An exploration of partnership through interactions between young ‘expert’ patients with cystic fibrosis and healthcare professionals

Kath MacDonald, Lindesay Irvine and Margaret Coulter Smith

Aims and objectives. To explore how young ‘expert patients’ living with Cystic Fibrosis and the healthcare professionals with whom they interact perceive partnership and negotiate care.

Background. Modern healthcare policy encourages partnership, engagement and self-management of long-term conditions. This philosophy is congruent with the model adopted in the care of those with Cystic Fibrosis, where self-management, trust and mutual respect are perceived to be integral to the development of the ongoing patient/professional relationship. Self-management is associated with the term; ‘expert patient’; an individual with a long-term condition whose knowledge and skills are valued and used in partnership with healthcare professionals. However, the term ‘expert patient’ is debated in the literature as are the motivation for its use and the assumptions implicit in the term.

Design. A qualitative exploratory design informed by Interpretivism and Symbolic Interactionism was conducted.

Methods. Thirty-four consultations were observed and 23 semi-structured interviews conducted between 10 patients, 2 carers and 12 healthcare professionals. Data were analysed thematically using the five stages of ‘Framework’ a matrix-based qualitative data analysis approach and were subject to peer review and respondent validation. The study received full ethical approval.

Results. Three main themes emerged; experiences of partnership, attributes of the expert patient and constructions of illness. Sub-themes of the ‘ceremonial order of the clinic’, negotiation and trust in relationships and perceptions of the expert patient are presented.

Conclusions. The model of consultation may be a barrier to person-centred care. Healthcare professionals show leniency in negotiations, but do not always trust patients’ accounts. The term ‘expert patient’ is unpopular and remains contested.

Relevance to clinical practice. Gaining insight into structures and processes that enable or inhibit partnership can lead to a collaborative approach to service redesign and a revision of the consultation model.

Key words: adolescence, chronic illness, partnership, patient experience

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What does this study contribute to the wider global clinical community?

• Much of the literature on partnership is reported from a professional perspective. This study seeks to explore partnership from patients’ and professionals’ perspectives.

• Long-term conditions are often associated with middle aged and older people and young peoples’ voices are not always heard. This study seeks to give young people with a long-term condition a voice.

• Cystic fibrosis clinics globally tend to be based on similar models, thus some generalisations may be made from this study. This may have implications for revision of consultation models and structures to enhance a needs-based approach to care.
Introduction

Twenty-first century healthcare aspires to present an ideology of patient-centred care operating in partnership with health professionals, with an emphasis on the empowerment of patients and building ‘a mutual National Health Service (NHS)’ (DH 2013). The desire for this partnership and participatory approach is well documented in the nursing, medical and sociological literature as evidenced by the abundance of published research in this area, (Charles et al. 2000, Wilson 2007, Coulter 2012). However, literature suggests that professional barriers to equality within partnership still exist and include: lack of trust and defensiveness, (Thorne et al. 2000), inattention to cues and concerns (Gabe et al. 2004), gatekeeping (Coyne 2006), asymmetry in the consultation and the ‘ceremonial order of the clinic’ which is dictated by a bureaucratic system governed by written and unwritten ceremonial and social rules and situated roles (Strong 1979, Fischer & Ereaut 2012). Barriers also exist from patient perspectives, through the withholding of information or lack of truth-telling (Wilson 2007). The aim of this study was to explore how young expert patients with cystic fibrosis (CF) and the healthcare professionals (HCPs) with whom they interacted perceived partnership and negotiated care.

Background

Partnership is defined as ‘an interpersonal relationship between two or more people who work together towards a mutually defined purpose’ (Hook 2006, p137), and is enabled by shared decision-making and knowledge, respect, reciprocity, communication and autonomy. The rationale for the study was driven by several factors. First, as discussed, the increasing focus on mutuality and partnership in healthcare between professionals and patients was perceived as worthy of further exploration. However, the topic of interest was also driven by experiences of working as a nurse specialist with young people with CF (KM).

Cystic Fibrosis is found in Caucasians and affects almost 10,000 people in the UK (CF Trust 2013). Almost half of these are over 16 years of age (UK CF Registry, 2013). This progressive condition is caused by a gene defect which results in abnormal thick sticky secretions in the lungs and digestive system, causing repeated chest infections and low weight (Cystic Fibrosis Trust 2013). Although previously a disease of childhood, median predicted survival in 2011 is 41.5 years (UK CF Registry, 2013). This is attributed to improved screening, nutrition and surveillance; nevertheless the current median age at death in UK adult services is still only 26 years (UK CF Registry, 2013).

As a multisystem disease, the burden of care is considerable. Sawicki et al. (2008) calculated mean self-reported treatment burden of inhaled and oral medicines, airway clearance and exercise to be 108 minutes per day (excluding intravenous therapies).

Most people with CF are diagnosed in the first three months of life (CF Trust 2011). Thus, by the time they attend an adult clinic, young people (YP) with CF have been self-managing treatments for many years and might be perceived to be ‘expert patients’ (Tyreman 2005). The term ‘expert patient’ has been widely debated and is said to provoke anxiety among HCPs who may feel threatened by its usage (Thorne et al. 2000, Wilson 2007). Alternative terms have been suggested such as; involved, autonomous or lay experts (Prior 2003), but no consensus exists on a universal term. The attributes of ‘expertness’ in the expert patient are also debated in the literature, but it is widely acknowledged that it is qualitative, experiential knowledge of self, rather than technical or craft knowledge that prevails in this group. This expertise is accrued through self-testing and monitoring and differs from physician expertise which is defined as quantitative and includes pathophysiology, diagnosis, knowledge of progression, prognosis and outcomes (Tyreman 2005). There is agreement, however, that self-management has encouraged patients to take on increasingly technical tasks which were once the remit of HCPs, such as enteral feeding and administration of intravenous drugs (Peterson 2006), now a routine part of CF self-management. However, while this is recognised, this is often context dependent within patients’ own homes. Thus, when patients enter a different arena (hospital), they must relinquish their expertise and rely on the professional experts to assume the role. Lay expertise therefore is often associated with less power and status than the recognised formal expertise of health professionals (Thorne et al. 2000, MacDonald & Greggans 2007).

Thorne et al. (2000) assert that when individuals with chronic illness ‘enter the arena’ of negotiation for their healthcare services they are inevitably thrown into complex relationships with HCPs. In CF, relationships between individuals and HCPs may span many years. This study explores partnership from professional, patient and carer perspectives to explore how young ‘expert patients’ with CF and the HCPs with whom they interact perceive partnership and negotiate care.
Methodology

Design

The research draws on Descriptive Interpretivism (DI) (Thorne et al. 1997): a broad methodology which sits within the qualitative paradigm and acknowledges that the researcher brings their own values and experiences to the interpretive process. DI accepts that an individual’s health/illness experience is socially constructed and contextually dependent, thus, context (the CF clinic) is considered part of the phenomenon under study.

The theoretical framework; the lens through which the research is viewed is that of Symbolic Interactionism (SI) which contends that the world is viewed through its use of language and symbols and is concerned with the importance of culture, interrelationships and community (Strong 1979). It can be argued that the context in this study is both persons (the group of expert patients and HCPs) and the setting (the CF clinic). This subculture can be said to have its own language: the CF-specific jargon used in everyday conversations and covert and overt symbols and practices which can be observed and explored through the research.

Methods

Setting

The research was conducted in 2012 in an outpatient clinic at a large teaching hospital in Scotland as part of a Doctoral study. The lone researcher was a nurse specialist in the hospital some 10 years before. One of the current patients in the sample and some of the staff were known to her.

Unlike a ‘standard’ clinic, patients in the CF clinic do not wait in a communal waiting area, but are ushered straight to a single room to ensure there is no opportunity for them to meet in the communal area and potentially cross-infect each other.

Healthcare professionals move from room to room to see patients rather than occupying their own room.

This ensures minimal patient traffic across the clinic to minimise cross-infection. Each room has a check-list on the door on which the HCP marks their time ‘in’ and ‘out’ so that other staff can see which room is occupied by whom and with which staff the YP still has to consult.

Recruitment

Following ethical approval from a regional ethics committee, YP who met the inclusion criteria (Table 1) were purposively recruited to the study. Information sheets and posters were displayed in the ward and Out-Patient (OP) clinics. Participants were invited to contact the researcher by e-mail or telephone numbers noted on the posters. This was followed by a face to face meeting, usually at the clinic, to issue information sheets and discuss the research further. Research participants were asked to identify the health professionals they encountered in their consultations and they were also invited to participate in the study. All HCPs who were approached agreed to participate. Written consent was given by all study participants for nonparticipant observation and recording of the consultation and subsequent individual semi-structured interviews.

Data collection

There were often gaps in between consultations where the YP were left alone in the room. For those YP who did not wish a separate follow-up interview after the observed consultations, this ‘dead’ time was used for interview. The other YP and all of the HCPs were interviewed separately at work or home one to two weeks after the observed consultations. During consultations the researcher sat at the back of the room taking notes and audio recording the conversations. By checking that participants were still happy to

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged 16–35 years</td>
<td>Under 16, over 35 years</td>
<td>Consent issues if under 16. Young &lt;35 years</td>
</tr>
<tr>
<td>Transformed to adult Cystic Fibrosis (CF) service &gt;1 year ago</td>
<td>Transformed &lt;1 year</td>
<td>Must have formed relationship with CF team (partnership)</td>
</tr>
<tr>
<td>Diagnosis of CF, Must manage a range of CF treatments</td>
<td>Non CF Diagnosis</td>
<td>Long-term condition (LTC) involving significant Self Management (expertise)</td>
</tr>
<tr>
<td>Male or female CF &gt;5 years</td>
<td>CF &lt;5 years</td>
<td>Suggests experience of LTC</td>
</tr>
<tr>
<td>Must attend specialist CF centre</td>
<td>Attends other CF clinic</td>
<td>Suggests familiarity with team</td>
</tr>
<tr>
<td>Must attend ≥2 clinic Per Annum</td>
<td>Seen &lt;2 yearly</td>
<td>Suggests regular engagement</td>
</tr>
</tbody>
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were developed to explain phenomena. Concept maps were then created to form a descriptive narrative around each theme. Finally explanatory concepts were present they interjected regularly in the interaction between the HCP and the YP.

Three major themes emerged from the data: experiences of partnership, attributes of the expert patient and constructions of illness (Table 4). Within these themes a number of sub-themes were identified: for example, from the first theme: experiences of partnership; sub-themes of enablers and barriers to partnership, negotiation and relationship factors emerged. Barriers to partnership were organisational, attitudinal and developmental. ‘The ceremonial order of the clinic’ as an organisational barrier to partnership and negotiation and trust in partnership were highlighted frequently in discussions and are presented here. Two further sub-themes are also highlighted here: negotiation and trust (theme 1) and attributes of the expert patient (theme 2).

The ceremonial order of the clinic
Young people reported that the clinic was repetitive, time consuming, boring and exhausting. YP were observed retelling the same stories several times to each of the HCPs. On one occasion a patient was observed recounting their substantial drug history three times to three different HCPs:

I guess its, (sighs) .. clinic appointments happen what 6/8 times a year, and you’re there for 21/2 hrs, you’re stuck in a room, been questioned, everybody asks the same questions, goes over the same things and you just feel like you’re repeating yourself a lot, so you just want to go in, if there’s a problem, identify it, fix it and leave, .. p2

Results
Eight YP (six male, two female, aged 19–34) and 12 HCPs from across six disciplines: (physiotherapists, dieticians, nurses, pharmacist, psychologist and doctors) were observed at a series of Out-Patient (OP) clinics over a three-month period, resulting in a total of 34 observed consultations. Of the eight YP observed at clinic, four were interviewed at home soon after clinic, the others (and the two accompanying parents) agreed to talk in the ‘dead time’; (where YP were alone in rooms) before, in between, and after consultations. A further two YP (female), who were not observed at clinic were interviewed at home or in the ward. These two had responded to the recruitment posters by telephone, but had either cancelled clinic or been admitted straight to the ward.

All but one of the HCPs (n = 11) were interviewed in their workplace soon after the clinic observation. One HCP was unavailable for interview having moved elsewhere. Twenty-three interviews were undertaken (11 HCPs, 2 caregivers, 10 YP).

Total duration of the observed consultations ranged from 60–121 minutes per patient (Table 3). ‘Dead time’ ranged from 13–30 minutes across the observed clinic visits and accounted for 17–36% of the patient’s total time in clinic (median 29%). Interactions were led by the HCPs. The majority of the interactions was biomedically focused and took the form of questions and answers. Where parents were present they interjected regularly in the interaction between the HCP and the YP.

Data were analysed as it was collected and continued until theoretical saturation was reached (Bryman 2001). Concept maps were then created to form a descriptive narrative around each theme. Finally explanatory concepts were developed to explain phenomena.
Table 2 Excerpt from thematic chart: Sub-theme: 1.1; Barriers to Partnership

<table>
<thead>
<tr>
<th>1.1.2</th>
<th>1.1.3</th>
<th>1.1.4</th>
<th>1.1.5</th>
<th>1.1.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of trust</td>
<td>Developmental stage</td>
<td>Competing agendas and compliance</td>
<td>Relationship between yp/hcp</td>
<td>Systems and processes (the ceremonial order of the clinic)</td>
</tr>
</tbody>
</table>

- **Covert administration of meds**, should’ve told them ages ago but thought they might take them off me. P9
- In paeds it wasnae between me & drs it was between you *(parent & Dr)*
- Dinnae get moaned at so much *(at adult clinic)*. P3
- Sometimes you wonder, do they actually think I’ve got a social life, I’ve got a job, I’ve got a family and I’ve got a house and I’ve got all these other things happening. P1
- Patient trusts nurses more than anyone, would just like to deal with them. P1, 4, 5, 6
- In the past I would’ve looked at the tests but now would err on side of listening to what they say and treat.
- Dinnae get moaned at so much *(at adult clinic)*. P3
- Think they’re bullet proof at this stage, easier at paeds we knew where to turn. C3
- Sometimes it feels like they just want you to focus on your CF, and that’s all they see. Others never take into account life anything but CF. P1
- Attitude now is get things sorted, less likely when younger, priority was dancing on a sat. night. P7
- Knowing that I played football 2 x week, sort of tells them there’s nothing wrong with me but it’s not on the form! P2
- Patients may not speak there, they’d speak to the nurse afterwards. HPC6
- Would tell them I didn’t do anything, no point hiding it. P1, 4, 5, 9
- I don’t want to do it, I’ve been doing it for years, it’s boring. P3
- Nurses treat you like a person, easier to talk to. P1, 4, 6, 7
- Clinic is not patient led, patients may not speak there, they’d speak to the nurse afterwards. HPC6

P, Patient; HCP, Health Care Professional; C, Care.
Healthcare professionals recognised the limitations of the clinic model, but had to balance this against their professional accountability:

But I think the doctors would argue that they have to cover the bases, ask the person in case there’s something missing. HCP4

Some YP chose to avoid attending clinic especially if they had nothing new to report and instead used the ward as an out-patient facility. Here, they could be seen quickly and get to the heart of the matter rather than follow the perceived ritualised and repetitive clinic model. However, YP usually chose to avoid the ward at weekends when the CF team were not on duty as they perceived care to be inferior:

Weekend care is horrendous, that’s one of the major barriers. If I took unwell on a Saturday I would hang on till Monday because sometimes I feel it’s pointless if there’s no’ a CF team there. P7

Table 3  Average consultation time per HCP

<table>
<thead>
<tr>
<th>HCP</th>
<th>Average consultation time (minutes)</th>
<th>Range</th>
<th>No. of witnessed consults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmacist</td>
<td>7</td>
<td>(3–12)</td>
<td>5</td>
</tr>
<tr>
<td>Dietician</td>
<td>16</td>
<td>(10–25)</td>
<td>6</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>16</td>
<td>(9–23)</td>
<td>7</td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>14</td>
<td>(7–22)</td>
<td>8</td>
</tr>
<tr>
<td>Dr 1</td>
<td>8</td>
<td>(6–10)</td>
<td>3</td>
</tr>
<tr>
<td>Dr 2</td>
<td>16</td>
<td>(16)</td>
<td>1</td>
</tr>
<tr>
<td>Dr 3</td>
<td>25</td>
<td>(17–33)</td>
<td>2</td>
</tr>
<tr>
<td>Dr 4</td>
<td>11</td>
<td>(9–13)</td>
<td>2</td>
</tr>
</tbody>
</table>

Negotiating care

Negotiating care was witnessed frequently in the interactions and emerged as an important outcome of and enabler to partnership. In all but one case, YP were observed as being actively engaged in decision-making in the consultation:

It is negotiated ‘cos you … instead of seven days a week on the nebuliser you do five, ‘cos you’re doing sports … so stuff like that is negotiated. P3

There was heavy emphasis by HCPs on adherence with physiotherapy and medicines, but YP appeared to be very comfortable disclosing nonadherence to treatment and this was recognised by HCPs:

Are you checking your blood sugars ever?

No. P4

An unexpected finding in relation to negotiation was HCPs’ admissions of being too soft in the consultation, a finding also acknowledged by YP.

A new member of the team reported that the amount of rule-bending in this context might not be tolerated in other client groups. They rationalised this as unlike other groups, because of the duration of the partnership, the young age of patients and the nature of their condition, which meant that no matter what YP did, it was unlikely that they would ever be discharged. Underlying this leniency was recognition by HCPs that in an attempt to

Table 4  Thematic results

<table>
<thead>
<tr>
<th>Sub-themes/ concepts</th>
<th>Theme 1 Experiences of partnership</th>
<th>Theme 2 Attributes of the expert patient</th>
<th>Theme 3 Constructions of illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers to partnership:</td>
<td>1  Organisational Barriers: (the ceremonial order of clinic)</td>
<td>Attributes, definitions, values and beliefs (e.g. experience vs. expertise)</td>
<td>Impact of Cystic Fibrosis and coping</td>
</tr>
<tr>
<td></td>
<td>2  Attitudinal barriers: [attributes &amp; beliefs, e.g. power, trust, respect, knowledge of young people (YP)]</td>
<td>Expert patient as navigator (self, systems, processes)</td>
<td>Normalcy (minimisation, embeddedness of treatment burden)</td>
</tr>
<tr>
<td></td>
<td>3  Developmental barriers, (parental surveillance)</td>
<td>Emotion work (voicing cues and concerns, agendas, prioritising)</td>
<td></td>
</tr>
</tbody>
</table>

| Enablers to partnership: | 1  The power of the nurses |                                  |                                  |
|                        | 2  Acceptance of YP’s experiential knowledge |                                  |                                  |
|                        | 3  Adherence to treatment |                                  |                                  |

| Negotiation (HCPs as too soft) |                                  |                                  |                                  |

| Relationship-building and influencing factors (building bridges to trust, competing agendas, preferred personalities) |                                  |                                  |                                  |
keep patients on board some battles are worth fight-
ing and others are not. Thus, building rapport was
important to try to win YP over to optimise treatment
adherence. However, HCPs found this rapport-building
particularly challenging in adolescents who had recently
transitioned:

Oh yeh, I learned a huge amount from the early transition clin-
ics. There were patients staring at the floor, no eye contact,
patients not saying anything at all during difficult transition
clinics. So that’s the extreme end of the lack of partnership. HCP2

Despite HCPs perceived leniency, YP expressed frustra-
tion at the amount of self-management they were expected
to achieve in accordance with HCPs’ expectations. This ten-
sion of competing priorities was acknowledged:

Sometimes you know that what you’re asking them is almost too
much to bear … so yeh sometimes I think we ask too much, but if
you don’t ask … HCP10

Although it was apparent that YP placed their trust in
the HCPs, HCPs in general were less likely to trust YPs’
accounts of adherence to treatment. This was evidenced
by HCPs constant checking of adherence to treatment and
by responses to the question of trust at follow-up inter-
views:

Should we trust them to take their medicine? No we shouldn’t trust
them. I hope we can trust them to tell us they are or are not taking
their medicines. HCP2

The nature of patient expertise

No consensus existed between the two groups as to the def-
inition of the expert patient. Both groups were uncomfort-
able with the term ‘expert’ and preferred ‘experienced’. HCPs
were more sceptical about the term suggesting that
there were many patients who perceived themselves to be
an expert who were not. Furthermore, they suggested that
some patients were expert in navigating and manipulating
systems to get what they wanted:

Yea, who’s button to push, … they’ll phone the CFNS’ : I’m wait-
ing to see the ortho’ surgeon for my sore knee, can you speed it
up? HCP5

From witnessed observations it was apparent that expert-
tise existed in self-management practices with patients ques-
tioning and monitoring side effects of drugs, querying
doses, requesting results and considering the implications of
investigations.

Further, HCPs recognised through experience that
patient’s subjective accounts can be just as important as
objective data:

When I started this job I would think well the FEV1’s fine, but
now I would err much more on the side of listening and use the
FEV1 as a supporting thing. HCP2

Discussion

Both groups reported that the relationships held many ele-
ments of partnership consistent with the literature: respect,
autonomy and negotiation (Gallant et al. 2002, Hook
2006). The long duration and uniqueness of relationships
between YP and the team were often cited as enabling part-
nership. Although longevity of relationship may be consist-
ten with other groups with long-term conditions, the
uniqueness may also arise because the study population are
young, vulnerable, relatively small in number and suscepti-
ble to physical decline. This unique relationship may sup-
port increased empathy and make HCPs more inclined to
be flexible when applying unwritten ground rules, in the
face of nonattendance at clinic, circumventing clinic by
turning up on the ward unannounced or nonadherence to
negotiated treatment plans. Recent literature (Tong et al.
2013) suggests that this lenient approach also happens in
other young client groups.

A further explanation for HCPs’ perceived leniency may
be accounted for by their awareness of the challenges that
occur in this developmental stage of YP (Pai & Ostendorf
2011). Cognitively adolescents are still developing skills of
forward planning and hypothesising the outcomes of differ-
et actions. Thus, their self-management practices may be
chaotic and disorganised. Further, some adolescents may
still be developing communication and social skills towards
the establishment of an identity (Bee & Boyd 2010). Thus,
this time of transition coupled with engagement with a new
healthcare team can be challenging for all and impact on
establishing good relationships. The effects of this may be
notable on resources, clinic and staff time.

Tong et al. (2013) noted that transitioning adolescents
with diabetes preferred adult care compared to paediatric
care due to its lack of vigilance in follow-up of missed
appointments and nonadherence. However, not everyone
preferred this approach. In addition, Tong et al. (2013)
reported that adolescents took time to build relationships
with a new team before they could openly discuss issues.
This may account for the new knowledge apparent in this
study of HCPs’ softly-softly approach to care as a means to
pick battles and build relationships for the long term.

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Although in this sample not all YP were transitioning adolescents, HCPs appeared to find this subgroup the most challenging in relation to engagement, truth-telling and building rapport. Bilton (2013) suggests strategies to develop meaningful partnerships should consider the importance of setting ground rules, particularly in transition clinics when adult CF teams first meet with adolescent patients. She suggests they help create a culture of honesty and trust and asserts that ground rules must be agreed within the team as well as between YP and the team. This ensures that there are no ‘in-groups’ and ‘out-groups’ within the team and discourages YP from playing team members off against each other. It is not clear whether formalised ground rules were established with patients in this study.

Almost exclusively both groups were uncomfortable with the term ‘expert’. YP acknowledged their ability to be in tune with themselves and recognised deviations, but preferred to use the term ‘experienced’ to describe themselves. This experience, although informed by some empirical knowledge was largely concerned with personal knowledge of their bodies in response to their condition a finding consistent with the literature (Prior 2003, Tyreman 2005). YP rejected the notion of expertise in relation to identifying and managing new symptoms; instead they revert to dependence on the HCPs for their empirical knowledge and experience. This finding resonates with previous studies (Paterson et al. 2002, McIntosh & Runciman 2008).

Several reasons are offered as to why patients may be perceived by the HCPs as experts in ‘playing the system’. YP have to navigate through many systems and deal with large numbers of personnel in their day-to-day management of CF (Wilson 2007). They continually retell their stories and are given advice that they may have already rejected. Thus, perhaps their experiential learning has enabled them to be efficient in navigating these systems, a finding consistent with Wilson’s (2007) theme of ‘the expert patient as navigator’. Furthermore, the amount of time that YP must devote to illness work (Corbin & Strauss 1985, Sawicki et al. 2008), attending appointments, organising drugs and equipment may result in their taking short-cuts (such as circumventing the clinic) to prioritise other demands of everyday work (Corbin & Strauss 1985).

Organisational barriers to partnership included the ‘ceremonial order of the clinic’ a finding consistent with the work of Strong (1979). Thirty years later Pilnick and Dingwall (2011) report a continuation of asymmetry in the consultation, where patients do not specify preferred outcomes, but continue the ‘orchestral dance’ of the consultation which does not take account of patient priorities. This is a dance ‘where only the doctor knew the steps and could hear the music’ Fischer and Ereaut (2012, p48). HCPs cite accountability as a reason for the use of a repetitious biomedical model approach at clinic. They assert that the lack of direct questioning approach may mean something significant is missed for which they may later be accountable; a finding consistent with the literature (Horne et al. 2005).

There was clear evidence of negotiation within consultations and although the questions were generally standardised using a clinic form, person-centred approaches were evident within this approach. Where YP had few issues, consultations were shorter as reflected in Table 3. When YP expressed concerns, these were attended to through further discussion or referral onwards. Thus, analogous with Gabe et al. (2004), it appears that in this study it may be the setting that is not conducive to holistic approaches. However, YP’s avoidance of ‘the ceremonial order of the clinic’ implies that it may be time for change (Fischer & Ereaut 2012). When asked to consider alternative models of consultation, YP expressed a preference for the model similar to that used by GPs – where the approach might be ‘What can I do for you today?’

This approach is person-centred, problem-focused, gets to the heart of the matter quickly and would avoid repetitive questions. This approach, although welcomed by some HCPs as a possible alternative was rejected by others. Reasons for this are related to rigour and context. People usually go to their GP with a problem that they want fixed, whereas attendance as CF clinic may be linked to review without necessarily having any specific problems. Thus, it is deemed essential to repeat the baseline questions each time to have comparable measurements. Further, some HCPs argue that the strength of repetition results in a more comprehensive picture of the YP who does not necessarily give the same answer to the same questions being asked by more than one person. Thus, there is a tension here between what YP want and what professionals fear will be missed (Fischer & Ereaut 2012). It is also acknowledged that the purpose and focus of the consultation may be different for different HCPs. Nevertheless, a significant degree of overlap in questioning was observed and warrants discussion.

Trust in this study appears to be viewed differently by both parties, with HCPs acknowledging that they lack trust in patients’ accounts of adherence. YP, however, were observed as being very open about nonadherence to treatment regimes. A further question might be to consider whether YP can be trusted to raise their own issues in a new consultation model and what the subsequent consequences might be? This is already happening in other CF clinics (Hubert et al. 2013), and revealed that YP do not always have the same priorities as HCPs, a finding consis-
tent with this study. However, inherent in the patient-centred model is an expectation that YP will take responsibility for illuminating those issues of central importance.

Limitations of the study
This was a snapshot of one case study and may not be generalisable to other contexts. However, CF clinic models are known to be similar across settings, thus some similarities may exist. YP who perceived themselves as experts self-selected into the study which is a further limitation. Although an attempt was made to recruit a heterogenous group within the inclusion criteria, recruiting non-attenders may have yielded very different information. The clinical team were well established and had worked together as a team for many years. A less well-established team may have also yielded different perspectives. Finally the researcher’s history as an ‘insider’ (Holloway & Freshwater 2007) may have impacted on the rigour of this study (Lincoln & Guba 1985). This was addressed through reflection, supervision, peer review, member checking and in presentation of findings to the team.

To ensure rigour, an uncoded transcript was sent to two independent researchers who had agreed to be peer reviewers. They independently scrutinised the transcript then reviewed the thematic and coding charts in relation to one sub-theme; barriers to partnership. Both peers reached a high level of agreement in relation to the identified themes. One participant validated the transcript and commented on the interpretation of data which was said to be accurate and well understood. The researcher kept a reflective diary throughout the duration of the research which logged field notes and personal, professional and methodological issues. These were then discussed in supervision.

Conclusion
Partnership is a complex phenomenon involving many attributes including; respect, trust, autonomy, negotiation and shared decision-making. Partnership involves relationship-building which takes time and requires HCPs to be prepared to compromise to ensure that long-term goals are achieved. YP and HCPs do not always share the same priorities, thus communication needs to address the differences in an attempt to meet in the middle. It is suggested that the ceremonial order of the clinic which has prevailed since the seventies is no longer fit for modern healthcare, thus new ways of working need to be developed to promote flexibility and autonomy in those with long-term conditions.

Relevance to clinical practice
Establishment of ground rules at transition clinics would ensure both parties had an awareness of expectations, roles and responsibilities and may help enhance trust and honesty. Team ground rules around questioning approaches may also enhance YPs’ clinic experience. Shifting to a person-centred approach to consultation may reduce repetition, boredom, clinic time and DNA rates. Technology may assist in this approach through the use of online diaries and questionnaires completed in advance of clinic, and may assist in triaging patients to focus on those issues which appear to be of greatest concern. Real-time feedback may also assist in developing new consultation models.

Identification of the issues which affect weekend in-patient care should also be addressed.

Findings of the study were presented to YP and the clinical team. The next stage of this project aims to bring both parties together to collaboratively develop new ways of working to enhance partnership.

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Contributions
Study design: KM; Data collection and analysis: KM; Manuscript preparation: KM, LI, MCS.

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