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Psychiatric Bulletin (2009), **33**, 26–29. doi: 10.1192/pb.bp.107.018325

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Problems across care pathways in specialist adult eating disorder services

AIMS AND METHOD

Despite considerable knowledge of outcomes for patients who complete treatment for eating disorders, less is known about earlier stages in the treatment journey. This study aimed to map the efficiency of the anticipated patient journey along care pathways. Referrals to specialist eating disorder services ($n=1887$) were tracked through the process of

referral, assessment, treatment and discharge.

RESULTS

The patient mortality rate was low. However, there were serious problems of attrition throughout the care pathways. Of the original referrals where a meaningful conclusion could be reached, in approximately 35% the person was never

seen, only half entered treatment and only a quarter reached the end of treatment.

CLINICAL IMPLICATIONS

This study demonstrates considerable inefficiency of resource utilisation. Suggestions are made for reducing this inefficiency, to allow more patients the opportunity of evidence-based care.

There is clear evidence that there are effective treatments for some eating disorders (e.g. Fairburn & Harrison, 2003; National Institute for Health and Clinical Excellence, 2004). In order to maximise the uptake of such evidence-based treatments, specialist eating disorder services need to ensure that the patient progresses across the course of care (referral, assessment, treatment, discharge). Considerable resources are deployed to this end. However, such services are costly, and efficiency of resource deployment is key. Efficiency is substantially impaired where time is spent working with people who do not reach the end of the treatment. Such attrition is already recognised in the forms of drop-out and failure to engage (e.g. Coker et al, 1993; Mahon, 2000). However, other factors cause referrals to deviate from the typical course of care (e.g. inappropriate referral by clinicians; failure by patients to enter the care pathway). This study of specialist eating disorder services examines the journey from referral to treatment termination, with the aim of identifying potential areas for improvement in clinical and administrative practice to rectify these difficulties.

Method

The study was carried out in two highly specialised adult eating disorder services in south London (local catchment area population about 2.7 million; tertiary care provision for a further population of about 3.8 million). Each service has a patient-centred model of care offering a range of therapeutic interventions, in line with clinical guidelines (National Institute for Health and Clinical Excellence, 2004). Patients were accepted from the age of 18 years upwards. Treatment duration for in-patients and day patients was determined individually, and transitions were arranged according to individual clinical criteria (e.g. weight stability and ability to travel for day-patient work). For most people treated as out-patients, the treatment guideline was about 20 sessions for cases of bulimia and about 40 sessions for anorexia.

Over the two calendar years of the study (2002–3), a total of 1887 referrals were made to the two services (87.1% from the services' catchment areas, 12.9% from outside those areas). All information was gathered from



local case registration systems and case-notes, rather than from centralised electronic systems. Preliminary analyses revealed no difference in referral outcomes between local and non-local patients, so the two groups were considered as a whole. In some cases more than one referral was made for the same patient over time; each was treated as a separate data point. Treatment end-points were grouped according to the following broad categories (Fig. 1):

- referrals not resulting in the patient being seen (e.g. lacking key information; referrer lacking referral rights owing to being outside the relevant geographical area; patient declining assessment);
- patient assessed, but no further input (e.g. person did not have an eating disorder or declined treatment; referred to another service);
- treatment offered and accepted (e.g. failed to engage when treatment began; dropped out during treatment; completed treatment);
- plan for activity that had not had the opportunity to be put in place or to reach an end-point (e.g. on waiting list for assessment or treatment at audit point).

There were also a small number of cases in which the person had died or for which the treatment file was not available at the assessment point.

Results

Figure 1 shows the number and proportion of referrals that resulted in each of the main end-points. By the end of the audit, 634 individuals had not reached a care end-point, being still on the assessment ($n=114$) or treatment ($n=165$), waiting lists or still in treatment ($n=355$). The 279 cases on waiting lists were excluded in calculating percentages reaching specific end-points in the care pathway, as their outcome could not be known. A further 25 sets of notes (1.3% of the original 1887 referrals) were not available at the assessment point (usually owing to the individual having declined assessment and the notes having been returned to the relevant medical records department, where they were missing in the system of filing). These cases were also excluded from the analyses because it was not possible to verify the outcomes. The analyses were carried out on the remaining 1583 cases (or relevant subsets of that group).

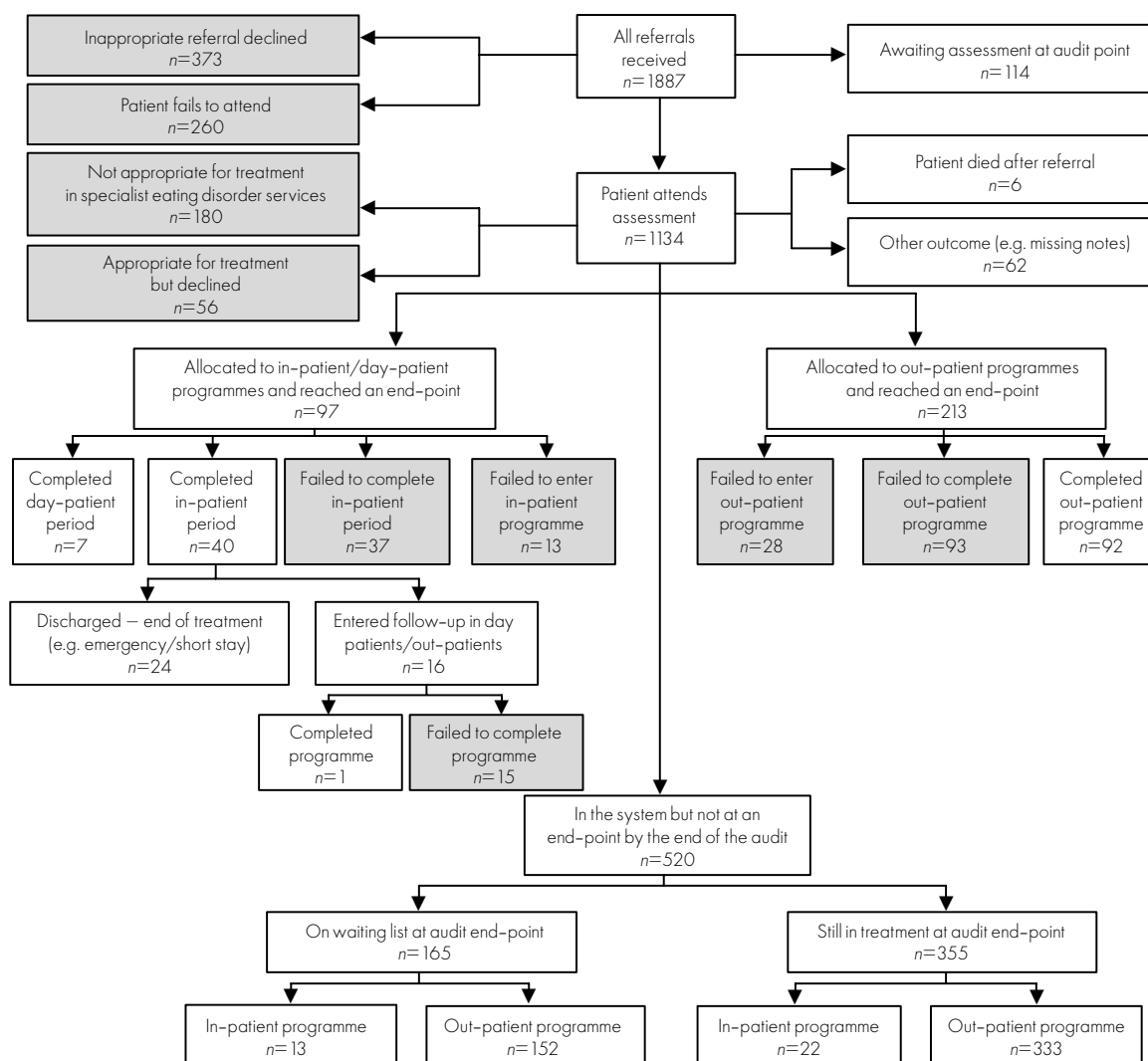


Fig. 1. Summary of outcomes of referrals. Grey boxes indicate areas where services could aim to improve (e.g. inappropriate referral; patient lost prematurely).



Common patient pathways

For the 1583 patients, the most common outcome was entry to out-patient treatment ($n=546$; 34.5%). A minority was entered into the more intensive forms of treatment of day-care and in-patient care ($n=119$; 7.5%). The second most common outcome was that the referral was inappropriate (e.g. no current eating disorder; no referral rights owing to being out of area) and was declined ($n=379$; 23.9%), and many patients failed to attend their assessment ($n=260$; 16.4%). A further 180 referrals (11.4%) were unsuitable for treatment in the local eating disorders service (e.g. primary problem of psychosis or substance misuse, moved out of catchment area), although none was refused on the basis of severity of eating pathology. In 56 cases (3.5%) the person was assessed and appropriate for treatment, but declined it. Six patients died over the course of the audit (0.053% of the 1134 patients who had entered the service and had reached the assessment stage). This figure is low compared with data from other studies (e.g. Nielsen & Bará-Carril, 2003; Crisp et al, 2006).

Outcome of entry to treatment programmes

Treatment pathway outcomes were available for 310 patients (a further 355 were still in treatment). The 'completed' group is likely to contain a somewhat higher proportion of cases of people who dropped out or failed to engage, as such patients are likely to remain in treatment for a shorter time.

Out-patient treatment

Of 213 patients who were offered out-patient treatment (face-to-face therapy or guided self-help) and reached an end-point, 28 (13%) failed to engage and 93 (44%) failed to complete the course of treatment. Thus, only 92 (43%) completed the programme. This figure represents only 5.8% of the 1583 referred cases under active consideration in this study.

More intensive treatment

Of 97 patients who entered an in-patient or day-patient programme and reached an end-point, 13 (13%) failed to engage and 37 (38%) failed to complete the course of treatment. Of the 47 who completed the programme, the majority had been in a short-term/physical recovery programme ($n=24$) or failed to complete the overall treatment programme following their transfer from in-patient to day care ($n=15$). Thus, only 8 of the 97 patients completed either stand-alone day-patient programmes ($n=7$) or day-patient programmes following in-patient admission ($n=1$).

Discussion

This study has shown considerable problems in the pathways for patients referred to specialist eating disorder services. There was substantial attrition throughout the referral–assessment–treatment–discharge pathway. Only two-thirds of referrals resulted in an assessment. Of

these, only three-quarters entered treatment. Finally, only half of those who entered treatment completed it. In simple terms, for every 100 referrals approximately 65 will be assessed, 49 will enter treatment and 25 will remain in treatment until the appropriate end-point (although it will be important to consider the actual dose of treatment received by those who drop out). Other studies show high rates of drop-out and failure to engage (e.g. Coker et al, 1993; Mahon, 2000), but have not taken the whole patient journey into account. The generalisability of these findings to other specialist and general psychiatric services remains to be established.

There is a need for changes in administrative and clinical practice in order to enhance efficiency of care. At an administrative level, clearer guidelines are needed for referrers regarding valid referrals (who has referral rights; what patients are suitable; what information is needed). Where there is a relatively transient population, such as that in London, many referrals are invalidated by patients moving home (into a new catchment area). This requirement might be reconsidered, to reduce patients needing multiple referrals that fail to result in an assessment or treatment.

Once a valid referral has been made, there are several ways in which clinical practice could be changed in order to enhance retention at the points where patients are commonly lost to services (Fig. 1). First, direct telephone contact with patients to negotiate potential initial appointment dates and times is likely to be more effective than sending appointment letters in ensuring attendance for assessment. Second, patients often find it valuable to have information provided in written form (e.g. National Institute for Health and Clinical Excellence guidelines, information sheets about the clinic and the eating disorders) so that they can review it before and after the assessment. Third, once the patient has attended for assessment, motivational techniques (e.g. Geller, 2002) can enhance the likelihood that the patient will prioritise her or his own recovery. Such techniques include motivational interviewing, comprehensive validation, the development of lists of short- and long-term 'pros' and 'cons' of the eating disorder, and considering how the eating disorder has blocked the development of the patient's personal values (e.g. the desire to be in a relationship or to be an effective parent) (e.g. Linehan, 1993; Waller et al, 2007). Such motivational enhancement is not a stage in the treatment of the eating disorder, but is necessary throughout the treatment episode. Increasing the focus on motivation reduces drop-out from psychological therapy for many patients with an eating disorder (Fairburn, 2008). Fourth, where appropriate, it can be valuable to engage carers in the patient's assessment and treatment (e.g. Treasure et al, 2007), in order to provide the patient with the opportunity to access support between meetings with clinicians. Finally, once treatment has started, patients are more likely to be motivated to remain in treatment if they can see its benefits. Therefore, it is critical that clinicians should use the best available treatments for eating disorders (Fairburn & Harrison, 2003; National Institute for Health and Clinical Excellence, 2004), monitor outcomes with the

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patient, and stress the positive prognostic value of making early behavioural changes (e.g. Agras et al, 2000).

Declaration of interest

None.

Acknowledgements

This research was funded by the NHS Audit Information and Analysis Unit for London, Kent, Surrey, Sussex, Essex, Bedfordshire and Hertfordshire, UK.

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