When my world just crashed: the care experience of parents during their child’s diagnosis of spina bifida

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Background
Breaking bad news well is a key clinical skill that aids delivery of professional and person-centred care. In the context of prenatal diagnosis, the literature describes the impact on parents with a myriad of terms, including ‘Emotional Confusion’ and ‘Emotional Grief’. However, Freshwater (2004) argues that the wider population does not have the broad or rich emotional vocabulary to be able to name emotions. Yet, naming the emotion can bring the individual closer to the affective element of it and support the needed healing process. Using Emotional Touch Points offers an opportunity to explore patients’ experiences and promote compassionate care (Dewar, Mackay et al. 2010).

Aims
This exploratory qualitative study was set to articulate and analyse the process by which parents are first informed that their child has Spina Bifida. It is a preliminary phase of a research project that considers the parental caring experience of young children with the condition across Scotland.

Methods
Following ethics approval, families were informed of the study by the collaborating partner: SBH Scotland. Four families were identified as suitable candidates and they were offered a home-based interview. Participants were shown cards with positive and negative words, from which they were asked to choose a few to describe their experience. The ‘touch point’ was the occasion when they were given their child’s unexpected diagnosis. Thematic analysis was performed using transcribed narratives aided by NVivo software.

Results
Several core themes emerged that have implications to practice including: Information Needs, Information Literacy and Information Seeking; Professional Communications, Trust and Conduct, Choice, Autonomy and Decision Making.

Discussion
The focus on specific words enabled mothers to revisit an emotional event and tell a vivid story of the beginning of their caring journey. They offered an insight to the impact it had on their families and a genuine desire to help others who may face a similar situation.

Mothers wish to have timely access to targeted support and relevant information in an accessible format. Advice, guidance and signposting to reliable resources on Spina Bifida is limited.

Effective communications in an honest, clear and detailed way is essential for building trust and maximising therapeutic relationships. Professional conduct and a non-judgmental approach should be offered to all irrespective of the ultimate outcome as determined by parents. Reflexive practice should be emphasised during professional training to enable practitioners to be aware of how their own beliefs may impact on the care they offer.

Taking the time to listen to parents and giving them an opportunity to review and deliberate their options, is an essential part of offering patients’ choice. Yet, time has become a precious commodity that lead some practitioners to lose sight of the human connection and the compassionate care that frightened patients desperately need.

Conclusions
The Emotional Touch Point method is an effective way to elicit stories and highlight best practice and specific challenges concerning prenatal diagnosis. Professionals must continue to hone needed skills and ensure effective communications are provided throughout the decision making process and follow up care.

References