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Clinic consultations with children and parents on the dietary management of cystic fibrosis.

Abstract

The aim of this paper is to examine clinic consultations on the dietary management of cystic fibrosis with particular consideration to the role of children. The role of parents is also examined to determine how their involvement impacts on the role of children during consultations. The data are drawn from interviews with 32 Irish school aged children with cystic fibrosis and their parents, and participant observations during clinic consultations with a sub-group of 21 children. Data were analysed concurrently with data collection using a method of constant comparison, which involved comparing and contrasting incidents in the data to develop themes. Theoretical sampling was used to further explore and develop emergent themes. Discourse analysis was applied to clinic conversations. Children were seen to have little active involvement during consultations leaving them marginalised as conversations were directed at parents primarily and their accounts were privileged over those of children. A surveillance approach to consultations involving interrogative style questioning and generally closed conversations was seen to contribute to the marginalised position of children. In addition, dietary advice limited children's involvement because it was of little relevance to children's understandings of being healthy and to the dietary implications of these. The findings highlight a need to acknowledge children as active participants in their dietary care. Implications for developing a child-centred approach to dietary consultations are discussed including implications for working with children towards improved health outcomes of managing CF diet.

Introduction

Diet is central to the clinical management of cystic fibrosis (CF) which is a chronic life shortening illness involving oversecretion of exocrine glands. Children with CF are advised to eat 120-150% of recommended daily energy allowance for age comprising 40% fat intake (Sinaasapsel, Stern, Littlewood, Wolfe, Steinkamp, Heijerman et al. 2002) to maximise growth, pulmonary function and survival (Steinkamp & Wiedemann, 2002). However, children's actual dietary intakes are consistently reported as falling short of these recommendations (Stark, Mulvihill, Jelalian, Bowen, Powers, Tao et al. 1997; Powers, Patton, Byars, Mitchell, Jelalian, Mulvihill et al. 2002). The practice of self management has been advocated as an approach to helping children with CF increase their calorie intakes (Luder et al. 1989) by educating them and their parents to actively partake in self monitoring, decision making and in communicating with professionals (Bartholomew et al., 1991). However, there is little known about the role of children during consultations in terms of accounting for their diet, expressing their views and having these considered in their overall dietary management. Research into children's involvement in dietary consultations is important because children's co-operation is required if dietary recommendations for CF are to be implemented and therefore contribute to improved health outcomes in relation to growth, pulmonary function and survival.

The idea of children with CF having a role during dietary consultations is in keeping with contemporary thinking about children which views them as social actors who actively construct their daily experiences and social relationships and who have a cultural identity distinct from adulthood (Prout & James, 1990). These perspectives

diverge from traditional understandings of childhood as a transitional period of development and socialisation towards adulthood. Prout and James (1990) have argued that traditional perspectives on seeing children as "immature, irrational, incompetent, asocial [and] acultural" (p.13) do not adequately explain children's activities and how they interpret their social experiences.

Contemporary thinking about children as actively constructing their daily experiences has informed discussions over the past decade on the need to develop child health services that are inclusive of children's perspectives in their own right (e.g. Alderson & Montgomery, 1996; Gabe, Olumide, & Bury, 2004). In addition, the children's rights movement encouraged by the United Nations Convention on the Rights of the Child in 1989 has influenced discussions about children's potential as active participants in their health care. The Convention highlights children's rights to have their views heard, respected and acted upon concerning matters that affect them in their daily lives. Such rights are now advocated in health policy initiatives (e.g. Government of Ireland, 2001) with consideration to developing partnership relationships with children (e.g. Government of Ireland, 2000).

However, seeking, listening to, and acting upon the views of children, may not be straightforward in practice. There are tensions within and between Articles of the UN Convention on the Rights of the Child that could present practical difficulties in developing partnerships with children. For example, Article 12.1 states that a child's right to be heard requires assessment of his or her capacity to formulate views taking account of age and maturity. However, judgements about children's capacity to formulate views are typically linked to age rather than competence. This point is highlighted in previous

observational studies on paediatric clinic consultations which concluded that a child's age was an important factor in determining whether he/she was included in conversations and those aged over 10 years were more likely to be addressed directly compared to younger children (Strong, 1979; Silverman, 1987; Tates & Meeuwesen, 2000; Tates, Meeuwesen, Elbers, & Bensing, 2002). Assumptions about children's incompetence to contribute to decisions about their health have been challenged (Alderson & Montgomery, 1996) Drawing on empirical data concerning children's and parents' consent to surgery, Alderson and Montgomery argued that children are more frequently able to make decisions than adults are willing to believe. They proposed compulsory school age as an indicator of competence because children are ready for formal education and are learning about their own health care. However, a child's age should not be the only criterion for assessing competence. Consideration also needs to be given to illness experiences, social experiences of communicating with adults, and willingness to contribute to consultations (Alderson, Sutcliffe & Curtis, 2006).

Article 3 of the Convention places the child in need of "protection and care" and this requires that their "best interests" be a primary consideration in all actions concerning them. In Article 5, the Convention places parents (or other persons legally responsible for the child's care) as the persons with "responsibilities, rights and duties" in guiding the child's exercise of his or her right. The 'best interests' principle of protecting children however could be counterproductive to developing partnership relationships if used by adults to justify excluding or limiting children's involvement in health consultations. A study on communicating about cancer to young people points to this problem (Young, Dixon-Woods & Heney, 2003) in that parents adopted an executive role

that guarded the amount and type of illness information that professionals told their children because of concerns about upsetting them.

According to Dixon-Woods, Young and Heney (1999), there is a need for research that would guide the management of consultations in ways that involve shared decision making with children within the context of complex relationships involving not only the child but also parents. Therefore, a challenge for professionals in developing partnerships is to acknowledge the rights of children to be consulted and the rights and responsibilities of parents as their principal guardians. This challenge includes acknowledging differing perspectives that each party – child, parent, and professional - brings to the consultation and then working with these differences which may be sources of potential conflict because of various beliefs held by each party (Gabe et al., 2004).

There is little known about children's and parents' perspectives on consultations concerning CF diet and about whether differences between them are considered by professionals. In particular, children's perspectives on their role during consultations and on how they might be actively involved remain largely unexplored. Observational studies have examined consultations with doctors (Strong, 1979; Silverman, 1987; Tates & Meeuwesen, 2000; Tates et al. 2002). More recently interviews have been conducted with children and adolescents to examine their accounts of communications with professionals (Young et al. 2003; Beresford & Sloper, 2003). Mixed methods studies that combine observation and interviews can provide opportunities for children and parents to reflect on and to describe their perspectives on observed consultations, and can sensitise researchers to observe aspects of consultations highlighted as important to children and parents.

This paper draws on observation and interview data to examine children's and their parents' perspectives on how children, parents and professionals communicated with one another about CF diet. Children aged between 6 and 14 years were selected because this marks a period of unstable nutritional and growth patterns in CF (Zemel, Jawad, FitzSimmons, & Stallings, 2000) and also is a period when children become increasingly independent in making food choices outside their homes and away from parents (Ross, 1995).

Methods

The Sample

The sample was recruited from 2 CF centres in Ireland conducting multidisciplinary clinic consultations involving doctors, dieticians, CF specialist nurses, and physiotherapists. Once ethical approval was obtained from the relevant research ethics committees, a selection of parents and children were sent study information leaflets inviting them to participate. A follow up phone call from ES determined their willingness to take part.

Specific inclusion criteria were that children were diagnosed with CF for more than one year and were aged between 6 and 14 years. Children and their parents were purposively selected over time to ensure maximum variation of characteristics including representation of both sexes, across the age range, and the range of weight and height percentiles from below the 3rd centile to above the 97th centile. This selection was guided by theoretical sampling so that emergent categories could be further explored in depth. For example, children with a record of persistent weight loss were selected to examine how deteriorating weight patterns influenced the ways in which professionals

communicated about diet during consultations. A total of 37 families were approached to participate and of these 9 refused. The final sample included 32 children (18 girls and 14 boys), 28 mothers and 5 fathers, from 28 families. Characteristics of the children sampled are presented in Tables 1 and 2 for age range and for weight and height profiles. In Table 2, children's weight and height profiles are categorised into two growth patterns: consistent weight for height, and deviation in weight for height. Comparing weight in relation to height is a method of assessing growth in children. Changes in growth patterns serve as critical pointers to health problems in CF, for example, as indicated by a child's line of weight deviating down and crossing lower percentile lines (Patel, Dixon & David, 2003) which was the pattern for all children profiled in the category 'deviation in weight for height' (Table 2).

The socio-economic profile of the sample categorised according to the paid employment status of parents is presented in Table 3.

Data Collection

All participants were interviewed by ES over a period of 21 months and the consultations of 21 of these children with professionals in outpatient clinics were observed. Each child was observed throughout one clinic attendance, during which they had separate consultations with a range of professionals so that a total of 80 consultations were audio-recorded and observed (Table 4). Field notes of non-verbal behaviours and interactions were recorded. All children were seen by a doctor at both CF centres and by CF nurses at one centre during which CF diet was addressed. As illustrated in Table 4, consultations with dieticians were not a routine part of clinic visits and were seen to occur if children were referred to them with weight loss. In addition, consultations with physiotherapists

were observed: while these did not address dietary management, their inclusion in the study provided data about an alternative approach to communication in consultations. Separate interviews were conducted with 32 children and their parents (mostly mothers) in their homes. An interview guide was used drawing on topics of relevance to eating and diet in CF. The interview guide was used in an open and flexible manner to encourage children and parents to raise topics spontaneously. For example, topics specific to clinic visits aimed to explore children's and parents' experiences of dietary consultations with consideration to the role each party played, the focus of dietary advice, and how dietary concerns of relevance to both parties were addressed (see Box 1) Theoretical sampling of specific topics was used during data collection to further explore and develop themes that were emerging from concurrent data analysis (Box 2). Interview data provided a context for observing communications between each party during consultations including whether the perspectives of children and parents were considered. Clinic observations from previous research (Strong, 1979; Silverman, 1987; Tates & Meeuwesen, 2000; Tates et al. 2002) also provided a context for observing consultations by sensitising the researcher (ES) to patterns of communication concerning the inclusion/exclusion of children, the surveillance nature of consultations, and the principal role adopted by parents in accounting for children's health (Box 2).

Data Analysis

Discourse analysis (DA) was used to examine clinic conversations which is a method that seeks to understand naturally occurring talk as social practices. In other words, DA examines what people do when talking to one another. A fundamental feature of DA is that it leads to an examination of "participants' constructions and of how they are

accomplished and undermined" (Potter, 1997, p.146). In analysing consultation data, attention was paid to the fine detail of both content and form of discourse, the latter being especially important to identifying communication patterns between parents, children and professionals. Conversations were examined for pauses, interruptions, types of questioning, turn taking, tone, associated non-verbal cues, and word choice.

The interviews were transcribed and imported into a NUD*IST version and reference database. Data were analysed concurrently using a method of constant comparison which involved coding and categorising them by comparing and contrasting incidents moving from a level of description to conceptualising to theorising about the data (Coffey & Atkinson, 1996). The emergent themes emphasising core features of consultations (Box 2) provided a framework for concurrent data collection and analysis.

Findings

Children were marginalised for the most part during dietary consultations although there were some attempts to include older children. Features of consultations seen to contribute to children's marginalised position were the surveillance approach to consultations, privileging parents' accounts of CF diet, and focusing on nutritional and medical aspects of diet which was seen to have little relevance to children's views about being healthy and the dietary implications of these.

The Marginalised Position of Children

Children's accounts indicated that they had a generally passive role during consultations because conversations were mainly held between their parents and professionals:

> **Karen**: …it's boring…you just have to sit there and listen to all this information about me. I don't like it. (pause)…they just talk to my Mum and Dad. [Interview C04, 8 years, Text Unit 21]

Children believed that they had to adhere to etiquette that allowed parents and professionals communicate with one another without interruption. During consultations, children were observed to sit quietly unless spoken to. Children who did not adhere to this etiquette risked being reprimanded by their parents. For example, some children who became restless were asked to "stop messing" and were reminded that professionals were "very busy people" who needed to get their work done.

Strong (1979) explained the exclusion of children from consultations as arising out of an identity of incompetence cast upon them by the adults present. However, when children's views were explored in this study, they believed that they should be the principal persons consulted on matters concerning their diet:

> **ES:** When they say [about putting on weight] at the clinic, who do they say it to?
>
> **Patrice:** My Dad, well whoever goes with me.
>
> **ES:** Do they say anything to you?
>
> **Patrice:** No.
>
> **ES:** Who do you think they should say it to?
>
> **Patrice:** Me…'cos I'm the one not putting on the weight like, not him [Interview C11b, 10 years, Text Unit 377]

Tates et al. (2002) commented that unless children are consulted they might adopt the role of "withdrawn bystanders" where they cease to hear what is being said

concerning them. The accounts of some children implied that this might have been the case for them:

ES: When you say she [doctor] talks to you and she asks "how are you keeping?" …are there other questions?

Sean: Not really, I don't know 'cos she talks to Mammy and I don't really listen.

ES: Is there any reason why you wouldn't listen?

Sean: It's not my business, well it would be 'cos they're talking about me and but sure I wouldn't be listening. [Interview C23b, 10 years, Text Unit 216]

Opening Consultations to Older Children

There were incidents observed at clinics and reported by some parents and children (aged 10 years and over) that pointed to consultations being sometimes inclusive of older children. Parents spoke of a turning point in how consultations were conducted as their children got older such that professionals "build up the rapport of actually talking with them" and no longer "ignore" that that they are present. This shift towards consulting older children indicates an acknowledgement of their independence as professionals "attempt to wean the child away from dependence on parents" by addressing them directly (Silverman 1987, p.211). Opening consultations to older children in this way was limited however because parental responses stifled children's attempts to address questions raised:

Doctor: Are you coughing still Sinead or has it settled down?

Sinead: It's [sett

Mother: Oh it's settled down.

Doctor: No green stuff coming up anymore? (eye contact with child)

Sinead: Well [ahem

Mother: Well it's more brown than green but no, it's very good. [Clinic Observation: C14, 11 years, Rec Unit 003: 01.10]

When parental responses continued to interrupt children, professionals were observed to realign consultations with parents in a form of "dyadic interaction" (Tates et al. 2002) that left children marginalised. Notice the change of pronouns from "you" in the above excerpt to "she" in the following excerpt illustrating how the consultation with Sinead changed over its course leaving her excluded from a conversation concerning her diet:

Doctor: Is she on a good diet, eating okay?

Mother: Oh yeah, good for her anyway…actually her weight is up….

Doctor: Yeah I've seen that. She saw [the dietician] today, did she? [Clinic Observation C14, 11 years, Rec Unit 003: 03.20]

The above exchanges also illustrate the interrogative style of questioning used by professionals which when directed at children limited the extent to which they could express their views, resulting in brief and closed answers to questions asked. Even when professionals sometimes adopted an open-ended approach to questioning children about diet, the conversations that followed were generally closed and there were few attempts to explore their views in depth:

Dietician: How did you get on with the bottle I gave you the last time you were here, the overnight feed?

Aidan: It was alright.

Dietician: Did you have tummy pain or anything like that after it? **(Aidan**: No) No, okay, I'll tell you what, if I get Dr. (Consultant) to do you out a prescription, how would you feel about trying it at home?

Aidan: Yeah, I'll try it.

Dietician: Okay then, I'll do that [Clinic Observation C22, 13 years, Rec Unit 013: 16.18]

Consultations with one physiotherapist were seen to differ from the generally closed communication style of professionals in seeking children's views about managing CF. In the following consultation, the child was placed in a position of advising the physiotherapist about the breathing technique he found most useful**:**

Physiotherapist: Dave, did you notice any change with that PEP [positive expiratory pressure] mask, did you clear any more phlegm or did you notice any change at all?

Dave: I thought the other way was better because ahem I moved a tiny bit [of phlegm] with the mask but I'd move more stuff with the humming [an alternative breathing technique used by the child]

Physiotherapist: …so what's your analysis of the whole thing Dave, if you were to pick one technique, what would you prefer?

Dave: The breathing [humming], that's better. [Clinic Observation: C06, 10 years, Rec Unit 006: 02.15]

The physiotherapist went on to negotiate with Dave about continuing the PEP mask in addition to humming. She advised him of various positions that he could use and acknowledged that he would be "the best judge" of what suited him. This type of negotiation was observed by Silverman (1987) with adolescents and although seldom used was seen to offer a practical solution to working with their autonomy because it gave them choices between alternative courses of action.

The pattern of communication between Dave and the physiotherapist illustrates that children could engage in discussion if the professional's style of communication encouraged participation. Of course the above exchange is concerned with physiotherapy technique rather than diet. It is conceivable that a similar communication style could be used to discuss diet, although there may be specific contextual features of discussion of physiotherapy. Exploring children's food likes and dislikes could be a way of giving them choices in encouraging them to implement a high fat diet for CF. However, children's accounts indicated that their food likes and dislikes were not always considered during consultations and some children from one CF centre in particular spoke of continuously being advised by the dietician to eat certain foods high in fat content irrespective of disliking them.

The Surveillance Approach to Consultations

Consultations were observed to take a surveillance approach which involved interrogative style questioning about diet. While general questions about diet relating to appetite and enzyme dosages were asked by CF nurses and doctors, more detailed assessment of dietary intake involved questioning by dieticians. However, not all children were reviewed by dieticians and consultations with dieticians were seen mainly to occur when

children were noted to have lost weight or were making little progress in gaining weight between clinic visits.

Clinic surveillance of dietary management also involved routine measurement of weight and height. Weight measurement was seen as the principal source of information used by professionals in judging adherence to CF diet and in determining the need to advise on dietary intake. One girl described the advice she received when not gaining weight:

> **Katie:** …they'd be kind of saying like it's not gone up so make it go up for the next time.
>
> **ES:** Who says that?
>
> **Katie:** The dietician or the doctor, actually, they all say it…I don't mind them telling me like but they don't know like you'd be eating the house down and you still wouldn't put up weight. [Interview C26, 14 years, Text Unit 176]

Surveillance of dietary management occurred within a moral framework consistent with Silverman's (1987) observations of diabetic clinics at which those who managed the illness at home were required "to show that they [were] doing their best to contain their disorder" (p.205). Implicit in the moral framework of surveillance is the notion of "policing the lying patient". He described blood glucose measurements by medical staff as a means of policing adolescents that "finds truth inside the patient rather than as conversationally constituted"(p.205). In the case of CF, the accounts of some children implied that they perceived weight measurements as a test used by professionals to determine whether they were telling the truth about adhering to dietary advice:

> **Deirdre:** It's annoying sometimes because they'd be saying "put up more weight", but you'd say like that you're eating all around you and do you know sometimes then they don't even believe you and that's very annoying. [Interview 11a, 12 years, Text Unit 363]

Some mothers believed that their presence at consultations was necessary to ensure their children told the truth about dietary intake and weight measurements were sometimes used as a lever to charge them with misbehaviour for not eating. For example, a mother referred to her son as a "bold boy for eating lunches" on hearing that he had not gained weight since the previous clinic visit. Parents believed that weight monitoring at the clinic was important to assessing dietary management and they saw weight gain as critical to protecting their children from chest infections and from shortened survival with CF:

> **Mother:** …it's the one thing that would be looked at all the time …weight is one of the things we [parents] have to keep on and that's the diet, you adhere to that to see that they do put on weight…that's what will keep her well up here [pointing to chest] for as long as possible [Interview P03 of 6 year old girl, Text Unit 145]

This quotation points to the mother's belief that parents are principally responsible for their children adhering to the recommended CF diet for weight gain. Other parents shared this view and spoke of their sense of responsibility in ensuring their children's co-operation with eating. Weight gain was perceived by parents as a testimony to their good work in feeding their children and a source of reassurance that they were "doing things right". A mother expressed her sense of satisfaction at the clinic on hearing that her child had gained weight:

> **Mother:** I'm delighted with meself now 'cos I'm getting her to eat more than she was. [Clinic Consultation: C20, 6 year old, Rec Unit 005.05.52]

On the other hand, evidence of weight loss was described by parents as a source of tension leaving them "feeling guilty" about their efforts at feeding their children. Parents' beliefs about being principally responsible for their children's dietary management were also reflected in the principal role they played during consultations as the persons who mostly accounted for children's dietary intakes.

Privileging Parents' Accounts of Children's Diets

Consultations were directed to parents primarily and their accounts of children's diets were privileged over those of children. Some parents described how professionals affirmed their role as the best persons to communicate information concerning their children, a position that was established when they first started attending the clinic:

> **Mother:** Dr. [Consultant] said to me many years ago…"tell me what you think", because he said "You're the child's mother and Mum knows best…[Interview P10 of 7 year old boy, Text Unit 155]

Although attempts to involve some children were seen during consultations, confirmation of their accounts was sought from parents. The presence of parents seemed necessary for consultations to proceed:

> **ES**: Do you actually go in [to clinic] with her?
>
> **Mother**: Yes, we have to…one day I left her into the clinic and I was trying to park

the car outside and they wouldn't see her until I arrived in. [Interview P26 of 14 year old girl, Text Unit 225]

When tensions arose between some parents and their children because of conflicting accounts of dietary intake, it was parents' accounts that were accepted when assessing dietary management, as illustrated in the following exchange:

Dietician: …are you managing to take one litre of nutrizon every night? [eye contact with child]

Mother: No

Dietician: Five nights

Aidan: Six nights

Mother: Ahh, Ahh, that's a lie, *how many,* four nights a week, *four.*

Aidan: Five **Mother**: Four **Aidan**: Five **Mother**: Four.

Dietician: Okay, four…[Clinic Observation: C22, 13 years, Rec Unit 006:18.31]

A dilemma for medical staff highlighted by Silverman (1987) was their need to strike a balance between the conflicting demands of accountability in terms of parental responsibility and adolescent autonomy. He found that medical staff emphasised respect for adolescent autonomy more than appeals from parents to have their sense of responsibility acknowledged. In the case of younger children in this study however, professionals were observed to privilege parents' accounts over those of children implying that parents were viewed as the principal persons responsible for protecting their children's physical health. The emphasis on parental responsibility is highlighted in

the following exchange when a dietician challenged claims made by a mother who spoke of her child not co-operating with eating:

Dietician: Jack's weight is going up…so make sure he keeps eating.

Mother: Jack is not good for eating, it's hard to get him to eat.

Dietician: So what is he eating, what is he getting for his breakfast?

Mother: I *can't* get him to eat much…

Dietician: But he must be eating something, what does he eat.

Mother: Well ask him what does he eat, Jack *speak up for yourself* [Clinic Observation C05a, 10 years, Rec Unit 004: 1.00]

The charge of responsibility cast upon this mother created an uneasy tension in the consultation, which led the mother to deflect the interrogation towards the child. Until this point however, the use of third person pronouns "he" and "him" in the discourse indicated that Jack's role in accounting for his own actions was marginal to the principal role expected of the mother in accounting for his diet.

Focusing on Nutritional and Medical Aspects of Diet

Consultations typically focused on nutritional aspects of diet to include assessing calorie intake through 24 hour dietary recall, identifying sources of fat intake, and weight measurements as indicators of how diet was managed. However, some parents described difficulties with understanding nutritional terminology and they expressed a preference to be spoken to in "layman's terms" which they then could communicate to their children. A mother explained how joining a Weight Watchers group helped her use nutritional

information in deciding how many enzymes her child should have according to fat content of food:

> **Mother:** …they said to me last year that "you have one enzyme for every seven gram of fat that you eat", so it's fairly okay. If you have a bag of crisps and you look at the back of it and there's fourteen grams of fat in a bag of crisps so you can sort of judge…I went to Weight Watchers myself for a while so I'm sort of getting the hang of knowing well actually this particular food doesn't have as much fat in it. [Interview P24 of 9 year old boy, Text Unit 49]

When advising about diet and the importance of a high calorie intake, professionals typically emphasised weight gain and the medical implications of this for children's health in terms preventing chest infections:

> **Doctor**: …we talked about this [need for weight gain] the last day, we stressed the importance of food and calories because we have to be able to fight any infections that might happen, to keep you in good health. [Clinical Observation: C26, 14 years, Rec Unit 002: 06.15]

Parents of children who had lost weight since the previous clinic visit spoke of their concerns about their children's physical health deteriorating especially the risk of getting chest infections. Their concerns led them to reinforce the importance of eating for weight gain to their children. However, this was seen as a source of tension for parents when their children seemed to pay little attention to their advice:

Mother: …I often came out worried alright about Jack and I'd say "My God, *look look* you are not eating, you are *going to have to eat* Jack and look Brian [brother with CF] is putting on weight and you are not" I might say, thinking I'd be doing good, but then he might just go "Ah" just shrug his shoulders. [Interview P05 of 10 year, Text Unit 131]

When children's beliefs about being healthy were explored it was apparent that their concerns differed from those of their parents and of professionals. Children focused on energy levels when describing their sense of health and wellbeing. For example, 12 year old Louise described herself as feeling healthy when:

…energetic and you know full of life and stuff and I'm able to do things…[Interview C12, 12 years, Text Unit 131]

Similarly, a focus on energy was central to children's descriptions of feeling unwell and 'not so healthy':

Sinead: …I wouldn't have enough energy…I would have a bit of energy but not as much as on a good day…[Interview C14, 11 years, Text Unit 62]

However, observations during clinic visits indicated that dietary consultations were not tailored to children's perspectives on being healthy. As reported in detail elsewhere (Reference), having energy for physical activities was the principal criterion used by children in judging their health and their interview accounts indicated that they attached little meaning to increasing weight and to prevention of chest infections as health outcomes of implementing dietary recommendations for CF.

Discussion

The need to consult children about their health care is now endorsed in policy initiatives but there is little understanding of how children view their role during consultations and of how their views can be included in helping them towards positive health outcomes. A mixed methods approach was adopted including observations of consultations and interviews with children and with parents. Previous researchers have mostly relied on observation methods during consultations and so the methodological approach of this study has gone some way to addressing issues raised by Gabe et al. (2004) concerning a need to understand the complexities of partnership in 'paediatric' clinics through research outside as well as inside clinic settings, including methods that explore the views of children.

While consultations involved a range of professionals including dieticians, physiotherapists and nurses they shared features with studies of doctors in that children were largely marginalised (Strong, 1979; Silverman, 1987; Tates & Meeuwesen, 2000; Tates et al. 2002). Overall, interactions between the various professionals and children followed similar courses indicating that changes in attitudes towards children in sociological theory and health policy since the 1970s were not reflected in the practice observed. There was little indication that professionals systematically assessed and planned CF dietary care in ways that were open to children contributing their views. Although attempts to include older children's views were reported and observed, these appeared to be ad hoc and inconsistent. These attempts reflected the initiatives of some individual professionals rather than being a strategic approach to consultations. Usually, children's roles were limited to silent observation as consultations became co-constructed between parents and professionals because as parents took a lead in relating dietary

information, professionals realigned with parents over the course of conversation. This realignment has been observed to arise out of 'strategic control' adopted by parents involving interruptions to communications between professionals (doctors) and children (Tates & Meeuwesen, 2000).

Parents believed that they were principally responsible for their children's diet and for consulting with professionals at CF clinics. These beliefs were reflected in parental control of communication with professionals. Their accounts of diet were privileged and children were given little opportunity to speak for themselves. Children believed that they were capable of communicating about diet but adopted a passive role because of beliefs about conforming to etiquette of good behaviour that did not interrupt conversations between their parents and professionals. The consequences of adopting a passive role during consultations were that some children became 'withdrawn bystanders' (Tates et al. 2002) paying little attention to what was being said about diet. Children's accounts therefore indicated that their passivity arose out of a consultation framework involving coalition between parents and professionals and that this passivity cannot be assumed an indication of incompetence to participate, as previously reported (Strong, 1979) and as recently questioned with a call to examine these assumptions through further research from children's perspectives (Gabe et al. 2004).

Clinic observations highlighted conflicts that arose between parents and children at times when children were losing weight or making little progress with weight gain. Weight gain as a principal outcome of dietary management for CF was emphasised by professionals and reinforced by parents in an attempt to highlight to children their need to co-operate with eating the recommended high fat high calorie diet., However children

attached little meaning to weight gain and their priority for being healthy was to have energy for daily activities (Reference). Dietary consultations were therefore of little relevance to children's priorities in staying healthy and well.

This study has illustrated that children, parents and professionals were not working within a partnership framework which involves at least some agreement or shared understanding of the differing perspectives that each brings to the consultation (Gabe et al. 2004). There is a need to acknowledge children as active participants and to consider their perspectives in order to develop a child-centred approach to dietary consultations that contribute to weight gain for improved pulmonary function and survival but presented to children in ways that are relevant and meaningful to them.

Children could be consulted without their parents for part of the consultation therefore hearing their views in their own right while at the same time consulting with parents independently. This approach has the potential to assist professionals to be sensitive to each party's perspectives and to address tensions and conflicts that can arise between them. Professionals could then systematically work towards a partnership framework where children and their parents could be expected to contribute to the consultation towards shared goals of CF dietary care.

A child centred approach to consultations also necessitates professionals to adopt an open style of communication that is exploratory in seeking children's views. An open style communication contrasts with the interrogative style of questioning typical of a surveillance approach to consultations (Silverman, 1987) seen in this study and that yielded generally closed responses. A physiotherapist was observed to seek older children's evaluation of various breathing techniques and to engage children's

participation in consultations. While there may be specific features of the physiotherapy context, it is conceivable that a similar approach could be adopted to help children make choices around high fat content food they like in an attempt to encourage them eat the recommended CF diet. Silverman (1987) explained this type of negotiation as a practical solution to working with young people's autonomy in taking responsibility for implementing health care advice. An open communication style could assist professionals in hearing children's perspectives from their particular stance which could then be considered in terms of how best to tailor dietary advice in ways that are relevant and meaningful to children's daily lives. This study was limited to one consultation for each child observed at two CF clinics in Ireland. Longitudinal study of series of consultations in future research could examine the developing role of children with CF during dietary consultations and may provide increased opportunities for observing the development of negotiated care between professionals and children.

Prior to this study, little was known about dietary management of CF with children and their parents during consultations. In advocating a child centred approach to dietary consultations we also recognise a need for further research into the roles and responsibilities that children and parents desire during consultations in order to identify what might be acceptable to both. There is a need for further exploration of the relevance of dietary consultations to the perspectives of children with CF while at the same time acknowledging the responsibilities of parents, because of the potential positive health outcomes of improved dietary management including longer survival through improved growth and pulmonary function (Steinkamp & Wiedemann, 2002).

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Table 1 Age Range of Children

6 -8 years	9 -11 years	12-14 years	Total
11	13	8	32

Table 2: Weight for height percentiles of children plotted at clinic visit nearest date of interview

	Consistent weight for height				Deviation in weight for *height			
	>75th	50th to 75th	25thto < 50th	3rd to < 10th	25th to < 50th	10th to < 25th	3rd to <10th	< 3rd
Females	2	2	3	2	1	3	4	1
Males	3	4	1	0	1	2	3	0
Total	**5**	**6**	**4**	**2**	**2**$^{(a)}$	**5**$^{(b)}$	**7**$^{(c)}$	**1**$^{(d)}$

*Height percentile: (a) > 75th for both children; (b) 50th to < 75th for 1 child, 25th < 50th for 4 children; (c) 25th < 50th for 3 children, 10th to < 25th for 4 children; (d) 10th to < 25th for 1 child.

Table 3 Socio-Economic Group and Occupation of Parents

Socio-Economic Group & Occupation	***Fathers*** [1]	***Mothers*** [2]
A. Managers & Employers	5	2
B. Higher Professionals	3	-
C. Lower Professional	2	7
D. Non-Manual Skilled	6	3
E. Manual Skilled	3	-
F. Semi-skilled	2	1
G. Unskilled	2	
I. Farmers	2	-
Totals	**25** [3]	**13**

Notes: 1. Two fathers were unemployed and the occupation of one father was unknown.
2. Mothers in paid employment outside the home.
3. Fathers who participated in the interviews included 2 from Group A, 1 from Group G and 1 unemployed.

Source of Socio-Economic Groupings: Central Statistics Office, Ireland (1996)

Table 4
Number of observed consultations with professionals

Consultants/ Registrars	Junior Doctors	Dieticians	CF Nurses	Outpatient Nurses	Physiotherapists	T**otal**
21	8	9	14	8	20	**80**

Box 1: Sample of interview topics/questions

-Description of clinic visits
-Aspects of dietary management assessed and by whom
-Who provided/sought information about diet?
-Dietary advice – messages communicated & to whom
- Who contributed to decisions about diet ?
-Views of parents on their role and the role of their children during consultations?
-Views of children on their role and the role of their parents during consultations?

Box 2: Sample of themes specific to consultations explored by theoretical sampling

-The inclusion/exclusion of children during consultations
- Surveillance approach to consultations
-Role of parents: principal persons accounting for diet/their accounts privileged
- Professional emphasis on weight gain as an goal of dietary management & its relevance to children's views about being healthy.