Support at the most difficult of times

With a background in midwifery, Professor Dr Valerie Fleming explains how she came to develop an interest in medical ethics and foetal malformations, and provides an insight into her current research project.

How did you first become interested in the subject of foetal malformations?

I have been a midwife for 35 years, qualifying in Aberdeen at a time when medical research there was widely developed but midwives were not encouraged to be partners in this. At the time there was a huge emphasis on ‘social medicine’, and mid-trimester abortions were being carried out. Despite the conscience clause in the UK’s Abortion Act, we were somehow expected to care for these women without knowing anything of their history.

I then moved to New Zealand and initially worked in a huge research centre. In 1988 a major scandal hit it, leading to a national enquiry. This prompted my interest in ethical research and it’s really escalated from there. I completed my Master’s in Nursing Ethics and a PhD focused on women’s choice of carers. I didn’t really get the chance to return to the topic of foetal malformations until the Swiss National Science Foundation (SNSF) launched a special programme on ‘death and dying’. I applied and was successful in obtaining funding.

When dealing with a delicate situation such as foetal malformation, are ethical issues such as confidentiality and informed consent a priority?

It is vitally important in any research to address these issues. I get really cross when I see internet surveys that are, for example, seeking the views of affected people about delicate issues and they haven’t even been scrutinised by an ethics committee. However, having said this, sometimes ethics committees are more about bureaucracy than ensuring research is ethically carried out.

Of course, we obtained permission from the Cantonal Ethics Committee of Zürich when conducting this study, but more important was the information we gave to participants, the fact that we had counselling available should they need this and the reiteration of their rights before interviews. I did not personally conduct interviews with the affected participants, though I did with the professionals. This was because I speak High German but not Swiss German and I felt if someone was upset in recalling an experience it would be unethical for me to say, “Hoch Deutsch, bitte” [High German, please].

What has been your key finding in terms of best practices for supporting parents whose unborn baby has a congenital malformation that makes it incompatible with life?

All parents in such situations need good support, but there is no overall support service at present. Some parents have lots of support; others have none. It is vital that parents do not rush into making decisions. At the same time, a balance needs to be struck so that they know where to go for unbiased support and answers to their questions. This is an area that is ripe for development.

Similarly, when women are discharged from hospital, there needs to be follow-up care – something about which they automatically think. The care that women receive around the time of birth/death is, however, excellent and needs to be commended.

How do you predict scientific understanding and practices in midwifery will develop in the coming years?

Midwifery still needs to carve out a niche. My personal belief is that we need to go back to basics and start with what women expect/want. So much research has been conducted – and still is being conducted – where scales to measure important things such as outcomes have just been developed from a researcher’s mind rather than stripping it back.

In what ways do you expect your project to impact the field?

It’s really quite a pioneering piece of work. However, we have to remember that in the First World it only affects a very small proportion of all women. We need to be mindful of doing really high-quality work so that it leads to other relevant studies. I have recently heard of two investigations with huge budgets that are absolutely meaningless because of either poor science or their irrelevance to the world in which we live. Our current work on giving birth has adopted the ‘back to basics’ principle, and will hopefully lead to further projects, as well as the application of results in clinical practice.
Determining how best to help parents

At the Zurich University of Applied Sciences, efforts are underway to elucidate the experiences of parents and health professionals after an unborn child is diagnosed with a congenital malformation that makes it incompatible with life.

WHEN PARENTS DISCOVER that their unborn child has a congenital malformation that makes it incompatible with life, they are tasked with the difficult decision of whether to terminate or continue with the pregnancy. Regardless of the parents’ choice, the course of events that follows diagnosis is likely to be an extremely traumatic experience that can have long-term psychological and emotional consequences.

Health professionals who come into contact with such parents can play a key role in alleviating their distress through the provision of empathetic and ethical care that actively involves parents and engages them in clear and open dialogue. However, a Swiss team has found that analysis of the experiences of parents and health professionals in these traumatic situations has received relatively little attention in the literature. Additionally, there are no definitive guidelines for health professionals to help them support parents during this difficult time, meaning that levels of support can vary greatly.

PARENT AND PROFESSIONAL PERSPECTIVES

It was this dearth of data that motivated Professor Dr Valerie Fleming of the Zurich University of Applied Sciences (ZHAW) to initiate the ‘Dying at life’s beginning: experiences of parents and health professionals in Switzerland’ project. The overarching aim of the study was to illuminate contemporary treatment practices across the German-speaking part of Switzerland.

Specifically, its objectives were to explore the experiences of affected parents in terms of their response to the diagnosis and the remaining time they had with their child; to capture the experiences of participating health professionals in relation to their perceived impact; and to identify professional development opportunities that health professionals might use in order to offer better help to affected families. In order to accomplish these goals, Fleming and her collaborators employed a qualitative research design in which...
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DYING AT LIFE’S BEGINNING

OBJECTIVES
- To explore the experiences of parents in terms of their response to the diagnosis of incompatibility with life for the unborn child and the remaining time they have with the child
- To capture the experiences of participating health, social care and other professionals in relation to their perceived impact

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PROFESSOR DR VALERIE FLEMING
has been a midwife for 35 years. She has shared women’s experiences of childbirth in Europe, New Zealand, India, Central Asia and several African countries. Fleming gained her PhD in New Zealand in 1994 and thereafter has undertaken research internationally in clinical and educational issues. She has also led several developmental projects, notably in the Middle East and Kosovo.

affected parents and health professionals were interviewed following a semi-structured, problem-centred format.

In total, 61 interviews were held with affected parents, who comprised seven couples, 12 mothers and one father. Given the distressing nature of the topic, a number of initiatives were put in place to ensure the study was ethical; for example, all of the interviewers were specially trained in interviewing vulnerable people and recognising signs of trauma or unresolved grief, were instructed to pause or stop the interview if the participants became distressed, and provided contact details for an external counsellor when appropriate.

In addition to this, 29 health professionals were interviewed about their experiences. These included three nurses, one social worker, two psychologists, 15 midwives, five gynaecologists, two spiritual advisors and one funeral director.

GAPS IN CARE

After the interviews had been transcribed, Fleming and her team initiated a thematic analysis. The researchers discovered that temporality was the major overarching theme, and this was underpinned by six additional themes: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, and moving on. It was also found that while health professionals identified four critical points of care across the process – diagnosis, decision, birth/death and afterwards – there were gaps between these time points that parents articulated as important.

The first gap was identified as falling in between diagnosis and decision making. At this point, parents frequently reported feeling pressured to make the decision quickly either to terminate or continue the pregnancy, whereas health professionals did not speak of an urgent need to make this difficult decision. Instead they all spoke of the need for parents to take their time in making the decision and ensuring that they had the necessary support structures in place.

A second gap was identified as occurring in the period between decision and birth/death. Among parents who decided to terminate their pregnancy, this timeframe was generally short and intense, with abortion appointments often being scheduled extremely rapidly. Conversely, for parents who chose to continue a pregnancy, this time period was usually longer and associated with several positive outcomes, such as giving them more time to form a relationship with their baby, come to terms with their forthcoming loss and value their remaining time.

Additionally, while the majority of parents reported that the care they received during and after the birth/death was empathetic, respectful and helpful, several elements of follow-up care were identified as showing potential for improvement. For example, the Swiss healthcare system requires a new mother to arrange immediate postnatal care herself – something that several participants did not actively seek. It was also discovered that the counselling and support services available to parents were largely dependent on their insurance coverage. Many parents had understandable fears about entering into a subsequent pregnancy that could be assuaged by appropriate information and advice from health professionals.

IMPROVING EXPERIENCES

Now that the project is complete, Fleming is hopeful that the findings will translate into clinical benefits. To this end, the researchers have put forward five recommendations for policy makers and experts in this field. Proposals include: that all parents, upon receiving a diagnosis that their unborn child is incompatible with life, be given an appointment within 24-48 hours to discuss next steps and possible options with a neutral expert; that a multidisciplinary group discusses each case prior to a care package being offered; that individual care packages are put in place for each parent regardless of their decision to terminate or continue with a pregnancy; that in-depth national guidelines are developed for health professionals; and that a palliative care programme for parents continuing a pregnancy be implemented and evaluated.

In addition to changing the way health professionals work with parents in such situations, it is likely that by contributing to the literature this project will lead to the generation of further data in this understudied but important area. While a diagnosis of a congenital malformation incompatible with life and all that follows will always be a tragic and life-altering event, any steps that can be taken to alleviate the suffering of affected families will be of significant and lasting benefit.