

Patients' perspective on inpatient treatment for eating disorders: A mixed-methods study of satisfaction, experience of care and perceived helpfulness of components of treatment

Sue Patterson^{1,2*}, Rachael Bellair¹, Shane Jeffrey¹ and Warren Ward¹

¹Metro North Mental Health, Metro North Hospital and Health Service, Australia

²Department of Applied Psychology, Griffith University, Australia

Abstract

Background: Inpatient treatment for anorexia nervosa is costly. Effectiveness is uncertain, influenced by patients' ambivalence. While patients' insights and experiences are integral to quality, their views have received little attention.

Aims: Describe experience and perceived 'helpfulness' of treatment and attributes of clinicians valued by patients.

Methods: Sequential mixed-methods; triangulation of findings of questionnaire surveys and qualitative interviews.

Results: Analysis of data from 41 questionnaires and 16 interviews demonstrate that relationships with staff and co-patients are sources of succour and angst, shaping experience of care. Patients seek empathic, personalised treatment and opportunity to develop skills needed to support 'real world' recovery.

Conclusions: While the focus of inpatient care is nutritional rehabilitation, matters of the 'mind' are important to patients and the skills and qualities of staff influence treatment engagement. Even where treatment is coercive, effort must be made to promote personalisation and flexibility and the non-authoritarian attitude valued by patients. After all, evidence based treatments can only be effective if patients engage. Further research should examine the process of care and outcome generation.

Introduction

It is axiomatic, in contemporary health care, that the views and experiences of people who use services are fundamental to quality. Translation of rhetoric to practice is challenging however within the complex health care environment. While clinicians aim to prioritise patient care, heavy workloads and bureaucratic demands can constrain patient contact. With services required to do more with finite resources the terms 'efficiency' and 'outcomes' often outweigh 'experience' in discussion of service development and resourcing decisions. That the latter is fundamental to the former, however is inherent in endorsement, internationally of patient experience as a key indicator of 'quality' [1-3]. Research demonstrates that patient experience is valuable not only intrinsically, but instrumentally; incorporating experience-based knowledge of patients in service development is sound business practice, supporting improvement in outcomes, reduction in costs, enhanced safety patient safety and provider satisfaction [4-6]. Patients' experiences of, and satisfaction with service(s) are particularly pertinent when treatment is not standardised and reliant on interpersonal engagement. Such circumstances are common in mental health care generally, and specifically in treatment of eating disorders (ED) such as anorexia nervosa (AN) [7].

AN is a severe mental illness characterised by persistent restriction of energy intake, intense fear of weight gain and disturbance in body image [8]. Two sub-types - restricting (AN-R) and binge-purge (AN-

BP) - may be diagnosed dependent on presentation, with a diagnosis of eating disorder not otherwise specified (EDNOS) used when criteria for specific conditions are not satisfied. The complexity of EDs and ego-syntonic nature of symptoms complicate treatment [8]. Various nutritional, psychosocial and medical interventions may be employed alone or in combinations, dependent on service context, and patient needs. Practice guidelines promote community-based treatment whenever possible, but hospital admission may be required, particularly when patients are medically compromised [8].

While patients' opportunities to express views about mental health care and influence practice have been limited [9], an emergent literature describes the mixed, and too often suboptimal experiences of admission to psychiatric wards. Studies repeatedly highlight the value patients place on compassionate, respectful therapeutic engagement and feeling cared for as a whole person, with a life story, rather than a collection of symptoms [10-12].

Correspondence to: Sue Patterson, Mental Health Centre, Royal Brisbane and Women's Hospital, Herston Qld 4029 Australia, E-mail: susan.patterson@health.qld.gov.au

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Studies of experience of inpatient treatment for AN demonstrate similar aspirations and the complex influence of treatment milieu on experience [13-22]. Consistent with research into community treatment, associating premature discontinuation of treatment with perceptions of 'not enough freedom', 'treatment being too difficult' and 'lack of trust' [20,23,24], inpatients emphasise the importance of addressing emotional distress in addition to medical needs, and predictability in relationships with staff [18-21]. A secure, trusting therapeutic relationship and therapist attributes are recurrently identified as critical to engagement and satisfaction with services [14,13-17]. Conversely perceptions that feelings are invalidated are associated with drop out [20,23,24]. Research demonstrates that outcomes of, and satisfaction with inpatient treatment for AN are variable [25] with minority of patients finding treatment 'extremely helpful' [7]. While weight may be restored, psychological symptoms remain and repeated readmission is common [7,26-28].

With engagement of characteristically ambivalent patients [15] critical to treatment success, and engagement dependent on acceptability of treatment, a thorough qualitative understanding of inpatient care from the patients' perspective is needed to optimise outcomes [29,30]. Aiming to contribute to the growing evidence base and inform service improvement locally we set out to describe the experiences of adults admitted to hospital for treatment of eating disorders. Specific objectives were to assess the perceived helpfulness of various components of treatment, and clinician behaviours and attitudes valued by patients.

Method

We employed a sequential mixed-methods design. We first analysed responses to satisfaction questionnaires routinely offered to patients on discharge from a Specialist Eating Disorder Unit (SEDU) (Text Box 1), within a general psychiatric ward at a tertiary hospital in Australia. Results were explored in interviews with a consecutive sample of patients from the same unit. The study was approved by Australian Human Research Ethics Committee EC00172 (12/QRBW/29) (Text Box 1)

Data collection

Satisfaction questionnaire: routinely used in SEDU since 2009, the questionnaire comprises a series of statements (Table 1) regarding

components of treatment. Respondents are invited to rate agreement using a four-point scale (strongly disagree-strongly agree) with space provided for free-text at each item. No identifying/demographic data are sought. For the purpose of this study, Author 1 was provided with a service data base containing responses to questionnaires.

Qualitative interviews. Recruitment and interviews were undertaken by Authors 1 and 2 during 2013-2014. Both are women aged over 35, trained as psychologists with PhDs. Author 1 with 15 years' experience working with patients with EDs is employed as a clinical psychologist, providing individual and group-based therapies within the SEDU. Author 2, a health services researcher experienced in mixed-methods research within mental health services, also has clinical experience treating patients with eating disorders. To maintain professional boundaries and privacy of participants, and encourage openness, Author 1 had no research-related contact with patients to whom she provided clinical care.

Consecutive sampling was employed with broad eligibility criteria: admission to SEDU for at least seven nights and assessed clinically as able to engage in interview. Patients meeting these criteria were approached, when nearing discharge, by a treating clinician who provided information about the study and sought permission to arrange a meeting with researchers. As appropriate (dependent on availability and clinical contact), either Author 1 or 2 met potential participants and provided comprehensive information about the study. Emphasis was placed on the voluntary nature of participation, confidentiality of data, anonymous reporting and independence of research from clinical decisions.

Interviews were completed in private spaces on SEDU not more than two days before discharge. Interviews were planned for this time because we anticipated potential participants would be medically and affectively stable, have experienced the full treatment program including progression from involuntary treatment; our anticipation was that patients would be in a position to reflect critically on experiences. We were also concerned to minimise risk of loss to follow-up once patients returned to the community.

A conversational approach was adopted with participants encouraged to speak frankly. After collection of demographic data, participants were invited to 'tell me about your experiences on the

Study Context: Specialist Eating Disorders Unit

A five bed unit located within a general psychiatric ward

Specialist services provided by multidisciplinary team comprising psychiatrists, nursing and allied health clinicians (psychology, social work and occupational therapy). Assistants in nursing provide ancillary support.

Some cares provided by general and mental health nurses working on host ward.

SEDU admits adults with diagnosed eating disorders when medically compromised and/or outpatient treatment has 'failed'.

Between 20 and 30 patients are admitted annually; mean admission duration 46 days.

The primary goals of treatment are medical stabilisation, nutritional rehabilitation, and weight-gain as clinically appropriate.

The treatment program incorporates various interventions designed to engender psychosocial recovery. Intervention 'detail' varied slightly over the four year study period, due to staffing skill mix, but core treatment components were:

Nutritional counselling: twice weekly individual sessions with a dietitian encompassing dietary education and meal planning

•Psychotherapy, psychoeducation and therapeutic group activities employing techniques from cognitive-behavioural and acceptance and commitment therapies. Content and techniques used varied dependent on therapist discipline, purpose of the activity and patient characteristics but all sought to promote behaviour, cognitions and emotional regulation consistent with recovery.

•Supported meal therapy: a staff member eats with patients, modelling non-disordered eating and completion of prescribed meals within an allocated time, and provides post-meal supervision to limit opportunities for compensatory behaviours.

•Community challenges: weekly psychologist-led off-ward sessions designed to build capacity to purchase food 'normally' (shopping for ingredients for a meal to be prepared with an occupational therapist) and engage in social eating (e.g. by sharing lunch at a local café).

Text Box 1

SEDU'. Prompts were used to elicit views about structure and process of care and perceived helpfulness of interventions. Questioning was informed by ongoing analysis of questionnaire and interview data. Data were saturated at the conclusion of interviews; that is redundant data were generated and varying perspectives had been gathered. Interviews which averaged 30 minutes were audio recorded and transcribed verbatim.

Data analysis

Data were managed using Microsoft applications and SPSS V21 (IBM Corp, 2012). Questionnaire data were analysed in three stages. First, quantitative data were descriptively summarised (ratings coded Strongly Disagree=1, Disagree=2, Agree=3, Strongly Agree=4). Next, free-text responses were analysed using an adapted framework approach [31]. Developed in the 1980s, the method is extensively used in applied health research. This method which provides a structure for organising, coding, and categorising data was selected because it enables development of responses to a priori questions while remaining open to concerns of participants not anticipated by researchers. After developing familiarity with the data in each questionnaire, text was allocated to cells, representing respondent/ item with multiple allocation allowed when commentary related to more than one component of treatment. Data within and between cells were then examined using a constant comparative process enabling identification of patterns and divergences. Similar comments were grouped in new cells and labelled descriptively. Quantitative and qualitative findings were then triangulated and narratively summarised. These findings informed the topic guide for interview.

Interview data were analysed using the framework approach as they were generated. After repeatedly reading transcripts to develop familiarity with the content and tone of the interview, data were coded to satisfaction with care, experience of treatment components and relationships with staff and aggregated with findings from the questionnaire for interrogation and synthesis. Rigor in analysis was promoted by member checking as developing findings were explored in ongoing interviews, and critical dialogue between authors who challenged each other to ground findings in data. The account below represents a synthesis of data findings from both study components; illustrative quotations and words in italics in the text are taken from either questionnaires (Q), or interviews (P).

Results

Participants and data

Forty-one questionnaires were returned from 109 admissions, giving a response rate of 57%. Admissions were of 72 individuals aged 18 to 51 years (M=28.1, SD=10.55), including five men. Single admissions were recorded for 51 (71%) patients with others admitted up to four times. Nearly all admissions were of patients diagnosed with AN (58%) or EDNOS (40%) with BMI <15. Mean BMI at discharge, following admissions averaging 7 weeks (range 2-186days) was 17. Given anonymity and absence of clinical/demographic information about respondents we cannot determine the 'representativeness' of questionnaire respondents of the 109 admissions. Nearly all returned questionnaires included extensive free-text commentary. (Table 1)

Interviews were conducted with 12 patients representing 16/22 eligible admissions. Four patients were admitted and interviewed twice; two declined researcher contact, and precipitant discharge precluded contact with the remaining four. As summarized in Table 2, participants were all women diagnosed with AN. Ages ranged from 18 to 50 years

but most (n=10) were aged <25. With mean of 10 years (range 2-29) since first diagnosis most had multiple admissions for treatment of EDs.

Duration of admission at time of interview averaged 10 weeks ranging from two to 38 weeks. While most described themselves as 'wanting to get better', five who considered the eating disorder integral to identity- *it's who I am*- reported planning to lose weight following discharge, and anticipated readmission. (Table 2)

Aggregate data demonstrate participants' insightfulness regarding the challenges of treating eating disorders (including their own contribution to this), clarity about the qualities of 'good' staff and general satisfaction with treatment process (if not weight-related outcome). As summarized in Table 1, respondents rated most treatment components as helpful. Free-text and interview data, however contextualized and qualified these findings, elucidating 'what matters' to people admitted for treatment of eating disorders.

Relationships with staff: Relationships with staff were central to experiences and satisfaction. Evaluation of whichever treatment component was rated/discussed was linked to staff behaviour and attitude, assumed to reflect knowledge and understanding of eating disorders.

Having staff that are trained, have that level of knowledge is a big, big, important aspect of treatment because without that support of people who have an understanding that you feel really, really vulnerable, like you're having to battle by yourself(P3).

While acknowledging that relationships, particularly with medical staff and/or early in admission, were fraught as treatment was 'imposed', participants commonly valued interactions with members of the specialist ED team. Team members were praised for appreciating the complexities of eating disorders and demonstrating compassion. Perceived empathy, particularly when treatment was coerced was described as motivating recovery. Feeling respected, accepted and validated were central concerns of all participants.

Interviewer: what qualities in the staff are helpful?

Table 1. perceived helpfulness of treatment components

| Statement re treatment component | responses | Disagree/ Strongly disagree | Agree/ Strongly Agree |
|--|-----------|--------------------------------|--------------------------|
| | n | | |
| Graduated leave encouraged me to challenge my eating disorder as part of my recovery | 40 | 8(20) | 32(80) |
| Adequate support was provided by staff when I needed it | 40 | 9(22) | 31(78) |
| My nutritional needs were met (within the hospital's capacity) | 40 | 9(22) | 31(78) |
| Supportive meal therapy was helpful to my recovery | 41 | 8(19) | 33(81) |
| There was a good balance between attention to my physical and mental wellbeing | 39 | 14(36) | 25(64) |
| I found meetings with the dietician helpful to my recovery | 38 | 4(10) | 34(90) |
| I found the "Community Challenge" helpful to my recovery | 28 | 1(4) | 27(96) |
| The follow-up arrangements for treatment after discharge were appropriate | 35 | 4(10) | 31(90) |
| The program has prepared me for life outside the hospital | 31 | 10(32) | 21(68) |
| Overall, I was satisfied with the treatment I received while a patient on in the eating disorders unit | 33 | 12(36) | 21(64) |

Table 2. Interview participant characteristics

| Participant | Interviews | Diagnosis | Age at diagnosis | Age at interview | Admission duration | Previous ED admissions | |
|-------------|------------|-----------|------------------|------------------|--------------------|------------------------|------------------|
| | | | | | | adult wards | adolescent wards |
| 1 | 1 | AN-R | 13 | 23 | 17 | 3 | multiple |
| 2 | 1 | AN-R | 15 | 24 | 6 | 2 | 1 |
| 3 | 2 | AN-R | 13 | 19 | 12 14 | 4 | multiple |
| 4 | 2 | AN-BP | 14 | 22 | 1 2 | 9 | 1 |
| 5 | 1 | AN-R | 16 | 18 | 3 | 0 | 3 |
| 6 | 1 | AN-R | 15 | 40 | 8 | 15 | 0 |
| 7 | 1 | AN-R | 14 | 23 | 38 | 6 | 0 |
| 8 | 1 | AN-R | 21 | 50 | 2 | 20 | 0 |
| 9 | 1 | AN-R | 17 | 21 | 4 | 5 | 0 |
| 10 | 2 | AN-R | 10 | 22 | 10 12 | 12 | multiple |
| 11 | 1 | AN-R | 18 | 22 | 3 | 1 | 0 |
| 12 | 2 | AN-R | 17 | 25 | 4 4 | 11 | 0 |

P2: ...understanding, supportive, patient...accepting you the way you are today. They may not like what the eating disorder makes you do and may express that, but they see you, the person, and the eating disorder as separate.

Participants in interviews and free-text reported developing insight and learning to manage disordered eating, thoughts and feelings in 'honest talks' with staff. 'Being listened to' by staff who were 'easy to talk to' was recurrently commended as therapeutic. Consensus was that, given ambivalence about treatment, a 'firm-but-fair' approach was helpful but, 'firm-but-fair' was a nebulous construct; perceived need for (continued) admission, motivation for recovery and comparators shaped expectations. Many participants observed that social isolation and long-standing family conflict which accompanied disordered eating meant that it was only in hospital that they were able to engage meaningfully with any others. Thus, the extent to which staff were able to establish and maintain interpersonal/professional boundaries, sharing just the right amount of themselves and expressing warmth, especially when managing 'challenging' behaviour (e.g. food refusal; self-harm) was central to assessment of calibre of staff.

Conversely, participants were robust in critique of staff (specifically non-eating disorder team members) whom they considered dismissive of eating-disordered behaviour and/or emotional distress. These non-specialist staff were typically described as untrained (in management of eating disorders, implicitly and sometimes explicitly considered a 'special area) and criticised for not appreciating the difficulties experienced by patients.

Untrained staff describe you as an eating disorder... they have not trust in us really... hold grudges and go about bringing things up in front of other patients. (P3)

Nutritional rehabilitation: Nutritional rehabilitation, not assessed in questionnaires was recurrently raised in interviews. While all participants agreed that re-feeding was 'successful' in that weight-gain enabled discharge, perceptions of the process and outcomes of re-feeding varied with motivation for recovery.

While many participants described personally struggling with meal planning, having lost the ability to gauge 'normal' eating and feeling ambivalent about weight gain, nutritional counselling was typically considered helpful. Participants reported valuing the 'wealth' of information provided, for example about how nutrition affected thinking, and acknowledged that the dietitian's 'reasoning' prompted awareness of and critical reflection on [eating disordered] views.

Knowledge of the ways people with eating disorders think is invaluable to challenging unhelpful beliefs. (Q7)

Consensus was that nutritional needs were met (or exceeded) but the quality and range of hospital food were widely criticised. Prescribed diets were variously considered 'too high' or 'too low' in specified food groups, depending on preference. Participants were concerned too about the 'strictness' of the re-feeding regime which they contrasted with 'real life'. Rigidity was said to inhibit development of skills needed to maintain healthy eating after discharge.

Supported meal therapy (SMT): Though rated as helpful in questionnaires, qualitative data demonstrated ambivalence about SMT, with views linked to approach of individual supervisors and participant's personal goals regarding eating and weight gain.

...the more aware and strict staff are at the table, the easier it is to fight the eating disorder.(P3)

Balancing attention to emotional needs and practicalities was critical to patients. While some supervisors were praised for making SMT 'fun', leading group-appropriate conversation to distract from concern about eating, others were described variously as 'too full on' or of 'little support', as 'policing' rather than supporting. Inconsistency between supervisors, repeatedly described by participants, was reported to undermine trust in SMT. Participants reported mixed experience of sharing meals with peers; they spoke of succour knowing that struggles were shared but also of feelings of irritation at others' unusual eating behaviour and learning ways to minimise nutritional intake.

I chose to eat my meals unsupervised because [SMT is] not helpful to me...I see them not eating; I don't want to be around that; I wanted this admission to be about getting better. (P6)

Psychosocial interventions: Psychosocial interventions, particularly group psychoeducation and mindfulness sessions were considered particularly helpful with many participants wishing for While some interview participants expressed concern about the potentially negative effects of interacting with patients whose motivation for recovery differed from their own, groups were typically described as engendering a 'sense of camaraderie between patients experiencing a similar transformation'. Having fun in groups was valued, 'schooly, authoritarian' group leadership was not. 'Community Challenges' (see text box) endorsed as helpful by the vast majority of questionnaire respondents (96%), were described in interviews as enabling connection with the real world', and, providing 'a chance to do things I didn't think I could. (Q3)

Adherence by the service to activity schedules/programmes was considered critical to building trust, enabling engagement and best outcomes.

Service improvements: Data were rich with suggestions for improvement. Chief amongst there were (i) increased personalization and flexibility of treatment, (ii) increased access to psychosocial interventions and, with many participants reporting concern about leaving the structured ward environment (iii) enhanced transition

from hospital to community. While typically acknowledging personal responsibility and access to 'tools and resources' needed for recovery, participants commonly 'wished' for 'step-down' care. This, in combination with increased emphasis on mental/emotional health during admission and more opportunity to practice skills and develop confidence in community settings would reduce risk of relapse.

Discussion

Our mixed-methods examination of the experiences of inpatient treatment for eating disorders has reinforced the view that positive experiences of care are intrinsically and instrumentally valuable. Even where weight gain was not welcomed, patients appreciated being treated respectfully by clinicians who were knowledgeable about their condition and empathic. Satisfaction with care was related to to be treated as a whole person, not *as* an eating disorder, with respect for individual experiences and vulnerabilities. Highlighting the importance of developing cognitive, emotional and practical skills needed in the 'outside' world, patients want attention to mind, along with body. In light of evidence that treatment drop-out is associated with lack of negotiation, and imposition of treatment focused on weight this seems particularly important [21]. Findings of this study resonate with and reinforce those of researchers who have examined patients' views in relation to eating disorder treatment [13-20] and psychiatric inpatient care generally [10-12].

Implications of findings should be considered in light of limitations. While eligibility criteria were broad we cannot know how representative the questionnaire and interview samples are of the population of inpatients and people seeking treatment in other settings. Moreover given data are a product of interpersonal engagement between interviewers and participants, and analysis is necessarily shaped by researcher characteristics findings are vulnerable to the subjectivity critique applicable to all qualitative research. The cross-sectional nature of the study and inability to link outcomes with reports makes findings descriptive rather than explanatory. Generalisability is uncertain. However these limitations are balanced by the real-world nature of the study and the ways in which interview data enriched questionnaire findings; we are encouraged by the frank and critical commentary in questionnaires and interviews. We put this account forward as a credible representation of the views of participants that could inform development of inpatient treatment for eating disorders.

Calls for support during admission to build skills needed in the 'real world' highlight the critical but partial role of inpatient care in responding to the unique predicaments [18,32]. of people with eating disorders. As observed by McKnight [32]. recounting her recovery 'each course of treatment' supported 'steps towards recovery' but hospitals and specialists cannot cure. 'They can help initiate change but the legwork is done at home day after day'.

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