

Acceptability and feasibility of collecting psychosocial data from fathers of very low birth weight infants

Short title: Fathers of very low birth weight infants

Abstract

The aim of this study was to determine the feasibility and acceptability of collecting outcome data from parents of very low birth weight infants, and to explore the psychological and social adaptation of fathers. Questionnaires were distributed to 38 parents of very low birth weight infants and 36 parents of term infants within a hospital Neonatal Intensive Care Unit. Field notes were also taken. Parents indicated collecting outcome data in this population was feasible and acceptable, but barriers and difficulties in data collection were identified, particularly for fathers. Furthermore, parents highlighted a lack of emotional support for fathers. In conclusion, research with parents of very low birth weight infants should happen with consultation, flexibility, and measures designed specifically for this population.

Key words:

Father, neonatal, parents, recruitment, support

Introduction

Recent medical advances mean more very low birth weight infants (VLBW; <1500 g) survive, needing medical and family investment (Horbar et al., 2002). Evidence suggests heightened psychological distress in parents of VLBW infants (Wraight et al., 2015), with an associated risk to their children's social-emotional development at 2 years (Treyvaud et al., 2010).

Most research on these families has focused on maternal experiences, stress and anxiety (Zelkowitz et al., 2007; Ahlund et al., 2009). Less is known about paternal experience and adaptation following the birth of a VLBW infant, or how this influences infant development and family functioning (Huhtala et al., 2011; Treyvaud, 2014). The 2009 UK National Health Service (NHS) Toolkit for High Quality Neonatal Services (Department of Health, 2009) recommends adopting a family-centred approach, but implementing this is challenging (Poppy Steering Group, 2009; Alam et al., 2010) and may not be sufficiently sensitive to the specific needs of fathers (Barlow et al., 2010). As evidence on fathers as 'risks' and 'assets' grows (Lamb, 2010) it is timely to investigate the experiences, psychological and support needs of fathers of VLBW infants (Huhtala et al., 2011).

The present study builds on the POPPY Project (Poppy Steering Group, 2009) which focused on interventions for parents of VLBW infants and which

identified a lack of support for fathers. Our exploratory study aimed to investigate, in comparison to parents of term infants admitted to the Neonatal Intensive Care Unit (NICU): the (i) feasibility and (ii) acceptability of collecting psychological outcome data from father and mother couples of VLBW infants, and (iii) the psychological and social adaptation of fathers to the birth of a VLBW infant.

Method

Development of protocol

It was a key aim of the study to assess whether parents of VLBW infants admitted to NICU would find participation in studies collecting social and psychological outcome data acceptable and feasible in order to inform research intending to investigate the as yet unknown stresses and particular needs in this group. We collected data from parents of hospitalized term and VLBW infants in an attempt to hold the NICU hospital experience as constant as possible (because even brief NICU admissions can create parental stress). We wanted to approach parents in the first days/weeks following admission to better understand the needs of fathers during this acute phase. Throughout the design of the study we drew on information from previous literature, ethics committee

feedback, and a parent steering group member in order to inform our decisions, and they suggested our protocol was acceptable.

Participants and study outline

The study was conducted in an East of England university hospital regional level 3 NICU. Permission was obtained from the National Research Ethics Service (NRES) Committee (now known as the Health Research Authority). (Ref. 13/EE/0036). Based on previous research (Ahlund et al., 2009), we estimated 60% of eligible parents would consent to participate and aimed to recruit 15-20 parent couples for each group. Parents of infants who died were not excluded. Our target sample of parents of recently born VLBW (<1500g) infants in NICU comprised 17 parent couples, 3 mothers, and 1 father (n = 38). Our comparison sample of parents of term infants (>37 weeks gestation) in NICU comprised 16 parent couples, 2 mothers, and 2 fathers (n = 36) (total n = 74).

Recruitment took place between May 2013 and October 2014. Eligible participants were identified from admission records. Parents were recruited based on their accessibility and availability, with input from nursing staff. Parents of VLBW babies were approached within the first days/weeks after the baby's admission to the NICU (when the baby was deemed stable by nursing staff), and given an information sheet. The researcher returned within a few

days, and following written consent, gave parents a questionnaire pack. Participants completed 4 (mothers) or 5 (fathers) validated instruments, an acceptability questionnaire, and demographic information. Participants were informed that completion of questionnaires was expected to take approximately 45 minutes.

Measures

Feasibility of protocol was assessed by rates of compliance with study procedures. Numbers of eligible parents who were approached, consented, returned questionnaire packs, and agreed to be contacted for follow-up were recorded.

Acceptability of protocol was assessed through a 6 question quantitative measure used in previous studies by the authors (e.g. "I feel that those in a similar position to me would not have a problem completing the questionnaires"). Responses were recorded on a scale from 1 (strongly disagree) to 5 (strongly agree). Average scores over 3 (neutral) were assessed as indicating 'acceptability'. The reliability of this measure was good (Cronbach's alpha = .85).

Parental attachment to infant was assessed by the paternal (Condon et al., 2008) and maternal (Condon and Corkindale, 1998) versions of the

Postnatal Attachment Scale, which has been used in similar recent research (Provenzi, Furnagalli, Bernasconi, Sirgioranni, Morandi, Borgatti & Maritrosso, 2016). Two time-related phrases were removed from this questionnaire, but meaning was retained.

Quality of care to partner was assessed by the composite 'responsive caregiving' score (Feeney, 1996) on the 32-item Couple Care-giving Questionnaire (Kunce and Shaver, 1994). The measure has been used previously with parents of pre-term and term infants (Taubman-Ben-Ari & Spielman, 2014)

Response to trauma was assessed by the 14 item Impact of Event Scale–Revised (IES-R, (Weiss and Marmar, 1997)), which has been used with mothers of VLBW infants (Ahlund et al., 2009).

Depressive symptoms were measured using the 20 item Centre for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977), previously validated for use with mothers of premature infants (Miles et al., 2007).

Father work-family conflict was assessed in fathers using the 18-item Work-Family Conflict scale (Carlson et al., 2000).

Each questionnaire had a space for participants' written comments on feasibility and acceptability. Detailed field notes were kept.

Data Analyses

Quantitative data was analysed using Statistical Package for the Social Sciences (SPSS) version 22. Illustrative comments from parent questionnaires were selected, alongside observations from the researcher field notes.

Results

Table 1 shows the two groups were comparable in age, ethnicity and level of education. There is limited ethnic diversity, typical of the study's geographical location.

[INSERT TABLE 1 HERE]

1: Feasibility of collecting psychological outcome data.

Figure 1 shows that just under the estimated 60% of parents consented to take part in the research. Over half the parents who consented completed and returned the questionnaires. Some responses are indicated in figure 1 as partial responses, which indicates there were 2 or more items missing on a questionnaire. These were still included in the data analysis where possible.

[INSERT FIGURE 1 HERE]

Field notes indicate that it was easier to access term parents than VLBW parents, especially when recruiting fathers. Often, mothers of term infants were inpatients, and proximity to the time of birth meant both parents were accessible. Recruitment of VLBW parents was more challenging. Mothers were often no longer in-patients, instead visiting daily. Fathers' paternity leave had often finished before the infant's discharge. Fewer VLBW than term infants were admitted to NICU, although the former generally had longer admissions.

2: Acceptability of completing psychological outcome measures

Acceptability questionnaire scores indicate that parents of both VLBW and term infants were happy to participate in the research, and found questionnaire completion relatively easy. Parents also indicated follow-up questionnaires would be acceptable. Acceptability questionnaire scores for VLBW fathers (*median = 4*), did not differ significantly from term fathers (*median = 3.5*), $U = 94$, $z = -1.747$, $p = .085$, $r = 0.3$ (see also table 2). Acceptability questionnaire scores for VLBW mothers (*median = 4*), did not differ significantly from term mothers (*median = 3.5*), $U = .151$, $z = -.583$, $p = .560$, $r = 0.09$.

Sixteen participants (21%) offered comments on the acceptability of completing the questionnaires. Two parents said that they were glad to 'give

something back': "*the least I could give back was filling in a questionnaire*" (term mother). Four parents queried whether some questions were relevant for parents of babies in NICU. Although standardised questionnaires were used, some questions were perhaps not directly applicable for this population. Some comments provided insight into the rapid evolution of parental perspectives and emotions with time from birth. One father stated that he felt "*some of the questions would be more appropriate a few weeks down the line.*" Another parent commented: "*it would be productive to ask patients to fill in a study questionnaire first post birth and [then again] after discharge from hospital as my feelings have changed greatly*" (term mother). Parent sometimes criticised questionnaire structure, for example, changing anchors, and "*too many identical questions*" (VLBW father). Time was also an issue: "*I wasn't expecting it to take so long... once I got into it I was fine*" (term father).

Some parents declined to take part in the study. From the researchers' perspective, parents' attitudes and willingness to participate did not seem to differ between groups. Reasons for declining participation included physical barriers (e.g. having limited sight), imminent discharge, and family or partner disputes. One VLBW couple who initially consented returned blank questionnaires stating that the questions were too intrusive.

3: *Psychological and social adaptation of fathers*

Although the study was not powered to explore quantitative differences between groups, in order to guide future study design we conducted exploratory non-parametric analyses. We found no significant group differences between fathers of VLBW and term infants on a number of factors: caregiving to partner, PTSD and depressive symptoms, attachment to baby and work-family conflict (see table 2).

[INSERT TABLE 2 HERE]

The need to explore the social and psychological adaptation of fathers was apparent from the qualitative comments provided. Lack of emotional support for fathers was highlighted by fathers and mothers: *“I think at times I have missed some emotional support, this may exist but it’s not mentioned to fathers” (VLBW father); “I don’t think there is enough support for dads particularly as they... have limited time at the hospital” (VLBW mother)*. Lack of male peer support was mentioned by fathers: *“generally men don’t talk to men about baby things, male friends feel awkward about talking about it” (VLBW father)*, and mothers: *“he did not have support from other parents as limited time to interact and women chat to each other” (VLBW mother)*. Some fathers of

VLBW infants commented that they were not included in discussions about the infant; *“I think hospital staff should direct their comments to both parents, not just the mother”*. Interestingly, most fathers did not mention the mother as a source of support to them, whilst mothers did see fathers as a source of support: *“I would have to identify my partner as my main source of support whilst our daughter [a VLBW baby] has been in NICU”*.

Discussion

This exploratory study demonstrates that it is feasible and acceptable to collect quantitative and written qualitative data from mothers and fathers of VLBW infants in NICU within the first days/weeks following admission. Our data show parents of VLBW infants are at least as likely as parents of term infants to consent to participate in this type of research. Our data highlight a number of strategies proposed as best practice during future research with this particular population. Field notes indicate that for our population, access to parents of term infants was easier than for parents of VLBW infants, especially when recruiting fathers. Challenges in recruiting parents of VLBW infants was often due to difficulties in locating parents, with mothers visiting in the afternoons, and fathers in the evenings. Other research also reports that mothers visit more frequently and for longer than fathers (Franck and Spencer, 2003). We

attempted to overcome this by recruiting at different times in the day, and giving mothers information sheets and consent forms to pass to fathers. However, face-to-face contact with fathers was largely based on being in the right place at the right time. The investment of researcher time should not be underestimated, and dedicated and flexible researcher working hours are crucial.

Overall, parents of both VLBW and term infants were happy to participate in the research and found questionnaire completion relatively easy, but qualitative feedback suggests some difficulties with specific questionnaire components. Generally, questionnaires are designed to minimise response bias, but these parents are already cognitively and affectively loaded. Therefore, in future studies, questionnaires should be tested with a small number of target population parents for suitability. Some VLBW infant parents said their feelings were likely to change over time. Previous research suggests that after the birth, psychological distress in this population can last longer than in the more general population (Saigal and Doyle, 2008; Rowlands and Redshaw, 2012). Future research should consider that a longitudinal approach may better reflect social and psychological adaptation to the birth of a VLBW infant.

Family-centred care and emotional and practical support for families is recommended for this population (Department of Health, 2009; Duley et al.,

2014), but historically, the inclusion of fathers in this research has been lacking (Wraight et al., 2015). Our qualitative insights clearly demonstrate that fathers and mothers believe support sensitive to the needs of fathers is required. Our study shows the value of qualitative and quantitative methodologies in capturing the experiences of this hard to reach and relatively poorly studied group in order to improve the literature base, determine appropriate support strategies, and improve outcomes.

Conclusion

This study focused on the acceptability and feasibility of collecting quantitative data from parents of VLBW and term infants in a hospital setting, as couples and individuals, through a questionnaire method. Parents seemed willing to engage in this type of study, even though their infants were sometimes in a critical condition. Although there are inevitable barriers and difficulties in collecting this type of data from this population, particularly in accessing fathers, these are not insurmountable. Qualitative data supports further exploration of the psychological and social adaptation of fathers to the birth of a VLBW infant. Research of this type should be carried out with a significant amount of prior parental consultation. Three key elements which would promote collecting quantitative data from both mothers and fathers of VLBW infants are: 1) flexible

researcher working hours and dedicated researcher time for active recruitment; 2) a shorter and simpler questionnaire pack; 3) questionnaires designed or adapted specifically with the experiences of parents with VLBW infants in mind.

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Figure 1

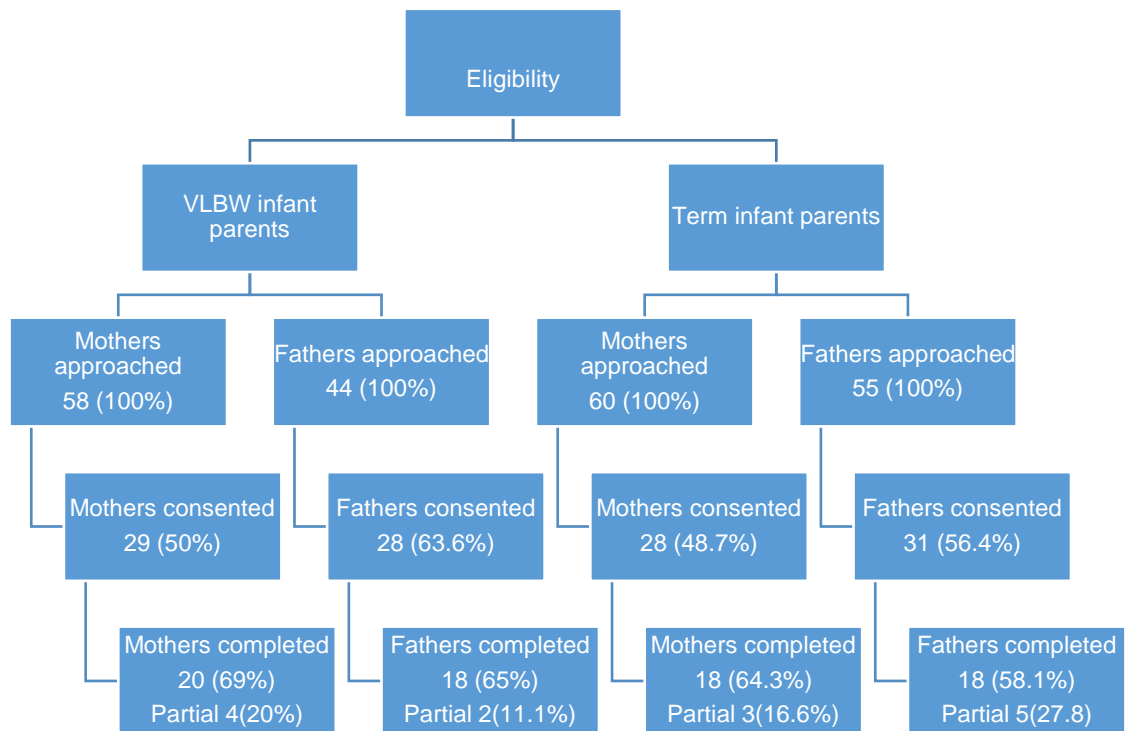


Table 1: Comparison of demographic variables between groups

Not all parents answered each question, so totals do not always equal 100%

	VLBW Fathers	VLBW Mothers	Term Fathers	Term Mothers
Age				
Median (range)	35.5 (23-55)	32 (24-41)	31 (23-37)	31 (25-47)
Other children				
Yes	55.6%	55.0%	16.7%	27.8%
No	38.9%	35.0%	83.3%	72.2%
Ethnicity				
White British	94.4%	85%	94.4%	88.9%
Indian	5.6%	5%	0%	0%
White & Asian	0%	0%	5.6%	0%
White & Black	0%	5%	0%	0%
Caribbean	0%	5%	0%	0%
Other mixed Black	0%	0%	0%	11.1%
Educational status				
No university education	72.3%	65%	77.8%	61.2%
University education	27.8%	35%	22.2%	38.9%

Measure	α	VLBW			Term			n	U	p	Z	r
		Mdn	Rge	MR	Mdn	Rge	MR					
CQ Responsive caregiving	.791	4.50	12.28	17.24	4.63	12.28	17.76	34	140	.892	-.155	-.03
IES Total	.859	28	43	17.47	25	41	15.65	32	113	.602	-.548	-.10
CSED	.903	9	41	9	12	38	12	27	86.5	.867	-.171	-.03
Work-family conflict scale	.561	64	52	16.24	59	68	14.46	30	97	.592	-.565	-.10
Paternal Attachment Scale Total	.809	81.65	30.9	15.71	82.8	22.3	16.24	31	115	.874	-.159	-.03
Acceptability Questionnaire	.850	4	2.83	20.47	3.5	2.17	14.53	34	94	.085	-1.747	-.30

Table 2: Descriptive statistics and comparisons between groups on psychosocial adaptation measures for fathers of VLBW and Term infants.

α = Cronbach's alpha score; Mdn = Median; Rge = Range; MR = Mean Rank; n = number of participants; U = Mann-Whitney U test; p = p value for Mann-Whitney U-test, that compared between group differences on various measures; r = effect size.

Note: CQ = Care-giving Questionnaire, IES = Impact of Event Scale, CESD = Centre for Epidemiologic Studies Depression scale, WFCS = Work-Family Conflict Scale, PAS = Paternal Attachment Scale.