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REVIEW

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A framework to conceptualize personal recovery from eating disorders: A systematic review and qualitative meta-synthesis of perspectives from individuals with lived experience

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Abstract

Background: An extensive literature exists describing treatment interventions and recovery from eating disorders (EDs); however, this body of knowledge is largely symptom-based and from a clinical perspective and thus limited in capturing perspectives and values of individuals with lived experience of an ED. In this study, we performed a systematic review to coproduce a conceptual framework for personal recovery from an ED based on primary qualitative data available in published literature.

Methods: A systematic review and qualitative meta-synthesis approach was used. Twenty studies focusing on ED recovery from the perspective of individuals with lived experience were included. The studies were searched for themes describing the components of personal recovery. All themes were analyzed and compared to the established connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (CHIME) and Substance Abuse and Mental Health Services Administration (SAMHSA) frameworks of recovery, which are applicable to all mental disorders. Themes were labeled and organized into a framework outlining key components of the ED personal recovery process.

Results: Supportive relationships, hope, identity, meaning and purpose, empowerment, and self-compassion emerged as the central components of the recovery process. Symptom recovery and its relationship to the personal recovery process are also significant.

Discussion: Individuals with lived experience of EDs noted six essential elements in the personal ED recovery process. This framework is aligned with several of the key components of the CHIME and SAMHSA frameworks of recovery, incorporating person-centered elements of the recovery process. Future research should validate these constructs and develop instruments (or tools) that integrate the lived experiences into a measurement of recovery from an ED.

Resumen

Antecedentes: Existe una extensa literatura que describe las intervenciones de tratamiento y la recuperación de los trastornos de la conducta alimentaria (TCA); sin embargo, este conjunto de conocimientos se basa en gran medida en los síntomas

y además desde una perspectiva clínica y, por lo tanto, es limitado para capturar las perspectivas y los valores de las personas con experiencia vivida de un TCA. En este estudio, realizamos una revisión sistemática para coproducir un marco conceptual para la recuperación personal de un TCA basado en datos cualitativos primarios disponibles en la literatura publicada.

Métodos: Se utilizó una revisión sistemática y un enfoque de meta-síntesis cualitativa. Se incluyeron veinte estudios centrados en la recuperación del TCA desde la perspectiva de individuos con experiencia vivida. Se buscaron en los estudios temas que describieran los componentes de la recuperación personal. Todos los temas fueron analizados y comparados con los marcos de recuperación establecidos de CHIME y SAMHSA, que son aplicables a todos los trastornos mentales. Los temas fueron etiquetados y organizados en un marco que describe los componentes clave del proceso de recuperación personal del TCA.

Resultados: las relaciones de apoyo, la esperanza, la identidad, el significado y el propósito, el empoderamiento y la autocompasión surgieron como los componentes centrales del proceso de recuperación. La recuperación de los síntomas y su relación con el proceso de recuperación personal también es significativa.

Conclusiones: Las personas con experiencia vivida de un TCA destacaron por seis elementos esenciales en el proceso personal de recuperación del TCA. Este marco está alineado con varios de los componentes clave de los marcos de recuperación de CHIME y SAMHSA, incorporando elementos centrados en la persona del proceso de recuperación. La investigación futura debería validar estos constructos y desarrollar instrumentos (o herramientas) que integren las experiencias vividas en una medición de recuperación de un TCA.

KEYWORDS

eating disorders, framework, meta-analysis, qualitative research, recovery, systematic review

1 | BACKGROUND

Eating disorders (EDs) are characterized by serious disturbances to an individual's eating functioning in which there are varying degrees of abnormal eating behaviors and preoccupation with food, body weight, and shape. Primary EDs are anorexia nervosa, bulimia nervosa, and binge-eating disorder, with the remaining cases being described as other specified or unspecified (World Health Organization ICD-11, 2018). Living with an ED can affect many aspects of quality of life and wellbeing, including sense of self, relationships, and occupational functioning (Jenkins & Ogden, 2012). The course of recovery in terms of symptom remission varies widely, and for a significant minority, ED symptoms can be lifelong and include co-occurring morbidities; EDs may also result in early mortality (Fairburn & Harrison, 2003; Franko et al., 2018).

The existing literature on recovery is focused on clinical outcomes that serve to define stages of ED recovery (e.g., Steinhausen, 2002; Steinhausen & Weber, 2009). This symptom-focused recovery delineates objective indices from the clinician's perspective, often involving symptom improvement (remission) or cure and therapeutic responses (Jacobsen & Greeley, 2001). While the importance of symptom remission should not be understated, it does not fully capture the experiences of personal recovery for individuals with lived experience of an ED.

A more comprehensive construct of "recovery" for any mental disorder requires extending the traditional clinical understanding of recovery and incorporating an understanding of personal recovery as articulated by individuals with lived experience. Led by the growing recovery movement (Anthony, 2000), the mental health personal recovery philosophy expands the definition of recovery beyond a conceptualization of static symptom outcome to a dynamic process whereby recovery is an ongoing life orientation of engagement in behaviors and attitudes that allow individuals to attain their highest quality of life (Resnick, Fontana, Lehman, & Rosenheck, 2005). Emphasizing the personal perspective, personal recovery is self-defined in terms of subjective experiences of internal transformation (e.g., hope, meaning, healing, empowerment, and connection to other people) and external conditions (e.g., recovery-oriented services, positive environments of healing, and human rights agenda) (Andresen, Oades, & Caputi, 2003; Jacobsen & Greeley, 2001; Reisner, 2005). Thus, a personal recovery framework is compatible with, and complementary to, the symptom reduction framework of clinical recovery. From the

TABLE 1 CHIME and SAMHSA recovery models

CHIME	SAMHSA
Five categories for recovery processes: • Connectedness • Hope and optimism about the future • Identity • Meaning in life • Empowerment	Four dimensions: • Home • Community • Purpose • Health Ten principles of recovery • Emerges from hope • Person-driven • Occurs via many pathways • Holistic • Supported by peers and allies • Supported through relationships and social networks • Culturally based and influenced • Supported by addressing trauma • Involves individual family and community strengths and responsibility • Based on respect

Abbreviations: CHIME, connectedness; hope and optimism about the future; identity; meaning in life; and empowerment; SAMHSA, Substance Abuse and Mental Health Services Administration.

perspective of service users, symptom remission is not a holistic construct of recovery; individuals can be engaged in personal recovery even when they continue to have clinical symptoms of their ED. In recent years, a personal recovery orientation as led by the recovery movement has become an essential framework for behavioral health care policy, practice, and research in most industrialized countries (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Piot et al., 2019).

Two frameworks that capture the experience of individuals living with and recovering from a mental illness are the connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (CHIME) framework and Substance Abuse and Mental Health Services Administration's (SAMHSA) working definition for recovery. CHIME, an evidence-based and operationalized framework for personal recovery, was conceptualized by a systematic review and synthesis of service user perspectives. It outlines the recovery journey as an active, life changing, unique, nonlinear, multidimensional, and ongoing process. As illustrated in Table 1, this framework includes: CHIME (Leamy et al., 2011). This framework increases individual empowerment and reflects the personal values of individuals with lived experience that go beyond a clinical notion of symptom recovery. van Weeghel, van Zelst, Boertien, and Hasson-Ohayon (2019) have expanded the original CHIME framework to establish CHIME-D, which incorporates the difficulties of living with and managing a mental health condition (i.e., trauma, victimization, stigma, negative life changes).

A similar model was developed by the U.S. SAMHSA. In conjunction with stakeholders, SAMHSA created a standard, unified definition of person-centered recovery that is designed to advance opportunities for, and clarify concepts related to, recovery. The SAMHSA model developed a working definition and set of principles for recovery utilizing the perspectives of individuals with a history of a mental illness. According to SAMHSA's framework, recovery is defined as a process of change focusing on the improvement of health and well-being, the ability to live a self-directed life, and the capacity to achieve one's full potential (SAMHSA, 2005). This framework delineates four recovery dimensions and 10 guiding principles of recovery (see Table 1).

Unfortunately, neither the CHIME nor SAMHSA framework specifically addresses EDs. In fact, the systematic review that developed CHIME explicitly excluded EDs, and the SAMHSA model was designed to apply broadly across all mental and substance use disorders without addressing specific features of recovery for any particular disorder. Our focus on EDs in this study aims to apply a person-centered approach to the construct of recovery specifically for EDs. While there are an increasing number of publications describing people's experiences of living with an ED, very few studies apply constructs of a personal recovery model to EDs (Dawson, Rhodes, & Touyz, 2014a; Piot et al., 2019). Given the recent incorporation of personal recovery approaches in professional practice and policy (Van Furth, van der Meer, & Cowan, 2016), the development of a person-centered framework of ED recovery has the potential to contribute significantly to the treatment and outcomes for people at risk and living with EDs as well as support providers and families.

The clinical symptom ED recovery framework focuses predominantly on treatment response related to weight status, regular menstruation, and behavioral criteria, that is, lack of bingeing and purging symptoms or absence of restrictive eating patterns (Couturier & Lock, 2006; Kaplan et al., 2009; Kordy et al., 2002; Lock et al., 2013; Pike, Gianini, Loeb, & Le Grange, 2015). The personal recovery framework for EDs provides a more holistic approach that prioritizes restoring the individual's general wellbeing rather than limiting recovery to a focus on symptom reduction (Bardone-Cone et al., 2010; Dawson et al., 2014a). This recovery model does not ignore the importance of clinical outcomes, but instead asks how individuals experience these outcomes in the context of a holistic notion of recovery and wellness. In this sense, it emphasizes an integrated perspective incorporating social, psychological, emotional, behavioral, and physical dimensions (Pettersen, Wallin, & Björk, 2016). Without individualized, experiential, and qualitative dimensions included in the construct of recovery, there is risk that individuals who are behaviorally symptom-free may continue to have negative thoughts and feelings about themselves that reduce quality of life and increase risk for symptom relapse over time (Bardone-Cone et al., 2010; Keski-Rahkonen & Tozzi, 2005). Understanding the key components that individuals with lived experience identify as essential to their personal recovery process can ultimately contribute to creating a standardized measure of factors facilitating recovery developed by and for people living with EDs. Such inclusion has the potential to help individuals and providers create conditions and opportunities to support personal wellness and long-term recovery outcomes.

To date, a limited body of research on personal recovery exists for EDs. A qualitative meta-synthesis focused exclusively on anorexia nervosa recovery identified themes of empowerment and self-reconciliation as key to positive change and recovery (Duncan, Sebar, & Lee, 2015). Another systematic review (de Vos et al., 2017) analyzed data from 18 studies with individuals who had recovered from EDs, finding that, according to individuals with lived experience,

ED recovery went beyond remission of ED symptomatology to include elements of psychological well-being and self-adaptability/resilience, positive relationships, personal growth, decrease in ED behavior and cognition, and autonomy. While the de Vos et al. (2017) review explored recovery from the perspective of "recovered" individuals, our study expands on this work by incorporating views from people who identify as fully recovered as well as people still in the process of recovery, since many people continue to experience waxing and waning mental health symptoms while recovering a meaningful life. In this way, we explore personal recovery, which is self-determined, to support and expand upon the clinical recovery model. The rationale for this approach is aligned with the recovery movement and harm reduction approaches, which view recovery as a process where it is possible to achieve enhanced wellness even when clinical symptoms remain.

In summary, the overall recovery literature has increasingly emphasized the importance and relevance of a person-centered approach to defining recovery (Dawson et al., 2014a). CHIME and SAMHSA are two broad frameworks that both reflect this recovery movement and have advanced the values and ideals of inclusion of individuals with lived experience in defining recovery. In the case of EDs, there is no single framework that operationalizes a construct of person-centered ED recovery outcomes. This review that was coproduced explores perspectives on recovery from people with lived ED experience and additionally evaluates whether the CHIME framework and/or the SAMHSA working definition of recovery are useful for thinking about the ED recovery journey. We ask what personal recovery means for individuals with lived ED experience and how recovery leads to improved quality of life for these individuals. This exploratory review aims to generate hypotheses and build theory for how to understand personal recovery for people living with an ED.

2 | METHODS

2.1 | Search strategy and selection criteria

We searched PsychINFO via EBSCO, Embase and Medline via Ovid, Medline via Pubmed CINAHL via EBSCO, EMCARE on June 10, 2019. The search terms included "eating disorder*," "anorexi*," "bulimi*," "binge eating," "ednos," "recover*," "semi-structured," unstructured, informal, in-depth, "face-to-face," "structured," guide, interview*, discussion, questionnaire*, focus group*, ethnograph*, fieldwork, "field work," "key informant". Differences in the words search reflect differences in thesaurus terminology between databases.

Original qualitative research that explored the process of ED recovery from the perspective of the person with a history of an ED in peer-reviewed sources was included in this review. Participants in these studies had to have obtained a formal diagnosis of an ED and were classified as recovered or in the process of recovery. We excluded outcome and intervention studies that did not specifically focus on the process of recovery as well as studies that used a prespecified definition of recovery to structure questions. Further we limited our search to papers published within the last 5 years (2013-present) as, given the recent rise of recovery-oriented mental health practice and policy, we particularly wanted to focus on current perspectives on personal recovery from EDs. All ED types defined in DSM-IV, DSM-5, and ICD-10 were included since we were interested in the transdiagnostic experience of recovery. Unpublished reports, dissertations, and theses were excluded.

Three authors (SW, CH, and GP) screened eligible studies in two phases. The first phase selection process was based on title and abstract, and the second phase was based on full text. To establish interrater reliability, 30% of the studies were screened together, and uncertainties were resolved by discussion (SW, CH, and GP).

2.2 | Procedure and analysis

2.2.1 | Data extraction

Two reviewers (SW and CH) extracted data. A table was used to extract demographic and methodological information (Table 2). The Critical Appraisal Skills Programme qualitative assessment checklist (2013) was used to assess study quality by three reviewers (SW, KC, and CH). One reviewer (EM) coded whether individuals with lived experience referenced weight, shape, and eating behaviors and attitudes as part of changes in their perceptions of their personal recovery. NVivo v.12 software was used to code first-order (participant quotations) data. Second order data (researcher interpretations, such as concepts, themes, and descriptions of findings) was used to additionally understand and contextualize the data and support coding. In order to establish reliability, one author (CH) independently extracted data of 20% of the papers using the code framework to check interrater agreement (59%).

2.2.2 | Studies and participants included in the systematic review

Database searching yielded 1,163, and after removing duplicates, 422 unique studies remained for screening (see Figure 1). The screening resulted in 79 full-text articles for eligibility. We included 20 studies in the thematic synthesis. The total sample size across studies was 351. As seen in Table 2, studies were conducted in eight countries (United Kingdom, Australia, United States, Norway, Sweden, Scotland, Brazil, and France). All studies included male and female individuals who had been formally diagnosed with an ED and were in recovery or remission. Diagnoses included anorexia nervosa, bulimia nervosa, binge-eating disorder, and ED not otherwise specified. Research methods included interviews, online questionnaires, online focus groups, online group sessions, and ED inpatient clinic application letters for data collection. The qualitative analyses in the studies included in the review utilized interpretive phenomenological analysis, qualitative content analysis, open-coding analysis, text-condensing analysis, the transtheoretical model, thematic analysis, and grounded theory methods.

TABLE 2 Summary of studies

Study	Country	No. of participants	Diagnosis	Study focus	Data collection	Data analysis	Summary of themes	No. of references
Arthur-Cameselle and Quatromoni (2014a)	United States	16, females	AN (*n* = 8), BN (*n* = –2), BED (*n* = 2), AN followed by BN (*n* = 3), AN followed by BED (*n* = 1)	Factors associated with initiation and achievement of ED recovery in female collegiate athletes	Interview	Thematic analysis	Initiation of recovery due to negative consequences of ED (physically, health problems, underperforming in sport) Cognitive/behavioral changes, supportive relationships, seeking professional care helped recovery, but lack of support from others, professional care complaints, and spending time with others with ED hindered recovery	143
Arthur-Cameselle and Quatromoni (2014b)	United States	47, females	AN (*n* = 16), BN (*n* = 7), EDNOS (specifically BED, *n* = 4), or two or more of the three (*n* = 20)	Factors that assist recovery in female collegiate athletes	Online questionnaire	Open-coding analysis	Motivation from internal factors: Participate in sport; change in ED beliefs, fed up with disorder; new coping mechanisms/distractions; avoid triggers Importance of others: Support from peers and family; professional support; empathizing, confrontation External factors: Change in environment, hiding, medication	61
Bowlby, Anderson, Hall, and Willingham (2015)	United States	13, females	AN-restricting (*n* = 6), AN-purging (*n* = 1), BN (*n* = 3), cycles of AN and BN (*n* = 3)	Experience of recovery from therapists with a history of an ED	Interview	Phenomenological with content	Recovery process is nonlinear; comprehensive; life-long Involves changing attitude toward self; de-identification with illness; developing a sense of purpose; fostering meaningful relationships	94
Dawson, Rhodes, and Touyz (2014b)	Australia	8, females	Chronic AN (*n* = 8)	Process of recovery from chronic AN from participants who fully recovered	Interview	Narrative inquiry	Phases of recovery include unready and/or unable to change; tipping point to change; active pursuit of recovery; reflection and rehab	127

(Continues)

TABLE 2 (Continued)

Study	Country	No. of participants	Diagnosis	Study focus	Data collection	Data analysis	Summary of themes	No. of references
Espíndola and Blay (2013)	Brazil	15, females	AN (*n* = 15)	Factors for successful remission of AN	Interview	Grounded theory	Main factors: Motivation to change; empowerment; autonomy; and focus on strengths Other related factors: Having outlets to express self without being judged; learning about nutrition and how the body works Treatment factors: Good treatment team and medication; Residual symptoms even in remission	53
Gulliksen, Nordbø, Espeset, Skårderud, and Holte (2015)	Norway	34, females	AN (*n* = 34)	Experience of women with AN's first contact with treatment	Interview	Open-thematic coding	Importance of health care professionals being considerate, having effective professional communication skills, being knowledgeable about EDs, listening and working to understand the service user Problems with professionals can make it scary and traumatic	48
Hannon, Eunson, and Munro (2017)	Scotland	5, females	AN	Individuals' with a history of an ED's experiences of severe AN long-term community treatment	Interview	Interpretive phenomenological analysis	Treatment is a process with two phases Recovery is a process of self-discovery and accepting oneself; it is long, hard, frustrating, with moments of isolation and hopelessness	134
Lindgren, Enmark, Bohman, and Lundström (2015)	Sweden	5, females	BN (*n* = 5)	Recovery from bulimia nervosa from young adult women's experiences	Interview	Qualitative content analysis	Common themes: Feeling stuck in the ED (linked with identity, distress and self-harm); longing for life without BN; hitting rock bottom; opening up to others; recognizing neg. Consequences of ED; gaining courage to leave ED behind; rebuilding identity; accepting help; invest in the work of treatment; gaining self-awareness/freedom; learning to value self	67

(Continues)

TABLE 2 (Continued)

Study	Country	No. of participants	Diagnosis	Study focus	Data collection	Data analysis	Summary of themes	No. of references
Lindstedt, Neander, Kjellin, and Gustafsson (2018)	Sweden	15, females (14) and male (1)	EDs with restrictive symptomatology	Explore experience of adolescents with EDs (restrictive symptomatology)	Interview	Thematic analysis	Common themes: Problems in everyday life; loss of experiences; isolation in ED; life put on hold; create new life context; finding meaning in life; discovering oneself	74
McNamara and Parsons (2016)	United Kingdom	75, females and males	BED (32%), BN (28%), AN (20%), AN and BN (20%)	Role of social interactions within a group can promote ED recovery	Online group session	Theoretically guided thematic analysis	Main themes: Importance of identity in EDs; importance of relating to others with similar issues due to a common understanding Motivation and advice from members; members feel less alone; full recovery is possible but ED will always be part of one's identity and impact one's life; learning how to manage ED is critical	123
Mitrofan et al. (2017)	United Kingdom	19, females; 11 parents	AN (n = 12), AN and BN (n = 3), other/atypical ED (n = 2), all 3 (=1)	Young people's and parents' views of care for EDs	Online focus group	Thematic analysis	Recommendations: Need to shift away from weight-focused to more holistic, individualized, continuous/consistent care approach; focus on psychological as well as physical problems; improve professionals' knowledge and attitudes toward patients and families at all levels of care; enhance peer and family support	65
Petry, Vasconcelos, and Costa (2017)	Brazil	3, females	AN (n = 3)	Perceptions of women in recovery for AN of their eating behavior during and after ED experience	Interview	Thematic analysis	Main themes: Experiences of AN are individualized, but during recovery it is important to gain more flexible behaviors around eating; the negative feelings like guilt and fear of loss of control can remain but no longer acting on these feelings; ED thoughts remain but are manageable	20
Pettersen, Thune-Larsen, Wynn, and Rosenvinge (2013)	Norway	13, females	AN, BN	Patients' experiences of the later phases of ED recovery	Interview	Content analysis	Later stages of recovery include ED symptom reduction, but women dealt with more psychological and existential issues related to themes of exploring identity, relearning eating, developing social skills, and coping with grief	22

(Continues)

TABLE 2 (Continued)

Study	Country	No. of participants	Diagnosis	Study focus	Data collection	Data analysis	Summary of themes	No. of references
Pettersen et al. (2016)	Norway and Sweden	15, male	AN (*n* = 10), BN (*n* = 4), EDNOS (*n* = 1), DOI varied 3–25 years	Male recovery process and what they perceive as helpful	Interview	Phenomenological with content	Main themes: Hitting rock bottom; gaining motivation to change (either through self or push from others); letting go of control; importance of professional help; learning new structures around food and exercise	130
Piot et al. (2019)	France	3, females	AN (*n* = 3)	Perceptions of people who were hospitalized during adolescence for severe AN on their recovery experience	Interview	Interpretive phenomenological analysis	Recovery in four stages: Corseted; vulnerable; plastic; playful Seven dimensions: Struggle and path of initiation; work on oneself; self-determination and help; body; family; connectedness; timeline Additional features to recovery process: Bodily well-being and pleasure of body; stigmatization; role of group; relation to time; importance of narratives AN recovery process includes many tipping points	206
Seed, Fox, and Berry (2016)	United Kingdom	12, females	AN (*n* = 12)	Experience of detention under mental health act for AN	Interview	Grounded theory	Main themes: Battle between patients and staff (mistreated by staff, not cared for, powerless, not feeling like a person); refusing treatment; turning points with cognitive realizations and compliance; safety, detachment, and dependence on inpatient unit; physical and cognitive recovery; variable stability outcome after leaving the unit and being challenged to be independent; the persistent identification with AN increases risk of relapse	17
Smith et al. (2016)	United Kingdom	9, females	AN	Women's experiences of specialist inpatient treatment for AN during treatment admission	Interview	Thematic analysis	Main themes: Shifts in control; transitioning into inpatient; importance of supportive staff relationships and with others; sharing with peers; process of recovery and discovering oneself	83

(Continues)

TABLE 2 (Continued)

Study	Country	No. of participants	Diagnosis	Study focus	Data collection	Data analysis	Summary of themes	No. of references
Strand, Bulik, von Hausswolff-Juhlin, and Gustafsson (2017).	Sweden	16, females (15) and male (1)	AN	Patients' experiences of self-admission to specialist ED clinic	Interview	Qualitative content analysis	Self-admission allowed for agency (self-help, taking control of recovery) and flexibility (flexibility of the treatment program) Used it to promote healthy behaviors and prevent relapse or deterioration, get a break from overwhelming demands, or provide relief for relatives Self-admission acts as a safety net, fosters agency and motivation, but requires maturity to overcome ambivalence and ask for help	151
Venturo-Conerly, Wasil, Shingleton, and Weisz (2019)	United States	13, females	Does not specify	Association between feminist ideas and ED recovery	Interview	Thematic analysis	Main themes: Value in feminist theories to help recovery; recognize and reject harmful cultural norms; identify with other empowering women; doing valuable work in one's life; exposure to feminist ideas/resources; importance of supportive relationships with other women	45
Woerner, King, and Costa (2016)	Australia	15, females	AN (n = 15)	Readiness to change and self-efficacy as it relates to symptom dimensions of AN	Questionnaire and interview	Transtheoretical model (TTM)	Readiness to change and self-efficacy were not consistent across dimensions More stability for readiness to change and self-efficacy reported during pre-contemplation, contemplation, and maintenance stages, but instability over time and across AN dimensions during central stages of change	23

Abbreviation: ED, eating disorder.

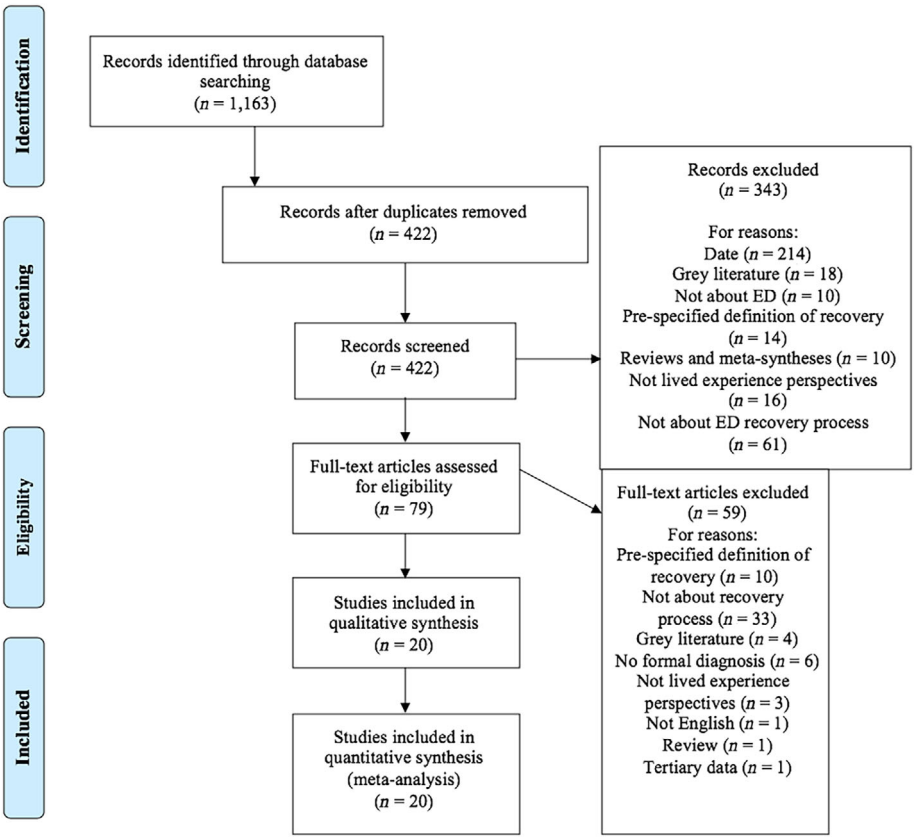

FIGURE 1 Prisma flow diagram [Color figure can be viewed at wileyonlinelibrary.com]

2.2.3 | Thematic synthesis

Thematic analysis entailed developing descriptive, analytical themes, which were then combined into a framework outlining the essential components of recovery based on the perspective of individuals with a history of an ED (Braun & Clarke, 2006). Experts by experience (JS, MS), clinicians (CH, DF, KP, EvF), and academics (SW, GP, KC, KS, EM) contributed to the analysis to combine the different perspectives into a consensus and minimize bias.

Our analysis occurred in two iterations. We extracted and coded all data that encompassed personal perspectives of recovery, while also evaluating the presence of the dimensions of personal recovery outlined in the CHIME and SAMHSA frameworks. We evaluated the utility and sufficiency of the CHIME and SAMHSA frameworks against the qualitative data that emerged from the ED literature to identify points of convergence and divergence.

Inductive thematic synthesis derived from the ED qualitative data resulted in a specific framework of personal recovery from EDs. Themes developed from codes are shown with their effect size (displayed in the key and numeric values in Table 3). Per the methodology outlined in de Vos et al. (2017), frequency effect size was calculated using the total number of studies containing the theme divided by the total number of studies. Intensity effect size, which indicates the importance of these themes relative to each other, was calculated also using the de Vos et al. (2017) approach by dividing the number of found criteria related to the theme by the number of found criteria in all studies. This process yielded components that focus on the internal experience of the ED recovery process. We also included results related to eating and weight attitudes and behaviors to better understand the relationship of symptom recovery to the personal framework of recovery as a process. Because there were both positive and negative themes regarding the impact of this area on personal recovery, these are outlined separately at the end of the results section.

3 | RESULTS

3.1 | Characteristics of ED recovery

Table 3 depicts a conceptual framework that defines six superordinate themes: supportive relationships, hope, identity, meaning and purpose, empowerment, and self-compassion. Each superordinate theme additionally has its own subsidiary themes.

3.2 | Conceptual framework for personal recovery from an ED

3.2.1 | Supportive relationships

The importance of supportive relationships was a common statement shared by participants in the studies reviewed, defined as receiving support, advice, and encouragement from others (i.e., family members, loved ones, friends, or professional careers) as well as perceiving a sense of feeling heard, understood, and validated by their supporters.

TABLE 3 ED personal recovery framework—Components of recovery processes

Theme	Frequency effect size (%)	Intensity effect size (%)
Supportive relationships		
Support and encouragement from others	75	17
Connectedness and sense of belonging	85	13
Peer support	50	5
Hope		
Belief in recovery	85	16
Identity		
Self-discovery	30	2
De-identification from ED	80	15
Personal growth and building strength	30	1
Meaning and purpose		
Meaning of ED and recovery experiences	30	2
Living and experiencing life with sense of purpose	65	5
Empowerment		
Taking responsibility and control	50	8
Self-empowerment and resilience	35	2
Self-compassion		
Self-kindness	50	5
Acceptance of self	70	7
Honoring emotional experience	35	2

Abbreviation: ED, eating disorder.

> The most helpful thing, I think, was seeing the social worker because she was really good at listening. (Arthur-Cameselle & Quatromoni, 2014a)

Connectedness and sense of belonging comprise a sub-theme—feeling cared about and connected to others, being part of a community, and not being ashamed and stigmatized.

> [My dad] just, was always, always there to listen… I knew he was going to love me no matter what. (Arthur-Cameselle & Quatromoni, 2014a)

Another subcomponent of the supportive relationships theme is peer support, which encompasses the prior two subcategories, but is its own theme due to its specific value to the individuals with a history of an ED. Participants indicated that support from others who shared similar experiences was beneficial in the form of encouragement or advice, which led to feeling understood, connected, less alone or isolated, and feeling part of a group.

> It is really good in terms of being able to hear how other people have gotten over the drive to exercise and how they have managed to eat certain foods. (Smith et al., 2016)

3.2.2 | Hope

The theme of hope seemed critical to activate and facilitate recovery, driving the motivation for individuals to seek help and push through the difficulties. This theme was described as belief in recovery, encompassing believing in oneself, in others, and in a better future. Individuals describe the desire to live a life not dictated by the ED. Hope, in particular, is context-dependent, and is an evolving concept; it is experienced differently at each stage/phase of recovery (i.e., early in recovery vs. the later phases).

> I do believe complete recovery is possible, and living a normal life is possible. But the underlying association with food, I think will always be there. So just to accept that, and try to live with that in the most healthy and positive way possible. (McNamara & Parsons, 2016)

3.2.3 | Identity

Identity is the way people see and understand themselves. The subcomponents of this theme include: self-discovery, de-identification from ED, personal growth, and building strength. Self-discovery is described as learning to understand oneself and discovering one's needs, interests, and desires in life.

> It was like having a valuable smashed plate and putting all the pieces back together to rebuild your identity and reclaim it. (Dawson et al., 2014b)

De-identification from ED is seen as a particularly important aspect of rebuilding identity and life separate from ED, such that the individual's self-esteem or sense of self is not contingent on the ED. In this sense, individuals learn to release the importance of the role the ED has in their life and identity, changing attitudes and beliefs to enable more self-acceptance. The ability to minimize the role of the ED leads to rebuilding identity based on the many other important personal assets that are possessed. Learning to understand the role of the ED is important but learning to build on personal strengths is paramount.

> I find it difficult to distinguish … what is me and what is the eating disorder … a lot of what my treatment

> has been is actually finding my own identity. (Smith et al., 2016)

Personal growth and building strength are defined as overcoming difficulties and developing as a person. The lived experience of having an ED and recovering from it was described as an enriching experience, and many people cited the recovery journey as a process of growth.

> I think saying I am in recovery causes me to think more consciously about that process and stay aware of how I am feeling and thinking about myself … Saying I am in recovery kind of helps in the process of continuing on, growing as an individual, and choosing to make decisions that are positive and life giving. (Bowlby et al., 2015)

3.2.4 | Meaning and purpose

Meaning and purpose were also found to be important components of the ED recovery journey that evolve over time. This category is comprised of helping to find the meaning of ED in one's life and learning to live life with a sense of purpose beyond being defined and controlled by the ED.

> I started to become aware that the anorexia wasn't a choice—it was a reaction. As a teenage girl, the only thing I could control was my body because I had no power. Exploring the issues behind the eating disorder was helpful. (Dawson et al., 2014b)

Living and experiencing life with a sense of purpose is described as finding purpose outside of the ED. Persons with an ED cited that recovery teaches them that there is more to life than the ED.

> Figuring out that there are some things in life worth more than clinging to an eating disorder. (Arthur-Cameselle & Quatromoni, 2014b)

3.2.5 | Empowerment

Empowerment consists of taking responsibility and control leading to confidence, agency, and resilience. Taking responsibility and control is described as the newfound sense of independence and autonomy both in the individual's life and in recovery. Persons with an ED describe regaining control over their lives and their future while also acknowledging the importance of self-help, self-determination, and self-direction for recovery.

> In order to get out of it, I had to decide to do it and also decide on the path to take… Nobody else was going to do it for me; It was something I had to make a choice to do, and I made that choice because I didn't want to be a prisoner anymore. (Dawson et al., 2014b)

Self-empowerment and resilience characterize the individuals' descriptions of focusing on their own strengths and learning to recognize their own value such that they have the ability to assert themselves and stand up for themselves.

> I have gradually learnt to use my strength and my resources in a right way. (Pettersen et al., 2016)

3.2.6 | Self-compassion

The final component of recovery that was repeatedly identified and coded from the data is self-compassion. This is centered on the way one relates to oneself. Individuals learn to be aware, acknowledge, accept, and be kind to themselves through strengthening their self-care skills and capacities. This component is comprised of self-kindness, acceptance of self, and honoring emotional experiences. Self-kindness is described as learning self-care practices, feeling more connected to oneself, nurturing oneself, and gaining self-awareness. Self-kindness and self-love may wax and wane throughout the recovery journey.

> Part of recovery is to know yourself and to develop emotional intelligence around yourself and others, such as learning to take care of yourself, how you cope with stress, how you deal with anger… It is learning to love your body and loving what it does for you; taking care of it and really loving yourself. It is learning to really love yourself with all your imperfections; not expecting yourself to be perfect and knowing you are not supposed to be. (Bowlby et al., 2015)

Acceptance of self is described as the idea of common humanity, recognizing that everyone struggles, and that it is okay to not be perfect. People described the process of learning to accept themselves as they are as critical aspect to recovery.

> I really gained self-respect back and everything just fell into place. (Arthur-Cameselle & Quatromoni, 2014a)

Honoring one's emotional experience is accomplished by applying mindfulness skills. Some participants described their ED as a way to numb the discomfort of one's daily life. By tuning into needs and emotional weather, individuals can sense, experience, and express their emotions—negative or positive—in a helpful, rather than self-destructive, manner.

> I think the greatest thing I have learned is that being a really sensitive person is not a bad thing and that it is actually a great thing to be a sensitive person. I think it is a great thing that I cry easily. I grew up thinking that was such a bad thing and that there was something wrong with me because I was so sensitive. Being able to

> embrace that was so important to my recovery because it was so much of who I was. (Bowlby et al., 2015)

3.2.7 | Improvement in eating and weight behaviors and attitudes

Improvement in eating behaviors and attitudes toward weight emerged as relevant to recovery but was not a primary component of the recovery process. Instead, as individuals reflected on their own recovery process, eating and weight concerns and behaviors were incorporated as means to achieve a life characterized by a dynamic state of recovery, rather than the sole end of recovery.

Individuals with lived experience connected changes in eating and weight to fuller engagement in life in ways they desired, such as returning to sports or other activities.

> I care about what I eat, and I work out, but not in the same way. […] It is not working out in order to be able to eat, but it is rather eating so that I can work out. […] When I'm training, my thoughts are not set on 'I want to lose weight' but I work out for my own sake because I enjoy it. (Lindstedt et al., 2018)

Many individuals also described eating and weight behaviors as important to the key components of recovery described above. Nutritionists were noted as supportive in connecting changes in eating habits and knowledge about food with larger themes of acceptance and self-compassion.

> It took at least one year before I learnt to eat. I went to a dietician who taught me how to organise my eating into breakfast, lunch and dinner. Even if ED are not just a matter of food, it is also about food and I was totally "out of place" on this food thing. (Pettersen et al., 2016)

Still, there was conflicting information identified on whether improved eating and weight behaviors actually led to overall personal recovery. Some individuals noted that an over-focus on eating and weight behaviors ignored the psychological aspects of their recovery, which they found detrimental rather than supportive. Others emphasized that improved eating and weight were markers of recovery but were not identified as the most important aspects of their personal recovery. Instead, these elements were part of a holistic process that emphasized the other components of recovery identified above.

> [Even after gaining weight] I want to get better, but I still have the negative thoughts…it is still difficult. I still struggle. (Smith et al., 2016)

> Really what you need is someone who sees the whole person – the link between the medical and psychological condition and treats both together. (Mitrofan et al., 2017)

3.3 | Effect sizes

In examining frequency effect sizes (see Table 3), connectedness and sense of belonging (85%), belief in recovery (85%), de-identification from ED (80%), support and encouragement from others (75%), and acceptance of self (70%) consistently and frequently appeared throughout most of the studies. Looking at the intensity effect sizes (see Table 3), which measure how essential criteria are when compared to each other, support and encouragement from others (17%), belief in recovery (15.7%), de-identification from ED (15.1%), and connectedness and sense of belonging (13.4%) have the most notable intensity effect sizes. While intensity sizes for the subthemes were low due to the large number of quotes that were analyzed, they are still useful for understanding the relative ranking of the various subthemes. The frequency effect size for eating and weight behaviors and attitudes was 50%, although this included both positive and negative references of the impact of eating and weight behaviors on recovery. Because of this, we could not calculate the intensity size and did not include eating and weight behaviors and attitudes as a component of recovery in the framework.

The ED personal recovery framework largely reflects and is consistent with the dimensions contained in the CHIME and SAMHSA frameworks. The results indicate that an ED personal recovery framework requires the additional dimension of self-compassion and distinct, slightly different focus of the subcomponents of the superordinate themes.

4 | DISCUSSION

This systematic review examined recent qualitative studies in order to develop a framework for understanding personal recovery for those with lived ED experience. We systematically selected and reviewed studies looking at the ED recovery process in order to develop a framework that applies and extends the CHIME and SAMHSA approaches to recovery. The results indicate that an ED's personal recovery framework requires the additional dimension of self-compassion, and some of the subcomponents of the superordinate themes were distinct or held a slightly different focus.

The conceptual framework that we derived outlines six key components of personal recovery from EDs that were consistently found across studies reviewed: supportive relationships, hope, identity, meaning and purpose, empowerment, and self-compassion. In addition, the framework recognizes the importance of individuals with lived experience's perception of improved symptom recovery—identified as eating and weight improvement—on these key components and overall personal recovery. These improvements are seen by those with lived ED experience as means to reach overall goals for personal recovery, rather than recovery itself. Our study suggests future research on potential connections for the personal recovery model to better integrate relevant components of clinical constructs of recovery.

These themes have implications for both clinicians and those with lived experience as they recognize the importance of meaningful activity and peer support and the value of incorporating compassionate approaches for treatment. Separating one's self from the ED as well as finding purpose outside of ED seem to be specific to ED recovery, explaining why they may not have been outlined in the CHIME or SAMHSA frameworks.

The six dimensions that we identify are closely related to the CHIME and SAMHSA frameworks, however, our approach gives prominence to the construct of self-compassion. An explicit focus on this dimension will be important to effectively describe and guide ED recovery. Similarly, our approach shares many commonalities with the de Vos et al. (2017) literature review (which included four of the same studies that we used), in particular with regards to the themes of supportive relationships and empowerment. There were, however, some nuanced differences as we expanded on the work of de Vos et al. (2017) by including more experiential themes, such as hope, meaning and purpose, and identity (especially the de-identification with the ED subtheme) as well as expanding the theme of self-compassion beyond the notion of self-acceptance and analyzing perceptions of weight and eating behaviors among individuals with lived experience.

Together, the six dimensions in the ED personal recovery framework are proposed for understanding the specific experience of recovery from EDs as they provide a conceptual framework to support individual reflection on experience and recovery. Each of the components of recovery encompasses and recognizes the difficulties/challenges within the recovery process (i.e., stigmatization, victimization, negative life changes, trauma, ambivalence, disempowerment, conflicts, and barriers to care). These difficulties are important considerations that have the potential to significantly impact recovery and are recognized in each of the six superordinate themes. Many people with EDs describe recovery as an active "battle," consisting of stages or phases; that is, a difficult, exhausting, and all-consuming process due to its ongoing and evolving nature. While some individuals with a history of an ED define their status as fully recovered, others in a similar position will say that they will always be in recovery. Our participants were in various stages of clinical symptom recovery. While we are unable to distinguish between respondents who did or did not meet the definition of clinical recovery, and how that status may have impacted our results, their responses are still relevant since our focus was on the personal experience of the recovery process as a whole. Even though not everyone's experience is the same, we found common aspects of recovery, which may inform how to map recovery processes that more fully integrate the individual personal experiences.

It is important to note that this study does not aim to negate the importance of clinical recovery for individuals living with EDs. EDs have a clear definition for symptomatic improvement, and we must be able to distinguish individuals who self-identify as recovered or in recovery while still poorly functional. In fact, our inclusion of eating and weight attitudes and behaviors in data analysis reflects that individuals with lived experience also recognize the importance of this aspect of recovery. Our findings illustrate that current studies are not invalid in their assessment of a patient as "recovered" once he or she reaches objective measure of clinical improvement, but instead they are incomplete. Using the six dimensions of the ED personal recovery framework from this study, future research should create a measurement tool that characterizes the lived experience of recovery to augment clinical measurement tools to better capture all dimensions of recovery and help guide treatment and approaches to support positive wellness outcomes. Additional research in this area could also expand upon the supportive relationships dimension of this framework to include the perspectives of close family and friends of individuals with EDs on their definitions of their loved one's recovery.

The systematic nature of the review, the quality assessment of the studies selected for inclusion, the saturation of themes reached in the synthesis, the input from expert consultation, and the comparison with overarching recovery frameworks are particular strengths of the ED personal recovery framework developed in this review. A limitation of the review is that the recovery framework was created from secondary data, that is, qualitative data from published studies examining experiences of participants living with a history of an ED. In addition, this review included individuals with lived experience of an ED regardless of their current clinical status at the time of data collection. Because our review was a secondary analysis of data, and because of limitations in the available data, we were not able to assess how clinical status (active, partial remission, remitted) may be correlated with the variables identified in the personal recovery framework. Future research should generate original data to systematically evaluate whether the components in this conceptual framework are replicated. If so, the next step would be to create a measurement tool to capture personal recovery as described above. Another limitation of the current study is that we were not able to fully consider cultural (and ethnic) differences since few studies included the perspective of diverse ethnic minority groups. The sample was comprised mainly of female participants, so future research should pay particular attention to the issues of culture and gender.

5 | CONCLUSION

This systematic review aimed to understand the perspectives of those with lived experience of ED recovery to develop a personal recovery framework outlining their key components of recovery. Six superordinate themes of supportive relationships, hope, identity, meaning and purpose, empowerment, and self-compassion were identified. According to those with lived experience, these constructs represent essential person-centered components of the experience of recovery from an ED. This study contributes to the increased focus on person-centered and self-defined understanding of recovery in mental health services. It specifically provides a framework for ED recovery that expands on clinical thinking and offers a holistic perspective on the components of personal recovery from EDs beyond objective symptomatic improvements. The terms "lived experience" and "person-centered" are relatively new to the discourse on recovery. With the evolution of person-centered recovery approaches, which recognizes people with lived-experience as experts in their own recovery, mental

health practitioners can reciprocally work with people to understand, live with, and manage EDs while pursuing a life filled with hope, meaning, and (re)creating a positive and accepting sense of self.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

This review used data previously published (publicly available) only. No primary data was collected for the purposes of this publication. Further information can be obtained from the corresponding author.

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