Parental information use in the context of newborn bloodspot screening. An exploratory mixed methods study

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Received: 6 October 2011 / Accepted: 31 January 2012 / Published online: 16 February 2012
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Abstract The aim of this study was to investigate how parents select and use information sources when considering newborn bloodspot screening. Mixed methods approach using semi-structured interviews ($n=18$) and a self-completion postal questionnaire ($n=154$) conducted with parents of children who had undergone newborn bloodspot screening. Qualitative data was assessed using a thematic analysis approach with quantitative data analyzed using multinomial logistic regression. Parents used a limited range of information. In the UK, maternity services are largely delivered by the midwife and the healthcare practitioner was the main information source for parents, with only half of parents using official health service leaflets. Barriers included the provision of information post-natally and with other non-healthcare materials. Neither number of children, age group, education level, nor income were significantly associated with the number of information sources used. Nor were they associated with the information source indicated as most important. The midwife is well placed to act as a gatekeeper for parents seeking information about newborn bloodspot screening. Even when additional sources are used, the midwife remains a prominent source of information. Furthermore, the use of written materials is dependent upon

appropriate delivery and consequently delivery is essential to information use.

Keywords Screening · Education · Midwife · Mixed methods · Midwife

Introduction

Newborn bloodspot screening is a long established public health measure, with the UK operating a national program since 1969. Since the initial screening program for phenylketonuria (PKU), there has been an increase in the number of conditions that are included, with the UK National Screening Committee currently recommending that newborn screening includes phenylketonuria (PKU), congenital hypothyroidism (CH), cystic fibrosis (CF), sickle cell disease (SCD), and medium chain acyl-CoA dehydrogenase deficiency (MCADD) (UK Newborn Screening Programme Centre 2008). An optional screen for Duchenne muscular dystrophy (DMD) is also offered in Wales. In the UK, prior to screening, health professionals are expected to both provide written information in the form of the *Screening tests for you and your baby booklet*¹ and discuss newborn bloodspot screening (UK Newborn Screening Programme Centre 2008). This is situated within an informed consent process, which requires health professionals to:

“Explain fully to parents and then record in the maternity record that newborn blood spot screening has been discussed and recommended, booklet given and consent sought.” (UK Newborn Screening Programme Centre 2008)

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¹ The booklet is available at: <http://www.screening.nhs.uk/annbpublications> (accessed 10th November 2011)

Hence, parents are required to receive both official written information and to have discussed screening with the midwife prior to screening being conducted. Previous research has found that while parents gather information from official sources, such as the midwife, they also learn about screening from friends, family, unofficial literature, and the internet (Tymstra 1986; Davey et al. 2005; Hargreaves et al. 2005; Parsons et al. 2007; Tluczek et al. 2009).

There is, however, a paucity of quantitative data relating to what parents perceive as the most important sources of information. Furthermore, despite the research relating to the different sources used, there is little evidence as to *why* parents use certain types of information materials over others when learning about newborn screening. One recent analysis surmised that:

“There is limited research reported about parents and professionals views and experiences of: pre-screening information (and none of antenatal information); consent for screening; the heel prick itself and subsequent tests; the information provided with screening results; and in particular communication about carrier testing.” (Stewart and Oliver 2003)

This paper presents the findings of this exploratory sequential mixed methods study that sought to address this lack of data. The study sought to explore with the parents the range of information sources, ascertain those which parents felt were most important, and *why* these sources of information were prioritized over others. Secondly, it sought to generate quantitative data regarding the relative use of different information sources as well as those sources identified by parents as being most important. As such, the study moves beyond the existing descriptive evidence on information use and begins the process of exploring the mechanisms that operate behind this.

Methods

A two-stage exploratory sequential mixed methods design was employed (Creswell and Plano Clark 2007) with an initial stage of interviews followed by a larger postal survey. Both studies received formal ethical approval and took place in the Merseyside and Cheshire region of England, UK.

Stage 1: interviews with parents

In line with established qualitative methods, sampling was purposive in nature and sought to engage with parents of differing socio-economic and uptake status.

Parents were eligible for inclusion if their child was born up to 2 years prior to being interviewed and excluded if their child was severely ill, had subsequently died, or if they were unable to converse freely in English. While the use of a retrospective sample introduces the potential of a recall bias, this was minimized by having a relatively short time frame. However, a time frame that was too short would be problematic on a practical level and may preclude the opportunity to recruit those who have declined newborn bloodspot screening given the very small number of parents who decline. Therefore, a balance was sought between a period that was short enough to minimize recall bias and one long enough to identify at least some parents who declined screening.

Following ethical approval, parents were identified through laboratory records held by the Merseyside and Cheshire Regional Screening laboratory, branches of the National Childbirth Trust (NCT), and local Sure Start schemes. Geographic location and associated area demographics were used as a proxy for socio-economic status. Details of these areas are shown in Table 1. Parents who declined screening were identified through laboratory records and over-sampled in comparison to actual occurrence. Prior to interview, all parents provided written informed consent to take part.

Interviews took place in a location of the interviewee's choosing, which in most cases was their own home. Interviews were audio-recorded using a digital recorder, although in one instance field notes were taken at the request of the interviewee. All recorded interviews were transcribed. During this process, transcripts were anonymized. As a process of validation, transcripts were made available to interviewees for comment (Miles and Huberman 1994). No further comments were received from participants.

The examination of the transcripts followed a thematic analysis approach (Boyatzis 1998) in which textual data is coded and labeled in an inductive manner. This process of coding was iterative with the codes being developed using

Table 1 Selected data profile items comparing recruitment areas

Data profile item	Sefton	Macclesfield	Wirral	Liverpool
Rank of the average indices of multiple deprivation super output area [scale=1 (most deprived) to 354 (least deprived)] (2004)	78	276	48	1
Annual average house price: overall (2005)	£156,855	£238,122	£140,153	£115,244
% of children that live in families that are income deprived	23.7%	9.9%	29.9%	44.9%

Data taken from the audit commission website: <http://www.areaprofiles.audit-commission.gov.uk>. Accessed 9 October 2009

the constant comparison method alongside the interviews. This allows for the constant revision, combination, or separation of codes in light of new data (Strauss 1996). Each newly coded incident was compared both within and across cases to previous incidents in order to refine or revise the code (Fielding and Lee 1998). Codes were then grouped into overarching themes or constructs through a process of data reduction. Consequently, the theme operates at a higher level than the immediate codes (Boyatzis 1998).

Stage 2: survey of parents

Parents were eligible for inclusion on the basis of their child's bloodspot being analyzed by the Merseyside and Cheshire Regional Screening laboratory and their child had been born in 2008 ($n=28,348$). From these, a random sample of $n=500$ parents were drawn. Parents were excluded if their child had subsequently died and consequently it was deemed that the discussion of newborn screening might have caused them distress. Parents were identified and approached, in writing, by a clinician with appropriate clinical access (KS). Questionnaires contained only a unique identifier that allowed for follow-up of non-responders using a linking file held by the clinician. As such, respondents were anonymous to the researcher (SN) conducting the analysis.

Parents could complete a paper copy of the questionnaire, which was sent along with the invite letter and information sheet, or an online version. Return of the questionnaire was taken to indicate consent. Parents were given a small financial incentive to return the questionnaire.

Two questions assessed information use: a multiple response item regarding the sources of information used and a single response item assessing the most important source. Item response options to both questions were determined by the interviews and a literature review and were: "The midwife", "Friends", "Family", "NHS leaflet/book", "Other leaflet/book", "Television/radio", "Internet", and "Other (please state)". Data analyses were conducted using SPSS version 17 (SPSS Inc 2008). Backward stepwise multinomial regression with maximum-likelihood ratio testing was performed to explore the relationship between information use and potential explanatory variables. Due to small cell counts, categories for some responses were combined for the regression analyses.

Variables included in the regression model were income ($\leq£28,000$ and $>£28,000$), education level (school/GCSE, college/A-level, and further education), age group (≤ 30 years and >30 years), and whether the parent was primiparous or multiparous. In addition, question responses regarding information use were included as independent variables as appropriate to assess whether the number of information sources used was associated with those deemed most important. Cases were limited to those that reported at least one source of information being used when learning about newborn

bloodspot screening. Variables were retained when they had a P value of ≤ 0.05 . Analyses were based on all cases with valid data for all variables in the model.

Results

Parent participation and characteristics of respondents

All parents who declined screening also declined to take part in the interviews. Consequently, we report interviews with 18 parents who had accepted newborn screening. Twelve interviewees were first-time parents. Interviews varied in length between 15 and 45 min.

Of the 500 parents approached to complete the questionnaire, 12 were subsequently excluded on the basis that the named individual no longer resided at that address. Of the remainder eligible for inclusion, a total of 154 questionnaires were returned giving a response rate of 32%. Of these, three were completed online, the remainder being returned by post. Table 2 shows the demographic characteristics of the questionnaire sample.

Sources of information

Interviewed parents identified a range of information sources including the healthcare professionals (midwife and health visitor), friends, family, books, official leaflets, and the internet. In the UK, maternity services are largely delivered by the midwife who has a designated role in providing written information to parents and discussing newborn screening (UK Newborn Screening Programme Centre 2008). This was reflected in parental recall of information predominantly being provided by the midwife. Information acquisition could be broadly classified as *active seeking* or *passive receiving*. For passive receivers, the number of sources discussed were minimal, and most often this was limited to being given information by a healthcare professional. Active seekers discussed multiple sources of information, although the midwife remained prominent.

The prominence of the healthcare providers was replicated with the questionnaire results. As shown in Table 3, the midwife was cited as a source of information by 93.4% of parents and official leaflets by 50%. Seven of the 11 cases where "Other" was indicated could be related to the use of other medical or healthcare expertise. Of the four remaining responses, two concerned other written materials and one referred to contact with a support agency.

Number of sources of information

The questionnaire results indicate that parents vary in how many sources of information they use. As Table 4 shows,

Table 2 Sample characteristics ($n=154$)

Item	Number	Percentage (%)
Age group (years)		
Under 21	2	1.3
21–30	48	31.2
31–40	94	61.0
41–50	10	6.5
Over 50	0	0
Number of children		
1	55	35.7
2	68	44.2
3	16	10.4
4	11	7.1
5 or more	4	2.6
Ethnicity		
White	147	95.5
Black Caribbean	1	0.6
Indian	2	1.3
Chinese	1	0.6
Other	3	1.9
Highest educational level		
School/GCSE	31	20.1
College/A-level	32	20.8
Undergraduate degree	32	20.8
Postgraduate degree	20	13.0
Professional qualification	32	20.8
Other	4	2.6
Missing data	3	1.9
Household income		
Less than £11,500	16	10.4
£11,501–18,500	20	13.0
£18,501–28,000	18	11.7
£28,001–41,000	27	17.5
£41,001–75,000	44	28.6
Over £75,000	21	13.6
Missing data	8	5.2

the majority of parents used only one or two information sources.

Table 3 Frequencies of use by information source ($n=152$)

Source	Number (%)
The midwife	142 (93.4)
NHS leaflet/book	76 (50.0)
Family	28 (18.4)
Friends	24 (15.8)
Internet	14 (9.2)
Other	11 (7.2)
Other leaflet/book	7 (4.6)

When controlling for number of children, age group, education level, and income, the most important source of information was found to be associated with the number of information sources used. Compared to those parents who used four information sources, parents who used one information source were significantly more likely to cite the midwife as the most important information source [odds ratio (OR)=26.25, 95% CI 3.8, 181.6, $P=0.001$], but not significantly more likely to select the NHS leaflet as the most important source of information (OR=2.0, 95% CI 0.2, 16.4, $P=0.518$).

Most important source

As with the most used sources of information, the midwife was generally regarded as the most important source of information. As Table 4 indicates, the midwife was overwhelmingly the most popular response with 76.2% of those parents answering this question citing the midwife as the most important source. Friends and family no longer appear, however, and were not cited by a single parent as the most important source of information.

As with the number of sources of information, multinomial logistic regression indicated that the selection of most important information source was not explained by number of children, age group, education level, or income. However, as reported above, there was a significant relationship between the number of information sources and the information source selected as most important.

Rationale for use

The interviews provided a contextualized rationale for the dominance of the healthcare professional as an information source. Parents identified both barriers and facilitators to information use, each of which served to promote the healthcare professional as the key source of information.

Constraints of time

The limited amount of free time during the post-natal period was a significant factor for parents in terms of information acquisition. A lack of time to read leaflets or other materials negatively impacted on their use whilst the midwife visit was reported to be highly useful as it provided an opportunity to gather information quickly during time that was already set aside. As one mother reported:

“...So I think, erm, if you could get your leaflets from when you’re going through your pregnancy so you have time to read, and you have time to think things through, rather than after the baby when you’re rushed off your feet, you’re tired. Reading the leaflet’s the last thing on your mind. I think that would be a good idea.” JS

Table 4 Number of sources of information used stratified by most important source of information

Most important source of information	Number of sources of information				Total
	1	2	3	4 or more	
The Midwife	47 (32.9)	43 (30.1)	14 (9.8)	5 (3.5)	109 (76.2)
NHS leaflet/book	4 (2.8)	6 (4.2)	5 (3.5)	5 (3.5)	20 (14)
Other leaflet/book	0	1 (0.7)	0	1 (0.7)	2 (1.4)
Internet	1 (0.7)	3 (2.1)	1 (0.7)	2 (1.4)	7 (4.9)
Other	0	4 (2.8)	1 (0.7)	0	5 (3.5)
Total	52 (36.4)	57 (39.9)	21 (14.7)	13 (9.1)	143 (100)

N (%) (n=143)

For others, a benefit was the ability to clarify points through discussion or gather additional information that could serve as either an end in itself or as a starting point for further investigation.

Visibility

The use of written information was contingent on its visibility to parents. This was sometimes due to the process of provision, with official material provided among other promotional literature as part of the post-natal package.

“well that's it, you get like your bounty pack and most of it is all like leaflets for come and have your photograph done here and, you know, 20% off vouchers and stuff and it just gets kind of waylaid in all that bump.” SB

When given in this way, the importance of the literature was lost. However, for those parents who read the leaflet it provided useful information, and in one case was reported to be highly influential.

Validity of information

Parents reported the difficulty in verifying information as a key reason why the internet was not used.

“I did look on the internet [...] but you don't know, especially with the internet, you don't know what you should [...] take and not take, because it could be very scary if you looked at that, you know what things, the statistics and everything. You could get quite scared if you looked on like one internet site, you know if you googled it and put it in.” NW

Hence, while there is a huge volume of information that one could gather, parents found a lack of guidance as to the relevance or quality of that information and so an uncertainty over whether the information provided could be trusted. In contrast, the midwife was seen to be a legitimate source of information. While qualifications and training were important,

the interaction was also central to this validation, as one mother explained:

“Erm, qualifications certainly, count for something, experience counts, err, but also how well somebody can explain what they've erm, explain how they've actually come to those conclusions [...]” PW

Ability was demonstrated through knowledge, itself assessed by answering questions or providing information. This was combined with personal qualities to generate trust. These personal qualities were demonstrated through the interaction with parents:

“I: And do you think, maybe, if she couldn't have answered your questions there and then it would have been a bit...”

JS: Yeah, yeah, well, it depends. I mean obviously if I would have asked her a question that's not, is something that she'd need to research, if she would have said I need to research that, then that would have been fine.” JS

This again indicates the importance of the interaction with the midwife as a way of gauging the quality or validity of the information provided.

Discussion and conclusion

Discussion

Consistent with previous studies, parents in the present study identified a range of information sources including the midwife, official NHS literature, non-NHS literature, and the internet (Tymstra 1986; Davey et al. 2005; Tluczek et al. 2009). However, the present study extends this knowledge by indicating some of the reasons for the use, or lack of use, of these information sources.

Our results indicate that, perhaps unsurprisingly, discussions with key healthcare professionals are a main source of information. These findings are replicated internationally; a

recent study in Canada found that most parents received, and thought it important to receive, education through discussions with healthcare professionals (Araia et al. 2010). Interviews indicated that the preference for the midwife as an information source was in part due to the interaction between the midwife and parent. The finding that discussions with the midwife were highly valued is in line with previous research that parents would prefer information provided orally but with additional written information, that may act as a tool for future reference (Tluczek et al. 2009; Araia et al. 2010; Davis et al. 2006). Again, our research develops our understanding of this process and suggests that one causal explanation for this stated preference is the lack of time post-natally to read and review written information. Consequently, parents reported using the midwife appointments as a way to gather information during time already set aside.

Despite the range of sources indicated, individual parents generally limited their information seeking, with over a third of parents gathering information from only one source. This again was largely centered on the midwife. This suggests that the provision of more information from a variety of sources is unlikely to be effective practice for informing many parents and facilitating informed consent. Indeed, information overload has been implicated as a cause of parental dissatisfaction with information (Parsons et al. 2007).

The interviews with parents identified information acquisition practices, which were broadly classed as active seeking or passive receiving. Passive receivers did not discuss demonstrable information avoidance or distraction behaviors but were found to accept information when this was provided to them. These practices are consistent with Wilson's model of information-seeking in which non-active modes of searching and acquisition take place (Wilson 1999; Case et al. 2005). The receipt of information from the midwife can be seen as an example of this passive searching occasioned by parental attendance at antenatal appointments and scheduled visits by the midwife. Multinomial regression of questionnaire responses supported this classification, with parents who used only one information source being 26 times more likely to cite the healthcare professional (here the midwife) as the most important source of information. This suggests that for some parents the midwife is the principal, and potentially only, source of information about newborn bloodspot screening.

Midwifery use was not limited to passive receivers of information; over 90% of parents responding to the survey cited the midwife as an information source. The failure to find significant associations between information use and age, number of children, income or education cements the importance of the midwife irrespective of parent background. However, the reasons for the differing information use remains unclear.

Recent years have seen extensive research into the development of patient information materials for newborn screening,

both in the UK and overseas (Hargreaves et al. 2004; Arnold et al. 2006). Yet despite this, only half of the parents surveyed here reported using the official NHS leaflet. The use of leaflets appeared to be contingent upon the way in which they were delivered, a finding also consistent with previous studies (Stapleton et al. 2002). Leaflets "wrapped" in other literature were noted to have reduced visibility and use. While the current guidance states that parents are to be provided with the "Screening tests for you and your baby booklet", this may be provided post-natally as long as this is prior to newborn screening. The findings from the interviews indicated that when provided post-natally, leaflets may be lost in other paperwork. Furthermore, the provision of leaflets post-natally, even if prior to the heel prick, is problematic for parents due to the constrained time they have available to review written information in this period.

Our findings indicate that context, that is the way in which the written information is provided, is as important as the content. To date, there has been little research assessing parental attitudes towards information provision, although the few studies that have considered this have found that parents would prefer information to be provided in the pre-natal period, arguing that it is easier to focus on and assimilate the content than if it were provided post-natally (Campbell and Ross 2004; Davis et al. 2006; Detmar et al. 2007). Our study sheds light on the reasons for this preference. Parents recalled that, in retrospect, early provision of information would facilitate uptake because of the increased time available and their ability to focus, which was reported not to be the case during the post-natal period. However, we have not engaged in a systematic investigation of the reasoning for use and further work to examine a priori preferences would be beneficial.

Conclusion

We suggest that parents should be provided with information in the pre-natal period in order to maximize information uptake. This should be provided, in the first instance, by the appropriate healthcare professional—here the midwife—given their prominence for both active seekers and passive receivers. Such a process, with the midwife acting as gatekeeper, would allow for an approach that would be flexible and responsive to the information needs of both active and passive parents. Further research is, however, required as to how this can be most effectively and efficiently achieved in a healthcare setting that has finite resources.

These findings should be interpreted in light of the limitations of the study. The purposeful sample of interviews, while selected to represent a mixture of geographic locations with associated socio-demographic levels, was not a random population sample. Further limitations are the small sample size for the interview phase and that fact that only parents who

accepted newborn screening were willing to take part. Research with larger samples and with parents who have declined screening would be of great value. The results, therefore, cannot be considered representative of the UK or any regional population. In addition, the retrospective sample and time frame may have introduced an element of recall bias.

The present study suggests that parents primarily receive and use information gathered through the health service when finding out about newborn bloodspot screening. Even when additional sources are used, the midwife remains a prominent source of information, although the level of importance attached does decrease with an increase in number of sources. However, for some parents the midwife appears to be both the main source of information and the only source of information. This confirms the importance of the midwife in the process of information provision within the context of newborn bloodspot screening.

The identification of two groups—active seekers and passive receivers—suggests that a “one-size-fits-all” method does not work, with some parents drawing heavily on the midwife while others actively sought information from a variety of sources. However, the lack of a clear association between the number of information sources used and participant demographics may point to a difficulty in applying standardized processes based on parent characteristics. This may point to a further important role for the midwife to act as a gatekeeper to facilitate information acquisition based not only on standards but also on patient preferences. Although the development of written information has been the focus of research, the findings here suggest that the use of these materials is, at least in part, dependent upon how they are provided. This points to the way materials are delivered as being important to their use.

Statement

I confirm all patient/personal identifiers have been removed or disguised so the patient/person[s] described are not identifiable and cannot be identified through the details of the story.

Acknowledgments The authors would like to thank Mrs. Elaine Hanmer at Alder Hey Children’s NHS Foundation Trust, Mrs. Liz Eccleston at East Cheshire NHS Trust as well as the NCT and Sure Start branches for their assistance with recruitment. Thanks also to all the parents who took part, those involved in the development of the questionnaire, including representatives of Save Babies Through Screening Foundation UK, Dr. Mairi Levitt at Lancaster University for her comments and support and to Mrs. Dawn Fox-Davies and Dr. Ingrid Holme for their constructive comments on earlier drafts of this article.

Competing interests None declared.

Funding Dr. S.G. Nicholls was funded by an Economic and Social Research Council (ESRC) Postgraduate Studentship PTA-031-2006-00013.

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