

Project plan

1. Objectives

1. Explore the experiences of affected parents in terms of their response to the diagnosis and the remaining time they have with the child. The focus is on the perception of the support offered in relation to the necessary decision-making processes, the death of the child and coping within the family.

2. To capture the experiences of participating health and social care and other professionals in relation to their perceived impact. These should, when possible, show typical approaches, strategies and resources, which are used in such cases.

3. To identify professional development opportunities which participating professionals could use to help affected families to come to terms with their loss. Interfaces between the professional groups will also be identified to see how best to optimise continuity of care.

2. Research design, theoretical framework, methods and data

Original plan with key issues highlighted.

A qualitative design was selected as the most appropriate to achieve the above objectives.

Sample

A purposive sampling method has been selected as fitting for this study and in keeping with the chosen design. Participants will comprise at least 30 parents (20 mothers and 10 fathers) and 30 health professionals. The actual sample size required, however, is

oriented to the principle of conceptual saturation which means that as long as new data is generated recruitment will continue.

Inclusion criteria for participating parents are a lethal foetal diagnosis in the last five years resulting in spontaneous death of the child during the pregnancy or shortly after birth, or through pregnancy termination. Inclusion criteria for health professionals are professional involvement in information, counselling, care and support of parents and children affected in a professional capacity. In addition, all interviewees should have sufficient command of the German language. The aim is to involve as many experts and occupational groups who are involved during the phase of family planning, pregnancy, birth, puerperium and, if applicable, during palliative care and (therapeutic) after-care as possible. This broad spectrum aims to record any continuity in counselling and its effects over the whole period of possible care.

Recruitment

Parents affected and health professionals will predominantly be accessed via the networks "Fachstelle Fehlgeburt und perinataler Kindstod" and "Dialog Ethik" as well as self-help groups with a public profile. Additional sources of recruitment will be counselling centres or hospitals will be approached through the relevant managers. If contact is made via counselling centres or hospitals, the consent required from the relevant ethics commission will be obtained. A further possibility is that affected parents may hear of this study coincidentally and want to speak of their experiences thus providing a further source for recruitment (Murphy, 2010: 73).

Data collection and analysis

Data will be collected by means of semi-structured interviews. Interviewers will be both men and women who have been specially trained in interviewing vulnerable people and in particular to recognise signs of trauma or unresolved grief. On recognition of any such distress the interviews will be paused or stopped completely. Contact details of an external counsellor will be provided should this be necessary.

For parents who participate these will be based on a problem-centred approach (Witzel, 2000) with men and women being interviewed separately so that each individual voice may be heard. This method offers the openness of narrative interviews whilst at the same time enabling a focus on questions that lead to new knowledge. Health professionals will be questioned using the process of expert interviews (Bogner et al 2005). Interview guidelines, developed especially for this project will be used as an aide memoire.

All interviews will be digitally recorded and transcribed verbatim. As is customary with qualitative research data will be collected and analysed in parallel. This will enable the research questions to be further developed and expanded as required. **The process of qualitative content analysis (Mayring, 2008) will be used to analyse the texts.** In this key terms will be generated from which the major categories will be developed.

Quality criteria

The criteria for evaluating the rigour of this study will be those of Lincoln and Guba (1985).

3. Changes regarding original research design

Recruitment and sample

Recruitment was initially carried out via Fachstelle Fehlgeburt und perinataler Kindstod. Dialog Ethik did not respond to emails so was not pursued. One health professional recruited in this manner was able to recruit more affected parents. When target numbers were not being reached, hospital management at the University Hospital Zürich agreed to recruit further participants. While not a change from the original proposal we had not envisaged such a great need for this originally. One mother made contact spontaneously after hearing about the project from a friend.

Twenty nine mothers and nine fathers were recruited initially. It was not possible to interview one of the fathers as he did not speak German. Four mothers also declined

after further explanation. Thirty one health professionals were also recruited, of whom one was not able to find a suitable appointment and another felt that she did not have sufficient experience to justify inclusion.

Data collection and analysis

Data collection took place as planned. Due to several personnel changes, however, detailed data analysis took place on completion of all data collection rather than concurrently. The process for thematic analysis of Braun and Clark (2006) was felt to be more appropriated for the analysis of the qualitative data than the content analysis of Mayring (2008) as it allowed for a deeper analysis of the themes as they emerged.

Quality criteria

These remained unchanged and all of Lincoln and Guba's criteria have been adhered to.

4. Results

Two articles are enclosed. Please refer appendices 1 & 2. Article one, which summarises the whole project's findings, has been submitted to the journal "Birth: issues in perinatal care" as this journal is aimed at a readership from a wide range of health professionals and the results were found to be appropriate for publication there. The second article, focusing on the views of health professions has been submitted to "Les Dossiers de Maïeutique" a peer reviewed journal aimed at midwives. A third article, focusing on the views of parents is also drafted and will be submitted to "Das Gesundheitswesen". Through these articles we hope to reach a wide readership but at least two further articles are planned. The first is for "Qualitative Health Research" and the generous word limit of this journal will allow a more in-depth exploration of the gaps between parent's' and health professionals' views. The second is for "Midwifery" and will focus on the intrapartum care aspect of the study and will be co-authored by our colleagues from Unispital Zürich who contributed to recruitment in that centre.

Summary of the main findings

Background

The disclosure of a diagnosis during pregnancy of a foetal congenital malformation incompatible with life normally comes completely unexpectedly to the parents. Instead of looking forward to the forthcoming child they are immediately confronted with the child's mortality and their own helplessness. While a considerable body of international literature has considered the topic from both parents' and professionals' perspectives, there is little direct evidence generated in Switzerland.

Objectives

This study aimed to illuminate contemporary treatment associated with a diagnosis in the antenatal period indicating an incompatibility with life for the unborn child and the subsequent death of the child regardless of whether parents make the decision to terminate or continue the pregnancy. Specific objectives were to explore the experiences of affected parents in terms of their response to the diagnosis and the remaining time they have with the child; capture the experiences of participating health and social care and other professionals in relation to their perceived impact; identify professional development opportunities which participating professionals could use to help affected families to come to terms with their loss.

Method

A qualitative design was used with data being collected by semi structured interviews lasting from 40 minutes to 1.5 hours.

Participants

Twenty nine health professionals; three nurses, one social worker, two psychologists, 15 midwives, five gynaecologists, two spiritual advisers and one funeral director were interviewed. Likewise 32 affected parents were interviewed, with 17 mothers, one

father and seven couples who had experienced a lethal foetal diagnosis in the previous five years participating. Twelve terminated their pregnancies, ten continued with the remaining three being unreported.

Analysis

Interviews were transcribed verbatim using the programme F4 with initial analysis undertaken using the MAXQDA software package. Data were analysed by the entire team using thematic analysis (Braun & Clarke, 2006).

Results

The theme of “temporality” dominated the results with four main time points: diagnosis, decision, birth/death and afterwards identified by the professionals. Underpinning this were six major themes generated from parents which extended across the span from receiving the diagnosis until the interview: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, letting go. While there was concurrence on many aspects of care at the point of contact, the parents had major issues which were expressed in three gaps between the point of contact and were not addressed.

Discussion

The various time points identified by the professionals were seen as key markers in each woman's journey. Participants acknowledged that it was good for women to have the experience behind them but that there was no need for hasty decisions to be made after the diagnosis. The themes identified arose both from parents and health professionals participating in the study. The time points identified from the professionals were given different emphases with obstetricians mainly being involved at the time of diagnosis while midwives' practice embraced the birth/death. However, data from parents showed gaps between these periods which were not articulated by the professionals. The periods between the diagnosis and the decision, from the decision until the birth/death and beyond the birth, reflect critical points for the care of the participants.

Such gaps between professionals' and patients' views of situations are not uncommon. Diagnoses reflecting situations incompatible with life are often not made until approximately the 20th week of pregnancy. The perceived pressure reported by the parents to make a decision were based on discussions they had with their doctors around the time of diagnosis.

The period between the decision and the birth/death, while experienced by all participants regardless of their decision, was short but intensive for those who opted for abortion as appointments were always made quickly. For participants who continued their pregnancies, this gap was longer and resulted in some positive consequences giving the women more time to experience pregnancy, participate in classes and form relationships with their babies. However, what alternative resources such as counselling that they could access was very dependent on the insurance cover that they had with some packages not covering maternity leave before 22 weeks of pregnancy.

Midwives came more into contact with women either when they presented at the labour ward for an abortion or in labour. Midwives were able to provide unbiased care for women in both instances. This was a time when health professionals' and parents' views converged. Whatever option the participants had chosen was respected by hospital staff and empathetic care offered with a range of support services provided by the hospitals. Hospital staff offered help with the formalities surrounding burial or cremation and provided opportunities for return consultations with genetic counsellors or other appropriate staff. One hospital provided postnatal care following discharge by midwives specialised in neonatal death.

Conclusions

Care varied according to region but was as sensitive as possible, attempting to give parents space to accept their loss but fulfilling all the legal requirements. A gap exists between diagnosis and decision with participants feeling pressured to make decisions regarding continuing or terminating their pregnancy although health professionals' testimony indicated otherwise. A major gap manifested following the decision with no palliative care packages offered. During the birth/death of the baby, care was sensitive

and appropriate but another gap manifested following discharge from hospital, depending on insurance cover.

5. Recommendations for policy makers and experts from the practical realm

Recommendation 1

All women on receiving a diagnosis that their unborn children are incompatible with life be given an appointment within 24-48 hours to discuss next steps and possible options. Ideally this should be with an independent person such as a health advocate.

Rationale

As shown in the preceding section and in the articles, a gap exists between parents' views and those of health professionals between the diagnosis and decision. While of short duration, many parents felt unsupported at this time. This arose not because of any shortcomings of individual health care providers but rather because of fragmentation of the health care system. Health advocates have been widely utilised in countries such as New Zealand for over 20 years and were not employed by each hospital but by a centralised agency. Initially their focus was on women's health areas where unnecessary procedures were carried out but gradually this extended to cover situations such as those resulting from this study.

Recommendation 2

A multidisciplinary group, including the proposed advocate, discusses the case of each woman prior to a care package being offered.

Rationale

This builds on recommendation one and other than the position of an advocate, which does not exist, is taken directly from the data where various health professionals in one facility spoke of such a strategy. We see this as an example of good practice which could be replicated in other facilities. The potential barriers are the differing sizes and compositions of each facility and we recognise that it may not be possible in some of the smaller facilities.

Recommendation 3

Individual care packages are put in place for each woman regardless of her choice of whether to terminate or continue with the pregnancy.

Rationale

At first this seems to embrace what is currently in place. Women have choices to a great extent on where they choose to give birth, even in situations like this. However, what has emerged from the data from parents is the need for a seamless service where issues such as maternity leave and ongoing care following discharge from the hospital are put into place. This would require a considerable amount of discussion and negotiation with insurance companies.

Recommendation 4

National guidelines are developed for professionals by a multi-disciplinary group so that women can be given full information about further care, maternity leave provisions, laws and options for burial of the baby and follow up care to include planning for the future.

Rationale

This comes primarily from the data from parents but as discussed in recommendation 2 above, from some health professionals. As with recommendation 3 it would involve considerable negotiation but it may form the basis of future care packages and it would be essential to include all interested parties under the direction of a neutral person.

Recommendation 5

A palliative care programme for women who choose to continue their pregnancies is implemented and evaluated.

Rationale

This comes directly from the parents' data. It is also well supported by literature particularly from the United States. There are many models of palliative care programmes but if recommendation 4 were taken up by the necessary policy makers its development could be included within the remit of that group. An action research project deriving from a group of parents and health professionals would also be a potential way forward in this instance.

6. Contribution to key questions (only if required by the steering committee)

Not required

7. Implementation activities

Please see mysnf . A paper has been accepted for presentation in England at the biennial Normal Birth conference in June 2015. This conference is usually attended by approximately 1000 midwives, nurses and medical practitioners.

8. Information to the Steering committee

none

9. Comments

none

10. Annexes

1 & 2 Publications submitted

3 Lay summary