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Making sense of children's medically unexplained symptoms:

managing ambiguity, authenticity and responsibility.

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Children's medically unexplained symptoms

Abstract

Medically unexplained symptoms such as headache, tiredness and stomach problems are common amongst children and research highlights the potential importance of the family environment in their development and maintenance. The present qualitative study aimed to explore how mothers make sense and manage their child's unexplained recurrent somatic symptoms. Mothers (n=13) with children with headaches, tiredness or stomach problems were interviewed. Transcripts were analysed using thematic analysis. Three main areas emerged relating to 'making sense of the symptom', 'impact of the symptom' and 'strategies for coping'. Transcending these areas were three core issues relating to managing ambiguity, authenticity and responsibility. In particular, more ambiguous symptoms were associated with making uncontrollable causal attributions that removed responsibility away from the family. Further, even though the mothers reported coping strategies that may have exacerbated their child's symptoms these were defended in ways to minimise their own potential influence on the symptom and to emphasise its authenticity. In conclusion, mothers' perceptions and behaviours may be counterproductive in the longer term but function in the more immediate term by facilitating a protective relationship with their child.

Key words: children; mothers; qualitative methods; somatic symptoms; Medically

Unexplained Symptoms,

Introduction

Physical symptoms occur in a significant number of children and adolescents with the most common being headache, abdominal pain and fatigue (Garber, Walker & Zeman, 1991; Perquin et al., 2000; Garralda, 2000). Only a small proportion of these symptoms have an identified organic aetiology (Garber et al, 1991) and they have been termed ‘psychosomatic’ or ‘functional’ by the paediatric literature although ‘medically unexplained symptoms’ (MUS) now appears to be used routinely in the clinical literature (Nettleton, 2006). Such symptoms have a number of implications including associated distress and functional disability, frequent consulting and school absenteeism (Smith, Martin-Herz, Womack & Marsigan, 2003; Reid, Wessely, Crayford & Hotopf, 2002).

People’s beliefs about their symptoms affect their symptom experience (Pennebaker, 1982) and self management. The common-sense model of self-regulation (CSM; Leventhal, Meyer & Nerez, 1980) proposes that individuals deal with symptoms by a process akin to problem solving and form illness cognitions which are representations of the health threat. Family members also hold perceptions of the illnesses of others (Weinman, Heijmans & Figueiras, 2003; Butler, Chalder & Wessely, 2001) but although parents’ perceptions undoubtedly influence their child’s beliefs and behaviour little is known about the explanations parents hold for their children’s illnesses (Claar & Walker, 1999). Furthermore, although it has been argued that parents may initiate and maintain their child’s symptoms and illness-related behaviours through processes such as selective reinforcement and over protectiveness the evidence for this process is weak (Walker et al., 2002; Walker, Claar & Garber, 2002; Peterson and Palermo, 2004; Simons, Claar and Logan, 2008; Fisher & Chalder, 2003). Although Walker and colleagues (Walker, Garber, & Greene, 1993; Walker & Zeman, 1992) concluded from their work that children with recurrent abdominal pain and gastrointestinal

complaints reported greater perceived parental encouragement of illness behaviour for abdominal symptoms compared to controls and children with emotional problems.

Research therefore indicates the importance of the family context for the development and maintenance of children's MUS. To date, however, no research has addressed parents' representations of their children's MUS or how these might influence their management of these symptoms. The present study, therefore, used a qualitative approach to explore mothers' experiences of their child's symptoms and the ways in which they may facilitate or exacerbate their child's problem. In addition, although many studies in the MUS literature focus on a single condition the present study focused on parent's beliefs and experiences across several common MUS to allow assessment of any commonalities or differences amongst them. Finally, given the prevalence of MUS in non-clinical samples, this formed the population of interest for the present study.

Method

Design

A qualitative design with semi-structured interviews was used.

Participants and recruitment

Mothers were recruited with a child aged between 4-16 years, who experienced somatic symptoms (headaches, abdominal pain or fatigue), for which they had sought help from their GP (or other health professional) at least once and received no clear diagnosis.

Participants (n=13) were recruited through a snowball sampling method from a Guildford and Oxford population. Their children's predominant symptoms included stomach ache (n=6), headache (n=5) and fatigue (n=2). Several children experienced a number of symptoms. Children's ages ranged between 6 and 16 years (see table 1 for details).

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Procedure

Interviews took place either at the participant's home or place of work, lasted between 30 and 75 minutes, were audio taped and transcribed verbatim. The study received favourable ethical opinion from the University Ethics Committee.

Interview schedule

The interview involved open-ended questions with some prompts covering: basic information about participants' family, the nature of the symptom, the child and family members' typical response to a symptom episode, contact with healthcare, mother's thoughts about the symptom and the impact of it for the child and family.

Data analysis

Interviews were analysed using thematic analysis (Braun & Clarke, 2006; Miles & Huberman, 1994).

Results

Analysis resulted in three overarching areas relating to 'making sense of the symptom', 'impact of the symptom' and 'strategies for coping'. Transcending these areas were three

main issues relating to ambiguity of the symptom, authenticity of the symptom and parental responsibility. These will be illustrated using verbatim quotations. All participants have been given a pseudonym.

1. Making sense of the symptom

All mothers described trying to make sense of their child's symptom. This involved two main themes, 'causal models' and 'illness identity'.

i) Causal models

All mothers described searching for a cause for their child's symptom. Some focused on controllable lifestyle causes. The majority however, endorsed uncontrollable causes whether biomedical or psychological in their focus.

Controllable causes

A few mothers considered controllable causes largely related to lifestyle, such as eating, drinking and tiredness. Several of these mothers believed dehydration to be a cause of their child's headaches. Elizabeth described how her family had generated a hypothesis:

'Because he hydrates so much because of the sport he does, his body is used to, we think - this is our theory - to being really hydrated because he drinks a lot of water, erm, so we think that when he's not able to be hydrated like that it seems to cause a headache'
(Elizabeth)

Several mothers attributed their child's symptom to matters related to the timing and content of what they ate. For some, this was because the parents were working late and for others it related to the child's own food preferences. Anne explained:

'we're really looking at eating and diet, he might have been snacking and I just think that he's probably not, you know, not taken the time to eat properly...I do give him the healthy snacks, I can't check everything that he does' (Anne).

Those who discussed controllable causes were predominantly mothers of children with migraine but even though these causes are deemed controllable their ultimate trigger lay outside of the mother in the domain of sport pressures, work pressures or the child's own determination.

Uncontrollable causes

The majority of mothers endorsed uncontrollable causes and several emphasised biomedical factors. For example, Karen understood her daughter's stomach aches as caused by a *'virus in her system that kept getting triggered'* and explained that she felt she needed to *'boost her immune system'*. Similarly, Fiona explained how she had considered her son's symptoms (stomach aches, diarrhoea and headaches) to be caused by *'the whole allergy picture'* whilst others focused on *'hormonal swings'*. Hannah also described testing out a variety of possible causes of her daughter's stomach aches including *'kidney stones'*, *'intestinal worms'*, *'trapped air'* and *'indigestion'* and said *'we don't know the reason [...] I just believe it's a medical thing'*. She also strongly rejected a friend's suggestion that the stomach aches reflected her daughter's need for attention from her father *'I just, you know, exclude that reason you know, I did, because I think everything with him is not a problem.'*

Biomedical attributions placed the cause of the child's symptoms beyond the control of the mother, fundamentally external to the family and any suggestion that the symptoms may not be authentic or that responsibility could lie within the family is rejected.

Psychological factors were also described which were similarly beyond the mother's control. For example, Diane, whose son was absent from school regularly due to stomach aches, vomiting and headaches, but most typically an '*unspecified not feeling well and feeling low*', said '*I think it's more, um, state of mind than anything*'. She found it difficult to accept her husband's suggestion that their son could be '*manipulating*' the situation and she explained, '*I would always be more inclined to give him (son) the benefit of the doubt I think*'.

Christine was in a similar situation with her daughter whose school absenteeism had reached the stage of legal proceedings. Her daughter's symptoms were described as '*down to her state of mind*' and '*the headaches and tiredness are the excuse for not going into school*'. But like Diane, she was careful to side-step suggestion of feigning on her daughter's part and was eager to express her confidence that the headaches were not a fabrication saying '*I don't doubt for a minute that that is true, I think the headaches are real and the tiredness is real*'.

For these mothers, believing the symptoms to be caused by psychological factors was accompanied by a desire to ensure that that causal attribution did not place responsibility or blame for the symptom with the child. Furthermore they were keen to emphasise that the symptoms were authentic and real – not put on by their child.

ii) Illness identity

Mothers also described their search for an illness label. This was particularly the case for mothers of children with headaches, several of whom settled on ‘migraines’. As Ruth said *‘I’ve sort of explained them as a migraine’*. Victoria also indicated that she had assigned a label and decided upon ‘chronic fatigue’ rather than ‘ME’:

‘I don’t think he’s got the sort of symptoms where, you know, where there’s a question mark over whether people are going to get better, he hasn’t got all that pain in his body and, you know, like people have with ME, thank goodness.’ (Victoria)

A label brought with it several benefits including access to effective medication and providing some reassurance for their child. Victoria discussed how labelling her son’s fatigue had offered a sense of authenticity of the symptom, in terms of justifying his absence from school, and also as a way to validate its seriousness:

‘I think it’s helped him [...] when people at school have said, “oh why are you off so much?” [...], it’s given him something to say, you know, he’ll say, “well look up chronic fatigue and then you’ll be glad you haven’t got it” (Victoria).

Mothers therefore described how they made sense of their child’s symptoms in terms of finding a cause and ascribing a label (Leventhal, Meyer and Nerenz, 1980). This process related to notions of ambiguity: mothers who made controllable causal attributions were dealing with a symptom that was reasonably well-defined, with features they could recognise; typically migraine. In contrast, mothers who endorsed uncontrollable causes were faced with less well defined symptoms, or a range of symptoms. The uncontrollable, external causes seemed to offer a mechanism by which mothers managed their unease caused by struggling with a symptom they saw as rather ambiguous. They endorsed attributions that placed the

cause beyond the influence of the family because these were probably most minimally emotionally upsetting for them to consider. Furthermore such causes enabled them to emphasise the authenticity of the symptoms and reject suggestions that their child was feigning.

2. Impact of the symptom

All mothers described how their child's symptom had impacted on their family in terms of 'an ongoing source of distress' and 'disruption to work and family life'.

i) An ongoing source of distress

Several mothers described how managing their child's symptom was '*hugely stressful*' and a source of distress for them over the longer term. Mothers whose main coping strategy involved seeking help from doctors, described much of their distress as centred around finding no diagnosis, feeling 'angry', 'upset', 'mentally hard going' or feeling that the medical profession had not appreciated the seriousness of the symptom or afforded it sufficient attention: For example, Victoria said:

'I mean my doctors were a nightmare [...] (the doctor) says "he's fabricating his symptoms to fit in with your belief system, which is that the only valid reason for not going to school is being sick", and I think what a load of rubbish. [...] if I'd been treating my son, rather than the doctor, he'd probably be well by now.' (Victoria)

Frustration also came from not being taken seriously by friends and colleagues:

'one of my colleagues said to me [...] he's a little, little malingerer, all he needs is a clip round the ear, you know, [...] that's very difficult to cope with that [...] because it's well it's like being tortured really for me' (Victoria)

Likening her experience to being '*tortured*' highlights this mother's anguish at the suggestion that her son is feigning his symptoms that he is in some way responsible.

ii) Disruption to work and family life

Mothers described the problems of absenteeism, days off work, taking lower status jobs and being unreliable in the workplace. Christine discussed how her work had been affected due to her daughter's problem and said '*Oh it squeezes you both end*' and explained that '*I haven't been able to get back to what I was doing professionally before I had children*'.

Those typically with adolescent children also identified the impact their children's symptom had on the family. For example, Diane explained how they would have '*terrible battles and arguments*' and Anne discussed how the discordance between her and her husband's approach to managing their son's symptoms had caused some difficulty.

Some mothers described how their other children felt emotions such as 'envy' and 'jealousy' at their sibling's special treatment: '*might be sending the message to Julia that Lisa is the preferred child*' (Sarah)

Mothers therefore how their child's symptom had a negative emotional impact which reflects previous work on the impact of childhood abdominal pain (Claar and Walker, 1999; Claar et al, 2008). They also explained how the symptom had been disruptive for their working and family lives, both day-to-day and long term. Mothers who described prolonged stress were often those who appeared to be still searching for answers regarding the causation of the symptom more ambiguous symptoms. For these mothers, a particular source of distress related to their ongoing search for a medical explanation for the symptom, and in striving for acknowledgement of the authenticity of the symptom.

3. Strategies for coping

This final area comprised the use and defence of three types of coping strategies which reflected the ways in which the mothers made sense of the symptoms.

i) Controllable causes; practical strategies.

Some mothers who focused on controllable causes described employing practical strategies to manage the symptom. For example, Anne, whose son's stomach aches were attributed to his diet, described how she would tell him to just get *'up and about, eat something, and off you go'*. Similarly, those who believed dehydration was the cause encouraged their child to drink more. Several of these mothers also discussed a general approach to managing the symptom which involved a conscious effort to down-play symptom complaints:

'we don't then pathologise the kids into saying, oh, you've got this terrible affliction and, you know, you mustn't, you mustn't, oh don't get yourself over excited.' (Joanna)

ii) Coping with the uncontrollable

Those focusing on uncontrollable external causes primarily sought medical help which was typically a fruitless endeavour. They therefore found ways to manage the symptom using short-term fixes and offered justifications for these strategies. This involved ‘*pandering*’ to their child or a need to ‘*fetch and carry whatever she needed*’. For example, Hannah said:

‘just try and say, ‘oh, do you want to watch telly? [...], or just, er, some sweets [...] and because she doesn’t have cuddle very often. I work, we both work full time and, you know, there’s no time, [...], so always cuddle me, cuddle me, really happy, yes always want cuddle.[...] That works...it won’t just make the pain just go away. So, so I just think it is a medical reasons’ (Hannah)

These strategies appear reinforcing of the symptom but by reiterating her confidence in the medical basis of the symptom, Hannah justifies her response towards her daughter. The reasoning implicit in Hannah’s comment is that since the treats and attention do not alleviate the symptom immediately, the stomach ache is not a result of her daughter seeking attention, and this strategy for managing it is therefore acceptable.

Several mothers managed their child’s symptom by allowing them to take days off school:

‘it is a quick decision making so consequently your child comes up to you going, ‘I’ve got a headache, I’m feeling really sick’, you kind of go, ‘yeah ok, take a day off school’.’
(Louise)

Sarah also allowed her daughter to stay at home, saying *'I think it's entirely normal for children to need a day off school every now and then'*. She could appreciate that this may be problematic, but her belief that the symptoms were caused by psychological distress meant that she was reluctant to encourage her daughter to ignore them. She defended her decision saying:

'I worry [...] that she can kind of get away with it and what consequences that has for her in terms of development, but actually I don't think it is getting away with it, I think [...] it's about recognising that we're complex and we have feelings that need to be taken account of.' (Sarah)

Other mothers discussed trying strategies such as incentives or rewards for attending school, which one mother described as a *'sticks and carrots'* approach. These strategies tended to be ineffective and these mothers explained how they had come to normalise the symptom or relinquish responsibility for it. For example, Christine, who described herself as *'resigned'*, said *'we don't make a big fuss of things...we treat it almost as normal behaviour'*. This strategy of normalising the symptom appeared to have become a strategy for coping with the impact of the symptom; to reduce conflict within the family they adopted strategies for *'self preservation'* saying *'you can't sort of fight every battle'*.

Mothers therefore described employing coping strategies which linked to their causal models. Those who attributed the symptom to controllable triggers were able to use practical management strategies. Other mothers developed short-term coping strategies either to manage their child or to manage the impact of the symptom. Although some of these strategies may reinforce the symptom explicitly or implicitly (Claar, Simons and Logan,

2008), mothers defended their approaches and emphasised how their failure further supported the reality of their child's symptoms.

Discussion

This study explored mother's experiences of their child's MUS with a focus on stomach aches, fatigue and headaches. Three main areas emerged relating to making sense of the symptom, the impact of the symptom and strategies for coping. Transcending these areas were three core issues relating to the management of ambiguity, authenticity and responsibility. In particular, when faced with a symptom they saw as ambiguous, mothers searched for a way to understand and solve the symptom whilst maintaining ambivalence about the responsibility for it. Mothers made sense of their child's symptom by endorsing uncontrollable causal attributions, such as viruses, allergens, life events or school stress, which, whether biomedical or psychosocial, were external to the family. Such uncontrollable causes have been described as least emotionally upsetting as they release the family from any blame for causing or perpetuating the symptom (Benjamini, Leventhal and Leventhal, 1997; Peters, Stanley, Rose & Salmon, 1998). In addition, they emphasise the authenticity of the symptoms and enable any suggestion of feigning to be rejected. Furthermore, when solutions for the problem proved ineffective and mothers developed alternative short term strategies which were potentially reinforcing, mothers typically defended their management strategies again with a reluctance to acknowledge any parental responsibility for either symptom onset or exacerbation and considered the failure of such strategies as evidence of the reality of the symptoms. When faced with less ambiguous symptoms, for which mothers had established a label (particularly migraine), more controllable causes were identified (eg diet) resulting in practical coping strategies (eg. dietary change). At times, however, even these causes were still considered beyond the responsibility of the mothers and were conceptualised as resulting

from external life pressures such as working hours or the child's own determination.

Research indicates that the family context can generate and exacerbate childhood symptoms (Walker et al, 2002). The results from the present study indicate that the ways in which mothers experience and manage their child's symptoms centre around a need to cope with ambiguity, emphasise authenticity and remove responsibility from the role of the family.

To conclude, the results suggest that having a child with an MUS can impact upon the mother's work and family life which generates a search for meaning and the use of a number of management strategies. Research indicates that the family response to a child's symptoms may make these symptoms worse. The processes used by the mothers in the present study, however, reflect their attempts to manage the ambiguity of the symptoms whilst emphasising their authenticity and locating blame and responsibility in their external world. Although mothers' perceptions and behaviours may be biased or counterproductive in the longer term, they may arguably be functional in the more immediate term. Ambiguous symptoms present a specific challenge to any carer. By emphasising the authenticity of the symptoms and locating responsibility outside of the parental dyad mothers may be able to manage an ongoing highly problematic situation in a way that both defends their self-esteem as a good mother and facilitates a supportive and protective relationship with their child.

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Table 1 Participant information

Mother's name	Child's symptom(s)*	Child's sex	Child's age (years)	Number of children	Approximate time since onset	Mother's occupation
Ruth	Headache (migraine)	M	9	2 boys	4 years	Nursing Home Manager
Anne	Stomach ache & fatigue	M	12	2 boys	2 years	Fundraising Manager
Elizabeth	Headache (migraine)	M	14	2 boys	6 years	Associate Editor
Christine	Fatigue, headache & sleep disturbance	F	14	2 girls	2 years	Secretary
Fiona	Stomach ache, diarrhoea & headache	M	15	1 boy, 1 girl	2 years	Counsellor
Diane	Stomach ache, vomiting, nausea & headache	M	16	1 boy	5 years	Library Coordinator
Hannah	Stomach ache	F	6	1 boy, 1 girl	3 years	Academic (Biosciences)
Sarah	Stomach ache, headache & fatigue	F	12	2 girls	3 years	Nurse Educator
Karen	Stomach ache & ulcerated mouth	F	6	1 girl, 1 boy	2.5 years	EA to Professor
Victoria	Fatigue (& other symptoms incl. stomach ache, headache, muscle weakness & dizziness)	M	15	1 boy	5 years	Mature PhD student
Joanna	Headache (migraine)	M	14	2 boys & 1 stepson	3 years	Senior Lecturer (Management)
Louise	Headache (migraine)	M	11	2 boys, 1 girl	2 years	Part-time midwife & housewife
Sophie	Headache (migraine) & stomach ache	F	7	2 girls	1 year	Personal Assistant

* Children's symptom(s) are listed in order of predominance in the child's life, as described by mothers.