



The expert CF patient: reality or lip service?

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In the UK nineteen million people, approximately one third of the population, live with a chronic illness. (DoH 2005). This trend is rising and with increasing life expectancy will continue to do so. The cystic fibrosis population of eight thousand in the UK forms part of this group (CF Trust 2008)

The term “expert patient” is currently a very topical one, with health professionals acknowledging that patients with chronic conditions are often more knowledgeable about their disease than they are. This is almost always the case in CF as most people with CF have a diagnosis within the first two years of life and thereafter spend the rest of their lives living with and managing the disease. This experience of living with a disease inevitably brings knowledge and other skills such as resourcefulness and decision making.

The Department of Health (2001) defined these “experts” as “people who have the confidence, skills information and knowledge to play a central role in the management of life with chronic diseases” ,

It is argued in the literature that the concept of expertise means different things to different people and even within the context of chronic illness, expertise has been defined differently between health physicians and patients. Whilst there is recognition that “patients are often experts in their own conditions” (DoH 2001), there is an argument that this expertise from the physicians standpoint refers to knowledge of the disease process, pathophysiology, projected outcomes etc.

Tyreman (2005) argues that expertise is a qualitative rather than quantitative concept which can apply both to knowledge and skills. He contends that understanding one’s disease is not the same as being an expert, so whilst patients may become knowledgeable about their disease he suggests their expertise is focused narrowly in their *own experiences* of that condition, rather than of the disease per se.

Tyreman (2005) also argues that it is the professional knowledge of the physician, that helps the patient contextualise the disease in terms of its effects on other body processes. It is more likely that patients will be expert in the management of their condition through experimenting, self testing and adapting to disease limitations. He suggests that unless there is a clear definition of what is meant by the “expert patient” then there will be a blurring of responsibilities in the management of care..

The issue of expertise inevitably leads to discussion about power balances between the expert patient and the practitioner. Traditionally the balance of power was weighted in favour of the health professional, who made the decisions about care management and the patient was expected to comply.

Badcott (2005) contends that there is an increasing political and social trend to recognise patients as partners rather than passive recipients of care, hence the term “compliance” with treatment has long since been replaced with terms such as “concordance” and “therapeutic alliance” (Kyngas et al 1999). Badcott suggests that this partnership brings with it a measure of patient empowerment and autonomy, and has led to literature (Smith 2000), suggesting that health professionals own up to patients that they may be better informed in some areas than themselves.

Badcott (2005) also asserts that whilst most patients do not have the technical knowledge to validate the basis of their treatment, what they do have is the “ongoing personal long term experience of illness”, p175,

which is difficult to articulate to the health professional. Sharing these experiences with others (lay and health professionals), is according to Fox (2005) a responsibility of those with chronic illness, and has been one of the drivers for lay self management programmes such as the Expert Patient programme (DoH 2001).

This paper aims to explore the concept of expertise in young people with CF and their carers, and examine the consequences for both of being perceived as experts.

Methods

This study forms part of a larger study which explored young people aged 8-18 years with CF and their carers' experiences of befriending (MacDonald and Goulbourne 2007). 17 interviews were carried out with 6 families in their own homes over a one year period. Four families were interviewed twice, with two families being interviewed on one occasion only.

Once ethical approval was gained for the study, families were approached through a CF organisation in Scotland (The Butterfly Trust) which sought permission for the researchers to make contact. Consent for the study was sought from parents and children separately in accordance with local ethics guidelines.

Each interview was tape recorded and transcribed verbatim. Field notes were also recorded detailing our thoughts and feelings during the interviews and any issues which might have influenced the collection of the data. Transcripts were peer reviewed to check for accuracy.

Data was analysed using Ritchie and Lewis's (2003) "Framework" model to build up a matrix of themes and codes from the data. Two main themes were identified from the original study. Theme one describes "Having CF and living with it".

Nine sub-themes were identified under the first theme, two of which will be discussed here; "Young people as experts of their condition", and "Parents as care givers".

Young people as experts of their condition

Young people with CF are knowledgeable about their disease and the effects CF has on them, with physical effects usually being described first. Older children showed more knowledge about the origins and progression of the disease:

Researcher: "What do you know about CF?"

"I get a bug, makes me cough, sick, breathless" FD2 YP (aged 8)

"Well I ken what it is and how I got it ... I was born with it, it effects your lungs and digestion ... I get thick mucus, I go to hospital every 3 months for 2 weeks for IV antibiotics" FD3 YP (aged 16)"

Metaphors were also used to describe the condition:

"... you use a 'shield' everyone else has got a shield, ours are like ... weakened" FD4 YP (aged 10)

Young people generally displayed expertise in knowing the nuances of their disease and were able to detect subtle changes in their conditions:

"Generally when I'm coughing during the night or I can't sleep, or in the morning when I wake at the usual time and I'm really, really tired and I think...oh god...(laughs) its gonna be a bad day" FD5 YP(aged 18)

"cause you know that something's coming up and you can feel it" FD6YP (aged 17)

In- depth knowledge about their condition is not surprising as most of these young people have been living with their disease since infancy and managing self care treatments such as physiotherapy from an early age. This in-depth knowledge links with Tyreman's (2005) contention of individuals being focussed on their own experiences, and links to Benner's (1984) work on knowing intuitively when something is not as it should be.

Despite the age of the young people, the language they used which described the condition and treatments were sophisticated and medicalised, for example IVs, 'Cepacia', DNase, antibiotic names (Ceftazadime / Meropenem) 'Pegs' 'buttons' 'nebs' and 'Ports'.



This level of expertise was seen by the lay befrienders who were working with them as a real challenge. They recognised that the young people (and parents) used unfamiliar terminology. This is in keeping with Peterson's (2006) notion of experts who are said to value technical information. Befrienders felt that perhaps parents and young people had high expectations of their knowledge base which made them feel uncomfortable. This same contention could be applied to health professionals new to the discipline who are unfamiliar with the jargon of CF. Badcott's (2005) advice of being honest with patients and accepting this change in power balance may go some way to address this challenge.

It would appear that the experience of coping with CF is so embedded in the daily routines of young people (and their parents), that they do not notice how specialised their language and terminology is. How they use these terms is matter of fact but never the less indicative of their expert knowledge and skill.

Parents as experts

The burden of care usually falls on parents, who are taking on more and more advanced technical roles such as administration of nebulisers and intravenous antibiotics. The literature recognises that these roles were once the remit of trained nurses (Lowton 2002), and further reinforces the parents as experts of their child's condition.

*"for an hour after these drugs, obviously you've got to monitor him so you can't go to bed or anything, just to make sure he doesn't have a reaction.....
generally if they're gonna have a reaction its within the first half hour so its not a big deal" FD4P
(on home IV's)*

Although clearly technically competent when administering IVs, providing physiotherapy, setting up nebulisers and feeding pumps their expertise could only be assumed when treatments were administered at home, but when in hospital this expertise needed to be relinquished.

because they're busy, but they're not necessarily... there's only so many trained to do IV'S and you get to the stage where like well give me them and I'll do them myself,... -no you cant! Its ok for me to do them at home, myself but not ok for me in hospital. FD4P

This opinion was not universal, what was however, was the non recognition by medical staff of the parent as expert of their own child at the time of diagnosis. .Despite the fact that for some diagnosis was 15 years ago, parents still felt the need to vent their frustrations about not being listened to during the interview.

"That was the biggest nightmare ever....diagnosed from a baby.....we were sent to (hospital)I for every test imaginable and they kept saying there's nothing wrong with him, he had asthma....i used to carry pots of his poo everywhere I went and they said I was feeding him too many dairy products.... And I was like- it's not normal.....you know yourself there's something wrong" FD2 P

In the intervening years since diagnosis, parent's knowledge about CF has grown and become embedded so that now, they are attuned to subtle changes in their child's mental and physical condition. Recognition of these changes acts as a cue for them to seek help, support and treatment:

"... I know what's going to happen ... I know when he's going to get ill" FD5 P

"... and sometimes in the morning you could tell that (he's) just no, he's not gonnae have a good day today – just not in the frame of mind. He'd be feeling really down" FD1 P

It's hard for parents being so close to their offspring. Being carers when it is their own offspring, the burden of 'expertise' can be overwhelming:

"... not sure if I could manage it (IVs) I approached them and I said I'd like to do home IVs and then they started saying 'Oh well, you'll need to do this and do ... and I was thinking maybe I'm not ready



for it yet ... I deal with handicapped kids at my work and I just felt Oh no, what if something It's your own eh?"
FD2 P

This raises questions about the assumption that care givers or parents *want* to take on technical or expert roles. It is well known that asking carers to assume these roles saves the NHS millions of pounds per annum, but the drawback according to Fox (2005) is the burden that is then placed on these "experts" to continue to fulfil this role. For some it would seem it is a bridge too far.

Parents see their role as monitor, assessor and deliverer of care. This has physical, social and emotional effects on the parents. Physical effects include lack of sleep deprivation and so exhaustion, and general fatigue due to the daily care routines or endless rounds of appointments and hospital visits. A great deal of parents' time was invested in physical caring to try and keep their children out of hospital;

"I would rather that I did everything than take him in and let the nurses deal with it, cos he's such a handful" FD2 P

Although caring for a child with CF is physically and technically demanding, this aspect of the role eventually becomes routine albeit with input and support from specialist practitioners. As the child develops and matures, this aspect of care is entrusted to the child, who then assumes the role of the expert and the responsibility for the parent shifts from one of physical carer to one of encourager and mentor. This process of letting go can be very difficult for parents.

Conclusion

Expertise is present in patients with CF and their carers but can be defined differently in accordance with the literature. When expertise is informal (such as parents managing their child's treatment), it is associated with less power and status than the recognised formal expertise of health professionals.

There is indeed at times a blurring of roles and responsibilities, especially when parents are defined as experts at home but appear powerless when their child is in hospital. The burden of being an expert carer requires many sacrifices and is not for everyone. Health Care professionals and policy makers need to consider how this new partnership between different experts can best be defined and utilised to maximise the best way forward in this new therapeutic alliance.

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