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Hospital–school liaison: perspectives of health and education professionals supporting children with renal transplants

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Abstract

This article explores collaboration between health and education staff as a key aspect of educational provision for children with chronic medical conditions, drawing upon material from interviews with eight health professionals (paediatric nephrologists and specialist renal nurses) and 11 mainstream schoolteachers involved in the care and schooling of children with renal transplants. Notwithstanding the apparent existence of good practice, a complex interplay of attitudinal, institutional and wider political and economic factors is identified that is likely to undermine the effectiveness of collaboration between health and education professionals. The importance of hospital–school liaison – that is, of a proactive, preventative and hence systematic and strategic nature – is highlighted. Such findings have a particular relevance for policy and practice in the context of the current *Every Child Matters* agenda, and are likely to have wider applicability to the education of chronically-ill children at large.

Keywords educational provision • health professionals' perspectives • hospital–school liaison • renal transplants • teachers' perspectives

Introduction

The need to improve inter-agency cooperation and integrated working across child welfare services reflects a current key policy priority in the UK in the context of the *Every Child Matters* agenda (Department for Education and Skills, 2004; Sloper, 2004).¹ With regard to children with medical needs and their education specifically, an analogous emphasis on partnership and collaboration between education and health agencies (Local Authorities, schools and the National Health Service) characterizes official educational and health care policy literature regarding this group of children in England (Department for Education and Skills, 2001; Department of Health, 2004).

Collaboration between health and education staff has been highlighted as vital for effective educational provision for children with medical needs (Farrell and Harris, 2003; Office for Standards in Education (Ofsted), 2003). Key reported elements of best practice with respect to liaison between health and education professionals supporting such children include, among others:

- professionals having an understanding of, and respect for, each others' roles and expertise;
- coordinated communication and information-sharing between professionals; multi-disciplinary planning and review meetings; and
- joint inter-agency training initiatives (Carter et al., 2004; Farrell and Harris, 2003).

Notwithstanding the apparent existence of good practice, existing research (completed in the UK) has documented a wide range of difficulties in communication between health and education staff in the case of children with chronic medical conditions (Lightfoot et al., 2001; Mukherjee et al., 2002; Ofsted, 2003). Sources of difficulty, as identified by health professionals, involve, among others:

- lack of adequate time for liaison;
- lack of knowledge about other professionals' roles and responsibilities in relation to children with medical needs; and
- a school ethos or culture perceived as unsupportive with regard to such children.

On the other hand, mainstream schoolteachers have called attention to the lack of formal mechanisms for regular, systematic communication with health professionals (e.g. annual reviews) in the case of children without a Statement of Special Educational Needs (SEN).² Similar barriers to effective liaison between health and education professionals have been highlighted in the literature on educational provision for children with speech and language difficulties and children with SEN (Band et al., 2002; Dyson et al., 1998). Additionally, such barriers have been documented consistently in the literature on inter-agency collabora-

tion in child welfare services at large (Easen et al., 2000; Roaf, 2002; Sloper, 2004; Tunstall and Aldgate, 2000; Ward et al., 2004).

Collaboration between health and education staff – as a key aspect of educational provision for children with chronic illnesses – represents a relatively under-researched area. In the case of children with chronic renal failure specifically, the dearth of research on issues of hospital–school liaison – and issues of educational provision at large – has been particularly pronounced. Furthermore, the relatively few existing studies (completed in the UK and the USA) addressing educational issues in children with chronic medical conditions have investigated mainly the perspectives of the children, their parents and their teachers, whereas the views of health professionals – key people involved in the children’s lives and care – are largely missing (Asprey and Nash, 2006; Bolton, 1997; Chacrabarty and Hamer, 2005; Everett and Fulton, 2002; Harris and Farrell, 2004; Lynch et al., 1992; McCann et al., 2002; Mukherjee et al., 2000, 2002; Norris and Closs, 2003). This suggests a particular need for further research investigating health professionals’ perspectives on the education of children with chronic illnesses. Last, the existing literature points to the need for a more central role for qualitative approaches in researching educational issues in children with chronic renal failure, given that the few existing studies addressing such issues have drawn almost exclusively on quantitative data, whereas qualitative methodologies have been scarcely used (Poursanidou et al., 2003a, 2003b). The research that this article draws upon sought to fill partially these gaps in the research literature.

Method

This article draws upon data from two studies that investigated difficulties and support at school for children with chronic renal failure, and more specifically, renal transplants. Both studies sought to:

- map the difficulties in the school lives of children with renal transplants;
- investigate and evaluate the educational provision available for them;
- identify the support necessary to promote their effective educational and social inclusion; and
- explore issues of collaboration between education and health professionals involved in their schooling and care.

The first study (completed in 2002) focused on a paediatric renal unit in Nottingham (Children and Young People’s Kidney Unit in Nottingham City Hospital), with its model of service and educational policies or strategies as the context of the investigation (Poursanidou et al., 2003a). The second study (completed in 2003) focused on a sample of four other paediatric renal units in the north of England and sought to compare their service models and educational

policies or strategies with those of the Nottingham unit. Both studies were concerned with raising awareness and providing professional development information to education professionals who encounter children with chronic renal failure in non-medical settings.

Qualitative methods of data collection were used in both studies. For the first study, individual semi-structured interviews were conducted with children who had renal transplants and attended the Nottingham City Hospital Renal Unit as outpatients, their parents and teachers in mainstream schools. Interviews were conducted with 12 transplanted children and 14 parents. Of the 11 teachers interviewed, seven were in secondary and four in primary education. Two of the secondary school staff were special needs teachers; one of them was head of his school's special needs department and had an SEN coordinator role. For the second study, individual semi-structured interviews were undertaken with key health professionals, namely four consultant paediatric nephrologists and four specialist renal nurses, during visits to the four paediatric renal units in the north of England mentioned above. The interviews with teachers and health professionals took between 45 and 60 minutes and were audiotaped. The key areas explored include the following:

- difficulties at school for children following renal transplantation;
- the support offered to these children by schools and their satisfaction with such support;
- teachers' difficulties in supporting the learning of the children in question;
- the support needs of children and teachers; and
- collaboration between health and education staff.

Ethical approval of the research was obtained from the Trent Region Local Research Ethics Committee. Interviews were conducted upon obtaining informed consent from the research participants, who were provided with the appropriate guarantees of confidentiality and anonymity as regards handling the interview material.

A preliminary analysis of the interview data occurred during the data collection, where key emerging themes and patterns were identified and recorded in a research journal. Interview transcripts were analysed inductively with the use of the constant comparative method, which is in line with grounded theory approaches (Maykut and Morehouse, 1994; Silverman, 2001). Following an in-depth reading of the transcripts, the data were coded and units of meaning were identified. Then units of meaning were compared and subsequently grouped (categorized) with similar units of meaning in a process where initial categories were changed and refined and new categories generated, whereas relationships and patterns across categories were explored.

The present article explores hospital-school liaison as a key aspect of educational provision for children with renal transplants using a multi-perspective

qualitative approach, focusing on the perspectives of the health professionals and mainstream schoolteachers interviewed in the context of the two studies outlined above.

Results

Key emerging themes

In the analysis that follows, material from the interviews with the health professionals and teachers is drawn upon in order to illustrate and discuss key emerging themes reflecting crucial issues of collaboration between health and education staff supporting children with renal transplants. The themes fall into two broad categories: collaboration between health and education staff as perceived by health professionals, and teachers' perspectives and support needs in relation to hospital–school liaison.

Collaboration between health and education staff: health professionals' perspectives

Interview data from health professionals suggest extensive variation with respect to collaboration between health and education practitioners responsible for transplanted children, highlighting a number of factors that are likely to play an important part in enhancing or undermining the quality and effectiveness of such collaboration. These factors, which appear to interact in a complex manner, comprise:

- teachers' attitudes towards collaboration with health staff;
- the type of school attended by transplanted children;
- knowledge and clarity with respect to other professionals' roles and responsibilities; and
- availability of time and resources or staffing for liaison purposes.

Interview data from health professionals also point to the need for a proactive and preventative model of hospital–school liaison.

Teachers' attitudes towards collaboration with health staff

Health professionals reported a number of examples of effective practice with respect to collaboration between health and education staff in which teachers were depicted as cooperative, welcoming communication and information-sharing with health practitioners, and showing interest and willingness to liaise with them. The following interview accounts, given by renal nurses, illustrate positive teacher attitudes towards hospital–school liaison:

Some schools are fantastic . . . you are in your school meeting and you have the headmaster or the headmistress, the form teacher, the head of year, the school nurse, the gym master . . . you have a room full of people who *all* want to know [about a transplanted child's health condition]

Some schools will actually say, 'We would like to involve issues surrounding transplantation and organ donation into our personal, social and health education' . . . So, we went out to one secondary school last year who were hoping to do a lot about organ donation . . . If that kind of thing happens, that's really useful . . . because you feel you are actually working collaboratively.

Alongside examples of good practice, health professionals also talked about a range of instances where teachers' attitudes were portrayed as significantly undermining the effectiveness of the liaison between health and education staff. More specifically, teachers were represented as uncooperative, and exhibiting a lack of interest and reluctance when it came to information-sharing and engaging collaboratively with health staff. As a paediatric nephrologist acknowledged:

One of our hospital teachers did an audit . . . she wrote to all the schools, where all the dialysis and transplant patients went, and asked them for feedback on attendance and about their [annual] report . . . *very few schools bothered to reply* . . . The majority didn't bother, and it's a great disappointment . . . Schools seem to be very bad at returning any information like that . . . *they expect us to provide the information quickly but they don't provide information back* . . . we hardly get anything back at all!

Health professionals linked some teachers' apparent reluctance to liaise with health staff to what they perceived as defensiveness, which may be precipitated by fears and anxieties to do with potential criticism from health practitioners. A renal nurse, characteristically, said:

We have a child at the moment for whom there are issues surrounding schooling post-transplant . . . We've had to push *extremely* hard to be allowed to go and see the school to discuss [the issues] . . . even reaching the point of saying, 'Look, we don't want to come and tell you what to do. We just want to understand what the issues are from your point of view.' We don't seem to be viewed as a resource . . . but almost . . . perhaps more as threatening and coming to tell them off, or whatever.

Last, the same renal nurse commented on the potential links between some teachers' apparent lack of interest in engaging with health staff and receiving health-related information, on the one hand, and the way in which teachers seem to define the parameters of their professional role, on the other:

Education authorities have got stricter and stricter about the whole concept of risk assessments and teachers not taking on what often seem to be nursing or medical tasks . . . [and] that seems to have exacerbated the issue [of teachers' reluctance to

be interested in what we have got to say] . . . because they're very cut and dry, that 'This is my job . . . I am a teacher . . . I have to do with education!' I wonder if that is maybe part of the issue that we are coming up against . . . a profession that is very protective, rightly so, of their need to be educationalists . . . and so doesn't want to be embroiled in [health matters].

Type of school attended by children with transplants

On the whole, teachers in primary and special schools were portrayed as more interested and willing to liaise with health staff, compared to their counterparts in secondary and mainstream schools. Mainstream secondary school teachers, in particular, were depicted as 'harder to engage', which was attributed to the considerably larger sizes of student populations in secondary education where the needs of children with renal transplants and chronic illnesses at large are less likely to constitute a high priority. Commenting on information-sharing between schools and her unit, a paediatric nephrologist said:

Where there are problems, the schools have approached us . . . probably more so in primary than secondary. The secondary school system in the state sector is so big and overwhelmed that their priorities are often troublesome [children] . . . rather than these kids who . . . I don't suspect are socially difficult or have behavioural problems in that sense, but through various problems with attendance or whatever, are struggling . . . I suspect within the things that are prioritized by secondary schools, these kids wouldn't be high on the agenda.

Health professionals also indicated that communicating and updating information about transplanted children's medical needs often becomes problematic when it comes to secondary schools, due to the large numbers of teaching staff and frequent staff changes. Familiarity with nursing staff, as a result of nurses being based on site, was put forward as a factor which may explain what the health professionals viewed as greater receptiveness to input from health staff among teachers in special schools, compared to their mainstream counterparts.

Knowledge and clarity with respect to other professionals' roles and responsibilities

Health professionals indicated that lack of knowledge and clarity on both health staff and teachers' part as regards each others' roles and responsibilities in relation to transplanted children is likely to augment liaison difficulties. The following interview accounts illustrate this issue:

Our problem is that we don't know who you write to in a school . . . Do you write to [the child's] teacher? Do you write to their form teacher in secondary school? What do you do? (Paediatric nephrologist)

[Secondary schools do not normally initiate contact with the unit] . . . I do not know if maybe that is because schools feel they don't know who to contact . . . we do give them a list of numbers and people they could call . . . but my guess is that this kind of thing probably gets filed away and whether somebody would then know who to speak to when they need to, [I do not know] . . . I can see potentially that from the schools' point of view, that might be a problem. (Renal nurse)

Availability of time and resources or staffing for liaison purposes

The health professionals identified conditions of professional work, namely increased caseloads and ensuing time pressures, as an important factor that is likely to affect the quality of the support that they are able to offer transplanted children, when it comes to their educational needs. In the following interview account, lack of adequate time for both health staff and teachers to use for liaison purposes is portrayed as undermining the effectiveness of hospital-school liaison:

It's very difficult [to overcome problems as regards liaison with schools] . . . because I know teachers are very busy people . . . and they have enough on their plate, just as *we* have. (Paediatric nephrologist)

Furthermore, some health professionals linked the lack of adequate time for liaison with schools to what appear to be substantial problems faced by some hospitals with regard to resources or staffing. By way of illustration:

Our community nursing staff resource is quite poor . . . we only have the equivalent of one proper person for the community side . . . and the community nurses are usually very busy with the dialysis patients . . . So, we are under-resourced where you might say that you need to have some community element that should link up with [transplanted children's] schools . . . and if you are going to do something *proactively*, there should be the community staff going out, making contact with the schools and establishing those lines to communication . . . but for us that's very hard because we don't have that resource. (Paediatric nephrologist)

Need for a proactive and preventative model of hospital-school liaison

Health professionals portrayed the collaboration between health and education staff responsible for children with renal transplants as occurring largely in a reactive and often ad hoc fashion. Recognizing the limitations of such an approach to hospital-school liaison, health professionals emphasized the need for liaison that is of a proactive, preventative – and hence systematic and strategic – nature. A paediatric nephrologist acknowledged:

[Communication with schools] is probably adequate when there are major problems, but I don't think it's sufficient to address potential problems or perhaps

sub-clinical problems . . . Probably what we should be doing is . . . really getting in there early [to address problems at school] . . . [Communication happens in more of a reactive fashion]. . . [I would like it to be more preventative], that would be the ideal! It would be very nice . . . if we'd got programmes where . . . if there was a dialysis kid, for example, in a school . . . perhaps our nurse could go in there and discuss with them 'This kid's on the list for a transplant and this is what's going to happen . . . he's going to be off for three months, then he's going to come back and he's going to be puffy' . . . So that they would be a bit more understanding of what some of the limitations are going to be afterwards. So, we could be more proactive.

Hospital–school liaison: teachers' perspectives and support needs

As with the health professionals, the teachers depicted collaboration between health and education staff as essential for the provision of effective educational support to transplanted children. They portrayed enhancing and updating teachers' knowledge concerning the children's health condition, and alleviating potential anxieties experienced by teachers, as a vital contribution of hospital–school liaison. By way of illustration, two secondary school teachers remarked:

I think communication between hospital staff and mainstream school staff is essential . . . you almost can't function without it.

I can remember two meetings with staff from the hospital service about Janet's³ condition . . . they were very useful . . . the first one in particular because of the things discussed that I didn't know . . . just medically and scientifically . . . It was a frightening time for us [after Janet's transplant operation] . . . we were concerned that we did our best job . . . the meetings were excellent for settling our worries.

Furthermore, teachers stressed their need for more regular and systematic communication with health staff, recognizing (similarly to health professionals) the limitations of hospital–school liaison occurring merely in a reactive and ad hoc fashion, on the one hand, and the advantages of health staff liaising proactively with schools, on the other. Such need seems to be particularly pronounced in the case of transplanted children who are not classified as having SEN. The apparent lack of formal mechanisms for regular, systematic hospital–school liaison when it comes to these children might put them at risk of falling through the existing systems of educational provision and thus having their needs undetected and ignored. The following interview account, given by a primary school teacher, is particularly useful in throwing light on these issues. The teacher, referring to Liz, a transplanted girl in his school, remarked:

There is the hospital link . . . but not as regular as I would like . . . I think it's just when Mrs M, the renal nurse, feels Liz is going through a difficult time that we perhaps have the link . . . I think maybe if we can have it almost annually as a set part of a review for Liz, then it would be better for us. It would just remind *us* about

what Liz is going through! . . . That would have helped *us*! Because sometimes we almost just forget that Liz's had a kidney transplant! Because she is a normal child, you know! [Communication between the hospital and the school works fairly well]. But I think it ought to be more systematic. It would be useful if every September we could have some sort of a review meeting. And somebody from the hospital who could explain to Liz's teacher, 'You can expect this to happen this year. As Liz's entering puberty and adolescence, this is what may happen.' . . . Having annual reviews is the system for children with special educational needs, particularly learning difficulties . . . because Liz has no learning difficulties, we haven't gone into initiating annual reviews.

Teachers articulated their need for enhanced communication with health staff at times of medical crises. They identified such communication as vital for the provision of effective academic and social or emotional support to transplanted children during periods of school absence. Commenting on hospital-school liaison during a kidney rejection episode experienced by Emily, a transplanted girl in her tutor group, a secondary school teacher said:

I think more detailed contact with the hospital at the time of Emily's kidney problem, during the long absence, would definitely have been very valuable . . . A nursing viewpoint on exactly what the possibilities were and how long Emily might be away for, might have been good at that point . . . And also information about exactly how school could help . . . we send work home, but it's helpful if we know how much they might be capable of doing at that stage . . . exactly what the condition is . . . And if you know in advance that it's going to be a fairly lengthy absence, then you can make arrangements . . . I went to visit other people myself at the hospital and took cards from the tutor group and so on, because we knew they were going to be in there for a little while . . . You can make that kind of contact which makes [the children] feel still part of the group.

Discussion and conclusion

The findings discussed in this article point to perceived extensive variation in the quality and effectiveness of liaison between health and education staff supporting children with renal transplants in England. Notwithstanding the apparent existence of good practice, the findings suggest that a complex interplay of attitudinal, institutional and wider political and economic factors is likely to undermine the effectiveness of collaboration between health and education staff. Attitudinal factors involve teachers' attitudes towards collaboration with health staff characterized by defensiveness, lack of interest and reluctance. Institutional factors comprise: the type of school attended by transplanted children, as it is suggested that on the whole, liaison with health staff tends to be less effective and spread with more difficulties in the case of secondary and mainstream schools,

compared to their primary and special counterparts; a lack of knowledge and clarity on the part of health staff and teachers as regards each others' roles and responsibilities in relation to transplanted children; and conditions of professional work for health professionals and teachers, namely increased caseloads and time pressures. Wider political and economic factors involve problems with regard to resources or staffing faced by hospitals. These findings fit with other research completed in the UK with health staff. In agreement with the present data, a lack of adequate time for liaison, lack of knowledge about other professionals' roles and responsibilities, and a school ethos perceived as unsupportive with regard to chronically-ill pupils, were identified in the research in question as key sources of difficulty in communication between health and education staff (Mukherjee et al., 2002). Additionally, the findings concerning barriers to effective hospital–school liaison are consistent with research completed in the UK with parents of children with complex health needs (Asprey and Nash, 2006), as well as parents of children with speech and language difficulties (Band et al., 2002), who reported problems in communication between health and education professionals.

Further, the findings draw attention to the critical importance of hospital–school liaison that is of a proactive, preventative and hence systematic and strategic nature, for the provision of effective educational support to transplanted children, whereas they highlight the limitations of liaison occurring merely in a reactive and ad hoc fashion. They also throw light on teachers' need for enhanced communication with health staff at times of medical crises. The findings concerning teachers' need for more regular, systematic hospital–school liaison in the case of transplanted children who do not have SEN, are consistent with other research completed in the UK with teachers supporting chronically-ill children in mainstream schools (Lightfoot et al., 2001). In agreement with the data, the research in question drew attention to the lack of formal mechanisms that would facilitate such liaison.

It is essential to acknowledge here that this article draws upon interview data generated by two relatively small purposive and opportunity samples of teachers and health professionals, 11 and eight participants respectively, in the context of the two studies outlined in the 'Method' section above. The selection of teachers for interview in the first study followed a process whereby the teachers approached and invited to interview had been identified by individual transplanted children (attending the Nottingham Renal Unit as outpatients) as the teachers who knew the children best. This was an attempt to warrant that the teachers interviewed were aware of the children's health condition and, subsequently, were able to comment on the impact of the latter on the children's school lives. Also, most importantly, that the children were comfortable with the teachers' participation in the study. We felt that the involvement of teachers in the research had to be negotiated in each individual case with a great deal of sensitivity, consideration and care, so as to ensure that transplanted children

retained some sense of ownership of, and control over, material concerning private and sensitive issues in their lives. As regards the health professionals interviewed in the second study, who were drawn from an opportunity sample of four paediatric renal units in the north of England, the selection of those four units was largely determined by accessibility issues; more specifically, by the close links existing between the units in question and the paediatric renal unit in Nottingham where the first study was undertaken. The size and nature of the teachers and health professionals' interview samples, as outlined above, preclude any claims concerning 'sample representativeness' (Silverman, 2001), which, in turn, entails that it is not possible to apply notions of statistical ability to generalize the findings presented in this article. Nevertheless, comparison of the findings with the wider existing literature on collaboration between health and education staff supporting children with medical needs, as discussed above, suggests that they are likely to have a wider resonance and applicability to the education of children with chronic medical conditions at large.

Most importantly, the findings reported in this article have a particular relevance and crucial implications for policy and practice. More specifically, the findings relating to difficulties and limitations in collaboration between health and education staff raise crucial issues for educational policy and practice in the case of children with medical needs, in view of the current rhetoric of 'partnership' and 'multi-agency cooperation' that characterizes official educational policy literature regarding this group of children in England (Department for Education and Skills, 2001). In a broader sense, these findings are particularly relevant to, and pose important questions in the context of, the *Every Child Matters* agenda as a whole (Department for Education and Skills, 2004; Department of Health, 2004) where inter-agency cooperation and integrated working across children's services, as well as an emphasis on prevention and early intervention, are central elements.

Last, the findings highlight the value of, and need for, research using multi-perspective qualitative approaches to investigate hospital-school liaison as a key aspect of educational provision for children with chronic illnesses. Such approaches enable comparison and triangulation of data (Silverman, 2001) and facilitate a more holistic and in-depth understanding of the complex issues and processes involved in providing educational support to these children.

Notes

- 1 The *Every Child Matters* agenda relates to a national policy framework that was introduced in England and Wales in 2004 with a view to implementing change in children's services and improve outcomes for children in terms of health, protection from harm, education, social relationships and economic well-being. The key elements of this framework include, among others: improvement of inter-agency

- cooperation and integrated working across children's services; emphasis on prevention and early intervention; and the development of a shared sense of responsibility across agencies for safeguarding children (Department for Education and Skills, 2004).
- 2 Statements of Special Educational Needs are documents prepared by local authorities in England and Wales which, following a process of statutory assessment, set out the SEN of an individual child and the special help that they should have. This is in addition to the help normally available from the child's school and is specifically provided for the child named in the statement.
 - 3 The names of transplanted children referred to in the article have been changed to preserve anonymity and pseudonyms have been used instead.

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