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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

1  
2 **Background:** An extensive literature exists describing treatment interventions and recovery  
3 from eating disorders (EDs); however, this body of knowledge is largely symptom-based and  
4 from a clinical perspective and thus limited in capturing perspectives and values of individuals  
5 with lived experience of an ED. In this study, we performed a systematic review to coproduce a  
6 conceptual framework for personal recovery from an ED based on primary qualitative data  
7 available in published literature. **Methods:** A systematic review and qualitative meta-synthesis  
8 approach was used. Twenty studies focusing on ED recovery from the perspective of individuals  
9 with lived experience were included. The studies were searched for themes describing the  
10 components of personal recovery. All themes were analyzed and compared to the established  
11 CHIME and SAMHSA frameworks of recovery, which are applicable to all mental disorders.  
12 Themes were labeled and organized into a framework outlining key components of the ED  
13 personal recovery process. **Results:** Supportive relationships, hope, identity, meaning and  
14 purpose, empowerment, and self-compassion emerged as the central components of the recovery  
15 process. Symptom recovery and its relationship to the personal recovery process is also  
16 significant. **Conclusions:** Individuals with lived experience of EDs noted six essential elements  
17 in the personal ED recovery process. This framework is aligned with several of the key  
18 components of the CHIME and SAMHSA frameworks of recovery, incorporating person-  
19 centered elements of the recovery process. Future research should validate these constructs and  
20 develop instruments (or tools) that integrate the lived experiences into a measurement of  
21 recovery from an ED.  
22 *Keywords:* Eating disorders, Recovery, Framework, Meta-analysis, Qualitative research,  
23 Systematic review

1 Abstract Word Count: 240

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### **Background**

4 Eating disorders (EDs) are characterized by serious disturbances to an individual's eating  
5 functioning in which there are varying degrees of abnormal eating behaviors and preoccupation  
6 with food, body weight, and shape. Primary EDs are anorexia nervosa, bulimia nervosa, and  
7 binge-eating disorder, with the remaining cases being described as other specified or unspecified  
8 (WHO ICD-11, 2019). Living with an ED can affect many aspects of quality of life and  
9 wellbeing, including sense of self, relationships, and occupational functioning (Jenkins et al.,  
10 2011). The course of recovery in terms of symptom remission varies widely, and for a significant  
11 minority, ED symptoms can be lifelong and include co-occurring morbidities; EDs may also  
12 result in early mortality (Fairburn & Harrison, 2003; Franko et al., 2018).

13 The existing literature on recovery is focused on clinical outcomes that serve to define  
14 stages of ED recovery (E.g. Steinhausen, 2002; Steinhausen & Weber, 2009). This symptom-  
15 focused recovery delineates objective indices from the clinician's perspective, often involving  
16 symptom improvement (remission) or cure and therapeutic responses (Jacobsen & Greenley,  
17 2001). While the importance of symptom remission should not be understated, it does not fully  
18 capture the experiences of personal recovery for individuals with lived experience of an ED.

19 A more comprehensive construct of "recovery" for any mental disorder requires  
20 extending the traditional clinical understanding of recovery and incorporating an understanding  
21 of personal recovery as articulated by individuals with lived experience. Led by the growing  
22 recovery movement (Anthony, 2000), the mental health personal recovery philosophy expands  
23 the definition of recovery beyond a conceptualization of static symptom outcome to a dynamic

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1 process whereby recovery is an ongoing life orientation of engagement in behaviors and attitudes  
2 that allow individuals to attain their highest quality of life (Resnick et al., 2005). Emphasizing  
3 the personal perspective, personal recovery is self-defined in terms of subjective experiences of  
4 internal transformation (e.g., hope, meaning, healing, empowerment, and connection to other  
5 people) and external conditions (e.g., recovery-oriented services, positive environments of  
6 healing, and human rights agenda) (Jacobsen & Greenley, 2001; Reisner, 2005; Andresen et al.,  
7 2003). Thus, a personal recovery framework is compatible with, and complementary to, the  
8 symptom reduction framework of clinical recovery. From the perspective of service users,  
9 symptom remission is not a holistic construct of recovery; individuals can be engaged in personal  
10 recovery even when they continue to have clinical symptoms of their ED. In recent years, a  
11 personal recovery orientation as led by the recovery movement has become an essential  
12 framework for behavioral health care policy, practice, and research in most industrialized  
13 countries (Piot et al., 2019; Leamy et al., 2011).

14 Two frameworks that capture the experience of individuals living with and recovering  
15 from a mental illness are the CHIME framework and SAMHSA's working definition for  
16 recovery. CHIME, an evidence-based and operationalized framework for personal recovery, was  
17 conceptualized by a systematic review and synthesis of service user perspectives. It outlines the  
18 recovery journey as an active, life changing, unique, non-linear, multidimensional, ongoing  
19 process. As illustrated in Table 1, this framework includes: Connect<sup>ed</sup>ness; Hope and optimism  
20 about the future; Ident<sup>ity</sup>; Meaning in life; and Empowerment (CHIME) (Leamy et al., 2011).  
21 This framework increases individual empowerment and reflects the personal values of  
22 individuals with lived experience that go beyond a clinical notion of symptom recovery. Van  
23 Weeghel et al. (2019) have expanded the original CHIME framework to establish CHIME-D,

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1 which incorporates the difficulties of living with and managing a mental health condition (i.e.  
2 trauma, victimization, stigma, negative life changes).

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

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

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1           The clinical symptom ED recovery framework focuses predominantly on treatment  
2 response related to weight status, regular menstruation, and behavioral criteria, i.e. lack of  
3 bingeing and purging symptoms or absence of restrictive eating patterns (Couturier & Lock,  
4 2006; Kaplan et al., 2009; Lock et al., 2013; Pike et al., 2015; Couturier & Lock, 2006; Kaplan et  
5 al., 2009; & Kordy et al., 2002). The personal recovery framework for EDs provides a more  
6 holistic approach that prioritizes restoring the individual's general wellbeing rather than limiting  
7 recovery to a focus on symptom reduction (Bardone-Cone et al., 2010; Dawson et al., 2014a).  
8 This recovery model does not ignore the importance of clinical outcomes, but instead asks how  
9 individuals experience these outcomes in the context of a holistic notion of recovery and  
10 wellness. In this sense, it emphasizes an integrated perspective incorporating social,  
11 psychological, emotional, behavioral, and physical dimensions (Pettersen et al., 2016). Without  
12 individualized, experiential, and qualitative dimensions included in the construct of recovery,  
13 there is risk that individuals who are behaviorally symptom-free may continue to have negative  
14 thoughts and feelings about themselves that reduce quality of life and increase risk for symptom  
15 relapse over time (Keski-Rahkonen & Tozzi, 2005; Bardone-Cone et al., 2010). Understanding  
16 the key components that individuals with lived experience identify as essential to their personal  
17 recovery process can ultimately contribute to creating a standardized measure of factors  
18 facilitating recovery developed by and for people living with EDs. Such inclusion has the  
19 potential to help individuals and providers create conditions and opportunities to support  
20 personal wellness and long-term recovery outcomes.

21           To date, a limited body of research on personal recovery exists for EDs. A qualitative  
22 meta-synthesis focused exclusively on anorexia nervosa recovery identified themes of  
23 empowerment and self-reconciliation as key to positive change and recovery (Duncan et al.,

1 2015). Another systematic review (de Vos et al., 2017) analyzed data from eighteen studies with  
2 individuals who had recovered from EDs, finding that, according to individuals with lived  
3 experience, ED recovery went beyond remission of ED symptomatology to include elements of  
4 psychological well-being and self-adaptability/resilience, positive relationships, personal growth,  
5 decrease in ED behavior and cognition, and autonomy. While the de Vos et al. (2017) review  
6 explored recovery from the perspective of “recovered” individuals, our study expands on this  
7 work by incorporating views from people who identify as fully recovered as well as people still  
8 in the process of recovery, since many people continue to experience waxing and waning mental  
9 health symptoms whilst recovering a meaningful life. In this way, we explore personal recovery,  
10 which is self-determined, to support and expand upon the clinical recovery model. The rationale  
11 for this approach is aligned with the recovery movement and harm reduction approaches, which  
12 view recovery as a process where it is possible to achieve enhanced wellness even when clinical  
13 symptoms remain.

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

1 exploratory review aims to generate hypotheses and build theory for how to understand personal  
2 recovery for people living with an ED.

### 3 **Methods**

#### 4 **Search strategy and selection criteria**

5 We searched PsychINFO via EBSCO, Embase and Medline via Ovid, Medline via  
6 Pubmed CINAHL via EBSCO, EMCARE on June 10, 2019. The search terms included “eating  
7 disorder\*,” “anorexi\*,” “bulimi\*,” “binge eating,” “ednos,” “recover\*,” “semi-structured,”  
8 unstructured, informal, in-depth, “face-to-face,” “structured,” guide, interview\*, discussion,  
9 questionnaire\*, focus group\*, ethnograph\*, fieldwork, “field work,” “key informant” (see  
10 Appendix for search strategy example). Differences in the words search reflect differences in  
11 thesaurus terminology between databases.

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



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

5

## 6 **Procedure and analysis**

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

17           **Studies and participants included in the systematic review.** Database searching  
18 yielded 1,163, and after removing duplicates, 422 unique studies remained for screening (see  
19 Figure 1). The screening resulted in 79 full-text articles for eligibility. We included 20 studies in  
20 the thematic synthesis. The total sample size across studies was 351. As seen in Table 2, studies  
21 were conducted in 8 countries (UK, Australia, USA, Norway, Sweden, Scotland, Brazil, and  
22 France). All studies included male and female individuals who had been formally diagnosed with  
23 an ED and were in recovery or remission. Diagnoses included anorexia nervosa, bulimia nervosa,

1 binge eating disorder, and eating disorder not otherwise specified. Research methods included  
2 interviews, online questionnaires, online focus groups, online group sessions, and ED inpatient  
3 clinic application letters for data collection. The qualitative analyses in the studies included in  
4 the review utilized interpretive phenomenological analysis, qualitative content analysis, open-  
5 coding analysis, text-condensing analysis, the transtheoretical model, thematic analysis, and  
6 grounded theory methods.

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

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

19       Inductive thematic synthesis derived from the ED qualitative data resulted in a specific  
20 framework of personal recovery from EDs. Themes developed from codes are shown with their  
21 effect size (displayed in the key and numeric values in Table 3). Per the methodology outlined in  
22 de Vos et al. (2017), frequency effect size was calculated using the total number of studies  
23 containing the theme divided by the total number of studies. Intensity effect size, which indicates

1 the importance of these themes relative to each other, was calculated also using the de Vos et al.  
2 (2017) approach by dividing the number of found criteria related to the theme by the number of  
3 found criteria in all studies. This process yielded components that focus on the internal  
4 experience of the ED recovery process. We also included results related to eating and weight  
5 attitudes and behaviors to better understand the relationship of symptom recovery to the personal  
6 framework of recovery as a process. Because there were both positive and negative themes  
7 regarding the impact of this area on personal recovery, these are outlined separately at the end of  
8 the results section.

## 9 **Results**

### 10 **Characteristics of ED recovery**

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

### 14 **Conceptual framework for personal recovery from an ED**

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

20

21 *“The most helpful thing, I think, was seeing the social worker because she was really good at*  
22 *listening”* (Arthur-Cameselle & Quatromoni, 2014a)

23

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

3  
4           *“[My dad] just, was always, always there to listen... I knew he was going to love me no matter  
5 what”* (Arthur-Cameselle & Quatromoni, 2014a)

6  
7           Another sub-component of the supportive relationships theme is peer support, which  
8 encompasses the prior two sub-categories, but is its own theme due to its specific value to the  
9 individuals with a history of an ED. Participants indicated that support from others who shared  
10 similar experiences was beneficial in the form of encouragement or advice, which led to feeling  
11 understood, connected, less alone or isolated, and feeling part of a group.

12  
13           *“It is really good in terms of being able to hear how other people have gotten over the drive to  
14 exercise and how they have managed to eat certain foods”* (Smith et al., 2016)

15  
16           **Hope.** The theme of hope seemed critical to activate and facilitate recovery, driving the  
17 motivation for individuals to seek help and push through the difficulties. This theme was  
18 described as belief in recovery, encompassing believing in oneself, in others, and in a better  
19 future. Individuals describe the desire to live a life not dictated by the ED. Hope, in particular, is  
20 context-dependent, and is an evolving concept; it is experienced differently at each stage/ phase  
21 of recovery (i.e. early in recovery vs. the later phases).

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

4

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

9

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

12

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

20

21          *“I find it difficult to distinguish...what is me and what is the eating disorder...a lot of what my*  
22            *treatment has been is actually finding my own identity”* (Smith et al., 2016)

23

## A Framework to conceptualize personal recovery from EDs

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

5  
6           *“I think saying I am in recovery causes me to think more consciously about that process and stay  
7 aware of how I am feeling and thinking about myself... Saying I am in recovery kind of helps in  
8 the process of continuing on, growing as an individual, and choosing to make decisions that are  
9 positive and life giving”* (Bowlby et al., 2015)

10

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

15

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

19

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

23

1 *“Figuring out that there are some things in life worth more than clinging to an eating disorder”*

2 (Arthur-Cameselle & Quatromoni, 2014b)

3

4 **Empowerment.** Empowerment consists of taking responsibility and control leading to

5 confidence, agency and resilience. Taking responsibility and control is described as the

6 newfound sense of independence and autonomy both in the individual’s life and in recovery.

7 Persons with an ED describe regaining control over their lives and their future while also

8 acknowledging the importance of self-help, self-determination, and self-direction for recovery.

9

10 *“In order to get out of it, I had to decide to do it and also decide on the path to take... Nobody*

11 *else was going to do it for me”*; *“It was something I had to make a choice to do, and I made that*

12 *choice because I didn’t want to be a prisoner anymore”* (Dawson et al., 2014)

13

14 Self-empowerment and resilience characterize the individuals’ descriptions of focusing

15 on their own strengths and learning to recognize their own value such that they have the ability

16 to assert themselves and stand up for themselves.

17

18 *“I have gradually learnt to use my strength and my resources in a right way”* (Pettersen et al.,

19 2016)

20

21 **Self-compassion.** The final component of recovery that was repeatedly identified and

22 coded from the data is self-compassion. This is centered on the way one relates to oneself.

23 Individuals learn to be aware, acknowledge, accept, and be kind to themselves through

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1 strengthening their self-care skills and capacities. This component is comprised of self-kindness,  
2 acceptance of self, and honoring emotional experiences. Self-kindness is described as learning  
3 self-care practices, feeling more connected to oneself, nurturing oneself, and gaining self-  
4 awareness. Self-kindness and self-love may wax and wane throughout the recovery journey.

5  
6 *“Part of recovery is to know yourself and to develop emotional intelligence around yourself and*  
7 *others, such as learning to take care of yourself, how you cope with stress, how you deal with*  
8 *anger... It is learning to love your body and loving what it does for you; taking care of it and*  
9 *really loving yourself. It is learning to really love yourself with all your imperfections; not*  
10 *expecting yourself to be perfect and knowing you are not supposed to be”* (Bowlby et al., 2015)

11  
12 Acceptance of self is described as the idea of common humanity, recognizing that  
13 everyone struggles, and that it is okay to not be perfect. People described the process of learning  
14 to accept themselves as they are as critical aspect to recovery.

15  
16 *“I really gained self-respect back and everything just fell into place”* (Arthur-Cameselle &  
17 Quatromoni, 2014a)

18  
19 Honoring one’s emotional experience is accomplished by applying mindfulness skills.  
20 Some participants described their ED as a way to numb the discomfort of one’s daily life. By  
21 tuning into needs and emotional weather, individuals can sense, experience, and express their  
22 emotions—negative or positive—in a helpful, rather than self-destructive, manner.

23



1        *“I think the greatest thing I have learned is that being a really sensitive person is not a bad*  
2 *thing and that it is actually a great thing to be a sensitive person. I think it is a great thing that I*  
3 *cry easily. I grew up thinking that was such a bad thing and that there was something wrong*  
4 *with me because I was so sensitive. Being able to embrace that was so important to my recovery*  
5 *because it was so much of who I was”* (Bowlby et al., 2015)

6  
7        **Improvement in eating and weight behaviors and attitudes.** Improvement in eating  
8 behaviors and attitudes toward weight emerged as relevant to recovery but was not a primary  
9 component of the recovery process. Instead, as individuals reflected on their own recovery  
10 process, eating and weight concerns and behaviors were incorporated as means to achieve a life  
11 characterized by a dynamic state of recovery, rather than the sole end of recovery.

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

14  
15        *“I care about what I eat, and I work out, but not in the same way. [...] It is not working out in*  
16 *order to be able to eat, but it is rather eating so that I can work out. [...] When I’m training, my*  
17 *thoughts are not set on ‘I want to lose weight’ but I work out for my own sake because I enjoy*  
18 *it.”* (Lindstedt et al., 2018)

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

23

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

4  
5        Still, there was conflicting information identified on whether improved eating and weight  
6        behaviors actually led to overall personal recovery. Some individuals noted that an over-focus on  
7        eating and weight behaviors ignored the psychological aspects of their recovery, which they  
8        found detrimental rather than supportive. Others emphasized that improved eating and weight  
9        were markers of recovery but were not identified as the most important aspects of their personal  
10       recovery. Instead, these elements were part of a holistic process that emphasized the other  
11       components of recovery identified above.

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

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

## 17       **Effect Sizes**

18       In examining frequency effect sizes (see Table 3), connectedness and sense of belonging  
19       (85%), belief in recovery (85%), de-identification from ED (80%), support and encouragement  
20       from others (75%), and acceptance of self (70%) consistently and frequently appeared  
21       throughout most of the studies. Looking at the intensity effect sizes (see Table 3), which measure  
22       how essential criteria are when compared to each other, support and encouragement from others  
23       (17%), belief in recovery (15.7%), de-identification from ED (15.1%), and connectedness and

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1 sense of belonging (13.4%) have the most notable intensity effect sizes. While intensity sizes for  
2 the subthemes were low due to the large number of quotes that were analyzed, they are still  
3 useful for understanding the relative ranking of the various subthemes. The frequency effect size  
4 for eating and weight behaviors and attitudes was 50%, although this included both positive and  
5 negative references of the impact of eating and weight behaviors on recovery. Because of this,  
6 we could not calculate the intensity size and did not include eating and weight behaviors and  
7 attitudes as a component of recovery in the framework.

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

### **Discussion**

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

20         The conceptual framework that we derived outlines six key components of personal  
21 recovery from EDs that were consistently found across studies reviewed: supportive  
22 relationships, hope, identity, meaning and purpose, empowerment, and self-compassion. In  
23 addition, the framework recognizes the importance of individuals with lived experience's

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1 perception of improved symptom recovery—identified as eating and weight improvement—on  
2 these key components and overall personal recovery. These improvements are seen by those with  
3 lived ED experience as means to reach overall goals for personal recovery, rather than recovery  
4 itself. Our study suggests future research on potential connections for the personal recovery  
5 model to better integrate relevant components of clinical constructs of recovery.

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

11         The six dimensions that we identify are closely related to the CHIME and SAMHSA  
12 frameworks, however our approach gives prominence to the construct of self-compassion. An  
13 explicit focus on this dimension will be important to effectively describe and guide ED recovery.  
14 Similarly, our approach shares many commonalities with the de Vos et al. (2017) literature  
15 review (which included 4 of the same studies that we used), in particular with regards to the  
16 themes of supportive relationships and empowerment. There were, however, some nuanced  
17 differences as we expanded on the work of de Vos et al. (2017) by including more experiential  
18 themes, such as hope, meaning and purpose, and identity (especially the de-identification with  
19 the ED subtheme) as well as expanding the theme of self-compassion beyond the notion of self-  
20 acceptance and analyzing perceptions of weight and eating behaviors among individuals with  
21 lived experience.

22         Together, the six dimensions in the ED personal recovery framework are proposed for  
23 understanding the specific experience of recovery from EDs as they provide a conceptual

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

16 It is important to note that this study does not aim to negate the importance of clinical  
17 recovery for individuals living with eating disorders. Eating disorders have a clear definition for  
18 symptomatic improvement, and we must be able to distinguish individuals who self-identify as  
19 recovered or in recovery while still poorly functional. In fact, our inclusion of eating and weight  
20 attitudes and behaviors in data analysis reflects that individuals with lived experience also  
21 recognize the importance of this aspect of recovery. Our findings illustrate that current studies  
22 are not invalid in their assessment of a patient as “recovered” once he or she reaches objective  
23 measure of clinical improvement, but instead they are incomplete. Using the six dimensions of

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1 the ED personal recovery framework from this study, future research should create a  
2 measurement tool that characterizes the lived experience of recovery to augment clinical  
3 measurement tools to better capture all dimensions of recovery and help guide treatment and  
4 approaches to support positive wellness outcomes. Additional research in this area could also  
5 expand upon the supportive relationships dimension of this framework to include the  
6 perspectives of close family and friends of individuals with eating disorders on their definitions  
7 of their loved one's recovery.

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

1 sample was comprised mainly of female participants, so future research should pay particular  
2 attention to the issues of culture and gender.

### 3 **Conclusion**

4 This systematic review aimed to understand the perspectives of those with lived  
5 experience of ED recovery to develop a personal recovery framework outlining their key  
6 components of recovery. Six superordinate themes of supportive relationships, hope, identity,  
7 meaning and purpose, empowerment, and self-compassion were identified. According to those  
8 with lived experience, these constructs represent essential person-centered components of the  
9 experience of recovery from an ED. This study contributes to the increased focus on person-  
10 centered and self-defined understanding of recovery in mental health services. It specifically  
11 provides a framework for ED recovery that expands on clinical thinking and offers a holistic  
12 perspective on the components of personal recovery from EDs beyond objective symptomatic  
13 improvements. The terms “lived experience” and “person-centered” are relatively new to the  
14 discourse on recovery. With the evolution of person-centered recovery approaches, which  
15 recognizes people with lived-experience as experts in their own recovery, mental health  
16 practitioners can reciprocally work with people to understand, live with, and manage EDs while  
17 pursuing a life filled with hope, meaning, and (re)creating a positive and accepting sense of self.

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### 19 **Data Use Statement**

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

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6 consultation on systematic review methodology. Funding to support this project was provided by  
7 the Cordeiro Summer Research Fellowship at Harvard University to Sara Wetzler.

8  
9 **Conflicts of Interest**

10 The authors declare no conflicts of interest.

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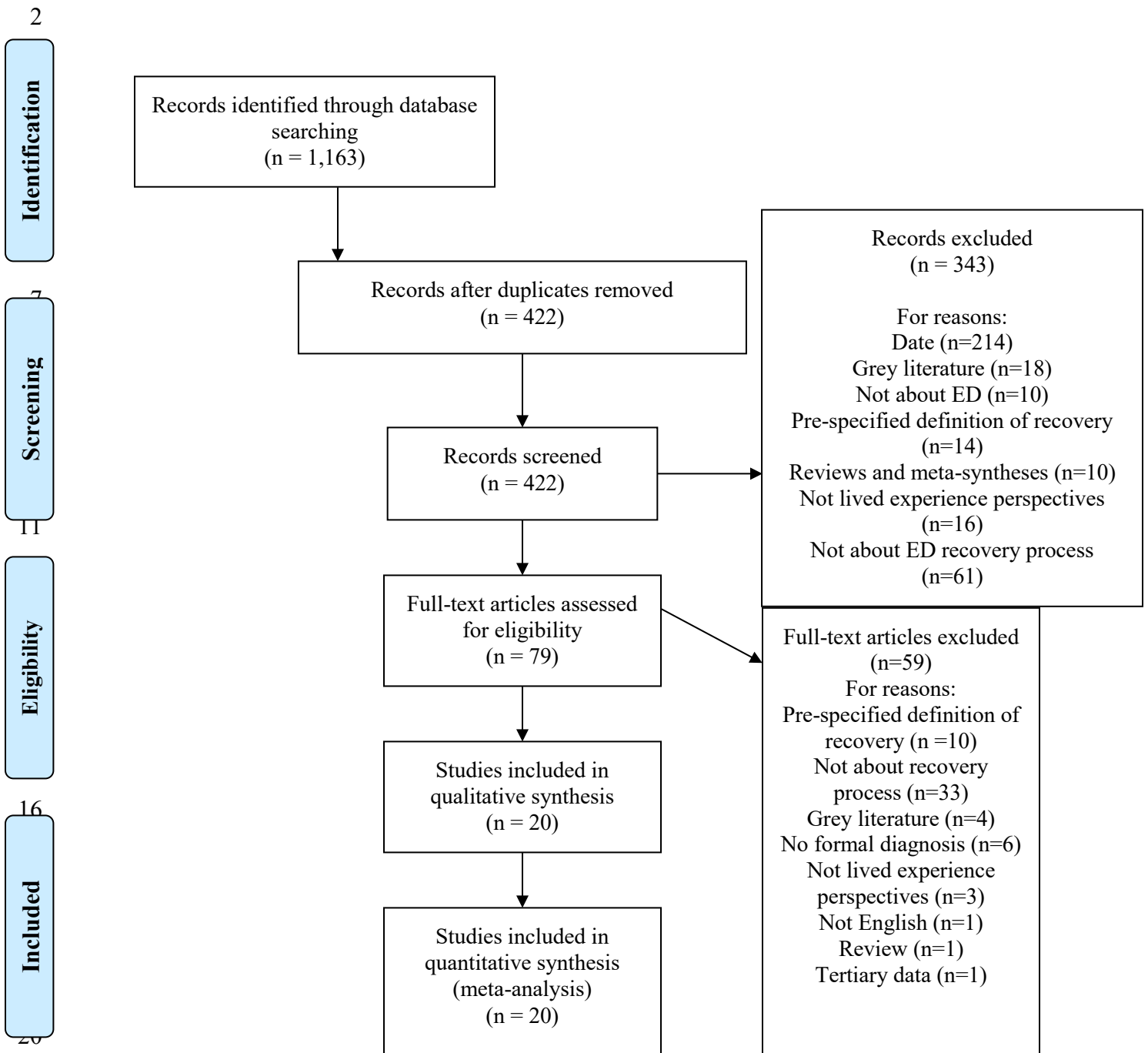
1 **Table 1: CHIME and SAMHSA Recovery Models**

<b>CHIME</b>	<b>SAMHSA</b>
<p>5 Categories for Recovery Processes:</p> <ul style="list-style-type: none"> <li>- Connectedness</li> <li>- Hope and optimism about the future</li> <li>- Identity</li> <li>- Meaning in life</li> <li>- Empowerment</li> </ul>	<p>4 dimensions:</p> <ul style="list-style-type: none"> <li>- Home</li> <li>- Community</li> <li>- Purpose</li> <li>- Health</li> </ul> <p>10 principles of Recovery</p> <ul style="list-style-type: none"> <li>- Emerges from hope</li> <li>- Person-driven</li> <li>- Occurs via many pathways</li> <li>- Holistic</li> <li>- Supported by peers and allies</li> <li>- Supported through relationships and social networks</li> <li>- Culturally based and influenced</li> <li>- Supported by addressing trauma</li> <li>- Involves individual family and community strengths and responsibility</li> <li>- Based on respect</li> </ul>

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1 Figure 1: Prisma Flow Diagram



**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 J.N., & Quatromoni P.A. (2014a). A qualitative analysis of female collegiate athletes' eating disorder recovery experiences. <i>Sport Psychologist</i> , 28(4), 334–346.	US	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, J. N., & Quatromoni, P. A. (2014b). Eating disorders in collegiate female athletes: factors that assist recovery. <i>Eating Disorders</i> , 22(1), 50–	US	47, females	AN (n=16), BN (n=7), EDNOS (specifically BED, n=4), or two or	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	61

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61. <a href="https://doi.org/10.1080/10640266.2014.857518">https://doi.org/10.1080/10640266.2014.857518</a>			more of the three (n=20)				<p>coping mechanisms/ distractions; avoid triggers</p> <p>Importance of others: support from peers and family; professional support; empathizing, confrontation;</p> <p>External factors: change in environment, hiding, medication</p>	
Bowlby, C. G., Anderson, T. L., Hall, M. E. L., & Willingham, M. M. (2015). Recovered professionals exploring eating disorder recovery: A qualitative investigation of meaning. <i>Clinical Social Work Journal</i> , 43(1), 1–10. <a href="https://doi.org/10.1007/s10615-012-0423-0">https://doi.org/10.1007/s10615-012-0423-0</a>	US	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	<p>Recovery process is nonlinear; comprehensive; life-long</p> <p>Involves changing attitude towards self; de-identification with illness; developing a sense of purpose; fostering meaningful relationships</p>	94
Dawson, L., Rhodes, P., & Touyz, S. (2014b). “Doing	Australia	8, females	Chronic AN (n=8)	Process of recovery	Interview	Narrative Inquiry	Phases of recovery include unready	127

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the Impossible”: The Process of Recovery From Chronic Anorexia Nervosa. Qualitative Health Research, 24(4), 494-505.				from chronic AN from participants who fully recovered			and/or unable to change; tipping point to change; active pursuit of recovery; reflection and rehab	
Espíndola CR, & Blay SL. (2013). Long Term Remission of Anorexia Nervosa: Factors Involved in the Outcome of Female Patients. PLoS ONE 8(2): e56275. doi:10.1371/journal.pone.0056275	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, K. S., Nordbø, R. H. S., Espeset, E. M. S., Skårderud, F., & Holte, A.	Norway	34, females	AN (n=34)	Experience of women	Interview	Open-thematic coding	Importance of health care professionals	48

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(2015). The process of help-seeking in anorexia nervosa: Patients' perspective of first contact with health services. <i>Eating Disorders: The Journal of Treatment &amp; Prevention</i> , 23(3), 206–222. <a href="https://doi.org/10.1080/10640266.2014.981429">https://doi.org/10.1080/10640266.2014.981429</a>				with AN's first contact with treatment			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	
Hannon J., Eunson L., & Munro C. (2017). The patient experience of illness, treatment, and change, during intensive community treatment for severe anorexia nervosa. <i>Eating Disorders</i> , 25(4), 279–296.	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 B.-M., Enmark A., Bohman A., & Lundström M. (2015). A qualitative study of young women's	Sweden	5, females	BN (n=5)	Recovery from bulimia from	Interview	Qualitative content analysis	Common themes: feeling stuck in the ED (linked with identity,	67

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<p>experiences of recovery from bulimia nervosa. <i>Journal of Advanced Nursing</i>, 71(4), 860–869. <a href="https://doi.org/10.1111/jan.12554">https://doi.org/10.1111/jan.12554</a></p>				<p>young adult women's experiences</p>			<p>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</p>	
<p>Lindstedt, K., Neander, K., Kjellin, L., &amp; Gustafsson, S. A. (2018). A life put on hold: adolescents' experiences of having an eating disorder in relation to social contexts outside the family. <i>Journal of Multidisciplinary Healthcare</i>, 11, 425–437.</p>	<p>Sweden</p>	<p>15, females (14) and male (1)</p>	<p>EDs with restrictive symptomatology</p>	<p>Explore experience of adolescents with EDs (restrictive symptomatology)</p>	<p>Interview</p>	<p>Thematic analysis</p>	<p>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</p>	<p>74</p>
<p>McNamara, N., &amp; Parsons, H. (2016). "Everyone here wants everyone else to get better": The role of social</p>	<p>UK</p>	<p>75, females and males</p>	<p>BED (32%), BN (28%), AN (20%), AN</p>	<p>Role of social interactions within a</p>	<p>Online group session</p>	<p>Theoretically-guided</p>	<p>Main themes: importance of identity in EDs; importance of</p>	<p>123</p>

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<p>identity in eating disorder recovery. <i>The British Journal of Social Psychology</i>, 55(4), 662–680. <a href="https://doi.org/10.1111/bjso.12161">https://doi.org/10.1111/bjso.12161</a></p>			<p>and BN (20%)</p>	<p>group can promote ED recovery</p>		<p>thematic analysis</p>	<p>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</p>	
<p>Mitrofan O., Ford T., Byford S., Nicholls D., Petkova H., Kelly J., &amp; Edwards E. (2017). Care experiences of young people with eating disorders and their parents: A qualitative study. <i>The Lancet</i>, 389 <a href="https://doi.org/10.1016/S0140-6736(17)30466-X">https://doi.org/10.1016/S0140-6736(17)30466-X</a></p>	<p>UK</p>	<p>19, females; 11 parents</p>	<p>AN (n=12), AN and BN (n=3), Other/atypical ED (n=2), all 3 (=1)</p>	<p>Young people's and parents' views of care for EDs</p>	<p>Online focus group</p>	<p>Thematic analysis</p>	<p>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 towards patients and families at all</p>	<p>65</p>



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							levels of care; enhance peer and family support	
Petry N., Vasconcelos F.A.G., & Costa L.D.C.F. (2017). Feelings and perceptions of women recovering from anorexia nervosa regarding their eating behavior. <i>Cadernos de Saude Publica</i> , 33(9).	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, G., Thune-Larsen, K.-B., Wynn, R., & Rosenvinge, J. H. (2013). Eating disorders: challenges in the later phases of the recovery process. <i>Scandinavian Journal of Caring Sciences</i> , 27(1), 92–98. <a href="https://doi.org/10.1111/j.1471-6712.2012.01006.x">https://doi.org/10.1111/j.1471-6712.2012.01006.x</a>	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	22

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							social skills, and coping with grief	
<p>Pettersen, G., Wallin, K., &amp; Björk, T. (2016). How do males recover from eating disorders? An interview study. <i>BMJ Open</i>, 6(8). <a href="https://doi.org/10.1136/bmjopen-2015-010760">https://doi.org/10.1136/bmjopen-2015-010760</a></p>	Norway and Sweden	15, male	AN (n=10), BN (n=4), EDNOS (n=1), DOI varied 3-25 yrs	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
<p>Piot M.-A., Gueguen, J., Michelet, D., Orri, M., Köenig, M., Corcos, M., Cadwallader, J.-S., &amp; Godart, N. (2019). Personal recovery of young adults with severe anorexia nervosa during adolescence: a case series. <i>Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity</i> <a href="https://doi.org/10.1007/s40519-019-00696-7">https://doi.org/10.1007/s40519-019-00696-7</a></p>	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	<p>Recovery in four stages: corseted; vulnerable; plastic; playful</p> <p>Seven dimensions: struggle and path of initiation; work on oneself; self-determination and help; body; family; connectedness; timeline</p> <p>Additional features to recovery process:</p>	206

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							<p>bodily well-being and pleasure of body;                      stigmatization;                      role of group;                      relation to time;                      importance of narratives</p> <p>AN recovery process includes many tipping points</p>	
Seed T, Fox J, & Berry K. (2016). Experiences of Detention under the Mental Health Act for Adults with Anorexia Nervosa. <i>Clinical Psychology &amp; Psychotherapy</i> , 23(4), 352–362.	UK	12, females	AN (n=12)	Experience of detention under Mental Health Act for AN	Interview	Grounded theory	<p>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</p>	17

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							challenged to be independent; the anorexic self-sustained increased risk of relapse	
Smith V., Chouliara Z., Morris P.G., Collin P., Power K., Yellowlees A., ... Cook M. (2016). The experience of specialist inpatient treatment for anorexia nervosa: A qualitative study from adult patients' perspectives. <i>Journal of Health Psychology, 21(1)</i> , 16–27.	UK	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
Strand, M., Bulik, C. M., von Hausswolff-Juhlin, Y., & Gustafsson, S. A. (2016). Self-admission to inpatient treatment for patients with anorexia nervosa: The patient's perspective. <i>The International Journal of Eating Disorders, 50(4)</i> , 398–405	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	151

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							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	
Venturo-Conerly K., Wasil A., Shingleton R., & Weisz J. (2019). Recovery as an “Act of rebellion”: a qualitative study examining feminism as a motivating factor in eating disorder recovery. <i>Eating Disorders</i> .	US	13, females	Doesn't 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

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<p>Woerner J., King R., &amp; Costa B. (2016). Development of readiness to change and self-efficacy in anorexia nervosa clients: Personal perspectives. <i>Advances in Eating Disorders: Theory, Research and Practice</i>, 4(1), 99–111.</p>	<p>Australia</p>	<p>15, females</p>	<p>AN (n=15)</p>	<p>Readiness to change and self-efficacy as it relates to symptom dimensions of AN</p>	<p>Questionnaire and interview</p>	<p>Transtheoretical model (TTM)</p>	<p>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</p>	<p>23</p>
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**Table 3: ED Personal Recovery Framework – Components of recovery processes**

<b>Theme</b>	<b>Frequency Effect Size</b>	<b>Intensity Effect Size</b>
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%

## References

- Andresen, R., Oades, L. & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586–594.
- Anthony, WA. (2000). A recovery-oriented service system: setting some system level standards. *Psychiatric Rehabilitation Journal*, 24(2000), 159-169.
- Arthur-Cameselle, J. N., & Quatromoni, P. A. (2014a). A qualitative analysis of female collegiate athletes' eating disorder recovery experiences. *Sport Psychologist*, 28(4), 334–346.
- Arthur-Cameselle, J. N., & Quatromoni, P. A. (2014b). Eating disorders in collegiate female athletes: factors that assist recovery. *Eating Disorders*, 22(1), 50–61.  
<https://doi.org/10.1080/10640266.2014.857518>
- Bardone-Cone, A. M., Harney, M. B., Maldonado, C. R., Lawson, M. A., Robinson, D. P., Smith, R., & Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualization, validation, and examination of psychosocial functioning and psychiatric comorbidity. *Behaviour Research and Therapy*, 48(3), 194–202.  
<https://doi.org/10.1016/j.brat.2009.11.001>
- Bowlby, C. G., Anderson, T. L., Hall, M. E. L., & Willingham, M. M. (2015). Recovered professionals exploring eating disorder recovery: A qualitative investigation of meaning. *Clinical Social Work Journal*, 43(1), 1–10. <https://doi.org/10.1007/s10615-012-0423-0>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.



## A Framework to conceptualize personal recovery from EDs

Couturier, J., & Lock, J. (2006). What is recovery in adolescent anorexia nervosa? *International Journal of Eating Disorders*, 39(7), 550-555.

Critical Appraisal Skills Programme (2013). CASP Qualitative Checklist. [online] Available from: [www.casp-uk.net](http://www.casp-uk.net).

Davidson, L. (2016). The Recovery Movement: Implications For Mental Health Care And Enabling People To Participate Fully In Life. *Health Affairs*, 35(6), 1091–1097.  
<https://doi.org/10.1377/hlthaff.2016.0153>

Dawson, L., Rhodes, P., & Touyz, S. (2014a). The recovery model and anorexia nervosa. *Australian and New Zealand Journal of Psychiatry*, 48(11), 1009–1016.

Dawson, L., Rhodes, P., & Touyz, S. (2014b). “Doing the Impossible”: The Process of Recovery From Chronic Anorexia Nervosa. *Qualitative Health Research*, 24(4), 494-505.

de Vos, J. A., LaMarre, A., Radstaak, M., Bijkerk, C. A., Bohlmeijer, E. T., & Westerhof, G. J. (2017). Identifying fundamental criteria for eating disorder recovery: A systematic review and qualitative meta-analysis. *Journal of Eating Disorders*, 5(1), 34.  
<https://doi.org/10.1186/s40337-017-0164-0>

Duncan, T. K., Sebar, B., & Lee, J. (2015). Reclamation of power and self: A meta-synthesis exploring the process of recovery from anorexia nervosa. *Advances in Eating Disorders: Theory, Research and Practice*, 3(2), 177–190.

Espíndola, C. R., & Blay, S. L. (2013). Long Term Remission of Anorexia Nervosa: Factors Involved in the Outcome of Female Patients. *PLoS ONE* 8(2): e56275.  
doi:10.1371/journal.pone.0056275

Fairburn, C. G., & Harrison, P. J. (2003). Eating disorders. *The Lancet*, 361(9355), 407–416.  
[https://doi.org/10.1016/S0140-6736\(03\)12378-1](https://doi.org/10.1016/S0140-6736(03)12378-1)

## A Framework to conceptualize personal recovery from EDs

- Franko, D., Tabri, N., Keshaviah, A., Murray, H., Herzog, D., Thomas, J., Coniglio, K., Keel, P., & Eddy, K. (2018). Predictors of long-term recovery in anorexia nervosa and bulimia nervosa: Data from a 22-year longitudinal study. *Journal of Psychiatric Research*, 96, 183-188.
- Gulliksen, K., Nordbø, R., Espeset, E., Skårderud, F., & Holte, A. (2014). The Process of Help-Seeking in Anorexia Nervosa: Patients' Perspective of First Contact With Health Services. *Eating Disorders*, 23(3), 1-17.
- Hannon J., Eunson L., & Munro C. (2017). The patient experience of illness, treatment, and change, during intensive community treatment for severe anorexia nervosa. *Eating Disorders*, 25(4), 279–296.
- Jacobsen, N. & Greeley, D. (2001). What is recovery? A conceptual model and explanation. *Psychiatric Services*, 52(4): 482-485.
- Jenkins, J., & Ogden, J. (2012). Becoming “whole” again: a qualitative study of women’s views of recovering from anorexia nervosa. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, 20(1), e23.
- Kaplan, A., Walsh, B., Olmsted, M., Attia, E., Carter, J., Devlin, M., Pike, K., Woodside, B., Rockert, W., Roberto, C., & Parides, M. (2009). The slippery slope: Prediction of successful weight maintenance in anorexia nervosa. *Psychological Medicine*, 39(6), 1037-1045. doi:10.1017/S003329170800442X
- Keski-Rahkonen, A., & Tozzi, F. (2005). The process of recovery in eating disorder sufferers' own words: An Internet-based study. *International Journal of Eating Disorders*, 37(S1), S80–S86. <https://doi.org/10.1002/eat.20123>

## A Framework to conceptualize personal recovery from EDs

- Kordy, H., Krämer, B., Palmer, R., Papezova, H., Pellett, J., Richard, M., & Tressure, J. (2002). Remission, recovery, relapse, and recurrence in eating disorders: Conceptualization and illustration of a validation strategy. *Journal of Clinical Psychology, 58*(7), 833-846.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *The British Journal of Psychiatry: The Journal of Mental Science, 199*(6), 445-452.
- Lindgren B. M., Enmark, A., Bohman, A., & Lundström, M. (2015). A qualitative study of young women's experiences of recovery from bulimia nervosa. *Journal of Advanced Nursing, 71*(4), 860–869. <https://doi.org/10.1111/jan.12554>
- Lindstedt, K., Neander, K., Kjellin, L., & Gustafsson, S. A. (2018). A life put on hold: adolescents' experiences of having an eating disorder in relation to social contexts outside the family. *Journal of Multidisciplinary Healthcare, 11*, 425–437.
- Lock, J., Agras, W., Grange, D., Couturier, J., Safer, D., & Bryson, S. (2013). Do end of treatment assessments predict outcome at follow-up in eating disorders? *International Journal of Eating Disorders, 46*(8), 771-778.
- McNamara, N., & Parsons, H. (2016). “Everyone here wants everyone else to get better”: The role of social identity in eating disorder recovery. *The British Journal of Social Psychology, 55*(4), 662–680. <https://doi.org/10.1111/bjso.12161>
- Mitrofan, O., Ford, T., Byford, S., Nicholls, D., Petkova, H., Kelly, J., & Edwards, E. (2017). Care experiences of young people with eating disorders and their parents: A qualitative study. *The Lancet, 389*. [https://doi.org/10.1016/S0140-6736\(17\)30466-X](https://doi.org/10.1016/S0140-6736(17)30466-X)
- NIMH. (2018). *Eating Disorders: About More Than Food*[Brochure]. Author. Retrieved July 8, 2019, from <https://www.nimh.nih.gov/health/publications/eating-disorders/index.shtml>

## A Framework to conceptualize personal recovery from EDs

- Petry, N., Vasconcelos, F.A.G., & Costa, L. D. C. F. (2017). Feelings and perceptions of women recovering from anorexia nervosa regarding their eating behavior. *Cadernos de Saude Publica*, 33(9).
- Pettersen, G., Thune-Larsen, K. B., Wynn, R., & Rosenvinge, J. H. (2013). Eating disorders: challenges in the later phases of the recovery process. *Scandinavian Journal of Caring Sciences*, 27(1), 92–98. <https://doi.org/10.1111/j.1471-6712.2012.01006.x>
- Pettersen, G., Wallin, K., & Björk, T. (2016). How do males recover from eating disorders? An interview study. *BMJ Open*, 6(8). <https://doi.org/10.1136/bmjopen-2015-010760>
- Pike, K., Gianini, L., Loeb, K., & Le Grange, D. (2015). Treatments for Eating Disorders In Peter Nathan & Jack Gorman *A guide to treatments that work* (Fourth ed.). Oxford; New York: Oxford University Press
- Piot, M. A., Gueguen, J., Michelet, D., Orri, M., Köenig, M., Corcos, M., Cadwallader, J.S., & Godart, N. (2019). Personal recovery of young adults with severe anorexia nervosa during adolescence: a case series. *Eating and Weight Disorders*. <https://doi.org/10.1007/s40519-019-00696-7>
- Reisner, A. D. (2005). The common factors, empirically validated treatments, and recovery model of therapeutic change. *The Psychological Record*, 55, 377–399.
- Resnick S. G., Fontana, A., Lehman, A.F., and Rosenheck, R.A. An empirical conceptualization of the recovery orientation (2005). *Schizophrenia Research*, 1(1), 119-128.

## A Framework to conceptualize personal recovery from EDs

SAMHSA. (2005). *National consensus statement on behavioral health recovery*. Rockville, MD:

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Seed, T., Fox, J., & Berry, K. (2016). Experiences of Detention under the Mental Health Act for Adults with Anorexia Nervosa. *Clinical Psychology & Psychotherapy*, 23(4), 352–362.

Smith, V., Chouliara, Z., Morris, P., Collin, P., Power, K., Yellowlees, A., Grierson, D., Papageorgiou, E., & Cook, M. (2016). The experience of specialist inpatient treatment for anorexia nervosa: A qualitative study from adult patients' perspectives. *Journal of Health Psychology*, 21(1), 16–27.

Strand, M., Bulik, C. M., von Hausswolff-Juhlin, Y., & Gustafsson, S. A. (2017). Self-admission to inpatient treatment for patients with anorexia nervosa: The patient's perspective. *The International Journal of Eating Disorders*, 50(4), 398–405

Steinhausen, H. (2002). The Outcome of Anorexia Nervosa in the 20th Century. *American Journal of Psychiatry*, 159(8), 1284-1293.

Steinhausen, H., & Weber, S. (2009). The Outcome of Bulimia Nervosa: Findings From One-Quarter Century of Research. *American Journal of Psychiatry*, 166(12), 1331-1341.

Van Furth, E., Van Der Meer, A., & Cowan, K. (2016). Top 10 research priorities for eating disorders. *The Lancet Psychiatry*, 3(8), 706-707.

van Weeghel, J., van Zelst, C., Boertien, D., & Hasson-Ohayon, I. (2019). Conceptualizations, assessments, and implications of personal recovery in mental illness: A scoping review of systematic reviews and meta-analyses. *Psychiatric Rehabilitation Journal*, 42(2), 169–181. <https://doi.org/10.1037/prj0000356>

## A Framework to conceptualize personal recovery from EDs

Venturo-Conerly, K., Wasil, A., Shingleton, R., & Weisz, J. (2019). Recovery as an “Act of rebellion”: a qualitative study examining feminism as a motivating factor in eating disorder recovery. *Eating Disorders*.

Walsh, B., Kaplan, A., Attia, E., Olmsted, M., Parides, M., Carter, J., Pike, K., Devlin, M., Woodside, B., Roberto, C., & Rockert W. (2007). Fluoxetine after weight restoration in anorexia nervosa: A randomized controlled trial. *Jama-Journal of The American Medical Association*, 298(17), 2008.

Woerner, J., King, R., & Costa, B. (2016). Development of readiness to change and self-efficacy in anorexia nervosa clients: Personal perspectives. *Advances in Eating Disorders: Theory, Research and Practice*, 4(1), 99–111.

World Health Organization. (2018). *International statistical classification of diseases and related health problems* (11th Revision). Retrieved from <https://icd.who.int/browse11/l-m/en>