

ORIGINAL ARTICLE

Paediatric Referral and Attendance Rates for the Clinical Genetics Service in South-East Scotland - a Comparison of a Regional Clinic with Satellite Clinics

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Abstract

Background and Aims

In some studies the establishment of specialist satellite clinics nearer to the homes of patients has resulted in increased referral and attendance rates, particularly amongst populations in lower socio-economic groups. We investigated the effect on these rates of establishing satellite genetic counselling clinics for families with paediatric conditions in South East Scotland.

Methods and Results

Families offered appointments at a clinic at the regional paediatric hospital were compared with those offered appointments at a satellite clinic at a local district general hospital. Both groups of families were more socially deprived than the general population (regional clinic $p < 0.001$, satellite clinics $p < 0.05$), and in both groups attendance rate at first appointment was 88% and inversely related to social deprivation. There was no evidence of greater attendance amongst more deprived patients at the satellite clinics compared to the regional clinic.

Conclusion

Our study found no evidence that the establishment of satellite clinics for genetic counselling in South East Scotland increases attendance by families with paediatric conditions in lower socio-economic groups. This suggests that factors other than clinic location determine referral and attendance rates, and these may include understanding of the reason for referral and the advantage of attendance.

Key Words

Genetic Counselling, Satellite Clinics, Socio-economic Deprivation

Introduction

It has been shown in several studies that the establishment of specialist clinics in general practice or community health care settings results in increased numbers of referrals (particularly from individuals in lower socio-economic groups),^{1,2} improved attendance rates and patient satisfaction.³ The present study was carried out to investigate the effect, for families with paediatric conditions, of establishing satellite genetic counselling clinics in South East Scotland.

The South East of Scotland Clinical Genetics Service serves a population of 1.2 million residents in the Lothian, Borders and southwest Fife Regions of Scotland. Families are referred for genetic counselling primarily by GPs and hospital consultants. At the start of the period of the current study the majority of families concerned about a paediatric disorder could only be seen at the regional paediatric hospital in Edinburgh. Satellite clinics were then established at three district general hospitals. Patients were then offered an appointment at the hospital nearest to their home. In the present study, families offered appointments at the regional clinic were compared with those offered appointments at one of the three satellite clinics with respect to referral and attendance rates and in particular the relationship of these rates to socio-economic status.

In the present study, comparisons were made between the referral and attendance rates (and in particular the relationship of these rates to socio-economic status) of the families offered an appointment at the regional clinic and the families offered an appointment at one of the three satellite clinics.

Method

Families

We studied 2,434 families who were first referred to the Clinical Genetics Service between 01/04/1989 and 30/11/2007. The families consisted of all those referred during this period who were offered an appointment at the regional clinic or were paediatric referrals (defined as those where a family member under 18 years of age was offered an appointment) to one of the satellite clinics. The numbers of families offered appointments at each clinic are given in Table I.

Social Deprivation

The Carstairs Deprivation Score (CDS) is a measure of social deprivation based upon overcrowding, male unemployment, low social class and car ownership.⁴ The distribution of the CDS

Table I. Numbers of families offered appointments at different clinics.

Clinic	Number of families
Regional	1501
Satellite 1	335
Satellite 2	306
Satellite 3	292
Total	2434

for Scottish postcode sectors has been restructured as a categorical variable (DEPCAT) (Carstairs Deprivation Category) ranging from one (the most affluent sector) to seven (the most deprived). Families were classified according to the DEPCAT Score for their postcode sector of residence, taken from the 2001 Census for Scotland.⁵ When several family members had the same first appointment date then the mean DEPCAT score for the family members was used. Families with DEPCAT scores 1-2.49 were classified as having low deprivation, those with scores 2.5-5.49 as having intermediate deprivation, and those with scores 5.5-7 as having high deprivation.

The number of families allocated a DEPCAT score was 2,284 (1,406 regional clinic, 878 satellite clinics). For some postcode sectors there was not a unique DEPCAT score, so families within these postcodes could not be classified according to social deprivation. Other families could not be allocated a score because their exact address at the time of the appointment was unknown. These families were omitted from the comparisons involving the use of these scores.

Population distributions of DEPCAT scores within regions of Scotland have been published.⁵ Observed numbers of families in the three DEPCAT groups offered appointments at each hospital were compared with expected numbers estimated from general population data for the catchment area of the hospital. Expected numbers were calculated by multiplying the total number of families referred to the given hospital by the percentage of the general population in each deprivation group. Individuals in the general population had DEPCAT scores as whole numbers from one to seven, and scores one and two were taken to indicate low deprivation, three to five to indicate intermediate deprivation and six to seven to indicate high deprivation. The chi squared test was used to compare observed and expected numbers of referrals for the regional clinic and for the three satellite clinics combined.

Attendance

For each family the date of their first appointment and whether it was attended by at least one family member were noted. If at least one family member attended the appointment, the family was classified as having attended. Cancelled appointments were not considered in the analyses as information about these was incomplete.

Comparisons were made between attendance at first appointment at the regional clinic and at the three satellite clinics combined (as numbers were small for the individual satellite clinics). Comparisons were made between overall attendance and between families in different deprivation groups and those

referred in different time periods using the chi squared test.

Results

Social deprivation of families referred

Numbers and percentages of families offered appointments at the regional and the three satellite clinics in the low, intermediate and high deprivation groups, together with the expected percentages from general population data, are given in Table II. A comparison was made between the observed and expected numbers of families in the deprivation groups. There was a highly significant difference between observed and expected numbers for the regional clinic ($p < 0.001$) and a significant difference for the three satellite clinics ($p < 0.05$), with a deficiency of families in the low deprivation group in both cases.

Table II. Observed numbers (%) of families offered appointments at different clinics in different deprivation groups, with expected percentages from general population data

Clinic	Deprivation Group	Observed number (%) families	Expected % families
Regional	Low	314 (22.3%)	26.9%
	Intermediate	944 (67.1%)	64.5%
	High	148 (10.5%)	8.6%
Satellite	Low	113 (12.9%)	16.2%
	Intermediate	722 (82.2%)	79.2%
	High	43 (4.9%)	4.6%

Attendance at first appointment

Table III gives the numbers and percentages of families who attended/did not attend their first appointment at the regional and the satellite clinics. The percentages of families attending were very similar for the two groups with almost 88% attending their first appointment.

Table III. Numbers (%) of families by attendance at first appointment at different clinics

Clinic	Number (%) families	
	Attended	Did not Attend
Regional	1288 (87.8%)	179 (12.2%)
Satellite	801 (87.5%)	114 (12.5%)
Total	2089 (87.7%)	293 (12.3%)

Attendance and Social Deprivation

Table IV shows the numbers and percentages of families who attended their first appointment at the regional and the three

satellite clinics according to deprivation group. For both clinic groups, attendance at the first appointment was greatest in the low deprivation group and lowest in the high deprivation group of families. Results for the regional clinic were almost identical to those for the combined data for the three satellite clinics. When comparing families who did and who did not attend their first appointment, the difference between the numbers in the three deprivation groups was highly significant for regional clinic families ($p < 0.001$) and significant for the combined data for the three satellite clinics ($p < 0.05$).

Table IV. Numbers (%) of families attending their first appointment at different clinics by deprivation group

Clinic	Number(%) families attending		
	Low deprivation	Intermediate deprivation	High deprivation
Regional	282 (91.0%)	817 (88.5%)	105 (73.9%)
Satellite	100 (90.9%)	623 (87.6%)	31 (73.8%)
Total	382 (91.0%)	1440 (88.1%)	136 (73.9%)

Attendance rates at first appointment at various hospitals in different time periods

Table V gives the numbers and percentages of families who attended their first appointment at different time periods since 1990. There has been a tendency for attendance at first appointment at the regional clinic to decrease and the trend was bordering on significance ($p = 0.052$). Combined data for the three satellite clinics showed no significant change in attendance rate. There was a highly significant ($p < 0.001$) difference between attendance at RHSC and at the satellite clinics. Attendance at the regional clinic at the start of the study was greater than in the three satellite clinics, but at the end of the time period the opposite was true.

Table V. Numbers (%) of families attending their first appointment in different clinics in different time periods

Years	Number (%) families attending		
	Regional clinic	Satellite clinics	Total
1990-94	269 (91.8%)	85 (85.0%)	354 (90.1%)
1995-99	236 (88.4%)	217 (88.2%)	453 (88.3%)
2000-04	490 (87.3%)	290 (88.1%)	780 (87.6%)
2005-07	293 (84.7%)	207 (87.0%)	500 (85.6%)
Total	1288 (87.8%)	801 (87.5%)	2089 (87.7%)

Discussion

Both the regional and satellite clinic groups of families with paediatric conditions were significantly more socially deprived

than the general population. By contrast, referrals with a family history of cancer to the South East of Scotland Clinical Genetics Service were less socially deprived than the general population.⁶ This may be because many referrals with a family history of cancer are well informed and take the initiative in seeking genetic advice. By contrast, for those with a family history of a paediatric condition, referral is likely to be initiated by a hospital physician. There is also evidence that Scottish couples with fewer educational qualifications have a greater number of children.⁷ In addition, several paediatric conditions may involve a degree of learning disability which may place the family at a disadvantage from a socio-economic perspective.

In a study of a satellite clinic programme in California,⁸ it was found that the patient population of the central clinic was essentially middle-class, but in the satellite clinics the mix was broader. In two studies of referrals to cancer genetic services^{1,2} the establishment of satellite clinics resulted in an increase in referrals of patients in lower socio-economic classes. There was no evidence for this in the present study. This may be because socio-economically deprived families with a history of cancer are more likely to request referral if a local clinic is available, whereas the referral practice of paediatricians may be independent of clinic location.

Approximately 88% of families attended their first appointment at both the regional and satellite clinics. In two other studies, outreach clinics had lower non attendance rates.^{1,3} The similar attendance rates in our study may reflect greater motivation to attend a clinic where a child with a disability is involved.

Both groups of families demonstrated an identical inverse relationship between attendance at first appointment and social deprivation. In another study this relationship was found amongst referrals with a family history of breast cancer and was felt to reflect poorer understanding in the more deprived group.⁶ We expected that attendance of more deprived families might be greater at the satellite clinics, as suggested by the results of two studies in the USA^{8,9} in which many patients were reluctant to attend a central clinic because of lack of understanding or financial resources.

There are a number of limitations to the present study. Firstly, it is possible that some of the families in the satellite clinic group may not have had paediatric conditions as they were selected simply by an appointment for an individual under 18 years of age. However, the majority of these families will have a history of a paediatric condition, so this should not bias the study findings. For simplicity we only considered attendance at the first appointment offered and some of those who did not attend may have been seen at a later appointment. However, the measurement of attendance at the first appointment does give an indication of motivation to attend.

We conclude that families referred for genetic counselling concerning paediatric conditions are more socially deprived than the general population, but attendance rates are lower in the more deprived groups. Contrary to expectation, in our study the establishment of satellite genetic counselling clinics in local hospitals has not resulted in an increase in referral or attendance rates amongst this group of more deprived families. Thus for these families, factors other than convenience of location determine referral and attendance rates, and these are likely to include level of understanding of the reason for attendance. There is thus a need to ensure that these families receive easily understandable information when a referral is made to the Clinical Genetics Service.

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Book Review

The Apocalypse of Napoleon Bonaparte

Robert Richardson

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The medically qualified author has written this book on the period at the end of Napoleon's battles, highlighting his last period from Waterloo through to his exile on Saint Helena. This medical biography deals mainly with the time of incarceration of Napoleon in St Helena, particularly drawing from the diaries of Napoleon's doctors.

The British Government through Lord Bathurst, Secretary of State for the Colonies, had decided to class Napoleon as a prisoner of war although Britain was not officially at war with France. The decision was that Napoleon should be taken to St Helena although Napoleon insisted that he had voluntarily surrendered to Captain Maitland. Inclement weather had delayed his intended departure to America and instead he was transported to St Helena.

The detailed account of Napoleon's existence on the island is recorded mainly from the information gained from his medical attendants. Much attention is focussed on the controls which the then Governor Sir Hudson Lowe exerted. This gentleman appears as a significant control freak. His tendency along this approach to Napoleon was enhanced by the appointment of Sir Robert Plampin as the Commander-in-Chief of St Helena and the Cape of Good Hope Naval Stations. Plampin's Achilles heel was that, when he was about to sail from Portsmouth, he was joined by a lady fetched by boat from the Isle of Wight. The 'Lady' Plampin was not met by approval of the upper class ladies on the island and resulted in Plampin having little authority and Lowe had more or less complete control.

In his preface the author comments on the fact that three years ago he had considered that in his book *Napoleon's Ulcer* he had solved the cause of the Emperor's death. Far from concluding discussion on the topic, the present book presents many further details of life on St Helena and the control exerted by Lowe. The doctors' diaries have substantial material included on the state of Napoleon's health, attitudes and behaviour. Where necessary the author has tried to express in current terminology the facts recorded. The autopsy report is there for analysis and interpretation but unfortunately there are not any histological details. Some previous diagnoses have been dismissed but a full and final answer has still to come.

This is an interesting addition to the substantial literature that has continued to interest and stimulate medical historians as well as the lay public

Reviewed by Professor Dan G Young

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