The experience of patient dropout from eating disorders treatment: A systematic review and qualitative synthesis

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Background

- Eating disorder treatment dropout rates can be as high as 50% – the greatest of any psychiatric condition¹.
- Patients dropping out are more likely to endure poorer health outcomes and a more chronic and severe condition, with implications for patients, their families and health services¹.
- High dropout rates have ramifications on research validity, reliability, generalisability and statistical power, limiting the value of study findings and the development and refinement of treatments.
- Current research does not offer a complete understanding of the explanation behind dropout, definitive dropout predictors or associated risk factors.

Aim

- To collate and synthesise the current qualitative literature available on the patient experience of dropout from eating disorder treatment, emphasising key themes and highlighting any clinical implications.

Methodology

- Databases searched: MEDLINE, PsycINFO, EMBASE and CINAHL
- Inclusion criteria: patient experiences of dropout from any eating disorder treatment type using qualitative methodology of data collection or analysis, any age or sex, eating disorder diagnosis meeting DSM or ICD criteria, a comparable dropout definition provided.
- Quality assessment was performed using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist.
- Thematic synthesis was used to analyse the primary research (Thomas and Harden, 2008).
- Codes were extracted, translated across the studies and grouped into descriptive sub-themes according to their meaning and context then inductively interpreted into overarching analytical themes.

Results

Ten studies were included in this review. Four analytical themes were developed, encompassing 14 descriptive sub-themes (Figure 1).

Theme 1: INNER CONFLICT

- Patients experienced significant psychosocial difficulties, culminating in an inner struggle that led to treatment dropout.
- Patients faced an internal battle when made to choose between maintaining long-standing disordered behaviours, that provided comfort and a sense of control, and entering treatment and “giving up” their disorder, considered intrinsic to their self-identity.
- Further factors implicated were the experience of disabling mental illness, illness denial, low motivation for treatment, crippling fear around weight gain and rejection, and a struggle with the stigma associated with mental health diagnoses and receiving treatment.

Theme 2: CONNECTION AND COMMUNICATION WITH OTHERS

- A lack of social support, family and home life tensions, and a breakdown of the patient-clinician relationship were commonly described as factors leading to treatment dropout.
- Patients felt misunderstood and unheard by staff whom they felt put in little effort to meet their needs as they did not understand their problems.
- Further implicated were feelings of not belonging within the treatment setting (e.g. group therapy) and feeling unable to share experiences.

Theme 3: EXPERIENCE OF THE TREATMENT SERVICE

- Patients dropped out due to dissatisfaction with treatment, feeling their needs and expectations were unmet.
- It was felt support was inadequate and impersonal, a greater degree of clinician-led guidance was expected, and certain programme aspects were not valued (e.g. poor food options, lack of freedom).
- Patients left treatments they felt were hyper-focused on food and body image and neglected their emotions.
- Patients reported negative experiences and feeling unsafe during treatment, implicating overwhelming feelings, lacking trust in other patients and the treatment process and inappropriate care settings (e.g. general psychiatric wards or age inappropriate wards).

Theme 4: PROGRESS IN TREATMENT

- Patients dropped out due to a variety of practical and health-related obstacles that hindered their progress through treatment, including service provision and accessibility concerns.
- Long commutes, lengthy treatment waiting times, financial concerns and difficulties using technology-based therapies were also implicated.
- Some patients needed to leave in order to enter more intensive treatment or needing supportive weight management.
- Patients also dropped out due to making sufficient progress in treatment or wanting to stepdown care.

Conclusions

The decision to drop out from eating disorder treatment is a complex, multi-faceted issue, involving an interplay between individual, social and service-level factors. This review highlights the need for:

- Continued larger qualitative investigation into dropout experiences, with increased representation across ethnic groups and gender identities.
- A reconsideration of current clinical practice and services provision with an emphasis on the use of patient perspectives to guide decision making in eating disorder services delivery and research.
- Standardised dropout definitions, fostering a unified literature base.