling entails deliberate selection by the researcher and, while it is regarded as more credible than convenience sampling (Marshall, 1996), it is prone to the bias associated with researcher subjectivity. However, both purposive and convenience sampling are consistent with a qualitative approach, in which the aim is not to generalize findings by ensuring the sample is representative of the population but to produce a new and nuanced understanding of the topic; the objective is depth, rather than breadth (Etikan, Musa, & Alkassim, 2016). Moreover, combining data from a large number of studies ensured that a range of perspectives were incorporated in the final synthesis, lessening the potential impact of sampling bias within individual studies (Bearman & Dawson, 2013).

Given that the research team includes HCPs, some of whom have worked extensively with people with EDs, there was a risk we might view the data through the prism of our own experiences. We endeavored to be mindful of this potential bias in team meetings, and alert to differences in the data according to national context and service type. The risk of bias was alleviated by the fact that collectively the research team held experience of both psychology and nursing, working in the public and private sectors, and practicing in the UK and New Zealand.

Clinical implications

Findings from this meta-ethnography can be used to inform clinical practice by supporting HCPs to consider the personal impact of their work with EDs, and by raising awareness of and reflection on their coping strategies. HCPs could draw on the findings to

help them provide safe and compassionate care, rather than avoid and blame people with EDs. This could lead to improvements in HCP wellbeing, job satisfaction, and treatment outcomes.

The findings suggest that providing time and space for HCPs working in the ED field to process the dissonance they experience would promote the wellbeing of clinicians and service users (Fox et al., 2012). This provision could take the form of supervision and/or reflective groups. As well as facilitating safe practice and providing containment, supervision can make HCPs feel valued and listened to (Fearon & Nicol, 2011); thus, it can alleviate damage to their self-concept associated with caring without curing. Supervision and reflective spaces may also support HCPs to adopt positions of safe-uncertainty, and select formulation- and evidence-based interventions rather than act in automatic pilot.

In primary care, Balint groups could enable HCPs to discuss stressors in a supportive environment (Rabinowitz, Kushnir, & Ribak, 1996), while in multidisciplinary teams Schwartz rounds could help clinicians to make sense of the emotional challenges of their work (Barker et al., 2016). Given that the surveillance culture and frustrations around communication were predominantly reported in studies with inpatient settings, reflective spaces and case conferences appear to be particularly valuable in these environments (Fox et al., 2012). In light of the fact that many HCPs with personal history of an ED experienced a sense of dissonance in relation to non-disclosure, it would be helpful for managers of ED services to promote a safe environment for sharing, perhaps by role modelling and asking in supervision about personal impacts of the work.

Introducing mindfulness practice for HCPs could promote the aware and accepting stance underpinning a balanced approach (Raab, 2014), and team formulation meetings could be used to foreground the individuality of service users and collectively support safe and compassionate care. The findings suggest that reducing systemic pressures (e.g., by

increasing staffing levels) could decrease demands on HCPs, and mitigate against them feeling emotionally drained and helpless. In primary care, closer links with specialist ED services could make clinicians feel more empowered to help.

Future research

A future review could triangulate the findings of this synthesis with quantitative studies. It would be profitable to examine the impact of HCP experiences of dissonance on client outcomes. Future research could evaluate support mechanisms for HCPs working with people with EDs, for example a pre-post evaluation of introducing a structured reflective space such as a Balint group (Rabinowitz et al., 1996) or a Schwartz round (Barker et al., 2016). Further qualitative research on clinicians' experiences of working with people with binge eating disorder and BN would help to clarify whether the challenges reported in this review extend to all EDs.

Conclusion

This meta-ethnography highlights how HCPs experience working with people with EDs, namely the painful dissonance this can entail and how it can be managed in practice. The synthesis provides an interpretation that can help frontline staff and managers to understand and tackle the barriers to thriving in this work, so they can make a positive difference to service users. A new concept was developed from the reciprocal translation: "Coping with caring without curing." Furthermore, we produced a line-of-argument synthesis, expressed as a new model for understanding HCPs' experiences of working with people who have an ED.

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