

CLINICAL PAPER

The long-term impact of Caesarean section scar problems on the individual and associated healthcare needs

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Abstract

The aim of this study was to investigate the long-term impact of Caesarian section (CS) scar problems on the individual. It also assessed the help that women would like to receive for these issues. Nineteen participants who had undergone a CS between 11 and 35 months previously took part in qualitative interviews. First, a survey explored the women's personal experiences of CS scar problems and related healthcare. The topics and participants for the survey were identified through Internet research into informal discussions and a postal survey. The women who took part in the study were recruited from the catchment area of a National Health Service trust in South East England. Caesarian section scars clearly affected the participants in a variety of ways. Although some women were troubled by their scars, few sought professional help because the majority had learned to live with any problems that they might have. Their main concerns related to subsequent pregnancy. However, many participants felt that better information, advice and access to peer support would have helped them to recover from CS and cope with any persistent problems. This study identified problems with the effective provision of information to service users. Women felt poorly prepared for the potential consequences of CS. Preparation and peer support may be more important than medical care with regard to CS scar problems. The efficacy of prenatal CS recovery information could also be improved, and should include details of support groups and facts about CS scars. Women who seek help for CS scar problems need a credible explanation of their symptoms. Therefore, practitioners should understand persistent postoperative pain, the potential impact of CS scars and the importance of patient communication.

Keywords: Caesarean section, patient information, postnatal recovery, post-operative pain, scar tissue.

Introduction

Surgical scars may be a source of distress, even when small and not visible to others (Carr *et al.* 2000; Lawrence *et al.* 2004; Young & Hutchison 2009). These are often more noticeable than patients anticipate, and many feel that even a small improvement in the appearance of the scar would be worthwhile (Young & Hutchison 2009). Persistent pain has also been identified

as a potential complication of surgery (Macrae 2008). Although relatively invisible, scars from a Caesarean section (CS) have the potential to affect a woman's well-being: a recent study reported that the satisfaction of 100 women with the appearance of their scars ranged from 18.8% to 100%, and satisfaction was ranked below 65% for 12% of the participants (Gaertner *et al.* 2008). Interestingly, their obstetric surgeons consistently rated their own satisfaction at 72.5–100% (Gaertner *et al.* 2008).

Persistent pain following CS has only received attention relatively recently, and has

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been a somewhat controversial issue. In 2004, Nikolajsen *et al.* reported post-CS pain in 12% of women at 6–17 months after CS. Some subsequent studies have suggested an even higher incidence (Loos *et al.* 2008; Woolhouse *et al.* 2012). On the other hand, a large multicentre breech trial found a post-CS pain rate of only 4.7% at around 24 months after birth (Hannah *et al.* 2004), and a recent large prospective trial concluded that the prevalence of pain as a consequence of CS was only 1.8% and 0.3% at 6 and 12 months, respectively (Eisenach *et al.* 2013). The authors of the latter paper argued that previous studies had overestimated its incidence by not excluding pre-existing pain (Eisenach *et al.* 2013).

Interestingly, research into persistent post-CS pain has largely been carried out from a biomedical perspective, leaving out the experiences and opinions of women who have undergone CS. Based on the existing literature and his experiences in a specialist pain unit in central London, the first author (H.v.G.) expected his colleagues in women's health and primary care to identify potential participants for the present study. However, he discovered that women rarely requested healthcare for CS scar problems in his area of South East England. While it was possible that CS scar issues were not prevalent or problematic, women's health research suggested that there was the possibility of barriers to healthcare consultation; for example, embarrassment, anxiety or depression (MacArthur *et al.* 1997; Shifren *et al.* 2009).

This investigation, which was part of the first author's (H.v.G.'s) doctoral research, set out to answer the following question: what is the long-term impact of CS scar problems on the individual, and what help would women like the National Health Service (NHS) to provide? Ultimately, the aim was to make recommendations for healthcare provision.

Approvals

The present study received approval from the following organizations:

- the Faculty Research Ethics and Governance Committee of the University of Brighton;
- the Research and Development Committee of Southend University Hospital NHS Foundation Trust;
- the National Information Governance Board; and
- the regional research ethics committee.

Participants and methods

The main and final phase of the present study consisted of qualitative interviews with women who had undergone CS at an NHS trust in South East England. The first author (H.v.G.) was keen for the study to be driven by women's perspectives, which, as mentioned above, were not presented in formal research literature or recorded by the local health service. Therefore, pilot work started with an exploration of women's informal reports on the Internet of persistent CS scar problems, followed by a postal survey of women who had undergone CS locally. This identified participants as well as topics for the key component of the study, the qualitative interviews.

Phase 1: Internet exploration of individual Caesarean section scar issues

Internet research. The Internet is suitable for health researchers who wish to “identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed” (Eysenbach & Wyatt 2002, p. e13). In the present study, it provided access to people who might otherwise have been excluded or hidden (Lee 2000; Holge-Hazelton 2002). However, the known drawbacks and limitations of Internet research include: a lack of knowledge of the participants' backgrounds and identities (Holge-Hazelton 2002); a lack of direct observation (Wittel 2000); unconventional use of written English by non-native speakers (Eysenbach & Till 2001); and bias caused by access inequalities (IWS 2010; ONS 2010).

In the present study, Internet research was used for an initial exploration of issues that were only reported by women. These topics were to be verified and expanded upon in subsequent phases. Recommendations pertaining to Internet research ethics were followed by accessing information only if it was officially archived publicly, did not require a password and retrieval was not prohibited by a site policy (Bruckman 2002; Eysenbach & Wyatt 2002). Pseudonyms, direct quotes and other specific findings were not used in the present publication in order to prevent identification of individuals or groups (Eysenbach & Till 2001; Bruckman 2002).

Data collection. Three Google searches were carried out using the following search terms: “(Caesarean OR Cesarean) AND scar”; “(Caesarean OR Cesarean) AND pain”; and “C section AND scar”. The first 100 entries of

each search were checked for references to CS scars, which led to 163 entries in 41 discussion threads, with saturation reached at 100 entries. Only statements describing an individual's own experience were included. Statements pertaining to hearsay, advice or second-hand experience were excluded.

Findings. All issues discussed on the Internet were categorized by: the quality and intensity of symptoms; aggravating and easing factors; the appearance of the scar; cognitions and concerns; experiences with healthcare practitioners; timescales; and "other". Although many of these issues had not been reported in previous studies, CS scars were clearly a problem for some women. Symptoms could be present for many years and onset might be delayed. Some women had sought medical advice. This sometimes led to an investigation and/or resolution, but often left them without a satisfactory explanation for their symptoms.

In order to offset the bias inherent in Internet research and to investigate the relevance of the findings for the local population, the issues were followed up with a survey.

Phase 2: Postal survey of persistent Caesarean section scar problems in the local population

Methods. It was unclear whether the findings from the first phase would be relevant to the local population. Therefore, postal questionnaires were sent out to women who had undergone CS locally between 6 and 30 months previously. The aim of the survey was to explore issues identified in phase 1, and to identify potential participants for the qualitative interviews.

Questionnaire design. The questionnaire ("Appendix 1") asked for demographic information, such as: the number of children and method of birth; the time since the last CS; current age; and whether the last CS had been emergency or planned. The type of incision was not included because all surgeons used the Pfannenstiel approach. The questionnaire also asked what CS scar symptoms the participant might have experienced within the past month, and whether these had been bothersome. Subsequent questions dealt with: CS-scar-related healthcare (specifically, information given before or up to 6 months after CS); professionals, people or groups consulted, and the usefulness of this; and any examinations, investigations or treatments offered. Finally, the participant's concerns and the impact on her life

were assessed. The survey mostly consisted of multiple-choice questions, but free writing space was provided at several points. It was finalized following a review by the local branch of the Patient Advice and Liaison Service that involved lay people, and five women who had undergone a CS or hysterectomy in the past, none of whom had a background in professional healthcare. The survey participants were invited to take part in further interviews.

Exclusions. Any potential participants who had had stillbirths or whose neonates had died while in hospital were excluded. The risk of contacting women who might have experienced subsequent neonatal deaths was further minimized by excluding those who had given birth at less than 37 weeks of gestation.

Data collection. Based on phase 1 findings, symptoms continuing beyond 6 months were regarded as persistent. Ten to 20 participants were required for the interviews. It was assumed that they could be drawn from 50 symptomatic survey respondents. Previous research suggested that there would be a 10% incidence and an 80% return rate, and therefore, at least 625 questionnaires had to be sent out. Three hundred and fifteen questionnaires were sent to potential participants who had undergone a CS 6–18 months previously, and a further 315 were despatched to individuals who had had the operation 18–30 months previously. Each questionnaire had a unique identifying number; however, some had to be discarded because of a printing error, and therefore, the numbers ranged from one to 675.

Findings. Of the 203 completed questionnaires, five were excluded because the answers pertained to a CS that had been performed less than 6 months previously. The resultant return rate of 31.4% yielded a sufficient number of symptomatic participants and topics for qualitative interviews, but precluded additional statistical analysis. Demographic information is provided in Figures 1 and 2. There was no correlation between symptoms on the one hand, and the number or type of previous deliveries, age, the time since the CS, and whether it had been a planned or an emergency operation on the other. The incidence of scar issues did not correlate with age, the time since the CS, a previous CS, previous births or whether the CS had been planned. The symptoms identified in phase 1 were confirmed (Table 1); several of

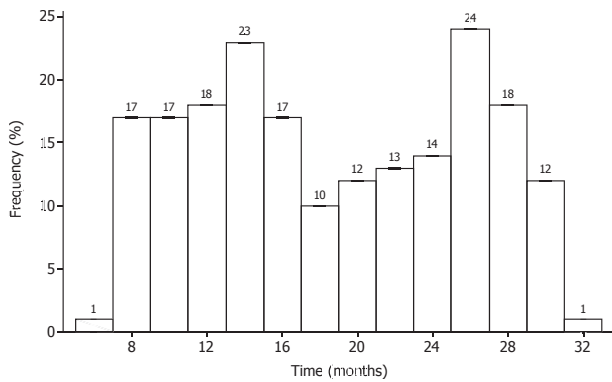


Figure 1. Time since the participants' last Caesarean section.

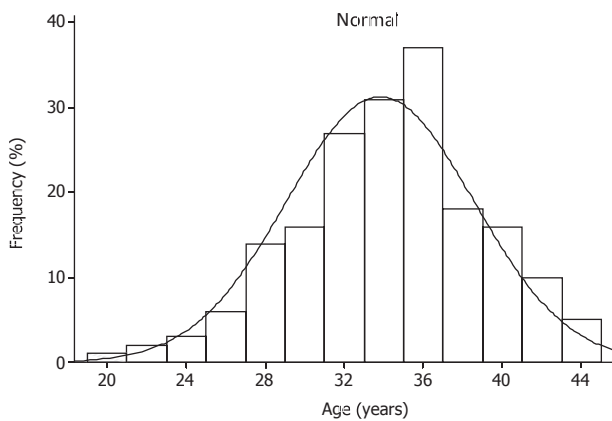


Figure 2. Age of the participants ($n=186$) when they completed the questionnaire (mean \pm standard deviation = 33.82 ± 4.748 years).

Table 1. Caesarean section scar issues reported in the survey, in order of prevalence

Scar issue	Incidence	
	Number	Percentage
Numbness to touch	112	55.2%
Itching	75	36.9%
Skin "apron"	71	35.0%
Strange feeling to touch	52	25.6%
Thickened or raised scar	51	25.1%
Sensitivity to touch	35	17.2%
Discolouration	31	15.3%
Ache	27	13.3%
Pain	24	11.8%
Pins and needles	23	11.3%
Sweating	22	10.8%
Pulling in of the skin	11	7.9%
Infection or weeping	5	2.5%

these had not been investigated in previous research. Typical physical or visible changes included thickening, discolouration and having a skin "apron". The effects of the CS scar on the interviewees are listed in Table 2. Most participants ($n=173$) said that they had not been told to expect long-term CS scar issues or how long these might last.

Table 2. Effects of the Caesarean section scar on survey participants, in order of prevalence

Scar issue	Incidence	
	Number	Percentage
Don't like looking at scar	64	31.5%
Concerned regarding following pregnancy	55	27.1%
Wearing different clothes	55	27.1%
Feeling less confident	52	25.6%
Concerned may have damaged insides	39	19.2%
Concerned may have adhesions	27	13.3%
Altered relationship with partner	20	9.9%
Concerned may not have healed well	19	9.4%
Avoiding some positions	18	8.9%
Avoiding some activities	15	7.4%
Moving carefully	8	3.9%
Concerned may have infection	4	2.0%
Sleeping less well	3	1.5%

The concerns expressed by the participants generally did not lead to healthcare visits; in 51 instances (25.8%), this was because they thought that nothing would be done for them. Five individuals (2.5%) had actually been told that this was the case. Nineteen women (9.6%) had visited their general practitioner (GP), but only nine (4.5%) had found this to be helpful. Treatment was offered to very few individuals, and even examination was reported as rare. Other resources accessed included friends and relatives, the Internet, other mothers, medical specialists, a massage therapist, and acupuncturists, and these had mostly been found to be helpful.

Although the questionnaire focused specifically on persistent CS scar issues, 20 participants suggested in the free-text sections that better information should be made available. Two participants wished that they had been told to expect numbness, a problem that might not be considered by healthcare professionals.

This survey confirmed the occurrence of a range of CS scar issues in the local population. In many cases, these were a cause for concern to the individual, and had an impact on her life. It was not clear why this did not lead to healthcare utilization. The importance of these findings was explored in qualitative interviews.

Phase 3: Qualitative interviews following up significant survey themes

Setting. The participants' concerns about their CS scars, the ways in which these affected individuals and their views on related healthcare were explored in qualitative interviews ("Appendix 2"). The option of focus groups was rejected because of the strong possibility that

Table 3. Interview grid used for the present study. Each dot represents one interview participant: (○) those who made suggestions regarding the provision of Caesarean-section-related information in the free-text sections of their questionnaire; and (●) those who did not

Number of areas of impact in questionnaire response	Number of concerns in questionnaire response					
	5	4	3	2	1	0
8						
7				●		
6					●	
5		●		○		●
4				●		
3				●●○		
2			●○	○		○
1		●		●●		○
0				●○		

sensitive information might not be disclosed in these settings (Kaplowitz 2000). In order to limit any inconvenience for participants with young children, semi-structured interviews were carried out by telephone. This also increased anonymity and made it easier for participants to terminate the interview, both of which were important considerations because of gender differences and the potential sensitivity of the interview topics.

Data collection. A table was produced in order to select participants for the qualitative interviews. This was done on the basis of their questionnaire responses regarding the ways in which they had been affected by their CS scars (hereafter “impacts”), and their specific CS scar-related concerns. The table set the number of impacts against the number of concerns. It also coded participants according to whether they had made suggestions for healthcare (see Table 3, in which only the participants who were interviewed are represented). The majority of questionnaire participants fell into the right lower quadrant of the table, and therefore, purposive sampling was applied to achieve a relatively even distribution.

Potential topics for interview included: the impact of the CS scar on the participant’s life; what the scar meant to the individual; coping strategies; help provided or accessed; and needs and suggestions. Nineteen recorded interviews were conducted, and data saturation reached at around 15. No participants declined to be interviewed when telephoned.

Method of analysis. Interview data were analysed with the Framework Method, a matrix-based data management tool that combines a deductive template with inductive editing (Robson

2002; Ritchie *et al.* 2003). This approach offered an opportunity to combine emergent data with predetermined information and pragmatic objectives (Pope *et al.* 2000). Issues derived from the present study’s pilot work provided an *a priori* set of themes, which was modified and developed into a thematic framework through reflection on the emerging interview data.

In line with methodological recommendations, the first author (H.v.G.) immersed himself in the data by reading the interview transcripts several times in order to identify framework themes (Ritchie *et al.* 2003). The thematic framework was subsequently applied to the data, and then modified through several cycles of constant comparison, until the first author (H.v.G.) was confident that it represented the data without undue distortions (Hesse-Biber & Leavy 2006). The indexed data were transferred to a table of themes and subthemes (Table 4), and then interpreted.

Methodological rigour was enhanced by prolonged familiarization, the inclusion of all interview data and the exclusion of the first author’s (H.v.G.’s) own comments (Creswell 2007). The link with the preceding phase of the study was strengthened by ensuring that the interviews expanded on important themes from the survey, and by drawing the interview participants from a much larger cohort of survey respondents (Creswell & Plano-Clark 2011).

Results

Three thematic categories emerged from the interview data: persistent CS scar problems; professional help for persistent CS scar problems; and recovering from CS. The first category related to the problems with CS scars that were experienced by the participants. The second covered participants’ experiences of and recommendations for healthcare. Finally, an unexpected and considerable number of entries related to the initial recovery from CS, and the preparation for this recovery. These did not relate directly to persistent CS scar problems, but were brought up spontaneously by participants. The entries turned out to have implications for the impact of the scar and healthcare provision. These represented a more inductive aspect of the analysis, and formed the recovering from CS category. This section reports on the findings in each category, and contains representative statements from participants. Survey participant identifiers are included in brackets.

Table 4. Themes and sub-themes identified in the qualitative interviews: (CS) Caesarean section

Theme	Sub-theme
Scar	Shape, appearance; issues relating to long-term scar tissue Healing, issues relating to the scar healing process Positive sensory phenomena (e.g. pain or itching) Negative sensory phenomena, i.e. reduced sensation
Implication, i.e. the effect that scar-related issues had on the individual's life	Activities of daily living (excluding exercise) Exercise Clothing Relationship with partner or husband
Meaning: more subjective aspects of issues related to the scar and its symptoms	Attribution Body image, confidence Subsequent pregnancy
Help accessed	Peri-CS information Self-help Peers, friends and relatives Professional help
Result of help or coping	Reassurance, understanding what is normal or acceptable Feeling dismissed Acceptance or resignation
Needs and suggestions	Check-up for CS scar problems Being prepared, knowing what to expect Information, knowing what is normal or acceptable Advice
Other comments (e.g. general comments about birth preference)	

Thematic category 1: Persistent Caesarean section scar problems

For many interview participants, the CS scar had no significant impact on their activities, and most adapted by wearing different clothing. There was an acknowledgement that giving birth changed one's body, regardless of the method of delivery. Some reported discomfort or pain during sexual intercourse, but there were no reports of abstinence. Interestingly, one participant mentioned feeling unable to do abdominal training because numbness had taken away her awareness of her stomach muscles.

Reports of an altered body image were common, and several participants expressed a strong dislike of the appearance of the CS scar:

“I don't like it, I hate it. I sort of have, like, a bit of a pouch, and consciously, I'm a bit . . . That sort of worries me. [. . .] I don't like the look of it. [. . .] I don't like the look of it and [. . .] I think it looks horrible, yes, so . . . I don't like looking at it.” (54)

Other participants expressed feeling self-conscious as a result of the CS scar, even when it was not visible to others:

“Not that you could possibly see it, I'm just quite conscious of it.” (32)

“It's very difficult – you look at yourself in the mirror and all you can see is just this stomach. . . So you feel very self-conscious, people looking at it and going, ‘Ooh, there's a flap of skin there that shouldn't be there.’” (231)

In some cases, this had had an effect on intimate relationships:

“I don't like the look of it and, obviously, I worry about what my husband thinks, and he's fine about it, but I think it looks horrible. Yes, [it has] probably [affected my relationship] because I am a bit more bothered about my body, I think, now. Whether that's just having a baby or if that's because of the scar – I think it is a lot to do with the scar – I don't like my tummy how it is.” (54)

Thematic category 2: Professional help for persistent Caesarean section scar problems

Participants did not always seek help for persistent CS scar problems; for example, because of time pressures, or because they expected the problems to be superseded by a subsequent

pregnancy. One participant commented that, although she had not sought help for her CS scar, she wished that she had been told what it might have looked like. Other participants had not received the explanation or reassurance that they wanted from their doctors:

“If you say to the doctors, ‘Well, it hurts when I do this,’ they say, ‘Well, don’t do it then. You’ve had two Caesareans, get on with it.’ And well, that’s not quite what I was after. [. . .] Everything’s been checked out and they say everything’s OK, and that’s all you can get out of them really. It’s healed, and that’s it!” (231)

“[The GP’s] answer [regarding my pain] was pretty much, ‘Well, you’ve had a spinal block, you’ve had a C-section, what do you expect?’ [. . .] because they said, pretty much, ‘Well, there you go, we’ve checked that, and that was the only kind of avenue.’ You feel like you’re making a big thing out of nothing. So you think, *OK, I’m obviously being a bit of a pansy and I’ll leave it.*” (383)

For some participants, the lack of a satisfactory explanation added to their concern:

“You think, *Well, I still don’t know why I’m getting aching pains every so often – so you still think, Is there anything, maybe something else, they might have missed?*” (32)

“I mean, obviously, it’s a bit more rushed if it’s an emergency Caesarean – I don’t know whether they’ve done any unknown damage because it was, like it was an emergency procedure.” (675)

Other participants felt dismissed by their doctor:

“Every time I mention anything to my GP, she says, ‘You should see mine, mine’s worse.’ [. . .] It doesn’t make you feel any better that she is saying hers is worse, it doesn’t make you feel better, it makes you feel childish, makes you feel silly when she doesn’t want to acknowledge what you are saying.” (268)

The most commonly expressed concern was not the current state of the scar, but rather, the way it might be affected by a subsequent pregnancy. Most participants had been reassured by healthcare professionals, but some felt dismissed:

“Yes, it still gets sore sometimes, and that’s why I spoke to the midwife about it. [. . .] I said I was a bit concerned that, when I got

big and pregnant now, that it would rip or something, and she just laughed at me. [. . .] I’m just a normal person, and I just wanted a bit more information, really, of what it could be – why it is still painful after what must be about 2 years and 3 months.” (500)

“When I said about [my concern regarding the scar splitting during my next pregnancy] to one of the doctors, he laughed at me, but he didn’t really give me a straight answer.” (70)

The most commonly reported activity that had been helpful to participants was not consultation with healthcare professionals, but comparing notes with other women who had gone through, or were going through, recovery from CS themselves. In many cases, these women were friends or relatives, but sometimes, they were also other mothers whom the participants had got to know directly or via Internet forums.

Thematic category 3: Preparation for and recovery from Caesarean section

While some participants were happy with their antenatal care and the information that they received in hospital, others felt underprepared for their recovery:

“You get sort of, this could happen during your labour, but then you don’t get anything for the afterwards. And that just seems the one part that the healthcare is lacking.” (231)

“I had a 17-month baby and then a newborn as well, and I wasn’t able to lift my first child for 6 weeks, so I had to have another adult with me for 6 weeks all the time.” (268)

“I did try [to get my stomach muscles back, as advised by the GP], but it was just impossible, you know, the pains were awful. Even things like lifting the buggy out of the car was just awful for ages after that.” (648)

Some participants felt that healthcare professionals underplayed the fact that CS was a form of major surgery:

“I don’t feel as if anyone’s ever informed fully of, one, how major an operation it is, and two, how long it’s going to take to heal externally, but also internally, and the sort of pains and afterpains you get – you’re not sure whether they are right or not.” (32)

“They only check to see that your scar has healed on the outside, that’s all they do. And

I really think there should be more because it's such a major operation". (648)

Participants suggested that women would be better prepared if they were told why symptoms might arise and how long these might take to settle, and also if they were given better written information. Some felt that uncertainty over which sensations were part of the normal recovery process made it hard to know whether and how to progress their activity levels. They reported that the focus of healthcare professionals was on the health of the baby and healing of the external CS scar, but that concerns about self-management and recovery were not always addressed:

"I had never been for an operation and I didn't know what to expect, and it was quite scary to be honest. . . Six weeks afterwards, you are left to your own devices, and you are still not sure what to do, what you can and can't do, what feels normal." (231)

Again, participants suggested that more information about the recovery process should be provided:

"Just something as simple as. . . someone saying, 'Look, you know, it is quite likely that for quite a few months you might feel very strange in that area, and it's nothing to worry about,' that would make quite a bit of difference, I think. . . It didn't have a major impact on my life, but it would have been one less thing for me to have to worry about." (674)

Participants who had experienced medical CS scar problems such as wound infections believed that they had been taken seriously. However, concerns about the CS scar did not always arise early on:

"I think the issue is that, by the time you start thinking, *Is this normal?* you're a few months down the line, and you don't actually have any follow-up appointments." (674)

As mentioned, participants frequently remarked on how helpful contact with other mothers had been to them. Some turned to the Internet for information:

"I looked on the Internet because nobody . . . everyone said it was fine." (500)

This paradoxical comment confirmed that, for reassurance to be effective, more was needed than a statement about the absence of pathology.

Discussion

The present research utilized multiple data sources to investigate persistent CS scar problems that appeared to be unknown to local healthcare practitioners. In order to ensure that the study was driven by the perspective of service users, topics for qualitative interviews were identified through Internet research and a local survey. This approach led to unexpected findings.

Although the research focused on CS scar problems occurring at least 6 months after surgery, many participants indicated that better preparation in the period leading up to the delivery was more important to them. Generally, they had learned to live with any CS scar problems that they might have. However, they felt that their minds would have been put at ease by knowing about potential symptoms and time-scales in advance, as well as what might require consultation with a healthcare practitioner. Some participants wished that they had known what the scar might look like, while others would have liked to have been prepared for numbness in the operated area, a symptom that may be present in 30% of women following CS (Loos *et al.* 2008). Although clinicians may view numbness simply as the absence of sensation, it was clearly of greater importance to some women who participated the current study.

The lack of information about potential CS scar pain may be a result of the fact that persistent post-surgical pain is a relatively new field (Macrae 2001), especially in obstetric surgery (Nikolajsen *et al.* 2004). Additionally, postnatal morbidity may be underreported (MacArthur *et al.* 1997; Thomas 2004), or discussed from a mostly biomedical perspective (Glazener *et al.* 2006; Bick *et al.* 2009; NICE 2011). For example, consent advice from the Royal College of Obstetricians and Gynaecologists (RCOG 2009) in relation to the CS scar is limited to initial discomfort and infection, and it is not clear whether surgeons outside the field of plastic surgery are aware of the impact that scars may have on the individual (Young & Hutchinson 2009). Moreover, the education of healthcare professionals is generally far behind veterinary medicine courses when it comes to pain (Watt-Watson *et al.* 2009; Briggs *et al.* 2011). Therefore, physiotherapists in women's health and other fields are encouraged to familiarize themselves with the physiology and psychology of pain in order to be able to provide full and realistic explanations that are

not limited to descriptions of nociception (van Griensven *et al.* 2013).

Participants reported a lack of information about recovery from CS and returning to normal activities. Interestingly, their obstetric physiotherapists systematically provided written information that included clear recovery advice for the first 12 weeks after CS. Previous research has demonstrated that the efficacy of written information is seriously undermined by the way in which it is distributed in obstetric care, but that time pressures often force a reliance on leaflets (Stapleton *et al.* 2002). The present research confirms that the information provided by obstetric physiotherapists may not reach its target. It also suggests that patient information may be enhanced by providing details of websites set up by support organizations; for example, the National Childbirth Trust (www.nct.org.uk), Netmums (www.netmums.com), Ready Steady Mums (readysteadymums.org) or Caesarean Birth and VBAC [Vaginal Birth after Caesarean] Information (www.caesarean.org.uk). For example, Netmums provides online forums and local groups, while Caesarean Birth and VBAC Information include photographs of a range of CS scars, as well as information and advice. Participants in the present study confirmed the importance of being able to compare notes with other women, something that has also been identified by previous researchers (Nolan 2009). Local groups can play a role in this without necessarily drawing on healthcare resources.

Interview participants confirmed that their symptoms were often not sufficiently problematic to require a visit a doctor, especially given their parenting responsibilities. Those who did attend appointments reported that sometimes they felt dismissed, possibly confirming a barrier to postnatal morbidities that has been reported previously (MacArthur *et al.* 1997; Albers 2000; Thomas 2004). Participants also indicated that they were not always reassured because their clinician was not concerned about their symptoms or the findings of the investigations. However, on the whole, participants suggested that, rather than long-term post-CS care, they required education during and immediately after their pregnancy.

Limitations

The participants in the qualitative interviews were selected on the basis of a numerical representation of the impact of their CS scar problems and their concerns. Unfortunately, it was not possible to gain detailed information about

the degree to which these individuals were affected through the use of a questionnaire. Whether the racial makeup of the local population influenced the results is uncertain: while 98.8% of the local population was reported as white (NHSSEE 2011), and dark-skinned races may be more prone to the formation of keloid scars (Bayat *et al.* 2003), the interactions between scar formation, culture and pain are far from certain (Unruh & Henriksson 2002).

Although every attempt was made to allow the participants to steer the qualitative interviews, it is possible that some issues were not identified during the pilot phases of the study, and therefore, that these were missed in the interviews. It must also be acknowledged that the first author (H.v.G.) is a male working outside the women's health field. Combined with the fact that the interviews were carried out over the telephone, this may have led to flatter and more factual responses than face-to-face discussions with a women's health professional would have done. On the other hand, the first author (H.v.G.) received supervision from two female professors (A.P.M. and V.H.) who were experienced in health research, and one of whom was a midwife by profession (V.H.). Moreover, if the study had been conducted by a female researcher, this might have led to issues with respect to limited reflexivity (Speer 2002), and the possibility of selective information being given by participants (Lewis 2003; Reinharz & Chase 2003). An outsider can sometimes overcome the traditional boundaries experienced by insiders (Hammersley & Atkinson 1995), as long as he or she combines reflexivity with a keen awareness of the interview situation (Reinharz & Chase 2003). Therefore, the first author (H.v.G.) introduced himself, explained his interest in CS scar problems, allowed participants to steer the conversation, specifically asked them to ask additional questions or add comments, and sought feedback from his supervisors (A.P.M. and V.H.).

Conclusions

The present study utilized a three-phase sequential approach to investigate persistent scar problems following CS. This methodology facilitated the investigation of a topic for which both potential participants and the subject area were relatively unknown to the NHS, issues which formed substantial barriers to mono-method research approaches. It identified a range of possible CS scar problems, and confirmed that these may be problematic for women.

Many participants believed that preparation for recovery from CS, rather than healthcare for problematic scars, should be improved. This study confirmed that the efficiency of providing prenatal information about recovery from this form of surgery may also be improved. It also found that peer support is important for women who have undergone CS. Greater use could be made of local and national support groups in the provision of information and peer support.

Participants who sought professional advice for either persistent CS scar problems or concerns over future pregnancies believed that it was important to be listened to, taken seriously and provided with a realistic explanation. Improvements in healthcare professionals' training in understanding persistent pain, the impact of scars on a woman and patient communication may help to achieve this.

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Dr Hubert van Griensven qualified as a physiotherapist in 1988. He completed a 3-year course in Chinese acupuncture in 1996, which led to his appointment as Clinical Specialist in Pain at Guy's and St Thomas' Hospital, London. During his time there, Hubert completed an MSc in Pain at King's College London, and wrote Pain in Practice: Theory and Strategies for Manual Therapists (2005), a textbook about the application of pain physiology in manual therapy practice. He was awarded his doctorate by the University of Brighton in 2013, and in the same year, published Pain: A Textbook for Clinicians, a multi-author textbook on pain, co-edited with Jenny Strong and Anita Unruh. Hubert is currently a consultant physiotherapist with Southend NHS Trust. He lives in London.

Ann Moore is Emeritus Professor of Physiotherapy in the School of Health Sciences at the University of Brighton.

Valerie Hall, now retired, was Professor of Midwifery in the School of Health Sciences at the University of Brighton.

Appendix 1

Postal questionnaire for phase 2 of the study

**Caesarean Scar Questionnaire
(Version four 01.09.09)**

Q 1 How many children have you given birth to? **Please tick the appropriate answers for both a and b**

- | | | | | | | |
|---------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 0 | 1 | 2 | 3 | 4 | 5 or more |
| a Normal vaginal delivery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b Caesarean delivery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 2 How long ago did you have your last caesarean?

Years and Months

Q 3 Was your last Caesarean section?
(Please choose one option only)

- Planned Emergency

Q 4 What is your age?

yrs

Q 5 Over the last month, have you experienced any of the following over or around your caesarean scar? **Please tick all that apply**

- | | |
|--|--------------------------|
| | Yes |
| Pain | <input type="checkbox"/> |
| Ache | <input type="checkbox"/> |
| Tingling/pins and needles | <input type="checkbox"/> |
| Sensitivity to touch | <input type="checkbox"/> |
| Numbness to touch | <input type="checkbox"/> |
| A strange feeling to touch | <input type="checkbox"/> |
| Itching | <input type="checkbox"/> |
| Discolouration, for instance red or purple | <input type="checkbox"/> |
| A thickened or raised scar | <input type="checkbox"/> |
| Infection or weeping | <input type="checkbox"/> |
| Pulling in of the skin | <input type="checkbox"/> |
| Skin hanging over the scar ("skin apron") | <input type="checkbox"/> |
| Sweating | <input type="checkbox"/> |
| Other (please describe) | |

In the rest of this questionnaire, these issues will be referred to as scar changes

THIS QUESTIONNAIRE IS DOUBLE-SIDED

P.T.O

Respondent 1

Page 01



Q 6 Before your last caesarean, did you have any scar changes from previous abdominal operations?

Yes No

Q 7 Before your last caesarean or within the first six months after it, were you told that you might have long lasting scar changes?

Yes - please go to question 8 **No - please go to question 9**

Q 8 At that time, how long were you told that these scar changes might last?
***If you were given more than one timescale, please tick all that apply.
For example, you may have been given different timescales by different healthcare practitioners.***

	Yes
Up to six months	<input type="checkbox"/>
Up to a year	<input type="checkbox"/>
Several years	<input type="checkbox"/>
I was told that they may never clear	<input type="checkbox"/>
I was never given a timescale	<input type="checkbox"/>

The rest of this questionnaire relates to the time from six months after your last caesarean onwards

Q 9 Do any of the following statements apply to you? ***Please tick all that apply.***

	Yes
I have not experienced any scar changes at all	<input type="checkbox"/>
I used to experience scar changes, but they have cleared completely	<input type="checkbox"/>
I have scar changes but they do not bother me	<input type="checkbox"/>
I did not have scar changes until I was pregnant again	<input type="checkbox"/>
My scar changes have bothered me, but not enough to seek help	<input type="checkbox"/>
I don't think that anything will be done about my scar changes	<input type="checkbox"/>
I have been told that nothing can be done about my scar changes	<input type="checkbox"/>
I expect my scar changes to settle eventually	<input type="checkbox"/>

Q 10 ***This question is about your scar and any scar changes you may have experienced.*** Have you tried to find information, advice or treatment?

No please go to question 13 Yes

THIS QUESTIONNAIRE IS DOUBLE-SIDED

P.T.O

Respondent 1

Page 02



Q 11 Where did you go for information, advice or treatment? Did you find it useful?
Please tick all that apply, and whether the contact or visit was useful for you?

GP surgery

Was this visit useful for you?

Visited

Yes No

Midwife

Was this visit useful for you?

Visited

Yes No

Obstetrician or Gynaecologist

Was this visit useful for you?

Visited

Yes No

Physiotherapist

Was this visit useful for you?

Visited

Yes No

Massage Therapist

Was this visit useful for you?

Visited

Yes No

Osteopath or Chiropractor

Was this visit useful for you?

Visited

Yes No

Acupuncturist

Was this visit useful for you?

Visited

Yes No

Internet

Did you get useful information or advice?

Visited

Yes No

Relative or friend

Did you get useful information or advice?

Contacted

Yes No

Other mothers

Did you get useful information or advice?

Contacted

Yes No

Charity or support group

Did you get useful information or advice?

Contacted

Yes No

Other (please say where and whether it was useful for you)

THIS QUESTIONNAIRE IS DOUBLE-SIDED

P.T.O

Respondent 1

Page 03



Q 12 Have you been offered any of the following for your scar changes?
Please tick all that apply.

- Yes
- Examination
- Tests
- Medication
- Injection
- Surgery
- Massage
- TENS machine

Other (**please state what**)

Q 13 Do any of the following statements apply to you?
Please tick all that apply.

- Yes
- I wear different clothes because of my scar
- I have to move carefully because of my scar
- I avoid some activities because of my scar
- I avoid some positions because of my scar
- I feel less confident because of my scar
- I don't like looking at my scar
- I sleep less well because of my scar
- My scar has changed my relationship with my husband / partner
- I am concerned that I may not have healed well
- I am concerned about my next pregnancy
- I am concerned that I may have damaged insides
- I am concerned that I may have adhesions
- I am concerned that I may have an infection

THIS QUESTIONNAIRE IS DOUBLE-SIDED

Respondent 1

P.T.O
Page 04



Q 14 I may wish to interview you about the issues raised in this questionnaire. May I contact you by telephone or e-mail if I have further questions?

- No - ***I shall not contact you again***
- Yes - ***please fill in your name and preferred method of contact below and complete the enclosed interview consent form***

Name.....

Daytime telephone number

Mobile telephone number

E-mail address

Preferred contact times (if any).....

Q 15 Do you have any suggestions, questions or observations regarding help for scar changes?

Q 16 Would you like to be informed of the results of this study?

- No
- Yes

Q 17 If yes to Q16, would it be by

- Email address as above
- Other email address

By mail please fill in your address

PLEASE DO NOT PHOTOCOPY THIS FORM

Respondent 1

Page 05



Appendix 2

Interview schedule for phase 3 of the study

- (1) The researcher introduces himself, reminds the participant about the study and suggests that the interview will take about 30 min.
- (2) The researcher asks permission to proceed. If this is not given, does the participant wish to be contacted at another time or to withdraw from the study?
- (3) The researcher asks permission to record the interview.
- (4) The recording is played back to ensure that the equipment is working.
- (5) The researcher provides information and gives the participant an opportunity to ask questions:

“I would like to tell you a bit more about my study and this interview. This research study is part of my PhD at the University of Brighton. I am funding it myself. No doctor or other person will receive payment for including you in the study. You are not obliged to take part. If you are not happy to continue at any time, you can end the interview. You don't have to give a reason.

“Any information that you give me will be kept completely confidential. In due course, the results of this study will be published and used to develop further research studies, but your identity will never be disclosed. Your GP and other healthcare practitioners will not be informed that you have been part of this study.

“As you may remember, I am doing a research study of problems with Caesarean

scars. Most women recover from Caesarean section without difficulty, but some experience problems such as pain, numbness and thickening of the scar. I have analysed the results of the questionnaires from women who have had a Caesarean section. This has given me information about some long-term effects of Caesareans and how women deal with these. I am now interviewing some of the women who responded, to find out more about their experiences.

“Do you have any questions about this?”

- (6) The researcher asks for permission to continue with the interview.

Guide for interview topics (related survey questions in brackets):

- Signs and symptoms reported on the questionnaire (Q5); intensity.
- Aggravating factors and impact on life (Q13).
- Has information given around the time of birth been helpful and accurate (Q8 and Q9)?
- Have there been reasons why advice, information or treatment were not sought (Q10)? If so, are these related to healthcare provision (e.g. Q7, Q8 and Q11)?
- Have advice, information or treatment been sought (Q10 and Q11)? If so, explore ease of access, experience of healthcare practitioners and alternative sources (Q11 and Q12).
- What has been experienced as helpful (Q11 and Q12)? Has anything been experienced as counterproductive (Q11 and Q12)?
- Participant's suggestions, questions and observations (Q15).