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The patient experience of illness, treatment, and change, during intensive community treatment for severe anorexia nervosa

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ABSTRACT

This study explores experiences of intensive community treatment, illness, and change among patients with severe anorexia nervosa (sAN), particularly seeking to understand the processes involved in change and inability to change. A qualitative design with purposive semi-stratified sampling, using semi-structured interviews and interpretive phenomenological analysis, investigated in detail the experiences of five participants. Participants all had sAN at the start of treatment and represented a spectrum of outcomes from deterioration to full recovery. Six super-ordinate themes emerged from the analysis: treatment experience, function of anorexia, self-criticism versus self-acceptance, isolation versus connection, hopelessness versus hope, and stuckness versus change. Results describe the valued function of the illness, barriers to change, the lengthy struggle for change, and how this can be supported by intensive community-based treatment. Necessary ingredients in the process of change, arising from the analysis, are proposed. We conclude that the experiences of these patients reflect the particular functions of AN for each individual, and that both clinical deterioration and full recovery can occur with prolonged intensive community treatment.

Anorexia nervosa (AN) is a complex illness. Among those for whom it becomes severe and enduring, quality of life is very poor with a significantly increased risk of death (Robinson, Kucuska, Guidetti, & Leavey, 2015). There is little evidence of efficacious treatments for patients with severe and enduring AN (Hay & Touyz, 2015). Although new neuro-biological and psycho-social models are emerging, substantial gaps in our understanding of AN remain. In this context, experiential qualitative evidence should play a significant role in developing understanding to inform new treatments.

The majority of qualitative studies addressing patients' experience of treatment have focused on inpatient settings. Many describe sufferers' difficulties making secure therapeutic relationships (Oyer, O'Halloran, &

Christoe-Frazier, 2016; Stockford, 2014). Patients sought greater focus from professionals on underlying feelings and psychological needs, and less on weight (Fox & Diab, 2015; Oyer et al., 2015; Pemberton & Fox, 2013; Stockford, 2014). Inpatient re-feeding led to experiences of loss of control and vulnerability (Fox & Diab, 2015). Difficulty in accessing services and lack of continuity in care during prolonged treatment journeys, were identified as generating experiences of abandonment (Fox & Diab, 2015). There is less data about the experience of community care, particularly among those with severe and enduring illness.

Patients' understanding of their illness and how it functions is summarized in a synthesis of 24 studies (Espíndola & Blay, 2009). This identified the functions of AN as providing a sense of control and identity. Positive and negative experiences of AN, for example as "self-protective" or as "taking over the self," are reflected in the literature (Erikson, Hansson, & Lundblad, 2012). Control as a means to protect oneself from feeling overwhelmed by fears and anxiety, has been widely described (Fox & Diab, 2015; Stockford, 2014). Self-harming may act as a substitute means of emotional control, when control of eating is not possible (Verschuere et al., 2015). A sense of pride in extreme controlling behaviour also appears to off-set feelings of shame and self-loathing (Robinson et al., 2015; Skårderud, 2007). There is acknowledgment in most studies of the negative consequences of AN, especially those involving chronic populations (Robinson et al., 2015), yet it seems the greater weight of experience lies in the positive functions of the illness (Espíndola & Blay, 2009; Stockford, 2014). This study addresses whether patients receiving a novel community treatment have a similar or different understanding of the function of their illness, to that currently described in the literature.

The literature also reflects investigation into the nature of recovery. A meta-synthesis of 11 qualitative studies of people who had recovered from AN, provides a rich analysis (Stockford, 2014). An initial problem with a fragmented experience of self and feeling insufficiently "in-control" led to AN as a "solution." A "turning point" is identified when awareness of the negative consequences of AN results in a commitment to take responsibility for recovery. A process of then reclaiming the self through self-acceptance and engagement in validating trusting relationships is described. Dawson and colleagues (Dawson, Rhodes, & Touyz, 2014) suggest four phases in recovery. They describe themes of: reaching a tipping point; understanding the function of the illness; externalization of the eating disorder; establishing understanding, trusting relationships; finding an internal locus of control; perseverance and practice in the pursuit of change. The qualitative literature to date provides few accounts of the barriers to change. This study uniquely addresses an understanding of both change processes and barriers to change,

by including the experience of patients who did and did not make positive change and at different stages of recovery.

The Anorexia Nervosa Intensive Treatment Team (ANITT) model seeks to provide an alternative to traditional treatment pathways for people with severe AN (Munro et al., 2014). This model of intensive community-based care seeks to address some of the difficulties patients with AN have described in traditional models of care. We provide long term consistency and continuity of care, usually with key patient-clinician relationships maintained over at least 3 years. We focus on all the universal core psychological and physical needs, of which nutrition is just one. Weight gain is not the only focus. Our specifically adapted model of individual Schema Therapy for AN (iST-AN) is built around the concept of universal core needs and understanding the role illness plays in interfering with meeting these needs. The focus is on working with vulnerable emotional states, underlying schemas, and psychological coping modes, building a trusting therapeutic relationship as the primary means of effecting change. The model integrates current ideas from neuroscience, physiology, and theories of emotion as they relate to AN (Munro, Randell, & Lawrie, 2016).

The wider purpose of this study is to inform the further development of our clinical service model (ANITT) and our psychotherapy model (iST-AN), by gaining a greater understanding of our patients' experiences. This study adds to the existing literature in three ways by providing: the first experiential data arising from a novel community-based treatment model among severe and enduring AN patients; further data on the patient experience of the function of their illness; and uniquely, experiential data on the processes involved in change and barriers to change. Our research questions are therefore: How does our sample of people with sAN experience long term community treatment? How do they understand the function of their illness? And what are the processes involved in change or failing to change?

Method

Philosophical assumptions and study design

All three authors (JH, LE, and CM) shared a broadly social constructivist outlook. We took with us into the study an assumption that our qualitative data would be inescapably influenced by our subjectivity in co-creating meaning with participants. We used a semi-structured interviewing and interpretative phenomenological analysis (IPA) methodology (Smith, Flowers, & Larkin, 2009) to achieve descriptions of complex subjective experiences and the meaning participants assign to these. A quantitative component to the study design was necessary to situate the sample regarding the severity of their clinical presentation and the variability of their outcome.

We used purposive semi-stratified sampling to achieve a sample representing a spectrum of clinical outcome, to answer the research question regarding experiences of change or of being unable to change.

Managing subjectivity

Our central approach to reflexivity was in the use of second and third authors in co-analysis and triangulation of perspectives to attend to potential biases. The first author had experience of IPA during a psychology undergraduate thesis and 2 years of experience of working with patients with AN as an assistant psychologist, including treating three of the five participants. The second author had experience of qualitative research during postgraduate study and a year of experience in the clinical service as an assistant psychologist, but had not treated any of the participants. The third author had 17 years of experience of working in the field with previous experience of publication of qualitative research. The third author also had therapeutic relationships with each of the five participants as psychiatrist or psychotherapist and the role as clinical team lead. The first and third authors were therefore more susceptible to assumptions arising from personal therapeutic relationships resulting in confirmatory bias. This was managed using “bracketing” as described by Husserl (1931). Reflective discussions among the authors at the start of the study helped to improve awareness of potential biases and to set pre-existing assumptions aside. The first author also anonymized transcripts to “blind” authors two and three to the identity of participants during the co-analysis. Author three was identified as at greatest risk of confirmatory bias. As team lead he was also at risk of overly influencing interpretations during analysis. This was managed by the first author completing all data collection and initial coding, and retaining primacy of decision making during consensus co-analysis.

Sampling strategy

We aimed to identify information-rich cases, of participants who had received a full package of intensive community treatment yet achieved variable outcomes. We used purposive semi-stratified sampling with four inclusion criteria: (a) more than 2 years of ANITT treatment; (b) diagnosis of AN, with markers of severe illness at entry to the service; (c) able to provide in-depth narratives of their illness and treatment experience; and (d) variable quantitative symptomatic outcomes from treatment.

All patients entering the service were diagnosed by a consultant psychiatrist (third author) or a consultant clinical psychologist, according to ICD-10 criteria. There is no definition of severe AN widely agreed within the field, but our local criteria, reflecting a deteriorating starvation state are: body mass

index (BMI) of <13, or BMI of <15 and losing weight at a rate of >1 kg per week. The first and third author selected 12 patients who fulfilled criteria 1 and 2, then in discussion with the multi-disciplinary team reached consensus on eight patients most likely to provide in-depth narratives, prioritising information-rich cases (Morrow, 2005). These eight patients were categorized in relation to treatment response in order to generate a semi-stratified sample, according to the following criteria:

- (1) *Unstable*: Persistently remain BMI < 13, with no significant objective psychological symptomatic improvement.
- (2) *Stable*: BMI > 13 with weight gain or stabilisation, but with no significant objective psychological symptomatic improvement.
- (3) *Remitted*: Weight gain BMI >13 sustained for over a year, with significant objective psychological symptomatic or quality of life improvement.
- (4) *Recovered*: Weight gain to BMI > 17.5 with significant objective psychological symptomatic or quality of life improvement.

To achieve a semi-stratified sample we aimed to recruit six participants, three participants from categories 1 or 2, and three from categories 3 or 4. The recruited sample consisted of one patient in category 1, one in category 2, two in category 3 and one in category 4. We accepted this five participant sample as adequate to meet our aim of describing experiences across the spectrum of clinical outcome.

Participant characteristics

All participants were un-married, Caucasian females. The age range was 23–30 years. Three were in relationships, three in full-time employment or education, one in part-time employment, and one unemployed. Socio-economic status is reflected by the Carstairs Index, used to describe levels of deprivation in the Scottish population (Carstairs & Morris, 1991). This generates five categories ranging from 1 (*most deprived*) to 5 (*least deprived*). Two participants were in category 2, two in category 3 and one in category 5. The age of onset of their eating disorder ranged from 8 to 18 years old. The duration of illness prior to ANITT treatment ranged from 4 to 11 years. Four participants had experienced inpatient care. At entry to the service, four participants had diagnoses of AN restrictive sub-type, one binge-purge sub-type, and all but one patient had comorbid psychiatric diagnoses reflecting complex psychological problems. The comorbid diagnoses included: anxious-avoidant personality disorder (3), recurrent depressive disorder (2), obsessive-compulsive disorder (3), schizo-affective disorder (1) and emotionally unstable personality Disorder (1). At the time of interview, one participant

was discharged, two were close to discharge with minimal input of no more than one appointment per month, and two remained fully in treatment.

To illustrate the spectrum of treatment outcomes within our semi-stratified sample, we provide quantitative physical and psychological change outcomes. The Jacobson and Truax (1991) method for describing clinically significant change amongst individuals was used to describe the data (Table 1). The specific outcome measures used were the Eating Attitudes Test (EAT-26; Garner, Olmsted, Bohr, & Garfinkel, 1982), the Generalised Anxiety Disorder screener (GAD-7; Löwe et al., 2008), the depression module of the Patient Health Questionnaire (PHQ-9; Kocalevent, Hinze, & Brähler, 2013) and the WHO abbreviated quality of life measure (WHOQOL-BREF; Hawthorne, Herman, & Murphy, 2006).

Setting

ANITT is a multi-disciplinary service delivering intensive community-based treatment for patients with severe AN, including home-visiting when appropriate. There are three main components of care: psychological treatment, dietetic treatment, and risk management. The formal psychotherapy work uses the schema therapy mode model. Patients remain in treatment with the service, with individualized packages of care, through to recovery or discharge. Further details of the service are published elsewhere (Munro et al., 2014).

Data collection and analysis

Data sources for the study were audio recorded semi-structured interviews; demographic and quantitative outcome data from the service database; and the field notes of the first author. Semi-structured interviews were our central data source. The first author's approach to the interviews was of a flexible stance using open questions and allowing participants to expand on the subjective meaning of their experiences, where this was spontaneously forthcoming. A series of additional prompts were used when necessary to encourage further depth of response. The interviews involved seven questions (interview schedule available on request). Questions were devised by the first author and agreed by consensus among the three authors. Each participant was interviewed in a single session. Interviews ranged in length from 45 to 70 minutes. Field notes reflected the environment of the interviews, observations of the participants' manner and mental state. Examples of the notes: "started crying"; "pause of around 15 seconds"; and "troubled expression."

Initial data management involved verbatim transcription of the audio recordings. The first author repeatedly listened to the recordings and read the transcripts, becoming fully immersed in the material and each participant's phenomenological experience (Smith et al., 2009). Next was initial

Table 1. Spectrum of quantitative clinical outcomes among participants.

Participant	BMI start	BMI end	Eating disorder symptoms (EAT-26)	Anxiety symptoms (GAD-7)	Depression symptoms (PHQ-9)	Physical health QoL (WHOQOL)	Psychological health QoL (WHOQOL)	Treatment response category
"Denise"	10.4	12.0	Deterioration	No change	Deterioration	Deterioration	No change	Unstable
"Helen"	13.3	14.8	Deterioration	Deterioration	Deterioration	Deterioration	Deterioration	Stable
"Elaine"	13.2	25.0	Improvement	Clin. signif. improvement	Improvement	Clin. signif. improvement	Improvement	Remitted
"Yvonne"	14.0	19.3	Improvement	Clin. signif. improvement	Improvement	Improvement	Improvement	Remitted
"Eilidh"	13.9	18.5	Clin. signif. improvement	Clin. signif. improvement	Clin. signif. improvement	Improvement	Improvement	Recovered

Notes: BMI = Body Mass Index; EAT-26 = Eating Attitudes Test; GAD-7 = Generalised Anxiety disorder screener; PHQ-9 = Patient Health Questionnaire; WHOQOL = WHO Quality of Life abbreviated measure; clin. signif. = clinically significant.

interpretation by the first author, using the left margins for highlighting specific points and right margins for condensing specific points into emerging themes. The co-analysis group then began meeting. The second and third author read all notes, and in discussion over two sessions, the group achieved consensus on emerging themes. The first author re-immersed herself in the original manuscripts with the emerging themes in mind, to explore super-ordinate themes whilst retaining fidelity to the original transcripts. Super-ordinate themes were considered in two further meetings of the co-analysis group. We continued to be mindful of suspending our personal judgements and views, to step outside of our natural attitude.

The immersion of the first author was reflected in her ability to point to disconfirming evidence within the transcripts when appropriate, and to question an emerging interpretation of the meaning within the co-analysis group, managing the risk of confirmatory bias. A further credibility check was to compare each individual's quantitative data with their qualitative data on experience of illness and change, which showed consistency for all 5 participants.

Approvals and consent

Approval was granted from the hospital's quality improvement team committee. The project was deemed a service outcome evaluation. Written informed consent was gathered. The study was conducted in accordance with the BPS code of human research ethics (2010).

Results

Six super-ordinate themes were derived from the data: (a) treatment experience; (b) function of anorexia; (c) self-criticism versus self-acceptance; (d) isolation versus connection; (e) hopelessness versus hope; and (f) stuckness versus change. Inevitably there are overlaps between themes, yet each construct was deemed meaningfully different. Participant quotations are used to illustrate, using pseudonyms for confidentiality. We have used the terms "all" to mean the theme was reflected in all five participants' transcripts, and "most" to mean in three or four transcripts. Themes arising in one or two participants only are described as such.

Treatment experience

All participants responded positively regarding their experience of treatment. Comments were made about the experience of this model of community treatment compared with inpatient care, by most participants. These related to a sense of safety and control and ability to practice change in the "real world":

Helen: I feel like I can be most honest when I'm at home ... it's my own environment so it's easier to talk.

Yvonne: I think it's good being in the community ... a bit more normal ... well if I can do it a little with you guys, then I could maybe eventually go out with one of my friends.

All participants focused on the therapeutic alliance in providing continuity of reliable, empathic and compassionate relationships and building trust over a prolonged period:

Eilidh: Everyone in the team was so compassionate, nobody judged me ... I think until you've built up trust with anyone it's hard to make the changes.

Yvonne: ... if I hadn't had X who knew me, helping me carry on, then I wouldn't have got so far ...

One participant described the difficulty when team members with whom they had built up positive relationships, left the team. Another verbalized fears that staff only appeared to care, as it was their job. This participant struggled to make change, which perhaps reflects the importance of trust as a key ingredient.

All participants drew attention to the importance of truly collaborative, personalized, flexible treatment planning, and a slow pace of change with focus on all aspects of their difficulties, not solely eating and weight:

Yvonne: ... more real, like she would think about if I was going to a party ... rather than just put down anything on my meal plan.

Eilidh: ... everything just happened really, really, really, really slowly and small changes at a pace that felt manageable for me.

Helen: I think with the ANITT team I like the fact that everything is not just weight and food related, because that's only part of it.

A sense of the team generating an experience of being "held" or supported, was articulated. Part of the sense of being contained and "held" by the team appeared to be the knowledge that they would be looked after if they were unable to look after themselves:

Elaine: If I'd been alone I honestly don't know what would have happened ... even if I haven't liked them sometimes, retrospectively I can kind of see it was for my own good.

Function of AN

Initially AN was described as a positive presence in an unhappy life, the sense that it could help participants feel better, more acceptable, and less isolated, was held by all at some point:

Helen: I was having problems in school and at home and (was) just unhappy and I thought that if I lost weight, I would feel better.

Elaine: I think I was just really low and then I started to lose a bit of weight and I would feel better about myself for just a second.

Part of the function for most appeared to be achieving a sense of pride in their ability to control their weight. With a backdrop of beliefs about being inadequate, losing weight could feel like something they were good at and could achieve:

Elaine: I had to go to *TJ Maxx* to get the tiny jeans ... I just remember standing in the changing room and being so proud.

Eilidh: ... like if I was out with friends, having the lowest calorie meal on the menu made me feel really strong.

AN could provide a source of comfort and safety when everything else felt bad. It seemed to function in subtly different ways for each individual, but overall gave a temporary sense of control or acceptability. For example, two participants experienced a sense of emotional or physical detachment:

Eilidh: ... my thing that I could turn to that would like numb all sadness or anger.

Another described a more cognitive experience of focusing on over-controlling thoughts and behaviour about losing weight, as distraction from uncomfortable feelings:

Helen: ... when I was feeling upset, or when I didn't want to think about other things, that if I was focusing on how much exercise I had done that day or how little I'd eaten or how many calories I'd burned ... that I could kind of not think about everything else.

One participant was able to recognize how AN actively allowed her to avoid situations she feared i.e. the benefits of the "sick role":

Denise: I guess when I was off school I got to avoid the pressure of school. ... I got looked after. Nothing bad would happen.

Self-criticism versus self-acceptance

Participants, especially the two who were most stuck, voiced self-blame and guilt for having AN, and could not see external factors as playing much of a role. They were self-critical about their appearance, and more globally:

Helen: I always thought it was my own fault and that I wasn't good enough.

Denise: It's my own fault and that makes it worse ... I'm the problem.

The three who progressed towards recovery recognized their tendency to be self-critical as a problem. They used support to test out being more caring, accepting and compassionate towards themselves:

Yvonne: Sometimes I'm nicer to myself definitely, but then I get scared of that.

Elaine: So it is useful, 'cause I'm really hard on myself, (that my therapist) says every time I see her, "you should stop being so hard on yourself!" It's useful to have little reminders of that. After every session I do feel a bit more empowered to be nicer to myself.

A participant who was fully recovered (Eilidh) embraced the value of self-acceptance. She reflected on her past self-criticism and learning to be kind and caring towards herself:

Eilidh: It was something at first that was so alien to me because I had never thought about doing anything nice for myself. I'd always do things for other people but for me it's like "no you can't have it"... (Now) you're like, "oh life's so much nicer living this way!"

These comments illustrate how self-criticism and self-acceptance can be viewed as a continuum. Those who had changed least were most self-critical, those who had changed most were more self-accepting.

Isolation versus connection

All of our participants felt different from others and "isolated." The "emptiness" and loneliness went along with being unable to trust others. They kept their struggles to themselves and sought to cope on their own:

Yvonne: I remember feeling quite lonely... (but) I felt I didn't want to be around anyone else because I felt like I had caused all the problems... I'm scared of being alone all my life.

All patients recognized the potential value in connecting more with others, and most participants began to view this positively. To feel connected to others it seemed important that "the other" understood them and was non-judgmental. Helen found this connection with people who had similar problems. Most of our participants experimented with emotional openness and trust with members of the team initially. These trusting relationships could open the door to building connections with others. A shift from isolation and loneliness in the "safety" of their internal relationship with their eating disorder, to feeling interpersonal connection with others, occurred for three participants:

Eilidh: I guess through speaking to people in the team and not getting judged kind of gave me that confidence to realize oh I can speak to people about things. So I started speaking to like some close friends and then they wouldn't judge me,

they would just feel closer to me. They felt like they could share things with me as well 'cause I was being so open with them.

It was noticeable that those further on in recovery had more open and trusting relationships and felt more connected to those around them. Those who had made little change were less trusting of others and expressed more isolation and loneliness.

Hopelessness versus hope

Two participants portrayed feelings of hopelessness. The longer the time spent in treatment with little or no change, the more hopelessness was present. The hopelessness seemed to paralyse some and was associated with a kind of resigned submission:

Denise: I feel like really, really hopeless and it's like soul destroying. Because I can't see anything changing.

Those further on in recovery reflected on past feelings of hopelessness and how this had changed:

Yvonne: ... There was no kind of thought to want the therapy or support to help. It was more just get through each day until you get to go to bed again... now I kind of think I look forward to doing things, they're hard still but I still look forward to it.

Those who held more hope described specific and obtainable goals, in comparison to those who were stuck, whose goals were often hard to fathom.

"Stuckness" versus change

Participants reflected on the process of change. Some were painfully stuck, they felt trapped, afraid and conflicted. They feared letting go of the over-controlling behaviour and so continued without change. This was an extremely frustrating and sometimes tormenting place to be:

Denise: It's really, really frustrating to understand everything ... but still not be able to do the right thing. It's like, why do I still do the wrong things? But then I am still at the stage that I don't want to change. I want to change... no I don't want to change. I want to be better, but I don't want anything to change and I know that completely doesn't make sense... It's just infuriating.

Two participants reflected on getting to a tipping point, recognizing that the powerful but transient rewards were outweighed by the costs of their AN:

Eilidh: ... mainly it was about achievement for me. Then after a while the emotions start to change, from like going to the other side of it, where you're just miserable and like I've got no life.

The process of change was interlinked with developing self-knowledge for most of the participants. Exploring, learning, growing, and building self-acceptance and an identity beyond the eating disorder:

Eilidh: I've realized recovery is about starting to learn about who you are and being able to accept yourself for that.

Yvonne: Recovery has also been for me, as well as the food and being able to eat normally ... it's being able to accept that like I am a quiet person and that's OK.

In contrast, where self-understanding had developed without readiness for change, one participant wanted to retreat back into a more detached, avoidant way of being:

Denise: If I didn't know quite so much, like I know you need to know what the problem is to fix it, but ... you know like anorexics are good at detail, I think I've got too much detail now and it's become a problem.

Another participant spoke of how constructing an understanding of how her problems had emerged, had been an important part of the process of shifting from self-criticism, to self-acceptance. She shows forgiveness and compassion for her younger self:

Eilidh: You don't just decide "oh I'm going to go out there and start starving myself," there's something that's happened to make you want to do that and being able to trace back and see what had led me to go down that pathway ... so like then it helped me to forgive myself, cause everything was so subconscious.

The three who had made some change spoke of having to be ready to change. AN was depicted as something needing extremely hard work to be fought against and was no longer seen as a protector:

Eilidh: ... just exhausting trying to fight it all the time and I would push and push and push and fight and fight and fight it all the time, and I would just go crumbling down with exhaustion and then I would get stuck for a wee bit, and then once the exhaustion passed I was ready to fight again!

There was some recognition of mechanisms that had helped them achieve change, including challenging automatic thoughts and learning to accept and tolerate uncomfortable feelings. An openness to questioning instinctive ways of thinking, feeling, and reacting, allowed them to gain a fresh perspective, catalysing a gradual process of change:

Eilidh: I started learning about disagreeing and disobeying the eating disorder voice... It's like it's a part of you, (but) it's just a thought, it's not me... Learning to sit with emotions rather than avoiding them through restricting your food and exercising.

Whereas Denise, who continued to be tortured and embattled with the prospect of change, avoided considering other perspectives and tended to hold a narrow focus:

Denise: All I think about is the narrow—that I put on 0.2 kg. That’s the end of the world!

One participant also shared her reflections on the value of making gradual behavioural change, with support of longstanding relationships with professionals:

Yvonne: When I look back on how it used to be, I’ve changed a lot . . . and some of the people who have been with me for a long time have been like “I remember when you said to me that you would never do this or, you’d never manage that,” and it’s things that I’m not doing often or easily, but doing it and not thinking so much about it.

Discussion

Our participants’ experiences of intensive community treatment largely reflected our attempts to make treatment feel safe enough by taking time over engagement, building a shared understanding, and moving slowly with change. We focus on weight gain as much as is necessary for safety, until the patient is ready. We aim to develop trust and offer long-term reliable relationships, which are not conditional on remaining severely unwell. The four participants who had been treated as inpatients, set their experience with our service in marked contrast to inpatient care. Many of the things patients with AN seem to value—slow pace of change, developing long-term therapeutic relationships, feeling in control and safe enough—are inherently more difficult to achieve in hospital.

Unlike perhaps all other mental illness, the experiences described in this study portray AN as a disorder initially characterized by its value to the individual. It was seen as a solution to loneliness, a source of pride, and a means of self-soothing and managing negative feelings. Yet our participants also recognized it became a cause of isolation, of self-criticism or even self-hatred, and that it could leave them stuck in an effortful bleak life and generate a potent sense of hopelessness. Using the Schema-mode model, we conceptualize this clinical picture as the result of psychological modes reflecting instinctive coping strategies, driven by unmet emotional needs. Recognizing these coping modes as partially functional, and giving some short-term reward helps foster a validating understanding of the illness. The maladaptive nature, yet functional value of the illness, must be understood and acknowledged to combat beliefs about defectiveness and inadequacy. That AN provides some form of self-soothing or compensation for excessive negative or vulnerable feelings or dysfunctional emotional processing, is well recognized. What emerged in the experiences of our participants was consistent with a biopsychosocial understanding of these maladaptive maintenance mechanisms,

described elsewhere (Munro et al., 2016). A self-critical mode is the toxic underpinning, fuelling beliefs about inadequacy and driving the central over-controlling and avoidant modes, with a variety of behavioural consequences including those related to eating. The self-criticism also reflects an underdeveloped capacity for self-acceptance. We try to help patients develop a balanced view of the origins and function of their illness. Our experience is that this can open the door to a genuine emotional, rather than purely intellectual, evaluation of the costs and benefits of AN, a step in establishing readiness for change.

The potential value of studying experiences of illness, treatment, and change, is to improve treatments. We sought in this study to explore the experiences of patients who have and have not been able to make significant progress with change. The spectrum of outcomes amongst our participants ranges from deterioration and subsequent death due to starvation for one; to full recovery, a long term relationship, and a professional career, for another. We have illuminated processes reflecting barriers to and facilitators of change, little explored in the existing literature. We think the outcomes from this study, the key factors described by Dawson et al. (2014) and others in the qualitative literature on recovery, suggest some necessary ingredients of change that could help focus clinicians and patients. Change is never a step-wise linear process, but could be considered as two phases, with phase 1 focusing on developing readiness to change and phase 2 on achieving the change. Some necessary ingredients of phase 1 we suggest are:

- Sufficient engagement in relationships with professionals;
- Gaining self-knowledge through a shared understanding of the origins of their illness and the role the eating disorder plays in their life;
- Recognizing the toxicity of self-criticism and self-deprivation; and
- A commitment to change, taking responsibility for learning new ways to manage feelings.

Some necessary ingredients of phase 2 we suggest are:

- Accepting “failing” or set-backs, as a healthy part of the change and learning process;
- Opening up to others to develop trusting, accepting relationships;
- Perseverance with behavioural change, reflecting self-care, including weight gain; and
- Developing self-acceptance and a good enough “healthy self” identity.

The crucial importance of readiness for change in relation to outcomes is clear (Bewell & Carter, 2008). Difficulty in successfully navigating phase 1 and achieving genuine readiness for change may suggest further treatment focused on change is not indicated at that point, even though support and monitoring of risks will be required. Persisting in treatment that pushes for

change, when the patient is not sufficiently ready, may result in negatively reinforcing experiences of failure for both patient and clinician.

We used purposive semi-stratified sampling to achieve an adequate spread of those who changed in treatment and those who had not. For optimal balance we would have had one further participant with minimal change to reduce the risk of sampling bias. However, consistent with the IPA methodology, we prioritized richness of information among the five participants over larger numbers (Smith et al., 2009). Another potential weakness is that investigators were not independent of the treatment experience being investigated, risking confirmatory bias with participants keen to please the interviewer. Yet, as others have noted (Skårderud, 2007), a pre-existing trusting relationship in this patient population may facilitate the depth of material shared.

Conclusions

We have added to the existing literature by describing the positive experiences of treatment among people with severe and enduring AN receiving a novel model of community treatment, which did not reflect the negative experiential themes reflected in studies of inpatient treatment. We also described how our participant's experience of the function of their illness broadly replicates that in a number of previous studies (Espíndola & Blay, 2009). We believe this is the first study to explicitly investigate experiences of change and of barriers to change, by including participants who did and did not make positive change and who were at different stages of recovery. As such we have illuminated mechanisms involved in change and barriers to change, which we suggest are of potential use for clinicians and sufferers of AN. We also highlight a focus on core needs, frequently mentioned in the qualitative literature and increasingly recognized as a potential focus in the treatment of AN (Van der Kaap-Deeder et al., 2014).

The contrasting experiences of those who changed versus those who had not, highlight the individual nature and function of each participant's anorexic illness, yet also point to the common factors for change. In other words, we start with a basket of possible ingredients that require thoughtful and gradual mixing, blending and testing, with a very slow cooker, to eventually generate a satisfying and nurturing good enough and unique "meal" of change. Despite the best efforts of those suffering with AN and the professionals seeking to help them, sadly, the recipe for recovery is often not found. However the experiential and symptomatic outcomes for three participants of this study do reflect a journey from self-deprivation to self-satisfaction, from self-criticism to self-acceptance, from isolation to connectedness, from perfectionistic over-control to flexibility, and from unmet needs to met needs. A journey from severe AN to a better life is possible.

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