Patient-centered health care for infants: a qualitative analysis of mothers' experiences and preferences

By Anna Clarissa Jeanne Telford, BSc[1], Amy Sarah Miller, BSc[1] and Joyce Miller, BSc, DC, PhD[2]

1. Final year chiropractic student, Anglo-European College of Chiropractic, Bournemouth University
2. Associate Professor, Anglo-European College of Chiropractic; Lead Tutor, Musculoskeletal Health in Pediatrics, Bournemouth University, United Kingdom.

Corresponding author: Joyce Miller,BSc, DC, PhD Email: jmiller@aecc.ac.uk

ABSTRACT

Objective: Nowhere is patient-centered care more important than in the vulnerable time of the first few weeks of a new-born's life. However little is understood about mothers' experiences and preferences with health care. **Method:** Thirty-four mothers were interviewed using verbatim transcripts to code for key and recurrent themes regarding their experiences and preferences in health care for their infant. **Results:** Mothers valued honest and realistic reassurance, time with a health care professional who really listens and continuity of advice rather than inconsistent or conflicting advice. Mothers are often sent for chiropractic care on the recommendation of other health care professionals who recognize a biomechanical problem from birth trauma. **Conclusion:** Patient-centered care begins with understanding the patient, or in the case of infants, the parents' needs for that patient. Clinicians who give time, attention, reassurance and consistent advice are valued by mothers who seek care for their infant.

Key words: infant health care, qualitative, maternal perceptions.

Introduction

The US National Center for Health Statistics found that the most commonly used provider-based Complementary and Allied (CAM) therapy for children was manipulation, provided by chiropractors or osteopaths.[1] Infants comprise a large percentage of the pediatric population seeking chiropractic care.[2, 3] Although there are published guidelines upon which to base the management of these patients,[4] the aims of the actual users of this service, the parents, have been little investigated. This is despite the general move toward more involvement of the service users within clinical settings.[5] Most studies that have asked parents what they want from health care for their child have been quantitative and based on needs, satisfaction and specific services provided.[6] A largely lacking strategy in the improvement of infant care has been the use of maternal perspectives on the health care received. Maternal experiences and expectations of health care for her infant are key to assisting health care providers to improve the usefulness and relevance of the care they give. The purpose of this study was to use qualitative methods to collect in-depth information from mothers about why they present their infant for chiropractic care along with their pre-existing experiences and expectations of health care.

Background

Qualitative methods are now widely used in health care research. This design involves open-ended, individual or group interviews with members of the target population in order to ensure that topics accurately reflect the perspective of that specific population.[7] A natural strength of qualitative methodologies is the production of results that have strong credibility and face validity (measuring what is intended to measure)[8] and in our case, bears the relative importance placed on the topic by the mothers.

Qualitative research is carried out in order to help the patient, but just as importantly, to help the clinician understand the patient. An important goal of qualitative research is to uncover patient needs and shape the opinion of decision-makers whose actions primarily affect patient's health and wellbeing.[8] Healthcare services have managed recently to gain a considerably deeper understanding of patient experience,[9] and this could be due to health researchers increased use of focus groups in their studies.[10] The rise in qualitative research and use of focus groups has been apparent since 1985 onwards with over a thousand studies published between 1985 and 1999, and a continuing sharp increase from this point onwards.[10] Colson et al. (2013)[11] report that of 4057 abstracts being submitted to the Paediatric Academic Societies in 2010, 1.6% used only qualitative methods. However, these abstracts were three times less likely to be chosen for platform presentations, but demonstrated greater odds of getting published. Those researchers suggested that their results may be due to inferior quality or inadequate review process of qualitative studies. Qualitative studies may not be undertaken because they are not always valued for their own sake and further,

there are inherent problems in doing them, particularly with children.

Infant sleeping, crying and feeding are consistently top concerns for mothers when it comes to research carried out in the paediatric setting. These issues are most commonly discussed relative to any change after any given intervention. The goal of our study was to find out what mothers want and expect from care, prior to any intervention taking place. There is very little research in this area. The qualitative research in the health care field with children is limited not merely because of the sample population but also due to ethical considerations.[12]

A qualitative study conducted by Radecki et al. 2009[13] is one of the few which touch the base we aimed to cover, as their goal was to find out what parents want from well-child care. Their study was conducted using 20 focus groups (N=131 — with parents of children aged 0-2, 3-5 and 6-12 years) with the emphasis on finding out parental experience and expectations about well-child care, which was then used to better the understanding of clinicians. This sample size was unusually large for a qualitative study which might have been affected by the financial incentive offered to the participants ($25).

Other relevant qualitative studies have used individual interviews, rather than focus groups. Lindberg and Engström (2013)[14] used semi-structured interviews (N=8), followed by thematic content analysis to gain understanding about fathers' experiences and of care in relation to complicated childbirth. Following on, Lundqvist et al. (2014)[15] completed a qualitative longitudinal study into father's lived experience after the birth of their very preterm child, again using interviews (N=13). It is interesting that both of these studies investigating fathers' perceptions were done in Sweden which has been regarded one of the most gender equalized countries of the world, where of the 480 days parental leave 60 days were reserved for the father.

In contrast, this study was based solely on the mother's experience of healthcare because a mother in most countries is still seen as the primary guardian of the child.

Methods

The objectives of this qualitative study were to investigate:
1. What mothers want from health care
2. Perceptions of the previous care they have received

This study was part of a larger study to develop a validated paediatric outcomes questionnaire based upon what mothers want from health care for their infant. Our study methodology was built closely around the work done by Richard Krueger in the early 1990's[16] whose work has then been used and modified by many others.[17]

Setting

The interviews took place at a chiropractic teaching clinic on the south coast of England. The setting was chosen because of a large number of infants presenting weekly. Ethical approval was granted by the AECC Research Ethics Subcommittee prior to beginning of interviews.

Subjects

The selection criteria for the interviews was based on a convenience sample of mothers who presented with an infant to the clinic, and were willing to take part in an interview or focus group after their clinical encounter had come to an end. Those subjects who consented were offered a choice between an individual interview immediately after their treatment on that day, or a focus group at a later time. Mothers could decline to participate or withdraw at any time during the interview process. All mothers were given an information sheet describing the study and signed an informed consent form, which included permission to record the conversation.

Procedures

Interview questions are seen in Table 1. The goal of the interview was to provide a place and space for the mother to express her experiences and views in entirety, whether favourable or not, in the presence of an empathic and non-judgmental listener. The interviews began with a statement explaining that the facilitator was interested in finding out what mothers want from care when they seek health care for their children. Participants were asked a set of questions to guide the conversation but the mothers were encouraged to talk freely about their experiences.

Table 1. Interview Questions

- Introduction of mother and baby
- What is the presenting complaint?
- What care have you received — here and elsewhere?
- Is resolution of the problem and explanation of the problem more important, or is it something else?
- What impact is the problem having on the mother and the rest of the family?
- What outcomes of healthcare are important?
- How much change is desired for this problem?
- How is this change measured by the mother?
- Time spent with a healthcare provider: is it useful? Is it long enough?
- What value would a follow up appointment after discharge have?
- Conflicting advice
- Is reassurance important when you see a health care provider with your baby?

Interviews were planned to last up to 30 minutes, to use as little of mothers' time as possible, but cover the topics. All interviews and one focus group were recorded anonymously and data were later transcribed verbatim.

The methodological approaches that were used in the qualitative analysis were based around content analysis as described by Hsieh and Shannon (2005).[18] Qualitative content analysis is defined as a research method where subjective interpretation of the text is processed by coding text into categories and themes.[18] Based on the transcripts, categories were created and through constant comparison of texts, these categories were grouped under overarching themes.

Coding was completed according to the methods described by Erlingsson and Brysiewicz.[19] Category means grouping was imposed on the coded segments, in order to reduce the number of different pieces of data in the analysis, and answer the question "what?".[19] A theme was identified as a higher-level of categorization, usually used to identify a major element of the entire content analysis. Themes answer the question "why?" and can be considered as the thread of underlying meaning that ties the data together.[19]

When new items or themes ceased to arise, saturation had been reached and patient interviews were discontinued. This is supported by Krueger's (1994) research, which suggested running focus groups until a clear pattern emerges and subsequent groups produce only repetitive information (theoretical saturation).[16] Brod et al. (2009)[20] commented on the previous research and suggested that after 12 interviews, between 88% and 92% of analysis codes (themes) could be identified.

Results

A total of 31 mothers agreed to participate in interviews and three mothers took part in the focus group (N=34). No mother refused to answer any of the questions. The characteristics of mothers and babies are seen in Table 2. Mothers presented their infant to the clinic for different reasons, and these reasons are summarised in Table 3.

Table 2. Demographic profile of mothers and babies in clinic

- Number of previous healthcare professionals seen for the problem: mean: 7.2 (range: 2-17)
- Age of infants: 7-172 days, 16 less than one month or less; 18 more than one month
- 26/34 mothers were primiparous
- 9/34 reported multiple interventions during birth
- 19 female babies, 14 male
- 19 exclusively breastfed, 5 combination breast and formula milk, 2 exclusively formula fed

Table 3. Infant problem at presentation to clinic

- 19/34 babies had feeding problems
- 8/34 babies came into the clinic for a check-up
- 6/34 babies presented because of a head preference
- 5/34 babies had sleeping problems
- 2 babies had crying problems
- 1 baby was unable to lie supine
- 1 baby had a positional head deformation
- 1 baby had musculoskeletal problems
- 1 baby had a sternocleidomastoid tumour
- 1 baby had cephalohaematoma

Major themes that came up in the interviews time after time were identified: reassurance, impact on family life, conflicting advice, birth related difficulties/concerns or reasons for seeking chiropractic care and maternal preferences for care. Each theme was supported by quotes from the transcripts.

Reassurance

Reassurance was a key aspect of care that received the highest number of comments. Reassurance is part of therapeutic alliance which refers to the relationship between a healthcare professional and a patient, where engaging with each other will affect potential change in the patient. Mothers were keen to discuss the importance of reassurance to them, whether this were their first baby or subsequent baby; mothers find it easy to worry, even about small things. This tendency, accompanied by lack of sleep and the stress of a new baby, made the need for reassurance a key aspect of care.

"Reassuring is the big, the biggest, the big thing." [15]

"Yeah I think even now (with a 5th child) it's still nice to someone to sort of say you know you're doing a good job...because I don't go look for it anywhere else." [34]

"Yes definitely, I'm quite a worrier so yeah it really helps me with my confidence with him as well making sure that I know that I'm doing it right and I think with me who was not having any sleep and hormones and all kicking in and then having this new thing to look after and totally out your comfort zone as well because haven't done it before so for me yeah it (reassurance) has been really important." [21]

"I think you know the reassurance is quite important because again being first child you don't know. You don't know anything until you have done it and overcome it." [27]

"Yeah you know the first time you literally take it as it comes and anything that doesn't fit these lovely textbooks that we all have a habit of reading frightens us as mums... you sort of over analyse things when you're worn out and tired because you may think you're doing something wrong as a parent when actually there's plenty of other mums and dads that go through it, it's just when you're in that moment that you're so exhausted you're like oh no, it's only happening to me." [28]

"That's really good to hear (reassurance) because we don't know. They don't come with a manual!" [10]

Impact on family life

Mothers talked a lot about the impact the baby's problem was having on their life and on the life of the father and the rest of their family. Mothers came up stoic towards their own troubles and hesitated to discuss their own stress levels. There was no clear difference in stress levels between the first time mothers and multiparous mothers.

"Oh yeah really stressful, she was unable to sleep on her back so we had to carry her all the time so it was really stressful." [5]

"Initially a lot (impact), it was awful. It did reduce me to the point of tears." [15]

"It's very tiring all round. The big boys that are 10 they worry a lot about him, you know if they wake up and hear him crying one of them immediately wants to come down and help... It's very tiring for all of them. For us as a family it's really important that we can get a more settled baby so everyone else can get some more sleep, everyone's tired." [28]

"Yeah my problem is I'm not able to put her down to sleep and do something with the rest of them which makes it difficult so things like house work, and then your mental state goes because you don't know just where to start and it just gets all on top of you." [34]

Conflicting Advice

Not all mothers had received conflicting advice or paid much attention to it, but the ones who had, were highly affected by it. It became clear that conflicting advice was one of the most upsetting things, especially for first time mothers as they felt hindered by it and felt it disrupted appropriate health care for the child.

"I've had conflicting advice so we discovered yesterday that she's got a high palate and a tongue tie for the 4 months so if that had been discovered earlier we would have had completely different feeding." [33]

"I found it quite difficult when I was in hospital because I changed wards three times so I didn't see... I was seeing a different midwife each time about feeding and they were all telling me slightly different things. I don't mean, they were really good but there was that kind of oh it might be just easier to speak to one person rather than, and then you have to start from the beginning and who am I going to get." [21]

Difficult Birth

Birth related issues were often volunteered by the mothers themselves and involved a lot of talk about assisted/interventional birth and the trauma associated with that. Mothers who had an assisted delivery or difficulties during birth were more likely to be referred to clinic by other health care professionals.

"The midwives at Dorchester [Hospital] said because it was quite a long birth and because it was a forceps delivery you were recommended." [10]

"It was because we had a bit of a long labour and her heart rate dropped so she was obviously in distress and we didn't know, it was the first time that something was wrong because she wouldn't look to the right at all and then the GP mentioned that her head would be a funny shape and then go on to have continual problems so I wanted to get it nipped in the bud." [16]

"I was advised by the midwife, she was delivery by forceps and I have a couple of friends who have come here and said they had good results from their own children." [27]

Maternal Preferences

Mothers valued honest communication and especially listening from healthcare professionals and preferred to have continuity of care where possible as well as sufficient time to interact with the clinician.

"I think it has been good for me because I've come out with, I wanted some answers and I've come out with answers." [33]

"They kept saying there's nothing wrong, she's fine and we didn't think she was...Very frustrating, worrying and frustrated. They weren't listening at all." [4]

"I think the first thing is that they listen." [28]

"It's nice to have time to ask questions." [14]

"You need the time because you want to know that you're not rushed in and out." [27]

Discussion

The goal of this research was to give mothers a voice in the health care that they choose for their infant. Although the sample was small, the luxury of in-depth interviews allowed for clarification of their desires and needs for relevant health care.

Qualitative researchers can conduct meaningful studies with small sample sizes.[11] They often choose participants for their knowledge of a specific topic and to reach thematic saturation, not to power a sample size for statistical analyses. They seek to understand the what and why of a problem, rather than statistically demonstrable associations.[11] The key to sample size is that the research continues until it is clear that no new themes emerge. Due to the relative inexperience of our research team, we continued the research past saturation to be certain that no new ideas would be missed. Also, there was overlap between themes even though comments were categorised by the predominant thought from mother's statements. Both of these reflect the inexperience of our researchers which were limitations.

We were surprised at the emphasis of the mothers on the need for reassurance. Since all mothers had seen other health care professionals (more than one and as many as 17), we thought that they would have received considerable amounts of reassurance from other health care teams. At this point, it is unknown whether it is rarer than we think, or whether there is an insatiable appetite for reassurance. What is clear is that mothers only want reassurance when it is accurately warranted. One mother's concern was that sometimes reassurance was given when there was a problem that required attention, and they preferred an honest interaction about the problem, and felt sometimes they had been reassured as a means of getting them to go away.

Reassurance is imbedded in all types of health care, and is designed to alleviate fears or doubts about the clinical situation. However, some mothers pointed out that there is a difference between blanket ("there is nothing to be concerned about") reassurance and the type of reassurance that came with adequate and solid information about the condition.

On the other hand, it was no surprise that mothers were aware of the huge limiting factors in life with baby. Exhaustion, lack of sleep, tiredness and fatigue were problems because it affected their ability to cope. Mothers constantly felt that they needed to protect the rest of the family from these exact issues, and so they bore the brunt of getting up at night for the baby. Mothers felt both physically and emotionally fatigued. This exhaustion was amplified when the baby had a problem where he couldn't be put down. One family understood that since the baby could not sleep on his back (supine as required in the SIDS protective Back-To-Sleep programme) that he needed to be held all of the time. This was a clear case for the need of chiropractic care, which is now being recognized as a key treatment approach for these babies to promote safe sleeping.[21] All health professionals must be vigilant in recognizing infants who cannot lie supine comfortably, and therefore require a rapid referral for musculoskeletal examination and treatment to face this important public health issue.[22]

Mothers often related the need for chiropractic care to the birth interventions and this was the key reason that infants were sent to our practice by medical professionals. Mothers talked freely and vociferously about the birth. Sometimes we felt as though they had never been asked before or had a chance to unload their feelings about the difficulties and details of the birth. Again, mothers felt particularly reassured that there was someone who could deal with these issues from a mechanical standpoint for their baby's comfort. There was quite a diversity in the type and amount of support that mothers had received from different health professionals. They were pleased that professionals who did not feel they could help at least referred onward for chiropractic care.

Mothers also valued listening and frank discussion about the specific needs of their child. They appreciated that it takes time to understand their concerns and time was one of the key variables valued. Too little time to have all of their questions asked or concerns discussed was a key pet peeve (although they were careful not to complain). Mothers, in general, did not complain about anything except conflicting advice, which they felt was rampant. Mothers felt there was inconsistency in information given out and this led to confusion and even to inappropriate or lack of care for their infant.

There was little discord in our findings from other research. Maternal fatigue is corroborated widely by research.[23] Seeking multiple practitioners and experiencing a wide range of inconsistent advice is common.[24]

Conclusion

The aim of this research project was to let clinician know what mothers want from health care. Chiropractors have developed guidelines for infant care that emphasize listening skills, musculoskeletal examination skills that can deal with problems arising secondary to birth trauma, specific goal oriented reassurance to alleviate anxiety, and congruent treatment and advice.[4] With high satisfaction rates, chiropractors are responding well to maternal needs for the care of their baby.[25] This indicates that shared goals of mothers and clinicians can serve as building blocks to provide the best possible patient-centered care for the infant patient.

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