

Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory

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Aims. In this paper the evolution of mothers' relationships with doctors and nurses during the chronic childhood illness trajectory is explored and discussed and the implications for child health care are considered. The discussion reports one aspect of a qualitative study that sought to determine whether time of diagnosis influenced mothers' coping across the illness trajectory.

Background. The quality of relationships between mothers, who are usually the primary carers, and nursing and medical staff is central to the experience of coping with chronic childhood illness. Mothers need to develop expertise in a wide range of technical skills and knowledge of complex health care issues, while also coming to terms with the uncertainty of a condition with an unpredictable trajectory. Attempts to understand the significance of relationships between those living with chronic illness and staff have highlighted a number of factors that may influence the degree to which they are viewed as satisfactory. The way staff communicate with families has been identified as one of the mediating processes through which the quality of such is determined.

Design. Mothers of 15 children diagnosed presymptomatically and 14 children diagnosed postsymptomatically with the chronic illness Vesicoureteric Reflux (VUR) were interviewed to assess and compare coping strategies across the trajectory. Mothers' written consent was obtained and interviews were tape-recorded, transcribed and analysed using the 'Framework Technique'.

Findings and Conclusion. The need to develop and sustain trusting relationships with staff was reported as a continual source of stress for mothers. The formation of satisfactory alliances, based on mutual respect and good communication early in the trajectory, in particular during the prediagnostic phase, was found to be instrumental in coping and competence development during the later chronic phase of the trajectory. Further research is needed to map prospectively the evolution of relationships between mothers and staff across the trajectory.

Keywords: competence, childhood chronic illness, diagnosis, mothers, relationships, scepticism, trajectory

Introduction

Families are increasingly becoming the primary care givers (Stewart *et al.* 1994) in chronic childhood illness with, in practice, mothers providing most care (Oakley 1976, Finch & Groves 1983, Eiser 1994). Chronic illness diagnosis may be protracted, either because of the vagueness of early symptoms (Reid *et al.* 1991, Ray & Ritchie 1993) or as a result of professional scepticism (Burton 1975, Cohen 1997). Charmaz (1983) observed that self and identity are demeaned by discrediting definitions of self from professionals, while Burton (1975) and Coyne (1995) found that professional scepticism, nonnegotiation of roles and inadequate information provision undermined parents' self confidence and impinged on their coping abilities. The burden of care for families stretches over a long period of time, which significantly affects quality of life (Jacoby 1992, Baker *et al.* 1997). A number of authors conclude that this places strain on the family's physical, financial and emotional resources (Gallo 1991, Swallow & Thompson 1992, Ray & Ritchie 1993, Williams *et al.* 1993, Stewart *et al.* 1994, Gibson 1995, Callery 1997a, Swallow & Jacoby 2001) and that the quality of relationships between families and professionals is central to the experience of living with chronic illness (Thorne & Robinson 1988, Thorne 1993, Gibson 1995). In an earlier paper we discussed one aspect of a study investigating the effect of presymptomatic diagnosis of chronic childhood illness on mothers' coping across the illness trajectory (Swallow & Jacoby 2001). In this paper we report on another aspect of the same study and explore the evolution of mothers' relationships with doctors and nurses across the trajectory. The need for families and professionals to coexist successfully is recognized as critical to the successful management of chronic illness within increasingly complex health care settings.

Literature review

Attempts to understand the significance of relationships between patients, carers and health professionals in chronic illness management have highlighted several factors that may influence their satisfactory development. These include the sources of stress for families, the attitudes and values of professionals, in particular nurses and doctors; and the status ascribed to children's health by policy makers. Maintaining balance in family life is a continual source of stress for parents, with professionals both hindering and supporting parents in their caring role (Barlow *et al.* 1998, Atkin & Ahmad 2000). During periods of hospitalization, although nurses and doctors make the child a priority, they also

cocreate relationships with parents (Darbyshire 1994, Callery 1997b). Research is now emerging which is directed at exploring the evolution of these relationships as families move through the trajectory (Clarke 1999).

Thorne and Robinson (1988) conceptualized the process of developing relationships across the trajectory as one involving *naïve trust*, followed by *disenchantment* and then *guarded alliance*. Naïve trust was based on the family's assumption that care would be mutually negotiated with professionals and so they waited passively for this to be initiated by the professionals while they familiarized themselves with the health care setting. However, when they realized that their subjective experience of living with illness was often of secondary importance to professional concerns, they moved into a phase of disenchantment, characterized by frustration and dissatisfaction, which resulted in relationships with professionals often becoming adversarial and families viewing their relative as vulnerable. As family members gained new insights into the realities of living with a chronic condition and realized that its satisfactory management depended on their ability to trust professionals, the transition was made to a phase of guarded alliance. In this phase they became more knowledgeable about the prevailing culture of health care and began to take the initiative and negotiate situations to achieve a satisfactory outcome.

Uncertainty invades all stages of the illness trajectory (Mishel 1983, Hilton 1992, Cohen 1995) but until recently little attention has been paid to parental uncertainty during the prediagnostic period. However, Cohen (1997), focusing on this period (that may last from a few hours to a few years), identified three phases – Lay Explanatory; Legitimizing and Medical Diagnostic – and found that learning to communicate effectively with professionals about their child's early illness cues was a significant source of stress for parents. The transition from the Lay Explanatory phase, when illness cues forced their way into parents' conscious awareness, to the Legitimizing stage happened only when they conceded their parental limits. In order to maintain parental credibility while ensuring that they engage the doctor's interest in their child, parents adopted a strategy for presenting the problem. Thus, transition to the Medical Diagnostic phase began with an appointment to see the doctor, and only ended with diagnostic certainty.

Advances in chronic illness management have led to the creation of a medically fragile and technologically dependent population of children whose life expectancy is unknown and whose future quality of life is unpredictable (Cohen 1995). Following diagnosis, this unpredictability gives rise to sustained parental uncertainty, which can be understood within the trajectory framework as a second chronic

condition situated within and dependent on the first. Paradoxically, while parents' efforts to minimize the impact of a child's illness on family life are often misinterpreted by professionals as denial of the true seriousness of the condition, professionals often fail to appreciate the degree of uncertainty and fear about the future which usually lies just beneath parents' conscious awareness (Cohen 1997).

The pivotal role played by nurses in promoting partnership and negotiation is critical to families in coming to terms with their child's health needs (Callery & Smith 1991, Casey 1995, Callery 1997b, Coyne 1997). Paralleling this there is growing interest by doctors in the bio-psychosocial model of medicine (Ong *et al.* 1995) which predicated a shift from an authoritarian and paternalistic relationship between doctors and families to one which, like nursing, values and promotes partnership and negotiation (Sharp *et al.* 1992, Eiser 1993, Sunde *et al.* 1993, Wissow *et al.* 1994, Eiser *et al.* 1995, Fairhurst & May 1995). In addition, health policy makers are being urged to ascribe a higher status to children and families and to incorporate their views into the formulation of strategies (Aynsley-Green *et al.* 2000). Based upon such work, professionals' communication with families has been identified as one of the mediating processes through which relationships are formed and parental competence acquired.

Gibson (1995), investigating the process of empowerment in mothers coping with chronic illness, found that frustration was a powerful force permeating the process. It was critical in helping the *discovery of reality*, which evoked ongoing cycles of *critical reflection*, leading to mothers *taking charge* of the situation and finally *holding on* to their sense of power, even in changing circumstances. The outcome of this process was 'participatory competence' and those who acquired it developed confidence in communicating what was best for their child. As a result an earlier concept of participatory competence as 'an abiding set of commitments and capabilities' (Kieffer 1984, p. 31) was redefined by Gibson (1995) as 'the ability to be heard by those in power' (p. 1202). It is reported that this crucial process is fraught with difficulties and challenges (Mishel 1983, Whyte 1992). Nevertheless, the outcome is often believed to be long-lasting and trusting alliances between the family and significant professionals (Thorne & Robinson 1988, Thorne 1993).

This paper discusses one aspect of a qualitative study investigating views of mothers coping with Vesicoureteric Reflux (VUR) (Swallow 1997, Swallow & Jacoby 2001). Vesicoureteric Reflux, the retrograde flow of urine from the bladder into one or both ureters, is congenital and asymptomatic. In the presence of VUR a urinary tract infection (UTI) can induce reflux nephropathy (RN), accounting for

approximately 20% of renal transplants (Scott & Stansfield 1968, Rolleston *et al.* 1970, Smellie *et al.* 1994). Currently, the preferred investigation for VUR is a micturating cystogram but, because of its invasive nature, this X-ray is only performed following a proven UTI. The latter occurs in 9% of those under 7 years (Scott 1996). However, UTI may be asymptomatic or present with non-specific symptoms (Royal College of Physicians Research Unit Working Group 1991) and therefore is difficult to diagnose. The reported prevalence of VUR in children is 1% (Scott *et al.* 1997), although it is found in 35% of children investigated following UTI and its optimum management includes early diagnosis combined with rigorous urinary surveillance and prompt treatment of UTI to minimize the development of reflux nephropathy (Verrier-Jones 1997).

The study

The study described here emerged from the Familial Ureteric Reflux Study (FURS), a quantitative study in which an 'at risk' group of newborns was subjected to presymptomatic screening for VUR (Scott *et al.* 1997). An unexpected finding was that many mothers who already had a child with VUR reported difficulty in coping with the consequences of the condition. Many felt isolated in the carer's role and were eager to gain more professional support and information about managing the condition. Attempts to develop satisfactory relationships with doctors and nurses were often reported as a source of stress for mothers.

Methodology

As the experiences of children and families are the focus of this research, qualitative methods were used and data were gathered and analysed using the principles of grounded theory (Murphy *et al.* 1998, Strauss & Corbin 1998). The theoretical approach to the study was the trajectory framework (Glaser & Strauss 1967), a conceptual model, built around the idea that chronic conditions have a variable course that changes over time. It is inductively derived, and facilitates understanding of problems associated with chronic conditions. Each individual coming into contact with the condition: doctor, nurse, patient and relative has their own trajectory projection about how management of the condition should be shaped. This is based on knowledge, experience, belief and hearsay (Thorne & Robinson 1988). The plan which is designed to shape the illness course and control and manage symptoms is referred to as the 'trajectory scheme' and can include medical, nursing and family caregiver management.

Sample of respondents in current study	
FURS group	Non-FURS group
Fifteen mothers who took part in FURS and whose new-born baby was diagnosed with VUR following pre-symptomatic screening.	Fourteen mothers whose child (aged 1–8 years) was diagnosed with VUR following recurrent urinary tract infection.

FURS = Familial Ureteric Reflux Study
 VUR = Vesicoureteric Reflux

Figure 1 Sample of respondents.

After obtaining ethical approval, participants were selected from amongst mothers whose children with VUR were patients at hospitals in the North of England (Figure 1).

A theoretical sampling matrix (Figure 2) incorporating key variables including pre- and post-symptomatic diagnosis, gender and birth order of the child was used and selected mothers received detailed written information supported by verbal information if required. All consented to enrol and were subsequently interviewed in their own homes. The semi-structured interviews, lasting between 1 and 2 hours, were tape recorded and later transcribed and subjected to analysis using the Framework Technique (Ritchie & Spencer 1994), a manual content analytic method drawing on the constant comparative method proposed by Glaser and Strauss (1967). This involved: familiarization with the data; identification of recurrent themes to develop a framework for subsequent retrieval; systematic application of the framework to the data so that emergent patterns could be identified and placed in context; lifting the data from its original context and charting according to the thematic reference and finally, abstraction and interpretation which involved searching for patterns and connections and seeking explanations for these within the data. At the abstraction stage the two data sets were compared to determine whether time of diagnosis influenced mother’s coping. To ensure trustworthiness (Guba & Lincoln 1989, Koch 1994), data were analysed independently by both authors and then compared before arriving at a consensus.

The FURS group comprised 14 mothers whose newborn babies were diagnosed presymptomatically and the non-FURS group comprised 15 mothers whose child’s VUR was detected in the normal way after symptom presentation (Figure 2). All the mothers presented rich accounts of their experiences. The main themes concerning the development of relationships with professionals form a useful framework for understanding the impact of time of diagnosis on this aspect of chronic disease management and are discussed in greater detail below.

Findings

The findings will be presented to represent three stages of the trajectory: before the diagnosis; making the transition to a diagnosis; and after the diagnosis. The implications of these findings for long-term relationship development will then be discussed.

Before the diagnosis: being taken seriously

The relationships which developed between mothers and medical and nursing staff before diagnosis were strongly influenced by mothers’ perceptions of these professionals’ trustworthiness and credibility. These relationships were very important to mothers; indeed, one of the most important issues facing them was the need to identify staff in whom they felt completely confident. Some mothers started out on the trajectory with little or no previous experience of communicating with doctors or nurses about their child. In this phase, a professional’s willingness to take seriously the concerns of mothers in the non-FURS group about their child and the ability of that professional to communicate information at the appropriate level, were qualities the mothers valued highly. Perhaps because of the vague and confusing nature of early symptoms, the non-FURS mothers’ first approaches to staff were often very tentative. If concerns were dismissed as

Pre symptomatic diagnosis								Post symptomatic diagnosis							
1st Born				2nd Born				1st Born				2nd Born			
Mother		Other relative		Mother		Other relative									
M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F

Figure 2 Sampling matrix.

insignificant, they often felt resentful towards the professional and lost confidence in them:

...being told there was nothing wrong with him [son] when I knew he wasn't right was very annoying and gave me no faith in him [GP] no faith at all. (non-FURS mother)

Some, like this non-FURS mother who had faced professional scepticism, subsequently lost trust in the General Practitioner (GP) or Health Visitor (HV) and so were likely to delay pursuing the problem further:

After my HV kept saying it [baby's irritability] was 'teething' I sat on it for ages, didn't like to go to the GP, but one weekend he was so poorly...went to casualty where they said [it was] a water infection, tested him and he had reflux damage to his kidneys. (non-FURS mother)

Those mothers with previous experience of coping with a chronic illness, either their own or a child's, were more likely to question the professional's competence if their concerns were trivialized and to approach other professionals until they received satisfactory acknowledgement of their concerns. One mother described the strategy she adopted:

Initially it [high temperature] was two or three times a week...went on for a few weeks and I had different doctors...so I came home one day and took him straight to my own GP, I know him quite well because I've got arthritis myself and have been seeing him for years. (non-FURS mother)

By the time the child attended hospital for review or investigation, mothers who trusted the professionals they had encountered usually approached these new encounters with confidence.

Our GP was very good, told us what to expect; the hospital staff were good too. (non-FURS mother)

At the time of catheterization for the micturating cystogram (a procedure involving insertion of a catheter into the urethra for introducing radio-opaque dye into the bladder to screen for VUR), mothers from both groups appeared to judge the integrity of staff according to their competence and honesty:

The staff nurse got a more experienced nurse because she hadn't done [catheterized] such a young baby before. I was very impressed by that, it increased my confidence in her. (FURS mother)

However, where staff struggled to perform the catheterization mothers quickly perceived this as an indication of incompetence:

The young doctor fumbled, didn't seem to know what she was doing, the nurse seemed to have more idea. (non-FURS mother)

Making the transition to a diagnosis: communication between mothers and staff

The main theme to emerge in the transition to a diagnosis concerned communication of the diagnosis. Some FURS mothers received the diagnosis on the day the micturating cystogram was carried out and then discussed this with the paediatrician. These mothers appeared to have greater confidence in the doctor's ability to care for their child. Whilst feeling shocked by the news, some commented on the importance of honesty and frankness in the doctor's communication and believed that this helped them to gain trust in the health care team:

He explained everything very well, I was shocked but knew she [daughter] was going to get well cared for and felt reassured talking about everything straight away. (FURS mother)

The doctor talked to me as if I was a person not something from a conveyor belt, she explained everything clearly and drew diagrams. I could ask what I needed. (FURS mother)

Being shown the X-ray films at the diagnosis also increased mothers' confidence in the doctor:

The doctor in X-ray was lovely and showed me the films so I could see what was going on. (FURS mother)

The hospital were brilliant, just so calming, they showed me the pictures which I found very reassuring. (FURS mother)

In contrast, mothers who appeared to have little confidence in the health care team also expressed dissatisfaction with the way they received the diagnosis:

I got to know by phone and didn't understand much...it came over quite blasé, I don't think they realize what a big thing it is for us. (non-FURS mother)

The way we were told...we just didn't know how big a problem it was or even if it was a big problem, we weren't told what it means for us and wonder if they [professionals] really do know. (non-FURS mother)

Receiving a positive diagnosis proved to be more distressing for FURS mothers than they had anticipated. Non-FURS mothers were also distressed by the diagnosis, although for some this was balanced by a certain relief at eventually having their early concerns vindicated. The way the diagnosis was relayed was a source of much unsolicited comment from

both groups, with a strong preference being stated for face to face communication using a 'lay person's' style and language. Mothers, particularly non-FURS mothers, had difficulty assimilating all the information, and their ability to understand this appeared to influence the way they felt about the diagnosis. This phase was the time when most mothers began to form trusting relationships with professionals, those inspiring most confidence being those who could explain the diagnosis in a way mothers understood.

The relationship between staff and children was a very important element of parents' assessment of an individual member of staff. Where staff attempted to gain the confidence of the child in an examination or investigation, this usually resulted in them also gaining the trust and confidence of the mother. For instance, this mother praised staff involved with her daughter's catheterization:

The nurse was very good, she brought out a book that had a little girl that was going to get the exact same thing as Kelly and there wasn't a cheep out of her. She got the whole thing done and it's quite nasty really, getting a catheter put in. She was very good with her, the staff there are very good. (non-FURS mother)

In contrast, this mother's negative attitude towards the staff was coloured by a traumatic experience for her daughter:

She was screaming and wouldn't let them do it [catheterize her]...I mean she was 3 years old and she didn't know what was happening, finally they got it in but were horrible to her, she was crying and I was crying too. I don't trust them but know she has to have it done! My husband doesn't agree with her having the tests done because she comes home so upset. He says they are experimenting on her. (non-FURS mother)

After the diagnosis: managing relationships

Moving along the trajectory, mothers adopted various strategies for communicating with professionals. Their accounts suggested that by this phase many non-FURS mothers had become more confident in their ability to communicate successfully and consequently had attained a more interactive role in their child's management and reached a stage of participatory competence. Those who had attended the hospital several times after their child's diagnosis, became selective about the staff in whom they placed their trust. This appeared to depend on whether or not staff took the mother's concerns seriously early in the trajectory:

I always prefer to see the consultant when he's [baby] poorly, the junior medical staff don't seem to take my concerns seriously although I once overheard the consultant telling a junior doctor they should always listen to a concerned parent. (FURS mother)

A number of mothers made comparisons between staff in primary care (GP and HV) and hospital-based staff, believing that GPs and HVs were not as well informed about VUR and its consequences as hospital staff and were therefore unable to provide the required support:

I've been told how important it is that she doesn't get a UTI [urinary tract infection] in case she gets damage, but they [GP and HV] don't seem to understand and don't give me the help I need. (FURS mother)

After one or more failed attempts to get a urine sample processed quickly when they suspected a UTI in their child, mothers talked of bypassing GPs and going straight to the hospital for advice. This mother's account was typical:

The first two samples I sent through the GP and there was a mixed growth reported on both of them but they didn't tell me at the time and never got back to me to ask me to send another or anything, so I thought it's just not worth the risk and go straight to the hospital now with samples. (FURS mother)

Nevertheless, some mothers lacked confidence to bypass GPs if they encountered difficulties or found it too inconvenient to take the child to hospital when concerned about a possible UTI. Indeed one abandoned urinary surveillance because of this. Mothers from both groups recounted difficulties in obtaining equipment for urinary surveillance from the doctor's receptionist as this mother described:

In the beginning the receptionists were very difficult and said 'Well what do you want this [urine bottle] for?' and I got a bit stropky [annoyed] and said 'just give it to me-he needs it.' (FURS mother)

In contrast, some mothers expressed satisfaction about the level of communication between the hospital and primary care team, as these comments indicate:

I got straight on to my HV after I found out about it [baby's VUR] and straight away she sorted everything out for me. Any problems I get straight onto her. (FURS mother)

My GP receives a letter from the hospital telling him when there is any change to my daughter's management. That means he can explain to me the bits I don't understand. (non-FURS mother)

Non-FURS mothers frequently reflected back in this phase on the events of the prediagnostic period, their own failure to engage GPs more quickly and GPs' failure to take them seriously sooner. By this phase, mothers who had faced such scepticism early on had generally become wary of accepting medical opinion without question. However some, like the following mother, concluded that their expectations of the doctor had, perhaps, been unreasonable:

You've got to accept the fact that they [professionals] are fallible. You go and say there's something wrong with your child and they say there isn't. Do you ask for a second opinion every time? (non-FURS mother)

This realization appeared to enhance mothers' self-confidence and undo some of the damage caused by the earlier scepticism. For many, this realization was a turning point in the way they coped with concerns about their child, and they acquired a level of assertiveness that had been absent earlier:

We bitterly regret the fact that we accepted the doctor [before the diagnosis] when he said it was a viral thing because of course there's an element of guilt comes into it...you think, 'Well if I hadn't just accepted it and we'd insisted she might not have got the kidney damage.' I follow my instinct now and insist if I'm worried. (non-FURS mother)

Where a trusting relationship had developed between mother and paediatrician before diagnosis, this appeared to continue into the phase following diagnosis, with mothers attaching great significance to hospital appointments:

I prefer to talk to the doctor at the hospital, he seems to be more able to answer my questions [than the GP]...gives me more confidence, I save up my questions until I go there. (FURS mother)

Where mothers had been dissatisfied with the communication of the diagnosis, this also appeared to influence subsequent relationships with doctors and nurses:

...we never actually ask [about the child's prognosis]. We just feel like we'll be told when they feel we ought to know. You just don't like to bother them, which is daft really because I think we've got a right to know. I think a lot of people are like us. (non-FURS)

As a consequence, these mothers usually assumed that the true seriousness of the situation was being hidden from them, as a further comment from the same mother richly illustrates:

They should sit you down and say, 'This is the problem and this is what is ahead'. I think from day one we should have been told exactly what the problem was and what it was called, but they didn't, so we assumed they didn't want to upset us...it's like he [son] had a terrible problem and we would find it too upsetting to cope with. We used to think that a lot, as if they were hiding something. (non-FURS mother)

Discussion

Implications for relationship development across the trajectory

The findings from this study indicate that FURS mothers appeared to be better able to form trusting relationships

with staff. They appeared to form satisfactory and trusting relationships before the diagnosis, which were based on frank and open communication about the study testing and its possible consequences. This sustained their ability to negotiate on behalf of their child later in the trajectory. In contrast, non-FURS mothers had considerable difficulty in the prediagnostic phase, particularly those who had little or no previous experience of communicating with doctors or nurses. The emotive accounts from these mothers of their gradually increasing suspicion that something was wrong with their child in some instances described a period lasting several years. During this period they moved back and forwards between what Cohen (1997) described as the Lay Explanatory phase, when they tried to apply familiar or minimally threatening explanations for their child's early illness cues, and the Legitimated phase, when the problem was de-normalized and they planned a strategy to engage medical support. This indicated a transition into the Medical Diagnostic phase, although in the current study mothers often spent several months or even years in this phase. Sometimes failure to have early concerns taken seriously led to them adopting strategies such as consulting different doctors until eventually a diagnosis was reached.

Around the time of diagnosis, both groups of mothers judged staff according to the way in which they communicated information about their child and the way they communicated with their child. Greene *et al.* (1987) and Adelman *et al.* (1991) viewed professional/patient interactions as two separate interviews in which communication was a mutual enterprise where turns were taken, emotions shared and joint decisions made. In the current study, FURS mothers initially reacted to the positive diagnosis with shock. Nevertheless, location of control in the relationship was balanced (Radley 1994) and joint decisions were made by mothers and staff on behalf of the child. FURS mothers therefore, appeared to move very quickly following diagnosis into a phase of guarded alliance (Thorne & Robinson 1988). This may be explained in part by the fact that mothers and staff had been partners in the screening process, and so subsequent encounters with staff were influenced by the quality of previous experience (Ley 1982).

In the period after diagnosis non-FURS mothers took much longer than FURS mothers to develop lasting and trusting relationships with staff. They took a long time to move from a position of naive trust to one of disenchantment as they realized that their early concerns had been vindicated, but frustration, as described by Gibson (1995), became a powerful force permeating their coping. This was a mediator in their discovery of reality which quickly

evoked cycles of critical reflection during which some had several difficult encounters with different staff. It appeared that the scepticism encountered during the early part of the trajectory, particularly that which occurred before a legitimate diagnosis was confirmed, jeopardised their ability to develop satisfactory relationships with staff. Eventually, however, non-FURS mothers came to realize that their child's best interests could only be served if they acknowledged that there are constraints associated with the health care system. In addition, a belief that they were the expert in their child's needs and therefore played an important role in their care enabled them to begin to take charge of certain situations, which eventually led to development of participatory competence. In contrast, FURS mothers achieved a state of participatory competence very soon after the diagnosis so that, although some experienced the same practical management difficulties as non-FURS mothers, the egalitarian nature of relationships they had developed with staff early in the trajectory helped them successfully to negotiate on behalf of their child later in the trajectory, and so they encountered fewer problems.

Study limitations

The main limitations of the study were time constraints, meaning that we were unable to interview fathers and staff and to consider socio-economic variables such as mothers' age, social class and educational background, all factors that may have affected developing relationships between them and the staff they encountered. Also the status of the first author as 'practitioner researcher' may have influenced participants' responses. Finally, data were gathered retrospectively rather than by mapping relationship development prospectively across the trajectory.

Conclusion

Implications for child health care

The importance of the mother's role as primary carer in chronic illness is well-established in child health care. This study provided a unique opportunity to compare and contrast, retrospectively, the views of two groups of mothers whose children were diagnosed pre- and post-symptomatically with chronic illness. For professionals, the chronic illness trajectory begins at the time of investigation or diagnosis, while for mothers the trajectory begins much earlier and the prediagnostic period is often protracted, with anxious mothers encountering many different professionals. The quality of these early encounters has been

found to influence the evolution of relationships across the trajectory. Where location of control early in the trajectory was balanced and joint decisions were made by mothers and staff on behalf of the child (Aynsley-Green *et al.* 2000), then egalitarian relationships were that which enabled mothers to advocate successfully for their child, however, worrying or complex the situation later became. A willingness to listen to mothers and take their early concerns for their child seriously are qualities that mothers value highly in staff. However, mothers' voices often go unheard until they develop effective strategies for communicating and negotiating with staff on behalf of their child. The formation of satisfactory alliances, based on mutual respect and good communication early in the trajectory, in particular during the prediagnostic phase, was found to be instrumental in coping and competence development during the later chronic phase of the trajectory. Prospective research is now needed to map the evolution of relationships between mothers and staff as the child moves through the illness trajectory.

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