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Are parents and professionals making shared decisions about a child's care on presentation of a suspected shunt malfunction: a mixed method study?

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**Running title:**

**Shared decision-making when a child presents with suspected shunt malfunction**

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## **Summary Statement**

### **What is already known?**

- Shared decision-making has particular relevance for individuals with long-term conditions because the day-to-day care and management of their condition becomes primarily their responsibility and/or their families;
- When the patient is a child shared decision-making involves their parents and where appropriate the child;
- In the context of children with shunted hydrocephalus, health professionals rely on parents to recognise and respond to possible shunt malfunction necessitating the integration of parents' knowledge of the child in the decision-making process.

### **What the paper adds?**

- For both parents and health professionals recognising shunt malfunction dominates the management of children with hydrocephalus, with the priority of care to reach an accurate diagnosis rather than planning treatments;
- Parent-professional collaboration is variable when assessing and diagnosing a child who presents with potential shunt malfunction;
- Within the care pathway parents and professionals differ in relation to when they perceive collaboration should occur: parents want to collaborate at both the information gathering and diagnostic stage, whilst health professionals orientate themselves to collaborating during information gathering and when planning treatments;
- The shared decision-making paradigm, where parents and health professionals exchange treatment preferences to reach an agreement on a plan of care, is not a helpful one to guide parent/child centred interactions in this clinical context.

### **Implications for practice and/or policy**

- Health professionals must value parents' expertise if they are to effectively collaborate with and support parents in their role as care manager for their child's long-term condition;
- The challenge for health professionals is to identify ways of integrating parents' expertise of the child's presenting symptoms with their own clinical assessment when diagnosing and planning care;
- Further research is needed to explore how health professionals engage effectively with and incorporate expert parents' opinions into care decisions.

### **Key words:**

Long-term conditions, children, shared decision-making, collaboration, hydrocephalus

### **Author contributions**

#### **Dr Joanna Smith**

Study design

Data collection and analysis

Developing the paper

#### **Professor Francine Cheater**

Study design

Developing the paper

#### **Dr Hilary Bekker**

Study design

Development of questionnaires

Developing the paper

#### **Dr John Chatwin**

Study design

Application of conversation analysis

Developing the paper

## **Abstract**

### **Background**

Shunts, the main treatment for hydrocephalus, are problematic as they frequently malfunction. Identifying shunt malfunction requires parents to recognise its symptoms and health professionals to integrate parents' information about the child's symptoms within the clinical assessment in order to reach a diagnosis.

### **Aim**

To investigate parent-professional shared decision-making during the diagnosis of suspected shunt malfunction in acute hospital admissions.

### **Design and methods**

A mixed method study involving audio recordings of admission consultations, a shared decision-making questionnaire and interviews one-week post consultation, was undertaken. Twenty-eight family members and fourteen health professionals participated. The interactions were analysed using conversational analysis, framework approach for the interview data, and descriptive statistics for questionnaire responses.

### **Findings**

Both parents and professionals focussed on establishing a diagnosis and ruling out shunt malfunction when a child with hydrocephalus was ill. Participants' perceived effective collaboration as central to this task: parents wanted to contribute to the process of diagnosis by providing information about the likely cause of symptoms. Professionals were satisfied with the level of involvement by parents, though parent satisfaction was more variable. The challenge for professionals was to integrate parents' expertise of their child's presenting symptoms within clinical decision-making processes.

### **Conclusion**

In this context, both parents' and professionals' perceived their interactions to be about problem solving, rather than making decisions about treatments. Although the shared decision-making model can help patients make better decisions between treatment options, it is unclear how best to support collaboration between professionals and parents to ensure a good problem solving process.

## Background

Current health policy within western societies endorses a model of service and care delivery based on patient-centeredness emphasising the need for health professionals to actively engage with and involve service users in decision-making processes.<sup>1</sup> In the child health setting this encompasses involving parents, and children where appropriate, in decisions that affect their child's health care.<sup>2</sup> Shared decision-making is the process whereby patients and health professionals take an active role in decisions concerning the patient's health.<sup>3</sup> This broad conceptualisation of shared decision-making can be applied to a range of decision-making activities such as patients' contribution to the nature of their problem<sup>4</sup>, and the patient's involvement in decisions about care delivery and treatment monitoring.<sup>5</sup> A shared decision-making model of care has particular relevance for parents living with a child with a long-term condition because the day-to-day management of care becomes primarily the responsibility of the family. Professionals rely on parents to provide healthcare interventions for their children and to recognise changes in the child's condition. Yet, research exploring parents' experiences of living with a child with a long-term condition suggests that parent-professional collaboration is variable despite parents' expectations of involvement in care decisions.<sup>6</sup> Parent-professional communication appears to be primarily focussed on information giving, gaining consent for treatment and establishing good rapport rather than encouraging active contribution towards care decisions.<sup>7,8</sup>

Shunts, the main treatment for hydrocephalus, are problematic as they frequently malfunction,<sup>9,10</sup> which can have life threatening consequences.<sup>11,12</sup> Detecting shunt malfunction is challenging because symptoms are variable and may be similar to those of common childhood illnesses, particularly viral infections.<sup>11,13,14</sup> Identifying shunt malfunction, therefore, requires effective parent-professional collaboration: recognition and appropriate response by parents to the symptoms of shunt malfunction and the integration of parents' information about the child's symptoms by professionals within clinical decision-making and diagnosis. Parents of children with hydrocephalus develop considerable expertise in

recognising and responding to illness symptoms in their child but perceive that this expertise is not always valued by professionals.<sup>15</sup> A detailed examination of the interactions between parents and health professionals may identify approaches that support or hinder parents' contribution to their child's care when they seek healthcare advice in the context of suspected shunt malfunction. Although there is a growing body of research focusing on interactions in healthcare settings and particularly studies using conversation analysis as the primary method,<sup>16,17,18,19</sup> the idiosyncratic nature of the clinical problem which is the focus of this article has received little attention.

### **Study aims**

To investigate parent-professional shared decision-making during the diagnosis of suspected shunt malfunction in acute hospital admissions. Specific objectives:

1. Identify parents' and professionals' contribution to the diagnosis of shunt malfunction;
2. Explore parents' and professionals' perceptions and experiences of shared decision-making within this clinical context.

### **Participant recruitment**

Participants were recruited from a regional children's neurosciences ward within a United Kingdom National Health Service acute hospital trust. The sampling criteria were broad and included any parent of a child admitted to the children's neurosciences ward because they were concerned about their child's shunt and the health professionals involved in the child's initial assessment. Although typically not responsible for diagnostic decisions, nurses were included because in this clinical context self-referral to the ward resulted in senior nurses making immediate clinical judgements about the severity of the child's clinical condition and initiating initial management strategies.

## Study design and methods

A mixed method design, primarily based on qualitative approaches, was adopted in order to explore the breadth and depth of parent-professional interactions and experiences when a child is admitted to hospital with suspected shunt malfunction. Detailed descriptions of the methods, data collection strategies and data analysis are available on-line. Data were collected between September 2008 and September 2009. A range of data were collected and included:

- Twenty-one audio-recorded interactions between parents and health professionals during the assessment of a child admitted to hospital because of possible shunt malfunction. Combinations were parent (mother or father or both) and nurse or doctor each child varied, depending on which health professionals consented to participate, and whether junior staff consulted with senior colleagues when uncertain about the child's diagnosis;
- Thirty-one follow-up interviews undertaken one-week following the child's discharge from hospital. An interview topic guide was used to explore parents' and professionals' perceptions of involving parents in care decisions when a child is admitted to hospital because of possible shunt malfunction. Some health professionals participated in more than one interview;
- Forty-four questionnaires consisting of 10 statements relating to decision-making tasks. Statements were developed from the OPTION (observed patient involvement)<sup>20</sup> and COMRADE (combined outcome measure for risk communication and treatment decision-making effectiveness)<sup>21</sup> tools. Statements were scored on a 5 point agree-disagree continuum scale. Parents completed separate questionnaires to evaluate nurses and doctors, and some health professionals completed more than one questionnaire. The questionnaires enabled parents' and professionals' evaluation of the extent to which professionals involve parents in care decisions to be compared.



Local research ethics committee and site specific approval from the research and development department were obtained (LREC reference 08/H1313/18). Consent was obtained from participants prior to both recording of the interactions and undertaking interviews. Health professionals received information about the study in advance of and during the data collection period. The acute nature of the child's admission to hospital did not allow parents the usual period of 24 hours to decide whether to participate. In an emergency situation the senior nurse on duty made a clinical judgement on whether to provide parents with information about the study. Parents were allowed sufficient time to read the study information before the senior nurse ascertained if they wished to participate.

### **Data analysis**

A range of analytical approaches were undertaken. First, the principles of conversation analysis (CA) were applied to the interactional data. CA is a well established socio-linguistic method for analysing conversation. The patterns, structures and practices of talk-in-interaction were explored through the application of the analytical processes associated with CA (turn-taking, turn design, social actions and sequence organisation).<sup>22</sup> The CA notations used are presented in Figure 1. Essential to the validity of the interactional data was the verification of the analysis by an experienced CA researcher (JC). Second, the framework approach, based on thematic analysis, underpinned the analysis of data obtained from the individual interviews.<sup>23</sup> Third, data obtained from the questionnaires were quantitative in nature and analysis of the extrapolated data consisted of descriptive statistics, primarily percentages and frequencies.

(Insert Figure 1)

## **Findings**

Forty-two participants participated in the study and included 28 family members (13 mothers, 6 fathers, 9 children) and 14 health professionals (2 senior nurses, 2 junior nurses, 4 senior doctors, 6 junior doctors). One mother and one junior doctor did not participate in the interview. A summary of participant and child characteristics is presented in Table 1.

(Insert Table 1)

The findings are presented in two sections; first an overview from each of the data collection methods is reported. Second, findings from the interactional and interview data are drawn together to present a cohesive account of patient-professional collaboration in the context of diagnosing shunt malfunction in children and to enhance the credibility of the findings.<sup>24</sup>

### ***Overview of the findings***

#### *Parent-professional interactions*

Topic sequences within doctor-patient consultations are well established and relate to greetings, the presenting complaint, examination, making a diagnosis, treatment planning and closings sequences.<sup>25</sup> These well established sequences were not always evident in the interactions, for example a possible reason for the child's presenting symptom was not always offered. Interactions involving nurses and senior doctors had a greater emphasis on exploring the presenting complaint and care planning compared to those of junior doctors. Two themes were evident across the interactions that related to the study focus and were explored in depth; 'establishing a cause for illness symptoms' and 'involving parents in care planning'. Twenty-three cases of interest were identified relating to establishing the likely cause of the child's illness symptoms. Four types of turn designs were identified: health professionals invited parents to offer a possible cause for the child's illness symptoms, parents initiated the offer of a possible cause for the child's illness symptoms, and parents

either accepted or rejected health professionals' judgements about the likely cause of the child's illness symptoms. Parents were more likely to offer a possible cause for the child's illness symptoms if invited to do so by health professionals (Table 2).

(Insert Table 2)

Eleven cases of interest were identified in relation to involving parents when planning care and treatments. Analysing the cases of interest identified two types of turn designs: parents either accepted or rejected care plans. Parents were more likely to accept than reject care plans offered by health professionals (Table 3).

(Insert Table 3)

#### *Interview data*

Six themes emerged from the analysis of interview data: 'eliciting and valuing parents' concerns'; 'incorporating parents' knowledge with the clinical assessment'; 'establishing a cause of illness symptoms', 'involving parents in care planning'; 'barriers and levers to effective parent-professional collaboration'.

#### *Questionnaire data*

Data from the questionnaires are summarised in Table 4. Overall parents and professionals were satisfied with the level of parental involvement in their child's care. Across all questions, 55% of the scores for both groups related to 'strongly agree' or 'agree' responses. Health professionals did not score 'strongly disagree' in response to any of the statements and 'disagree' for only one statement relating to 'ascertaining the level parents wanted to participate in care decisions'. In contrast, parents used the full range of response categories with 'strong disagreement' or 'disagreement' indicated in 9 of the 10 statements.

(Insert Table 4)

## **Integration of findings from the interactional and interview data**

The themes from the interactional data and interview data were brought together to form two core concepts that characterised participants' experiences and perceptions about parental involvement when diagnosing shunt malfunction. The first concept related to the challenges when establishing a diagnosis of shunt malfunction in children. The second concept related to parents' and professionals' perceptions of collaboration, and the practices of health professionals that enabled or hindered effective collaboration. The concepts and associated themes are presented in Figure 2.

(Insert Figure 2)

### ***Establishing a diagnosis of shunt malfunction***

For both parents and professionals a significant feature of managing hydrocephalus in children was establishing whether or not illness symptoms were evidence of shunt malfunction. Professionals recognised the role of parents' knowledge of their child and the need to take account of their concerns in the assessment processes. However, there were variations in parents' experiences of having their views valued, illustrated in the following interview extracts:

'One nurse said you know your daughter best and how she is in herself. So they do listen to you. Well they did to me and my concerns. I mentioned it (the shunt) and they said they'd get it checked straight away and they did'. *Admission 10, mum*

'I am not sure if they (doctors and nurses) believed me at first, I kept saying this was not usual. Although they listened they didn't really seem to believe me'. *Admission 1, mum*

Conversation analysis of the interactions provided evidence of both a bilateral and unilateral style of communication between parents and professionals. 'Bilateral' collaboration occurs as a process of negotiation, whereas in a 'unilateral' approach health professionals operate, in the main, independent of their interactions with the patient<sup>26</sup>. First, the 'bilateral' example

is presented where there is evidence of effective communication with the parent to elicit information about the child's symptoms and collaboration to diagnose the problem (Figure 3).

(Insert Figure 3)

The sequence begins with the doctor inviting parents ('you' corrected to 'your') to offer a reason for their child's illness symptoms (lines 1 - 4, Figure 3). Although the doctor's turn in line 5 is unclear, it is followed immediately by the mother taking a turn where she offers a possible reason for her concerns (line 6); 'obviously concerned about the shunt', with an emphasis on 'obviously'. The sequence progresses in lines 6-18 as a dialogue between the parents which builds on and clarifies the information initially provided. During this exchange there is no interruption from the doctor. His next turn (line 19) is essentially a clarification and acts as a continuation prompt, evident in lines 20-26 where parents continue the narrative relating to their concerns. The sequence concludes with a receipt of parents' accounts by the doctor (line 28).

The second example (Figure 4) illustrates a more 'unilateral' style of communication. Although the purpose of the doctor's turns in the openings of the interactions presented in Figures 3 and 4 are aimed at soliciting the parents' perceptions about the likely cause of their child's presenting symptoms, the turn designs have contrasting sequential consequences. In the first sequence presented (Figure 3), the second action in the opening turn (line 1, Figure 3) is designed as an open invitation to parents to offer a reason for their child's illness symptoms. In contrast, the second action in the turn in line 1, Figure 4, an assessment is made of the mother's likely concerns prior to seeking the mother's view (line 2). The turn design is shaped to produce a 'preferred' response';<sup>27</sup> the mother could have agreed with the doctor's assessment but she offers a related but alternative 'dispreferred' response (line 3).

(Insert Figure 4)

The doctor's offer in relation to the reason for the mother seeking medical advice and the mother's response appears problematic; he corrects his offer from 'your concern' to 'you think', there is a pause before completing his turn and falling intonation at the end of the turn (line 2) suggesting he does not necessarily concur. Following the mother's offer of an alternative explanation for her concerns (line 3), the sequence progresses (lines 4-25) with an expansion of the initial invitation (line 1); the mother offering reasons for the child's illness symptoms and the doctor responding. Explanation-response sequences in medical encounters have been described in depth.<sup>28,29</sup> Typically doctors may leave elements of patients' explanations unacknowledged as they focus on the tasks of the medical consultation. However, as in this extract in Figure 4, doctors may also disregard patients' explanations and insert their own explanatory responses, which can lead to conflicts between the viewpoints of the doctor and patient.<sup>29</sup>

Doctors' responses when soliciting patients' (or parents) presenting concerns are crucial in establishing or rejecting the legitimacy of the presented problem.<sup>30</sup> The doctor 'receipts' the mother's concern with 'ok', this acknowledges, but does not address her prior turn (line 27), indicating a rejection, or at least a down-grading, of the legitimacy of problem she presents. The sequence concludes with a receipt of the mother's account by the doctor (indicated by 'fine' in line 29), and the turn continues without pause to a new sequence and topic proffer in the form of an invitation. During the follow-up interview the doctor recognised the mother as having considerable experience in relation to identifying the signs of shunt malfunction in her child; the child had undergone a considerable number of shunt related operations. However, the mother perceived that her views during the encounter were not valued.

'Parents know the child far better than you and know when their children aren't well.

Mum is probably as experienced as anyone in terms of shunt problems and the symptoms that (child's name) shows. Shunts are very difficult so we are obliged to treat everything seriously, especially if parents have concerns. His symptoms aren't always the text book symptoms'. *Admission 1, junior doctor<sub>1</sub>*

‘They don’t seem to take on board what you're saying’. *Admission 2, mum*

Establishing a diagnosis of shunt malfunction based on clinical symptoms is difficult; uncertainties related to differentiating between symptoms that might be shunt related and those of common childhood illnesses, particularly viral infections. The relationship between participants’ initial impressions and the admission outcome, in terms of the symptoms being shunt related, were variable. The examples below relate to the same admission (the child’s shunt was revised):

‘This is not how he usually is and I just knew this wasn’t him. He wasn’t right he started holding and shaking his head. His behaviour is out of character that it had to be his shunt. I just thought what else could it be’. *Admission 1, mum*

‘Children at that age pull their ears with an ear infection, so I didn’t entirely dismiss the shunt but it did go down on my list of possibilities because clearly he has signs of an ear infection with frank pus, and it was a nasty ear infection. So I thought the ear infection was causing all the problems’. *Admission 1, junior doctor<sub>1</sub>*

‘These were new symptoms, shaking his head, and they were not like usual when (child’s name) gets a cold or earache and could be due to the shunt’. *Admission 1, senior nurse<sub>1</sub>*

### ***Collaboration: perceptions and practices***

Parents’ and professionals’ struggled with the concept of shared-decision making in relation to treatment decisions in this clinical context because following a diagnosis of shunt malfunction surgery to revise the shunt is the only realistic option. For some professionals working with parents was primarily about ensuring they understood the child’s care requirements in order to obtain consent for treatments. In contrast, professionals also described the value parents added to care decisions and the need to build effective and lasting relationships with the child and family.

'I think the value a parent contributes is really quite high and not recognised as such. Where we fall down is actually not to do with lack of that belief but time constraint, when you're on call you're focusing on a set of specific questions of what to assess. I think parents sometimes want to talk about their concerns and anxieties, we don't address that a lot of the time and it can set off a chain reaction for the whole future because a shunt is for life. If set off to a bad start, it can run the whole experience bad over a long term'.

*Admission 5, senior doctor<sub>1</sub>*

'I think they should be involved to some degree and you need to listen to them and explain and usually they are on the same page as you anyway'. *Admission 12, junior nurse<sub>1</sub>*

'They informed us of everything that had gone on, emm I don't know how to answer that (involvement in care decisions) because they do obviously go through everything with you on each procedure, so you are involved all the time. There's only one decision to be made really and obviously we just want him to be right and want his shunt working. I would not like to think we would have the final decision, but I would also like to think that everything has been discussed'. *Admission 13, mum*

'Vitaly important to involve parents. It's about working in partnership with parents' rather than their contribution to decisions. Clinicians obviously deal with children with different problems, so have a better understanding of the problem as a whole, although parents might know their child better. It's essential that clinicians do lead the management, involving parents it's more of a case of making parents understand the condition, or the cause of the symptoms. Working in paediatrics, one of the tenants must be including parents, but the emphasis is on good communication, decision-making is more about listening and education'. *Admission 1, junior doctor<sub>1</sub>*



Professionals' perceptions of the factors that created barriers to communicating effectively with parents were more likely to relate to time constraints due to workload pressures and environment restrictions such as a lack of privacy when interacting with parents. In contrast, parents' perceived that effective communication with professionals was hindered by not being listened to, being excluded when professionals grouped together to discuss their child's care (for example during ward rounds), were not kept informed of care plans and received conflicting information.

'I needed to know what was happening so I could let family know back at home. I was just having to guess because nobody told me anything'. *Admission 7, dad*

'There is so much conflicting information really. They don't seem to take on board what your saying, that's my feeling. No they really have their own agenda and that's what we are on now their agenda'. *Admission 2, mum*

Although parents were unlikely to reject care plans offered by professionals, the design and properties of the parent-professional interactions when accepting or rejecting care were different (Figures 5 and 6). In the sequence presented in Figure 5 the senior doctor offers his views in lines 3-6 of the child's assessment. An initial plan of care is offered (line15) which is immediately accepted by the child in line 18. Once accepted the doctor moves on to providing more details in relation to establishing the cause of the child's illness symptoms (lines 24, 27, 30, 32). Although a diagnosis is not established, both the child and mother, orient themselves to accepting the plan of care, evident by immediately responding to the doctor's turns, with 'ok', 'yep', and 'that's fine' (for example lines 29, 31, 33). These features are typical in medical encounters when there is acceptance of treatment decisions.<sup>31</sup>

(Insert Figures 5 and 6)

When rejecting care plans, interactions with parents become problematic, the sequence presented in Figure 6 demonstrates active resistance to the care plan offered. The doctor's

turns are punctuated with pauses, changes in pitch and hitches when delivering a possible diagnosis (lines 3-5) and when suggesting a plan of action (for example lines 11-12). In contrast the mother's turns are even in tone, measured and controlled (lines 18 and 23). The doctor's plan of investigations is not accepted by the mother, this 'dispreferred' response appears to result in the subsequent sequences being problematic (lines 3-6, and 14). The mother's responses are quiet and she emphasises, evident by a fall in intonation, that she would resist 'pressure monitoring' (line 13). The mother builds a case for the investigations which she believes are appropriate in lines 18, 19 and 23. The doctor resists the mother's suggestions and moves to close the sequence, 'well at this stage we'll need to get a CT' in line 24. This turn is delivered at an even pace without the pauses and changes in intonation evident in his prior turns. The mother in her pre-closing turn 'receipts' that she understands this sequence is closing with a quiet 'right' in line 26. The quiet responses coupled with the no response (line 28) suggest the mother does not necessarily concur with the care plan. Doctors are orientated towards patients accepting treatment offers; resistance places the doctor in the position of having to encourage the patient to accept the treatment or offer an alternative.<sup>31</sup> In contrast patients, as in the example presented in figure 6, do not necessarily conform to the doctors' preference for agreement, challenge prepositions and maintain contrary preferences.<sup>32</sup>

The descriptions of parent-professional interaction presented in Figures 5 and 6 differ in the way that care plans are presented and negotiated. In the first interaction a definitive course of treatment is not offered but alternatives are provided for further consideration in relation to establishing a cause of the illness symptoms. Deciding the cause of the child's illness symptoms is framed in a way that any decisions will be based on agreement between the child and the doctor evident by the use of 'we' and 'our' ('we are going to have to scratch our heads together', line 24, 'think about what we need to do', line 25, 'let's have a think', line 32).<sup>26</sup> In contrast, decisions about the type of investigations that will be undertaken in the second interaction (Figure 6) are presented as information giving and the discussion is

centred on medically controlled options consistent with a unilateral approach to parent-professional collaboration.<sup>26</sup>

A range of factors that facilitate or hinder effective parent-professional engagement were identified. Parents' and professionals' identified listening, information sharing, valuing parents' experiences, establishing rapport and continuity with the professionals providing care for the child as ways of effectively engaging with parents. Establishing rapport has been recognised as one way of engaging effectively with parents,<sup>33,34</sup> and was evident during the conversation analysis of the interactions. In the sequence presented in Figure 7, rapport building is evident from the beginning of the senior nurse-parent interaction (lines 1-8) when the child's recent hospital admission is summarised. The nurse enabled the mother's 'telling of her story' which is evident by her acknowledging the mother's talk with minimal utterances, such as the 'yes' in line 58. In her pre-closing sequence the nurse offers support for the mother's decision to bring the child back to the ward 'it's↑ always best to come emm (.) and get it checked out' (line 69), 'for your piece of mind' (line 70). The mother's narrative is primarily presented in her own terms and the nurse's responses display understanding, empathy and agreement with the mother's account.<sup>33,34</sup> Listening to patients' stories is one of the ways professionals can attend to patients' concerns and understand their illness.

(Insert Figure 7)

## **Discussion**

The key message from the findings of this study is that for both parents and health professionals establishing a diagnosis of shunt malfunction required working collaboratively but the position in the care pathway where optimal collaboration could occur differed. Shared decision-making is more likely to occur during the treatment planning stage of consultations because patients and professions are orientated towards treatment plans

having joint responsibility.<sup>25,31</sup> Typically, patients accept professionals' judgements when responding to the delivery of the diagnosis and with minimal utterances, and actively respond to treatment decisions.<sup>31</sup> Parents in this study contributed to diagnostic sequences, and although their contributions were more likely to be in response to an explicit invitation from health professionals, parents also offered possible causes for their child's illness symptoms. Previous studies of the negotiation of treatment decisions between doctors and parents related to new health problems<sup>31</sup>; differences in the findings reported here may reflect the different care context, such as the acute nature of the child's admission to hospital, and parents' vast experience of their child's condition.

Despite shared decision-making being the dominant model of patient-professional engagement<sup>5</sup>, it is poorly defined and has not been widely adopted by health professionals.<sup>35,36,37</sup> For children with long-term conditions and their families, there appear to be difficulties in operationalizing a model of shared decision-making, which assumes that a range of treatment choices exist in relation to the care under discussion. This scenario is potentially problematic as many interactions between patients and professionals require involvement around problem solving and illness management rather than deciding between a range of options. The shared decision-making model can help patients make better decisions between treatment options,<sup>38,39</sup> but is less helpful in urgent care setting.<sup>40</sup> When a child presents with potential shunt malfunction the priority of care is to establish a diagnosis rather than offering a definitive treatment plan. In this clinical context, there was evidence that parents' knowledge of their child and previous experiences of shunt malfunction were used alongside the clinical assessment when health professionals made a judgement about the child's illness symptoms.

The quality of interactions between patients and health professionals can influence the effectiveness of information exchange, the development of patient-professional relationships, rapport building and the way care is negotiated at each stage of the care pathway.<sup>41</sup> The

process of including parents was not always transparent; health professionals' perceived that they included and valued parents' contribution to care decisions, while parents did not always perceive that their contributions were valued. Collaboration in this clinical context is not about shared decision-making in relation to treatments but about the value health professionals' place on parents' experiences, and the way these experiences are incorporated into clinical decision making. Collaboration, in the context of making health care decisions, has been defined as 'a process of engagement in which health professionals and patients work together to understand clinical issues and determine the best course of action'.<sup>36</sup> As collaborators in their child's care parents expected to be included at each stage of the care pathway; health professionals' perceived involvement to occur primarily at the information gathering and treatment planning stages. Further research is required to understanding the nature of 'expert parents' in terms of the attributes that constitute becoming an expert, and the ways health professionals engage with and incorporate parents expertise into care decisions when working with children with long-term conditions. Exploring the reasons for differences between the perceptions of parents and professionals in relation to collaborative practice may facilitate better parent-professional engagement and collaboration.

Central to effective patient-professional collaboration and a good problem solving process is the rapport and trust that patients develop with health professionals. Investing in eliciting patients' perspectives such as identifying their concerns, exploring the impact of illness symptoms on patients lives and involving patients in decisions can enhance patient-professional partnerships.<sup>42</sup> Findings from the study presented suggest that although good practice was evident, collaborating with parents, particularly when parents had considerable expertise in managing their child's long-term condition, was challenging. Practical training to help health professionals develop and use a range of communications strategies, rather than basing interactions on subjective judgments<sup>43</sup>, could be a means of improving parent-professional collaboration. Furthermore, the development of a measure and evaluating

collaborative practice could assist in measuring the effectiveness of interventions aimed at improving parent-professionals collaboration.

## **Conclusion**

The shared decision-making paradigm, where parents and health professionals exchange treatment preferences to reach an agreement on a plan of care, is not a helpful one to guide interactions in this clinical context where the diagnosis of the health problem has not yet been established. Further, in this context, once a diagnosis has been made, there is only one course of action. When a child presents with potential shunt malfunction the priority is to reach an accurate diagnosis rather than planning treatments. Parents' satisfaction when seeking health care advice for suspected shunt malfunction was linked to the way professionals' engaged and involved them in decisions about the likely cause of illness symptoms, a model of collaboration is more appropriate. Parents developed considerable expertise in recognising the symptoms of shunt malfunction in their child and were able to distinguish between shunt related illness symptoms and those associated with common childhood illnesses. Parents want to contribute towards decisions about their child's care but this input does not appear to be a priority for health professionals. Yet, professionals vary in their effectiveness to integrate parents' expertise with their clinical assessment and involve explicitly parents in the diagnosis prior to planning the child's care.

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## **Supporting Information**

Detailed descriptions of the methods and data collection tools are available on-line.

**Figure 1: Transcription notation system for CA**

<u>Relative timing of utterances</u>	
(0.5)	Numbers in brackets indicate timings in whole and tenths of a second
(.)	A full stop in brackets indicates a micro pause of less than two tenths of a second
=	No discernible interval between turns
[ ]	Square brackets are used to denote overlapping speech
<u>Characteristics of speech delivery</u>	
.	Full stops are used to indicate a falling intonation
<u>here</u>	Underline is used to indicate an emphasis of words relative to surrounding talk
↑ or ↓	Indicates speech spoken with a high or low pitch relative to surrounding talk
°here°	Degree signs indicate speech that is quiet or soft relative to surrounding talk
>this<	Talk speeded up or compressed relative to surrounding talk
<this>	Talk slower or elongated relative to surrounding talk
.hhh	Indicates an in breath (number of h's indicate length)
hhh.	Indicates an out breath (number of h's indicate length)

**Figure 2: Concepts and themes**

Concepts	Themes
Establishing a diagnosis of shunt malfunction	<ul style="list-style-type: none"> <li>• Eliciting and valuing parents' concerns</li> <li>• Incorporating parents' knowledge with the clinical assessment</li> <li>• Establishing a cause for illness symptoms</li> </ul>
Collaboration: perceptions and practices	<ul style="list-style-type: none"> <li>• Involving parents in care planning</li> <li>• Barriers and levers to effective parent-professional collaboration</li> <li>• Perceptions of parent-professional collaboration</li> </ul>

**Figure 3: Eliciting and valuing parents' concerns - the 'bilateral' example**

1	JDr <sub>1</sub>	fine (.) ok (.) so (.) h. ok↑ and so what↑ are you <u>your thoughts</u> as to what's
2		what what's going on with this
3	Mum <sub>1</sub>	[.h °well° h. well don't <u>really</u> know↑
4	Dad <sub>1</sub>	[°what's causing it° =
5	JDr <sub>1</sub>	°problems° (unclear)
6	Mum <sub>1</sub>	I just I mean we were <u>obviously</u> concerned about the shunt cos we know
7		about that and we know that that's there =
8	Dad <sub>1</sub>	from [what we got told from when the shunt got done they says <u>don't</u>
9	Mum <sub>1</sub>	[emm
10	Dad <sub>1</sub>	be surprised↑ if he gets to have it replaced within the first six months
11	Mum <sub>1</sub>	well [the that was that was ages ago but emm
12	Dad <sub>1</sub>	[but were always wondering aren't we but were always [wondering
13	Mum <sub>1</sub>	[that was our↑
14		only concern=I mean the only <u>thing</u> that stopped us ringing <u>straight</u> away
15		when it=he started having them is because they're <u>not constant</u> and it just
16		seems strange that all of a sudden he can go back to normal↑ but (.) today
17		he just seemed in so much pain and it were we were just <u>concerned</u> and it
18		does seem to be related to his head and his eyes↑
19	JDr <sub>1</sub>	he puts his hands to his head
20	Mum <sub>1</sub>	yeh=
21	Dad <sub>1</sub>	he's always [(gripping) screwing his eyes [up
22	Mum <sub>1</sub>	[yeh [yeh so that was our only concern
23		really
24	Dad <sub>1</sub>	there has been a few times where he's looked like is eyes have been really
25		[stingless clawing at his eyes n sort of like hitting himself on head
26	Mum <sub>1</sub>	[yeh
27		(child in background)
28	JDr <sub>1</sub>	°ok° (child in background) (0.3) ok any vomiting at all

**Figure 4: Eliciting and valuing parents' concerns- the 'unilateral' example**

1 JDr<sub>1</sub> °fine fine° (.) ok so (.) so your concern=you (.) you think there is something  
2 wrong with the shunt (.) °do you.° (.)  
3 Mum<sub>2</sub> or he's not tolerating the pressure=  
4 JDr<sub>1</sub> so you want↑ (0.3) so (.) so ok↑ (.) so it might be (0.5) might be low  
5 pressure because (.) he cause (.)  
6 Mum<sub>2</sub> < I don't know what pressure valve they put in you see I know it's  
7 different>=  
8 JDr<sub>1</sub> different but err (.) but err (.) before↑ this (0.3) we hh. we= they said  
9 [it was  
10 Mum<sub>2</sub> [they said it was over draining  
11 MedSt [over draining (unclear)  
12 JDr<sub>1</sub> [over draining ok >so they've probably put a slightly  
13 higher pressure↑ one in< =  
14 Mum<sub>2</sub> right  
15 JDr<sub>1</sub> >but then if the ventricles have shrunk down< then that sounds like (.)  
16 they've drained quite well. (.)  
17 Mum<sub>2</sub> mmm but have they drained too much.  
18 JDr<sub>1</sub> yeh hhh(,) but should suggest it might be a low pressure headache  
19 Mum<sub>2</sub> °mmm°  
20 JDr<sub>1</sub> they they usually resolve in time I think=>my understanding is< (.) that low  
21 pressure headaches °sort° of because as you get you just have to readjust  
22 to them (.) sort of readjust [to the pressure  
23 Mum<sub>2</sub> [mmm  
24 JDr<sub>1</sub> but err (.) [but  
25 Mum<sub>2</sub> [but it's like where it moves around you know that's °you know  
26 really° (.)  
27 JDr<sub>1</sub> ok=  
28 Mum<sub>2</sub> but I'm not sure (.)  
29 JDr<sub>1</sub> fine but otherwise he's been eating and drinking ok↑

**Figure 5: Agreeing a plan of care**

1	SDr <sub>1</sub>	ok↑ =
2	Mum <sub>6</sub>	°yeh right° (unclear)
3	SDr <sub>1</sub>	emm (.) <u>the</u> scan of your head↑ yeh-I mean (.) you have a slightly <u>unusual</u>
4		hydrocephalus condition↓ (.) °essentially yeh called° >benign intracranial
5		hypertension< (.) emm your scan (.) does not show <u>dilation</u> up the ventricles
6		but in <u>your</u> condition↑ I <u>don't</u> tend↑ to <expect↑ to see [that >
7	Mum <sub>6</sub>	[°right° (unclear)
8	SDr <sub>1</sub>	err if anything the ventricles are actually <u>smaller</u> compared to the that ct the
9		<u>special</u> ct we used in your last operation (0.3) emm and the the <u>shunt</u> has not
10		broken↓ >you know that its [a plastic tube and they<
11	Child <sub>6</sub>	[yeh
12	SDr <sub>1</sub>	> can break the whole way down so we've done a whole series of x- rays the
13		[whole way down↓<
14	Child <sub>6</sub>	[yeh
15	SDr <sub>1</sub>	emm (0.4) I <u>don't</u> think we need to <u>rush</u> to do anything <u>urgently</u> tonight↑
16		ok= yeh↑ I mea-I think (.) from what I can gather↑ and <u>tell</u> me↓ if you agree
17		with hhh. (.) this has been <u>gradually</u> getting [worse↑
18	Child <sub>6</sub>	[yeh
19	SDr <sub>1</sub>	there hasn't been a dramatic <u>bang</u> [today↑ [or anything↓
20	Child <sub>6</sub>	[no=
21	Mum <sub>6</sub>	[no
22	SDr <sub>1</sub>	emm (0.3) so I- I don't think we will <u>rush</u> to <u>theatre</u> to do anything evening↑
23	Child <sub>6</sub>	°ok°=
24	SDr <sub>1</sub>	yeh↑ although I think we are going to have to <u>scratch</u> our heads together here↑
25		to think about what we do need to do↑
26	Child <sub>6</sub>	yep=
27	SDr <sub>1</sub>	ok and what we probably will do is get the ophthalmologist to see you
28		tomorrow↑ morning
29	Child <sub>6</sub>	ok=
30	SDr <sub>1</sub>	so I think you should <u>stay</u> with us (.) yeh=
31	Child <sub>6</sub>	yep= (muffled)
32	SDr <sub>1</sub>	stay in tonight and let's have a think
33	Child <sub>6</sub>	yep [that's fine↑
34	Mum <sub>6</sub>	[ok
35	SDr <sub>1</sub>	because <u>you're</u> not just simple↓ hhh... (laughter)
36		ok↑ (0.5) I don't know the solution to your <u>problem</u> just [yeh↑
37	Child <sub>6</sub>	[no that's↑ <u>fine</u>
38		(laughing?)
39	SDr <sub>1</sub>	er (.) I think we need to do some more <u>tests</u> =
40	Child <sub>5</sub>	ok°
41	SDr <sub>1</sub>	>probably better just staying with us<° till we <u>hit</u> this nail on the head proper
42		again
43	Mum <sub>6</sub>	[yes
44	SDr <sub>1</sub>	[°yes°
45	Child <sub>5</sub>	[that fine not a problem↓ ok↑
46	Mum <sub>6</sub>	[yep
47	Child <sub>6</sub>	[yep (.) am I <u>allowed</u> to eat↑
48	SDr <sub>1</sub>	<u>Yes</u>

**Figure 6: Rejecting a plan of care**

1	JDr <sub>1</sub>	right (child's name)=
2	Mum <sub>2</sub>	oh [yer feet are cold↑(child's name)
3	JDr <sub>1</sub>	[emm ok there's <u>nothing</u> to find again↑ no (.) no (.) obvious signs or
4		anything it's just the symptoms your complaining of (.) emm (.5) you you look
5		(.3) look your <u>normal</u> well self to me↑ (.) in your (.) in terms of your emm (.5)
6		°how he is↓°
7	Mum <sub>2</sub>	oh yeh↑ he always <u>does</u> yeh
8	JDr <sub>1</sub>	but emm I °ll take what your saying so I'll have a chat to the emm° (.) the
9		registrars =
10	Mum <sub>2</sub>	yeh he's always <u>well</u> in himself =
11	JDr <sub>1</sub>	and I think it's probably going to be (.) the usual the usual emm (.) sort of
12		investigations I think
13	Mum <sub>2</sub>	°not pressure↓ monitoring°
14	JDr <sub>1</sub>	>no-n-no↑ (.5) no↑ (.5) we'll not get there first (.) < we'll have to do the
15		<u>CT scan</u> first
16	Mum <sub>2</sub>	[CT scan (.) yeh↑
17	JDr <sub>1</sub>	so (.) no (.) so I think probably =
18	Mum <sub>2</sub>	with↑ it with him saying its hurting here rather than the nape of his neck I
19		thought about is the <u>cyst</u> changing↑ at the back of his head=
20	SHO <sub>1</sub>	°well↓° =
21	Mum <sub>2</sub>	since surgery↑
22	JDr <sub>1</sub>	°I don't know I don't know to be honest° =
23	Mum <sub>2</sub>	would he need an MRI↑ to see that [or
24	JDr <sub>1</sub>	[well I think at this stage we need to get a
25		CT scan
26	Mum <sub>2</sub>	°right°=
27	JDr <sub>1</sub>	and have a look
28		(background noise/ continues clinical examination of child)
29	JDr <sub>1</sub>	emm (.3) I've a feeling °they're ° going to want the emm (.3) err get a CT scan
30		done a shunt series and take it from there ok (.) <u>bloods</u> (.) °they might want
31		bloods doing° ok
32		(mum does not respond interaction continues with child's clinical examination)

**Figure 7: Effective parent-professional collaboration: rapport buildings**

1	SNurse <sub>1</sub>	emm (.4) so my name's (name) I'm Sister on here. emm (.) and <you're
2		(child's name) mum↓> emm (.) h. you phoned me earlier (.) about an hour
3		or so didn't you=
4	Mum <sub>13</sub>	yeh=
5	SNurse <sub>1</sub>	to say that (child's name) had been in last week he had a shunt↑ <u>revision</u> ,
6		is that correct↑
7	Mum <sub>13</sub>	he had a complete new shunt revision yes
8	SNurse <sub>1</sub>	right ok
9	Child	and I've been into to school
10	SNurse <sub>1</sub>	<u>you've</u> been to school↑
11	Mum <sub>13</sub>	he went just went in to see them
12	SNurse <sub>1</sub>	ok hhh.(laughter) that's fine but today he's been complaining of some
13		headaches (.) sorry I'm- it's just (.) you've hhh. you've got a spider in your
14		hair
15	Child	(joint laughter) what were in your hair mum
16	SNurse <sub>1</sub>	(child's name) hhh. mummy had a little spider in her hair hhh. (.) are you
17		ok↑
18	Mum <sub>13</sub>	[hhh. (laughter)
19	SNurse <sub>1</sub>	[hhh. (laughter) so he was complaining oh headache
		(20-56 sequences continues with mum explaining illness symptoms, with
		turns designed to facilitate the mother to tell her story)
56	Mum <sub>13</sub>	whereas since I brought him on home <u>Tuesday</u> he's (.) kind of made good
57		progress (.) each day↑
58	SNurse <sub>1</sub>	yes
59	Mum <sub>13</sub>	and then today he's gone back <u>again</u> I don't know if it's the signs↑(.) =
60	SNurse <sub>1</sub>	that's ok↑ cause often children you↓ know don't↑ follow set (.) you=
61	Mum <sub>13</sub>	[no
62	SNurse <sub>1</sub>	[know stages↑=
63	Mum <sub>8</sub>	no
64	SNurse <sub>1</sub>	and sometimes <it's that (.) they're just a little bit off colour> and you can't
65		quite put your finger on (.) but you know but you know yourself↑
66	Mum <sub>8</sub>	yes=
67	SNurse <sub>1</sub>	the're not quite a (.) hundred percent themselves (.) emm especially↑ (.) if
68		he did bounce↑ back after he had the shunt revision done (.) <u>so</u> it's↑
69		always <u>best</u> to come emm (.) and get it checked out really just for
70		your piece of [mind ↑
71	Mum <sub>13</sub>	[yes that's that's [what worrying me (unclear)
72	SNurse <sub>1</sub>	[especially with it being a weekend and things (.) so erm,
73		what I'll just need to do <I mean obviously he's feeling a bit better now
74		and he looks ok> emm (.) we'll do his <u>temperature</u> and <u>blood pressure</u>
75		and all that and just check that over
76	Mum <sub>13</sub>	Ok

**Table 1: Participant characteristics**

<b>Parents characteristics</b>		<b>(n = 13)<sup>1</sup></b>
<i>Gender</i> male: female		1:12
<i>Age (years)</i>		Mean 38.5: range 21-56
21-30		3
31-40		6
Above 40		4
<i>Highest Qualification</i>		
A levels or above		4
GCSE		4
None		5
<i>Socio-economic classification</i>		
2		3
5 - 7		4
8		6
<i>Ethnic group</i>		(n=14) <sup>1</sup>
White British : Asian		13 :1
<b>Child characteristics</b>		<b>(n=14)<sup>2</sup></b>
<i>Gender</i> male: female		9: 5
<i>Age (years)</i>		Mean 8.6 : range 1-15
Under 5		5
6-10		2
11-15		7
<i>Shunt revisions</i>		Mean 2 : range 0-12
0		4
1		3
2		3
3 +		4
<b>Health professional characteristics</b>		<b>(n=14)</b>
<i>Gender</i> male: female		6:7
<i>Age (years)</i>		Mean 33.6 : range 27-56
21-30		5
31-40		8
Above 50		1
<i>Years since qualified</i>		Mean 8.8 : range 3-17
Less than 5		5
6-10		6
Above 10		3
<i>Role and grade</i>		
Senior nurses	Band 7	1
	Band 6	1
Junior nurses	Band 5	2
Senior doctors	Specialist registrars	4
Junior doctors	Specialist trainee (yr 2)	2
	Specialist trainee (yr 3)	4
<i>Ethnic group</i>		
White (British and Irish)		10
Asian (Indian and Pakistani)		4

<sup>1</sup> One parent participated in the interaction but not the interview, data missing but ethnic group was obtained from medical notes; <sup>2</sup>Characteristics for all 14 children obtained from medical notes, (children participated in the interactions)



**Table 2: Establishing a cause for illness symptoms (n = 23)**

Turn design	Parent invited to offer a diagnosis	Parent initiated the offer of a diagnosis	Parent accepted professional judgements	Parent rejected professional judgements
Frequency	30% (n=7)	18% (n=4)	26% (n= 6)	26% (n= 6)
Example	<p>Doctor: so what are you your thoughts as to what's going on</p> <p>Mum: well I don't really know but the shunts is a concern</p>	<p>Mum: he could have chicken pox he has spots on his legs</p> <p>Doctor: it's worth taking a look</p>	<p>Doctor: he looks like he has a virus, we'll do a scan just in case</p> <p>Mum: ok yes I think he's virally</p>	<p>Doctor: does anyone have coughs, colds tummy bugs</p> <p>Mum: if I thought she had a virus I wouldn't have brought her in</p>

**Table 3: Involving parents when planning care (n = 11)**

Turn design	Accepted care plans	Rejected care plans
Frequency	82% (n=9)	18% (n= 2)
Example	<p>Doctor: the concern is the shunt isn't inside the tummy but I don't think it's that, we'll keep him overnight, if he's still headachy in the morning then we'll repeat his scan</p> <p>Mum: that's fine</p>	<p>Doctor: we'll have to do a CT scan</p> <p>Mum: with it hurting at the back I thought about the cyst changing at the back of his head, would he need an MRI to see that</p>

**Table 4: Participants' perceptions of decision-making tasks (questionnaire data)**

Summary of statements (questionnaire data) (n=26 parent responses <sup>1</sup> , n=18 professional responses <sup>2</sup> )	Score (%)	S/A	A	N	D	S/D
1. Listening/ being listened to	Parent	65	23	12	0	0
	HP	44	40	6	0	0
2. Causes for the child's symptoms suggested	Parent	35	27	23	11	4
	HP	61	39	0	0	0
3. Parents views included in the assessment	Parent	54	31	4	11	0
	HP	61	33	6	0	0
4. Treatment options discussed	Parent	35	35	15	15	0
	HP	50	39	11	0	0
5. Advantages/ disadvantages of treatment discussed	Parent	42	15	12	31	0
	HP	45	33	22	0	0
6. Parents understanding of treatment options ascertained	Parent	50	27	4	19	0
	HP	50	22	28	0	0
7. Parents had opportunity to ask questions	Parent	73	19	0	8	0
	HP	83	17	0	0	0
8. Ascertain level parents wanted to be involved in care decisions	Parent	27	46	23	9	0
	HP	33	44	17	6	0
9. Decisions about care were made with parents	Parent	65	15	8	8	4
	HP	50	39	11	0	0
10. Satisfaction with the level of involvement in care	Parent	61	23	8	0	8
	HP	61	39	0	0	0

SA-strongly agree      A-agree      N-neither agree or disagree      D-disagree      SD -strongly disagree

HP = health professional

<sup>1</sup>Parents completed two questionnaires- rating both doctors and nurses; <sup>2</sup>Some health professional completed more than one questionnaire