

Comparison of Specialist and Nonspecialist Care Pathways for Adolescents with Anorexia Nervosa and Related Eating Disorders

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ABSTRACT

Objective: To explore the role of specialist outpatient eating disorders services and investigate how direct access to these affects rates of referral, admissions for inpatient treatment, and continuity of care.

Method: Services beyond primary care in Greater London retrospectively identified adolescents who presented with an eating disorder over a 2-year period. Data concerning service use were collected from clinical casenotes.

Results: In areas where specialist outpatient services were available, 2–3 times more cases were identified than in areas

without such services. Where initial outpatient treatment was in specialist rather than nonspecialist services, there was a significantly lower rate of admission for inpatient treatment and considerably higher consistency of care.

Discussion: Developing specialist outpatient services with direct access from primary care is likely to lead to improvements in treatment and reduce overall costs. © 2012 by Wiley Periodicals, Inc.

Keywords: adolescents; anorexia nervosa; care pathways; inpatient treatment; outpatient treatment; service organization

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Introduction

The growing body of literature on the efficacy of outpatient treatments for adolescents with anorexia nervosa shows that family therapy is effective¹

and has excellent long-term outcomes,^{2–4} and it is consequently recommended in clinical guidelines.⁵ Studies show that the great majority of young people with anorexia nervosa can be treated on a purely outpatient basis, with 70%–90% at least partially recovered by the end of 6–12 months of treatment and relapse rates of less than 10%.^{1–4} Although the use of such evidence-based treatments is growing in this area, clinical practice still varies considerably. UK national figures show that prolonged inpatient treatment is relatively common, with admission rates of over 35% for adolescents⁶ and over 50% for younger patients,⁷ and psychiatric bed use for young people with eating disorders being higher than for any other diagnostic group.⁸ There is no clear evidence in favor of inpatient care over outpatient care,⁹ and some evidence that long-term admission may have a negative impact on outcome,¹⁰ as well as being more costly.¹¹

In the United Kingdom, outpatient treatment settings for adolescents with anorexia nervosa range from general mental health services to highly specialized eating disorders services, but little is known about the impact of these different settings on treatment outcomes. One randomized-controlled trial, the Treatment Outcome for Child and Adolescent Anorexia Nervosa (TOuCAN) trial, which compared general and specialist outpatient treatment, found no association between physical and psy-

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chological outcomes and service specialization.¹² In this trial, specialist services provided a relatively brief manualized intervention, with individual cognitive-behavioral therapy as a central component, and general services provided nonstandardized treatment as usual, which in most instances was a multidisciplinary family-based approach. Although this was clearly an important study, low rates of adherence to allocated treatment limit interpretation of the findings.

The TOuCAN trial, among others, illustrates the fact that health service-level questions often cannot be fully answered by randomized-controlled trials^{13,14} and, as many have argued, point to the need for a broad range of research designs to address different types of questions.¹⁵ This study aimed to make use of existing differences in service organization for adolescents with anorexia nervosa and related eating disorders using London^a as an exemplar and to explore the impact of these differences on rates of referral to services beyond primary care, rates of admission for inpatient treatment, and continuity of care. We conducted a naturalistic, retrospective cohort study to address the following main hypotheses: (1) accounting for population size, more adolescents with anorexia nervosa and related eating disorders would present to services beyond primary care in areas where specialist outpatient care was available than in areas with no specialist outpatient service provision; and (2) accounting for severity of symptoms at presentation, a lower proportion of those from the specialist care pathway than from the nonspecialist care pathway would be admitted for inpatient treatment^b during the first 12 months of treatment.

Method

Service Mapping, Recruitment, and Categorization

We conducted a mapping exercise to identify services providing the majority of treatment for adolescents with eating disorders in London. This comprised a search of public and private healthcare providers' websites, the UK Government-funded children's service mapping exercise¹⁷ and publications by the Royal College of Psychiatrists.^{18,19} A list of mental health services was compiled, excluding primary care services, specialist services for

problems other than eating disorders, local authority services, school health projects, and educational psychology services. A researcher contacted the services to confirm arrangements for managing eating disorders in their area and request completion of a questionnaire about treatment provision. Information provided was used to compile a final list of eligible services, who were invited to participate in the study.

Outpatient services were divided into specialist eating disorders services and general child and adolescent mental health services (CAMHS). Existing criteria^{19,20} were adapted to give the following criteria for a specialist outpatient eating disorders service: a minimum of 25 new eating disorders referrals per year; a multidisciplinary team, including medical and nonmedical staff and more than one person with experience of treating eating disorders; a team with the expertise to deliver recommended treatments (assessment of physical risk and psychological therapies including family therapy)⁵; and the resources to offer routine outpatient treatment.

Participant Identification, Recruitment, and Data Collection

Services identified 13–17 year-olds who met the following criteria: initial face-to-face contact with service, or recontact after a treatment break of at least 6 months, between 1 December 2006 and 30 November 2008; primary diagnosis of anorexia nervosa, bulimia nervosa, or an eating disorder not otherwise specified (EDNOS) at initial or recontact; and registered with a general practitioner from a London primary care trust (PCT).^c Cases were identified through searches of electronic patient records, correspondence with patients, clinical diaries, referral lists, funding records, or audit data. Cases with ambiguous diagnoses, such as "eating disorder" or "atypical eating disorder," were reviewed by researchers using anonymized data and classified into EDNOS-AN or EDNOS-BN (eating disorders not otherwise specified similar in presentation to anorexia nervosa or bulimia nervosa, respectively) if enough information about symptoms was available.

Services sent a standard letter, information sheet, and consent form to the people they identified, asking for permission for researchers to access their clinical case-notes. A standard item sheet was used to collect data for consenting participants, including their PCT, personal characteristics such as age and gender, illness characteristics, and treatment and service use for the 12 months after entry into services. Services were asked to provide more limited data for eligible people who had not given consent.

^a"London" here refers to Greater London, an area spanning ~600 square miles, with a population of ~7.83 million.¹⁶

^b"Inpatient treatment" here refers to medium- to long-term admission for weight restoration and/or psychiatric treatment, not admission for acute medical stabilization only.

^cAt the time of this study, publicly funded general practices in London were grouped under 31 PCTs—commissioning bodies determining the accessibility of secondary and tertiary services for National Health Service patients.

Data Analysis

To test Hypothesis 1, care pathways were mapped according to agreements between PCTs and service providers. The defining element of each pathway was the type of outpatient service providing treatment following referral from primary care. PCTs were grouped according to the pathway they funded, and adolescents were grouped according to their PCT. Data for both consenters and nonconsenters were included. "Presentation rates" were calculated for each PCT, using the number of cases identified by services and population statistics from the Office for National Statistics.²¹ For each PCT, the calculation below was performed, separately for females and males. Mean presentation rates were compared between PCT groups by an analysis of variance (ANOVA) using diagnostic plots to check that required assumptions held.

Presentation rate of N cases per 100,000 population of 13–17 year-olds per year = [N cases identified/(population of 13–17 year-olds in 2007+2008)] × 100,000

Data from consenting participants only were used to test Hypothesis 2. To assess the representativeness of the sample, comparisons of personal, illness, and service variables were made between consenters and nonconsenters, using independent samples *t*-tests for comparisons of continuous variables and chi-squared tests or Fisher's Exact Tests for categorical variables. Care pathway groups were established in two ways: by PCT, as for Hypothesis 1, and by actual care pathways followed. To establish actual care pathway groups, participants' journeys into and through services in the subsequent 12 months were drawn out and grouped according to the first service they had face-to-face contact with. The proportion of participants who followed each step in a pathway was then determined. Binary logistic regression was used to compare rates of admission for inpatient treatment between groups.

Power Calculation

A power calculation was performed, based on the expectation of two main care pathways (starting with either a specialist outpatient eating disorders service or a general CAMHS) and estimated admission rates of 10% (from audit data) and 35%,⁶ respectively. A chi-squared test at a significance level of 5% to detect a difference with a power of 80% indicated that 43 participants per group would be needed to show a statistically significant difference in rates of admission for inpatient treatment.

Ethical Approval

The study was reviewed and approved by an NHS research ethics committee (ref. 07/H0720/119). To maximize sample size and generalizability of findings, we applied to the Patient Information Advisory Group

(PIAG) for permission to access clinical casenotes without participants' consent. This application was not approved, as PIAG felt that potential participants were not recent enough contact with services to make obtaining consent practicable. Subsequently, the National Information Governance Board, which replaced PIAG, allowed us to store nonconsenters' initials and dates of birth, enabling identification of duplicates in the nonconsenting sample^d (ref. ECC 6-06(1)/209).

Results

Forty-four eligible services were identified, of which 37 provided the required data. Potentially substantive differences in eating disorders expertise between general CAMHS were identified: they were therefore split into self-defined "specialist CAMHS" and "nonspecialist CAMHS," and the plan of analysis was amended to include pairwise comparisons between care pathways based on referral to specialist outpatient eating disorders services and care pathways based on referral to both types of CAMHS.

Presentation Rates to Services beyond Primary Care

Once duplicates were identified and ineligible cases removed, the number of suitable cases identified by services was 378. The number of males was too small ($N = 22$) to run further analyses. Services provided specific diagnoses for 287 females, of which 200 were anorexia nervosa or EDNOS-AN, and 87 were bulimia nervosa or EDNOS-BN. For 58 females, services only provided a diagnosis of "eating disorder," and there were insufficient additional data available to place these into a more specific diagnostic group.

Three PCT groups were formed, based on the care pathways outlined above. Four individual PCTs were excluded, as the outpatient services in their catchment area did not provide data. The grouping of included PCTs and cases is shown in **Table 1**. Known diagnoses were used to calculate an "observed presentation rate" and "estimated presentation rates" were calculated based on the assumption that the same proportion of missing and known diagnoses were anorexia nervosa or

^dIdentification of duplicates was required to allow the accurate calculation of new cases per PCT, for the purpose of testing Hypothesis 1. As referral between treating services was common, and indeed a main focus of this study, we wanted to distinguish between movement of new cases from primary care into treating services and movement of cases between services once treatment was underway.

TABLE 1. Cases by primary care trust (PCT) group

PCT Group	Anorexia Nervosa/ EDNOS-AN		Bulimia Nervosa/ EDNOS-BN		Eating Disorder ^a		Total
	Females	Males	Females	Males	Females	Males	
Specialist eating disorders service (12 PCTs)	112	8	62	1	25	1	209
Specialist CAMHS (5 PCTs)	50	3	15	0	5	0	73
Nonspecialist CAMHS (10 PCTs)	38	3	10	3	28	3	85
Total	200	14	87	4	58	4	367

Notes: CAMHS: Child and adolescent mental health service; EDNOS-AN: Eating disorders not otherwise specified (EDNOS) similar in presentation to anorexia nervosa (AN); EDNOS-BN: Eating disorders not otherwise specified similar in presentation to bulimia nervosa (BN).

^aCases where services did not provide a more detailed diagnosis than "eating disorder."

EDNOS-AN (69.7%) and bulimia nervosa or EDNOS-BN (30.3%). As the focus of this article is anorexia nervosa and EDNOS-AN, results for these diagnoses only are presented.

Mean observed presentation rates (per 100,000 13–17 year-olds per year) were 62.6 for the specialist eating disorders service group, 74.4 for the specialist CAMHS group, and 26.9 for the nonspecialist CAMHS group. Estimated presentation rates were 72.6 for the specialist eating disorders service group, 79.3 for the specialist CAMHS group, and 44.4 for the nonspecialist CAMHS group. Unadjusted pairwise comparisons showed that rates for the nonspecialist CAMHS group were significantly lower than those of the specialist eating disorders service group (observed rate: $p < .01$; estimated rate: $p = .04$). The rates of the specialist CAMHS group did not differ significantly from those of the specialist eating disorders service group (observed rate: $p = .41$; estimated rate: $p = .98$).

Participant Recruitment and Characteristics

Of the 378 adolescents approached, 127 (34.6%) consented to the study, 15 (4.0%) refused consent, 235 (62.2%) did not respond, and 1 (0.3%) had died, having withdrawn from treatment in a nonspecialist CAMHS. Distribution of eating disorder diagnoses did not differ between consenters and nonconsenters ($p = .16$). Subsequent comparisons include those with anorexia nervosa or EDNOS-AN only, of whom 93/220 (42.3%) consented to the study. There were no statistically significant differences between consenters and nonconsenters in age, gender, ethnicity, body mass index at assessment, first service attended, number of participating services attended during the study period, or attendance at a participating inpatient service during the study period (for all $p > .05$). The only significant difference was in PCT group: a higher proportion of the specialist eating disorders service group (55.0%) consented to the study than the specialist

CAMHS (26.3%; $p < .01$) and nonspecialist CAMHS groups (23.3%; $p < .01$).

The mean age of the consenting sample at assessment was 15.1 years and 96.8% were female. Of those for whom data were available, 82.7% belonged to Social Class I or II. Mean weight for height^e at assessment was 82.8%, average weight loss before assessment was 12.3 kg, and mean duration of illness was 8.1 months. Data regarding ethnicity were missing for 6.5% of the sample. Of those for whom data were available, 73.6% described themselves as White British, 8.0% as White European, 4.6% as Mixed White and Black, 4.6% as Asian or British Asian, 3.4% as Mixed White and Asian, 2.3% as Black or Black British, and 3.4% as Other Ethnicity. The majority of participants (69.9%) were referred for treatment by their general practitioner. Comparisons between PCT groups revealed no statistically significant differences in age, gender, ethnicity, weight for height percentage at assessment, or referrer (for all $p > .05$).

Admissions for Inpatient Treatment

Admissions for inpatient treatment did not differ significantly by PCT group. However, a different picture emerged when actual care pathways were examined. Analysis of presentation rates and mapping of actual pathways suggested that specialist eating disorders services and specialist CAMHS were comparable in terms of presenting cases and admissions for inpatient treatment. Therefore, the following actual care pathway groups were formed:

1. Specialist assessment to specialist treatment ($N = 53$): assessment and treatment in a specialist National Health Service eating disorders service or specialist CAMHS;

^eWeight for height percentage was calculated using a computerized program based on the Child Growth Foundation data, which compares median percentile BMI adjusted for age and sex with actual BMI.

2. Nonspecialist assessment to specialist treatment ($N = 16$): assessment in a nonspecialist CAMHS followed by treatment in a specialist National Health Service eating disorders service;
3. Nonspecialist assessment to nonspecialist treatment ($N = 15$): assessment and at least initial treatment in a nonspecialist CAMHS;
4. Private assessment to private treatment ($N = 6$): treatment in a private eating disorders service (excluded from subsequent analyses as our aim was to explore publicly funded pathways).

The key difference between these actual care pathways and those that would be expected based on PCT agreements was that a number of CAMHS in the catchment area of a specialist eating disorders service did not automatically refer on following assessment and more people than would be expected were, therefore, assessed and started treatment in nonspecialist services.

A total of 8/53 (15.1%) of the specialist assessment to specialist treatment group were admitted for inpatient treatment, compared with 3/16 (18.8%) of the nonspecialist assessment to specialist treatment group and 6/15 (40.0%) of the nonspecialist assessment to nonspecialist treatment group. The binary logistic regression analysis estimated that when baseline weight for height percentage was adjusted for, compared with the specialist assessment to specialist treatment group, the chance of admission in the nonspecialist assessment to specialist treatment group was 32% higher (adjusted OR = 1.32; 95% CI 0.30–5.81, $p = .71$) and the chance of admission in the nonspecialist assessment to nonspecialist treatment group was 261% higher (adjusted OR = 3.61; 95% CI 1.00–13.02, $p < .05$).

Continuity of Care

Mapping of actual care pathways highlighted a difference in continuity of care, depending on where outpatient treatment started. In the specialist assessment to specialist treatment group, 83.0% of participants stayed in their original treating service for the subsequent 12 months, compared with 75.0% in the nonspecialist assessment to specialist treatment group, and 41.7% in the nonspecialist assessment to nonspecialist treatment group. A post hoc chi-squared test revealed the proportion of those who remained in their original treating service was significantly higher in the specialist

assessment to specialist treatment group than in the nonspecialist assessment to nonspecialist treatment group ($p < .01$).

Discussion

This is the first substantial observational study to examine different models of service organization for adolescents with eating disorders. The main strength of the study is that it made use of existing differences in a well-defined geographical area, from which it would be highly unusual for patients to travel to receive treatment. We were successful in identifying and obtaining data from the majority of the eating disorders services and CAMHS in London. However, the failure to obtain data from some services did have a negative impact on the overall sample size and may have contributed to the over-representation of those treated in specialist services in the consenting sample.

The key findings of this study are: (1) accounting for population size, more than twice the number of adolescents with anorexia nervosa or EDNOS-AN were identified in areas with specialist outpatient eating disorders services than in areas with only nonspecialist services; (2) the rate of inpatient admission during the first 12 months of treatment was 2.5 times higher for patients who commenced treatment in a nonspecialist service than for those initially treated in a specialist service; and (3) nonspecialist care pathways were more complex, in that only 42% of those who started treatment in nonspecialist services continued for the next 12 months without being referred on, compared with over 80% of those seen in specialist services. The strength of these findings varies due to methodological issues, which we will address under the specific headings.

The low level of case identification in areas with no specialist outpatient service is consistent with previous survey results.¹⁸ It is our most robust finding, as it is based on the full sample of 367 cases. One potential explanation is that specialist services might be more likely to develop in areas where there is a high incidence of eating disorders. The history of such services in London does not support this explanation, as they cover a broad range of boroughs with divergent socio-demographic compositions, and referrals took several years to increase to current levels. A second explanation is that general practitioners with links to specialist services may have increased awareness of eating disorders and knowledge about treatment, meaning

they identify and refer more cases than those with no specialist links. A third explanation is that a lack of referral options in areas with no specialist services means cases are managed exclusively in primary services. This possibility is supported by previous research which suggested that general practitioners in areas where inpatient units comprise the only specialist service provision have higher referral thresholds than those in areas with specialist outpatient services.²² Finally, patient and/or parent preferences for specialist over non-specialist services may be influenced by the availability of services and change the threshold for seeking help.

Although there have been anecdotal reports of decreasing inpatient admissions in areas with specialist outpatient services,²³ this is the first study to provide empirical support for this. Our findings do need to be viewed with some caution because of the relatively small number of participants in this part of the study (42.3% of eligible cases), which meant the analysis was underpowered. The differential recruitment rate for those treated in specialist and nonspecialist services could also have potentially have biased the sample and influenced the results. However, comparisons between consenters and nonconsenters showed no statistically significant differences in the number of participating services accessed or attendance at any participating inpatient service during the study period.

Our findings differ from those of the TOuCAN trial,¹² which did not show a difference between admission rates for those randomized to specialist (27%) and nonspecialist (31%) services, although the latter admissions were longer and more costly.¹¹ However, our 40% admission rate from nonspecialist services is comparable with the 35% rate from CAMHS audit data⁶ and 50% rate for younger patients from research data,⁷ and our 15%–19% admission rate from specialist services can be compared with 10%–15% rates from treatment studies in specialist services.^{1,24} The high admission rate in the nonspecialist care pathway raises concerns. Inpatient treatment is costly,^{11,25} has high relapse rates,^{24,26} and may be associated with poor outcomes, even once severity of symptoms is accounted for.¹⁰ There is also some evidence that it is associated with lower rates of patient satisfaction than outpatient care.²⁷

The data for this part of the study is the least robust, partly because of the low number of participants, partly because of the risk of bias in recruitment in nonspecialist settings toward those who had an inconsistent and so perhaps less satisfac-

tory experience of care, and partly because there is no corroborating data from other studies. Nevertheless, given the magnitude of difference in continuity between the specialist (>80%) and nonspecialist (40%) care pathways, the findings need to be considered seriously. Negotiating transitions from one service to another can be problematic for patients, their families, and clinicians,^{28,29} and too much movement can make it difficult to build and maintain helpful therapeutic relationships. In a related qualitative study, a sense of being “sent from pillar to post” was highlighted as a source of dissatisfaction by those referred to general services.²⁹

Although our findings should generalize beyond London, it does differ from the rest of the United Kingdom in a number of important ways. The most relevant is that London contains a disproportionate number of the specialist eating disorders services in the country, which could potentially lead to “de-skilling” of nonspecialist services, meaning they have poorer outcomes in London than in areas where they provide the majority of treatment. However, areas of London without access to specialist services should be comparable with other areas of the United Kingdom. On the other hand, in areas of the country where the only alternative to nonspecialist treatment is hospitalization (precluding the possibility of referring to a specialist outpatient service when treatment is not working) rates of admission might be even higher than those found here.

Much greater caution is of course needed in generalizing to services in other countries, particularly when considering hospital admissions, as relationships between inpatient and outpatient services vary considerably. In the United Kingdom, recent years have seen professional opinion shift toward patients remaining in the community and out of hospital wherever possible. The threshold for referral from some outpatient services is relatively high, and adolescents may remain at home even at very low weights (e.g., <70% weight for height). In contrast, US clinical guidelines suggest that admission should be considered for children and adolescents whose weight for height may be greater than 85%.³⁰ Across Europe, the United States of America, and Canada, inpatient treatment settings vary, with general psychiatric units, specialist eating disorders units, pediatric units, and adolescent medicine units used differently, potentially influencing what is viewed as the aim of the admission (e.g., medical stabilization, weight restoration, or recovery from the eating disorder). Admission rates, length of stay, and intensity of therapeutic input during admission also differ.^{31–33}

Our data suggest that establishing specialist outpatient services to receive and respond promptly to referrals from primary care could lead to improvements in treatment for adolescents with eating disorders and reduce costs by reducing inpatient admissions. One question not fully answered by our study concerns the relative advantages of larger specialist eating disorders services, with big catchment areas, over local general mental health services containing specialist “mini-teams.” On the surface, our findings suggest that differences between the two may be relatively small, but the limitations of our study mean that further investigation is warranted. It is worth considering that developing a truly multidisciplinary “mini-team” can be difficult, and that such teams may be less stable in the long term and more vulnerable to the impact of staff turnover.

Researchers frequently bemoan the reluctance of clinicians to modify their practice according to new findings. It has been argued³⁴ that the existing gap between research and clinical practice is partly due to an overly narrow focus on evidence-based treatments (or an even narrower focus on validated treatments) rather than looking in a broader way at effective practice. This study demonstrates the importance of looking at the impact of service contexts on dissemination of new interventions, how standards of care are maintained and, perhaps above all, the extent to which effective treatments are available to those who require them.

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