

Paediatric infliximab therapy: patients' and parents' perspectives on treatment options

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Aim: To assess patients' and parents' perspectives on the impact of infliximab treatment on daily life and the acceptability and feasibility of (infliximab or adalimumab) home treatment, in the light of the perceived value of hospital services.

Methods: A descriptive qualitative study was conducted at University College Hospital London. Data were collected via 25 semi-structured interviews with patients (aged 14–19) from both gastroenterology and rheumatology specialties, prescribed infliximab, and their parents.

Results: The majority of participants preferred to continue infliximab treatment at their current hospital, rather than be treated in their local hospital or at home. The main reasons were the specialised care in their current hospital, the continuity of care and hospital staff, resistance

to the method of adalimumab administration and expected problems with compliance. Hospital services were highly valued and current infliximab treatment at the hospital was considered to have either no impact on family and school life, or to have improved it.

Conclusion: Infliximab is an effective therapy for inflammatory bowel diseases and rheumatology conditions in young people, bringing either no negative impact on, or improvement of school and family life. In association with patients' and parents' positive appraisal for hospital services and their confidence in the clinical team, patients and parents do not express a preference for infliximab or adalimumab home treatment, despite current health policy aimed towards therapy closer to, or at, home.

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Introduction

Infliximab, an effective and licensed anti-TNF- α agent for both induction and maintenance therapy of inflammatory bowel disease (IBD) and rheumatoid arthritis (RA)¹⁻⁴, is currently only administered in the hospital setting, though this mode of provision is under review^{5,6}. In gastroenterology, it is delivered as an intravenous infusion at a dose of 5–10 mg/kg over a two hour period at intervals of eight weeks^{2,7}. For induction in juvenile idiopathic arthritis (JIA), a dose of 6 mg/kg is recommended⁸.

Adalimumab, a fully human monoclonal antibody against TNF- α , is an alternative to infliximab and in paediatric rheumatology is given as a subcutaneous injection every two weeks (dose 24 mg/m², maximum dose 40 mg). After the patient is trained in the administration method, adalimumab treatment can be safely given at home. Adalimumab is licensed for use in RA and has potential value in IBD⁴. Since adalimumab might have advantages over infliximab, in terms of less antigenicity⁹, convenient home administration, less frequent hospital visits and reduction of hospital costs¹⁰, it is a promising treatment option. Although these TNF- α blockers have improved treatment choices in adults, less experience has been reported in paediatric patients⁶.

The UK's National Health System (NHS) has set national targets, which include focussing on the importance of patient choice and on care provision closer to, or at, home¹¹. The National Service Framework (NSF) for Children emphasises these goals, to help children and young people with a chronic condition experience an "ordinary" life and to reach their full educational potential¹². Since only a quarter of England's hospitals provide an environment and services that are fit for children and adolescents¹³ and since the demands placed on the NHS by young people will grow¹⁴, it is useful to consider the future of paediatric and adolescent infliximab services. This will make it possible to improve health services and quality of care. In this study, we have considered patients' and parents' perspectives on the impact of current treatment on school, work and family life and the acceptability and feasibility of transferring therapy from hospital to home in the context of how individuals value hospital services.

Methods

A descriptive qualitative study was conducted at University College Hospital, London. Data were collected in semi-structured interviews

with paediatric outpatients and their parents during their routine attendance at the hospital for infliximab treatment. This study was part of an audit evaluation of services for young people and their parents, and an assessment of possible service development.

All paediatric patients from both gastroenterology ($n=12$) and rheumatology specialties ($n=6$) who were prescribed infliximab, and their parents, were invited to take part in the study. A letter with a separate information leaflet was posted to patients and their parents. At their outpatient appointment, the nurse in charge and the interviewer asked whether they consented to take part.

Interviews with the patients and parents were conducted separately, to gain independent perspectives. Patient interviews took place on the ward, during their regular infusion period. Interviews with the parents took place in a private interview area in the hospital. All participants agreed to audio-recording and all interviews were conducted in English.

Open questions following the principles of qualitative enquiry, in which requests for further details about the views and experiences of the participants, were used to obtain an accurate reflection of their views on the main topics described in this study. The audio-recorded data were anonymised and transcribed verbatim to enable qualitative analysis. By using a primary and secondary coding frame, all problems, ideas, disadvantages and advantages raised about the different themes of the interview were analysed separately from the perspectives of patients and parents. Quantitative procedures were employed to describe patients' and parents' characteristics and responses regarding features of the impact of treatment on daily life, the potential of home treatment and the hospital service provision.

Results

Twenty five patients and parents participated in the study. Three patients with JIA, two patients with Enthesitis Related Arthritis (ERA) and 10 patients with IBD ($n=15$) participated, as well as all the parents who accompanied their child to the hospital ($n=10$). The mean age of the patients was 17.3 years (range 14–19), with four patients under the age of 16. The mean duration of infliximab therapy was 29 months (range 2–100), with a distance from home to the hospital of 3–334 kilometres. For 22 of the participants, English was their first language.

Impact on daily life

No noteworthy different views or experiences were found between the patients and parents. Thirteen individuals stated that current infliximab treatment regimens did not have an impact on family life. Nine felt infliximab treatment had improved family life. Treatment had made a huge impact on the illness itself and made life for both patient and parent easier, with the family feeling less restricted and able to do more as a unit. One parent believed that infliximab treatment had had a negative impact on family life. Two individuals did not express an opinion about the impact of infliximab treatment on family life.

Ten individuals believed infliximab treatment had a positive impact on school life. Ten others felt it had no impact, while two did not comment. The majority of patients reported that they were able to catch up with missed school work, as classmates and teachers were supportive, understanding and helpful. Three individuals stated that infliximab treatment had a negative effect on school life, because of missing classes and lectures, especially before exams.

Home treatment

Fourteen individuals expressed their wish to continue infliximab treatment at their current hospital, rather than be treated locally. Seven showed no preference for either current or local treatment. Four individuals would prefer to move to a local hospital. The main reasons for the preference for treatment at their current hospital were the availability of specialised care, the good inter-personal contact with the hospital staff and having consistency and continuity of care. Reasons for preferring local treatment were convenience and less travelling time; in these cases travel time exceeded 90 minutes. Two parents commented that local treatment may be easier to accommodate alongside working commitments.

Although both patients and parents saw 'no travelling time to hospital' as the main advantage

of home treatment, 14 were negative about infliximab therapy at home. Six stated no preference, whilst five would prefer infliximab treatment at home. The reasons for preferring infliximab treatment at home or at the hospital are summarised and ranked in terms of participants' perceived importance in Table 1.

Adalimumab treatment at home

Similar views were expressed on adalimumab home treatment as for infliximab home treatment. Twelve individuals were negative about adalimumab and eight demonstrated no preference. As for infliximab therapy, reasons against adalimumab home therapy were the preference for specialised care at the hospital, and the discontinuity of care and availability of specialist hospital staff when transferring therapy to home. Concerns were expressed regarding the method of administration due to bad experiences with injections, or needle phobia, the shorter time interval between administrations, and expected problems with compliance. Moreover, due to the experienced effectiveness of infliximab therapy, patients and parents did not express a wish to change to adalimumab home treatment. Five individuals, however, were positive about adalimumab as they felt it would be easier and more convenient.

Three patients were unsure about adalimumab treatment and needed more information. They only wanted to change if the therapeutic effect of adalimumab was greater than infliximab, or if infliximab ceased to be effective. None of the parents with children with IBD were negative about adalimumab treatment, contrary to their children's opinion. They all considered it a possible future treatment option.

The participants' perspectives on (infliximab or adalimumab) home treatment need to be considered in the light of their assessment of hospital services. Hospital staff, the hospital environment and the ward were particularly highly valued by the participants. Several patients

Table 1 Reasons for and against infliximab treatment at home

Reasons for	Patients (n=5)	Parents (n=7)	Reasons against	Patients (n=9)	Parents (n=5)
No travelling time to hospital	4	6	Specialised care at hospital	5	4
Comfortable at home	4	1	Discontinuity of care and hospital staff	2	3
Easier	4	1	Interaction of treatment with family life	3	0
Less impact on parents' work life	0	2	Not efficient, not feasible, waste of resources	2	1
No stress during travelling	0	1	Bad experience with local coordination for home based care	1	1
Less impact on school, college, university or work life	1	0	Inconvenient at student flat	1	0
			No need for a change, good routine	1	0
			Hospital environment	1	0

declared that their relationship with the hospital staff was the most important aspect in managing the chronic illness. The main negative characteristic about the hospital services was the waiting time during the appointment. Additionally, four interviewed participants found the ward too large, too crowded and considered it difficult to be on the ward with ill inpatients of different age groups. The positive and negative characteristics about the service provision at the hospital are summarised and ranked in terms of participants' perceived importance in Table 2.

Discussion

Infliximab treatment for chronically ill adolescents is considered a major advance in improving patients' quality of life, family life and achieving full educational potential^{6,11,12}. This was confirmed by this study. Infliximab treatment regimens had either little impact on family life, or improved it, since the family as a whole was less restricted as a result of the effectiveness of therapy and the eight weekly regimen. Infliximab therapy makes it possible for patients to attend school on a regular basis, with only one day of absence every eight weeks.

There is a clear political desire to transfer outpatient appointments from hospital to a local or home-based setting^{11,14} and local care provision is one of the fundamental principles of the NSF for Children¹². A previous study of 10 children shows infliximab administration at home to be safe and cost-effective¹⁵. Additionally, respondents reported that absence from school was decreased and that it was associated with excellent patient and family satisfaction¹⁵. Aside from this study, there is a lack of data on the safety and potential risks of infliximab home treatment.

Studies have found adalimumab to be effective for the treatment of RA^{4,16} and have possible benefit for IBD^{17,18}. The change from infliximab to adalimumab (i.e. the change from hospital to home treatment) is seen as a promising treatment option because of its minimal impact on patients'

and parents' everyday lives¹⁰. However, this was not unconditionally supported by the present study. Specialised care at the hospital and good interaction with the hospital staff were the main reasons for wishing to maintain infliximab therapy at the hospital. Additionally, both patients and parents indicated the crucial and supportive role of the clinical nurse specialist, and the major impact she has in disease management.

Although this study is context specific, with infliximab patients as an example of hospital therapy with a potential for home-based treatment, these are essential matters that should be taken into account for future decision-making about transferring treatment from hospital to home. However, also pertinent to this discussion is the need for more evidence on the efficacy of adalimumab for IBD in children under the age of 16. Additionally, further qualitative research should be undertaken to examine patients' and parents' experiences of adalimumab home treatment.

Conclusion

Infliximab is an effective therapy for IBD and rheumatology conditions in young people aged 14–19, with either no negative impact, or improvement on school and family life compared to previous therapy. In association with patients' and parents' positive appraisal for the hospital services and their confidence in the clinical team, patients and parents do not express a preference for home treatment with either infliximab or adalimumab despite the current health policy direction towards therapy closer to, or at home. Since the availability of specialist teams at a tertiary level is of major importance in the successful outcome of disease management, such specialised care needs to be available for local or home-based infliximab or adalimumab treatment.

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Table 2 Positive and negative characteristics of hospital services

Positive	Patients (n=15)	Parents (n=10)	Negative	Patients (n=15)	Parents (n=10)
Hospital staff	10	8	Long waiting time during appointment	7	5
Hospital environment	8	6	Drug administration	1	4
Wards	6	3	Wards	2	2
Quick and efficient appointment	4	3	Chaotic organisation with capacity problems	2	2
Hospital facilities	5	2	Inconsistent care	3	0
Drug administration	5	1	Hospital environment	1	1
Combining consultant and outpatient appointment	1	2	Afraid of risk of infection/disease	0	1
			Bad experience with junior doctors and nurses	0	1
			Impersonal care	0	1

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