1 2 3 4 5 6 7 A framework to conceptualize personal recovery from eating disorders: A systematic review and qualitative meta-synthesis of perspectives from individuals with lived 8 9 experience 10 11 Authors: Sara Wetzler¹, Corinna Hackmann^{2,3}, Guy Peryer^{3,4}, Kelsey Clayman,⁵ Donna 12 Friedman, Kristina Saffran, Jody Silver, Margaret Swarbrick, Elizabeth Magill¹², Eric F. van 13 Furth^{10,11}, and Kathleen M. Pike¹² 14 15 Manuscript Word count: 5,300 16 17 18

¹ Harvard University

²Research and Development Department, Norfolk and Suffolk Foundation Trust, UK

³ University of East Anglia, Norfolk, UK

⁴ St. Nicholas Hospice Care, Suffolk, UK

⁵ Columbia University Vagelos College of Physicians & Surgeons

⁶ Project Heal

⁷ Project Heal

⁸ Collaborative Support Programs of New Jersey

⁹ Collaborative Support Programs of New Jersey; Rutgers Health University Behavioral Health Care

¹⁰ Leiden University Medical Center, Leiden, the Netherlands

¹¹ Rivierduinen Eating Disorders Ursula, Leiden, the Netherlands

¹² Global Mental Health WHO Collaborating Centre at Columbia University Irving Medical Center

1 Abstract 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-

22 Keywords: Eating disorders, Recovery, Framework, Meta-analysis, Qualitative research,

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

23 Systematic review

recovery from an ED.

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Abstract Word Count: 240

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3 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 (WHO ICD-11, 2019). Living with an ED can affect many aspects of quality of life and wellbeing, including sense of self, relationships, and occupational functioning (Jenkins et al., 2011). 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 symptomfocused recovery delineates objective indices from the clinician's perspective, often involving symptom improvement (remission) or cure and therapeutic responses (Jacobsen & Greenley, 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

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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 personal recovery orientation as led by the recovery movement has become an essential 11 framework for behavioral health care policy, practice, and research in most industrialized 12 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: Connectedness; Hope and optimism 20 about the future; Identity; 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,

process whereby recovery is an ongoing life orientation of engagement in behaviors and attitudes

which incorporates the difficulties of living with and managing a mental health condition (i.e.

trauma, victimization, stigma, negative life changes).

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support providers and families.

A similar model was developed by the US Substance Abuse and Mental Health Services Administration (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 ten 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 et al., 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

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The clinical symptom ED recovery framework focuses predominantly on treatment response related to weight status, regular menstruation, and behavioral criteria, i.e. lack of bingeing and purging symptoms or absence of restrictive eating patterns (Couturier & Lock, 2006; Kaplan et al., 2009; Lock et al., 2013; Pike et al., 2015; Couturier & Lock, 2006; Kaplan et al., 2009; & Kordy et al., 2002). 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 et al., 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 (Keski-Rahkonen & Tozzi, 2005; Bardone-Cone et al., 2010). 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 et al.,

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2015). Another systematic review (de Vos et al., 2017) analyzed data from eighteen 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 whilst 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

1 exploratory review aims to generate hypotheses and build theory for how to understand personal

recovery for people living with an ED.

3 Methods

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" (see Appendix for search strategy example). 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 were 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 five 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).

Procedure and analysis

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 Program 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%)

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 8 countries (UK, Australia, USA, 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,

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 minimize bias. 12 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 framework of personal recovery from EDs. Themes developed from codes are shown with their 20 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	

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).
22	

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 contingen
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 distinguishwhat is me and what is the eating disordera lot of what my
22	treatment has been is actually finding my own identity" (Smith et al., 2016)
23	

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.
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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

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	

"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)
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.

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. "[Even after gaining weight] I want to get better, but I still have the negative thoughts...it is still 12 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) 16 **Effect Sizes** 17 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

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.

12 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 1 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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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 eating disorders. Eating disorders 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

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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 eating disorders 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, i.e. 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 eating disorder 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

21 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

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

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

3 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.

Data Use 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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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

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CHIME	SAMHSA					
5 Categories for Recovery Processes:	4 dimensions:					
- Connectedness	- Home					
 Hope and optimism about the future 	- Community					
- Identity	- Purpose					
- Meaning in life	- Health					
- Empowerment	10 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					

1 Figure 1: Prisma Flow Diagram

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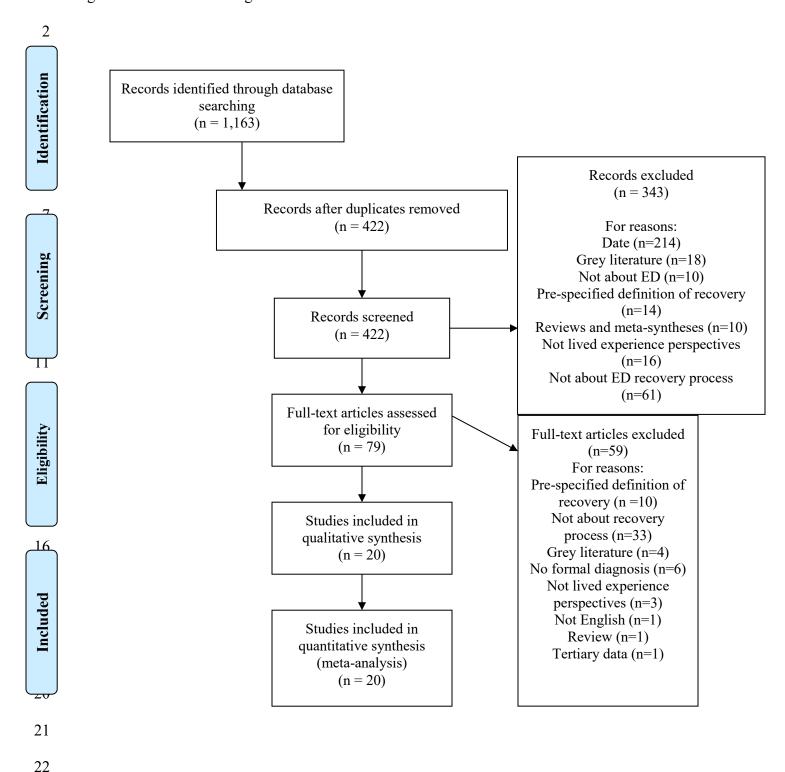


Table 2: Summary of Studies

Study	Country	No. of	Diagnosis	Study	Data	Data	Summary of	No. of
	110	Participants	137 (0)	Focus	Collection	Analysis	themes	References
Arthur-Cameselle J.N., &	US	16, females	AN (n=8),	Factors	Interview	Thematic	Initiation of	143
Quatromoni P.A. (2014a). A			BN (n=-2),	associated		analysis	recovery due to	
qualitative analysis of			BED (n=2),	with			negative	
female collegiate athletes'			AN	initiation			consequences of	
eating disorder recovery			followed by	and			ED (physically,	
experiences. Sport			BN (n=3),	achieveme			health problems,	
<i>Psychologist</i> , 28(4), 334–			AN	nt of ED			underperforming	
346.			followed by	recovery			in sport)	
			BED(n=1)	in female				
				collegiate			Cognitive/	
				athletes			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	
							1000,013	
Arthur-Cameselle, J. N., &	US	47, females	AN (n=16),	Factors	Online	Open-	Motivation from	61
Quatromoni, P. A. (2014b).		, 131111135	BN (n=7),	that assist	questionnair	coding	internal factors:	
Eating disorders in			EDNOS	recovery	e	analysis	participate in	
collegiate female athletes:			(specifically	in female			sport; change in	
factors that assist recovery.			BED, n=4),	collegiate			ED beliefs, fed up	
Eating Disorders, 22(1), 50–			or two or	athletes			with disorder; new	

61. https://doi.org/10.1080/1064 0266.2014.857518			more of the three (n=20)				coping mechanisms/ distractions; avoid triggers Importance of others: support from peers and family; professional support; empathizing, confrontation; External factors: change in environment, hiding, medication	
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	US	13, females	AN- restricting (n=6), AN- purging (n=1), BN (n=3), cycles of A N and BN (n=3)	Experienc e of recovery from therapists with a history of an ED	Interview	Phenome nological with content	Recovery process is nonlinear; comprehensive; life-long Involves changing attitude towards self; deidentification with illness; developing a sense of purpose; fostering meaningful relationships	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

the Impossible": The Process of Recovery From Chronic Anorexia Nervosa. Qualitative Health Research, 24(4), 494-505.				from chronic AN from participant s 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.00 56275	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)	Experienc e of women	Interview	Open- thematic coding	Importance of health care professionals	48

(2015). The process of help-seeking in anorexia nervosa: Patients' perspective of first contact with health services. Eating Disorders: The Journal of Treatment & Prevention, 23(3), 206–222. https://doi.org/10.1080/10640266.2014.981429				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	Individual s' with a history of an ED's experience s of severe AN long-term communit y treatment	Interview	Interpreti ve phenome nological 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 BM., 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	Qualitativ e content analysis	Common themes: feeling stuck in the ED (linked with identity,	67

experiences of recovery from bulimia nervosa. Journal of Advanced Nursing, 71(4), 860–869. https://doi.org/10.1111/jan.1 2554				young adult women's experience s			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	
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. <i>Journal of Multidisciplinary Healthcare</i> , 11, 425–437.	Sweden	15, females (14) and male (1)	EDs with restrictive symptomato logy	Explore experience of adolescent s with EDs (restrictive symptoma tology)	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, N., & Parsons, H. (2016). "Everyone here wants everyone else to get better": The role of social	UK	75, females and males	BED (32%), BN (28%), AN (20%), AN	Role of social interaction s within a	Online group session	Theoretic ally- guided	Main themes: importance of identity in EDs; importance of	123

identity in eating disorder recovery. <i>The British Journal of Social Psychology</i> , 55(4), 662–680. https://doi.org/10.1111/bjso.12161			and BN (20%)	group can promote ED recovery		thematic analysis	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	
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. <i>The Lancet</i> , 389 https://doi.org/10.1016/S0140-6736(17)30466-X	UK	19, females; 11 parents	AN (n=12), AN and BN (n=3), Other/atypi cal 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 towards patients and families at all	65

							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)	Perception s 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, KB., 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. https://doi.org/10.1111/j.1471-6712.2012.01006.x	Norway	13, females	AN, BN	Patients' experience s of the later phases of ED recovery	Interview	Content	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

							social skills, and coping with grief	
Pettersen, G., Wallin, K., & Björk, T. (2016). How do males recover from eating disorders? An interview study. <i>BMJ Open</i> , 6(8). https://doi.org/10.1136/bmjopen-2015-010760	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	Phenome nological 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 MA., Gueguen, J., Michelet, D., Orri, M., Köenig, M., Corcos, M., Cadwallader, JS., & Godart, N. (2019). Personal recovery of young adults with severe anorexia nervosa during adolescence: a case series. Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity https://doi.org/10.1007/s40519-019-00696-7	France	3, females	AN (n=3)	Perception s of people who were hospitalize d during adolescen ce for severe AN on their recovery experience	Interview	Interpreti ve phenome nological 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:	206

							bodily well-being and pleasure of body; stigmatization; role of group; relation to time; importance of narratives AN recovery process includes many tipping points	
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.	UK	12, females	AN (n=12)	Experienc e 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	17

							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. Journal of Health Psychology, 21(1), 16–27.	UK	9, females	AN	Women's experience s 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. The International Journal of Eating Disorders, 50(4), 398–405	Sweden	16, females (15) and male (1)	AN	Patients' experience s of self- admission to specialist ED clinic	Interview	Qualitativ e 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

							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	
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.	US	13, females	Doesn't specify	Association between feminist ideas and ED recovery	Interview	Thematic analysis	ask for help 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 J., King R., &	Australia	15, females	AN (n=15)	Readiness	Questionnai	Transtheo	Readiness to	23
Costa B. (2016).				to change	re and	retical	change and self-	
Development of readiness to				and self-	interview	model	efficacy were not	
change and self-efficacy in				efficacy as		(TTM)	consistent across	
anorexia nervosa clients:				it relates			dimensions	
Personal perspectives.				to				
Advances in Eating				symptom			More stability for	
Disorders: Theory, Research				dimension			readiness to	
and Practice, 4(1), 99–111.				s of AN			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	

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%
Норе		
- 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.
- 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

- 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

- Kordy, H., Krämer, B., Palmer, R., Papezova, H., Pellett, J., Richard, M., & Tresure, 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
- 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.

- 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