Improving the Delivery of Different News to Families by Healthcare Professionals

Executive Summary

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As part of the foetal anomaly screening programme, all eligible pregnant women in the United Kingdom are offered screening to assess the probability of their baby being born with Down’s (Trisomy 21/T21), Edwards’ (Trisomy 18/T18) and Patau’s (Trisomy 13/T13) syndromes or other structural abnormalities [1]. Some congenital anomalies may be associated with a learning disability. This includes chromosomal disorders such as Down’s Syndrome as well as other foetal structural anomalies such as complex congenital heart diseases [2, 3]. Antenatal screening identifies mothers with an increased chance of having a child with foetal anomalies and enables healthcare professionals (HCPs) and the families to make a more informed decision about whether to proceed with definitive prenatal diagnostic tests [1]. It also enables HCPs and families to agree on appropriate plans for the delivery; treatment options if available and in some cases and have discussions on possible termination of the pregnancy.

The way healthcare professionals deliver “different news” is an important factor in how it is received, interpreted, understood and processed by parents [4]. The term “different news (DN)” is used in this study to describe the process of imparting and receiving information relating to an unborn or newly born child being diagnosed with a condition associated with a learning disability. Parents may experience a range of emotions immediately after receiving DN including significant distress, fear, grief, depression, anxiety and chronic stress [4-6].

There is recognition that delivering different news may be difficult and stressful for healthcare professionals [4, 7, 8]. Lack of specific standardised training on delivering different news (DDN) contributes to the significant variation in how the news is relayed to parents. Many HCPs have learnt how to deliver DN from the “see-one-do-one” approach that may be limited because of the variation in the skills of the senior HCP observed by junior colleagues [9, 10]. Given the substantial impact that DN can have on families, it is imperative that HCPs are provided with training to enable them to minimise negative psychological impact of the news and maximise psychological wellbeing through effective support of the whole family. We received funding from Health Education England working across Kent, Surrey and Sussex (HEE KSS) to develop and pilot a training intervention to improve how HCPs deliver different news to parents.

This mixed methods study was conducted in two phases. In phase one, we conducted interviews with parents who had the lived experience of receiving different news during pregnancy or at birth. We explored these lived experiences in order to summarise current good practice; collate suggestions for
improving the process of DDN; identify methods to mitigate the psychological impact of the DN and to identify strategies which HCPs can use to effectively support families. We also explored the perspectives of HCPs on DDN to families with the intent of understanding their experiences of DDN, identifying training needs and current good practice. Based on the findings from the interviews, a review of relevant literature and theory, we developed a training intervention for HCPs drawing on the Behaviour Change Wheel. In phase two of this study, we piloted and evaluated the training to determine its feasibility and acceptability.

**ASSESSMENT**

All qualitative data were managed using NVivo and analysed using Framework analysis [11] guided by the Theoretical Domains Framework (TDF) [12, 13]. Framework analysis begins with familiarisation with the data, followed by the development of a thematic framework which will be used for indexing the data [11]. This will be followed by charting the data and then mapping and interpretation which allows the development of descriptive and explanatory findings [11]. These were illustrated using various anonymised quotations. Pseudonyms were used to protect the identity of families that participated in the study.

The pilot training was not powered to determine the effectiveness of the intervention but was used to determine parameters such as acceptability and feasibility that are useful for a future larger study. Acceptability was assessed by the number of HCPs who attended the full training. Feasibility was measured by assessing the percentage of eligible HCPs who eventually enrolled in the training. All secondary outcome measures were summarised descriptively. Categorical data were described by counts and percentages as appropriate. All analyses were carried out in SPSS.

**Key Findings**

Receiving DN had a significant impact on the emotional and mental wellbeing of parents. Parents experienced a range of emotions including shock, grief, denial, shame, and acceptance. Parents vividly remembered various aspects of how DN was delivered to them including; the tone of voice of the HCP as well as their posture; the privacy afforded them when the news was delivered; the words used to describe their child; the care given to them; the exact time that the news was delivered and the level of preparation demonstrated by the HCP in explaining the meaning of the diagnosis; answering their questions as well as the support given to them to minimise the negative impact of the unexpected news. How the news was delivered had a significant impact upon the parent’s ability to cope with the news, their mental and emotional wellbeing, the parent-child relationship, the parents’ relationship with one another and the relationship between the family and HCPs. These findings suggest that it is
important for all HCPs involved in DDN to be adequately trained in this aspect of their professional role.

The process of delivering DN was sometimes challenging for some HCPs particularly due to limited additional training to complement observing senior colleagues perform the task. Only 30.8% (n=8) of the HCPs who attended the pilot training indicated that they had received previous training on DDN. Due to lack of standardised training on DDN as well as lack of policy to guide professionals on this, there was significant variation in the way that DN was delivered by HCPs. Given the significant impact of how DN was delivered as well as the significance of the DN itself, parents and HCPs made important suggestions about the contents of a training intervention.

We developed and piloted the training intervention with a group of 26 HCPs. Our training aimed to equip HCPs to demonstrate empathy; show compassion; be flexible with time or plan around the demands of their ward; utilise kind, simple and truthful language; offer sufficient time to answer questions; know when and where to refer families on to for further care and support. These key aspects have also been suggested in other previous studies [4, 14-18]. We developed a mnemonic figure 1 below to support this HCPs to deliver different news effectively.

Figure 1: READY mnemonic
The training intervention was both feasible and acceptable. Acceptability was measured by the percentage of HCPs who completed the course as planned. On both training days, all participants (n=26) completed all aspects of the training and stayed for the duration of the training. We also found that it was feasible to recruit HCPs to attend the training via NHS trusts and HEE networks. 70.3% (n=26) of eligible HCPs (n=37) were enrolled into the training. We also found that it was both feasible and acceptable to integrate the voice of parents with lived experience and use real-life scenarios in the case studies. These aspects of the training were very well received and perceived as an integral part of the learning experience by participants.

All participants indicated that attendance at the half-day DDN training workshop enhanced or consolidated their knowledge and skills, that it covered topics which were relevant to their current practice and that they would recommend the training to their colleagues. The percentage of HCPs who stated that they agreed or strongly agreed that they understood the effect of DDN on families rose from 69.3% (n=18) before the training to 100% (n=26) after the training. There was an increase in the percentage of those who agreed or strongly agreed that they felt confident when DDN to parents from 26.9% (n=7) before the training to 96.1% (n=25). Whilst those who agreed or strongly agreed that they had the skills to deliver DDN increased from 34.5% (n=9) to 92.3% (n=24) after the training.

There were many positive comments about the structure, duration, and content of the training programme. On their return to their workplace participants reported that they felt that they were better informed and more confident in their ability to provide sensitive, responsive, balanced care when supporting families. Several HCPs reported practical changes that they had already made in their daily practice after the training.

**RECOMMENDATIONS**

The study findings suggest several potential research and training opportunities. It would be important to ensure that the voice of parents with lived experience remains part of these future opportunities so that training continues to reflect these lived experiences and the possible long term impact on families. In view of this, we make the following recommendations with regards to future research, the training content as well as rolling this out.

*Future research*

We conducted a small study to assess the feasibility and acceptability of a training intervention to improve the delivery of different news to families. We recommend that HEE working across Kent,
Surrey, and Sussex support the conduct of a larger definitive large-scale trial study to look at the implementation of the training and its impact on family outcomes. The study could answer questions about how having HCPs who have been trained to deliver DDN might improve the emotional response and mental wellbeing of parents immediately after the news is delivered and in subsequent months.

Training Content

The current training emphasises the unique position which HCPs have in being able to shape how parents start their often unexpected journey. Based on the findings from Phase 2, we recommend that the training is strengthened by adding the following aspects:

- Including the lived experience of a father of a child with a disability; a young person with Downs Syndrome or other carers such as a grandparent;
- Including the perspectives of parents of children with a range of disabilities.
- Incorporate ways to support families that choose to terminate a pregnancy based on foetal anomaly screening.
- Exploring ways of seeking feedback from parents who have received DN regarding the best ways of improving service provision.
- Use of videos, audios on how other people deliver and receive DN.

In order to close the gap between evidence and practice, we recommend that HEE KSS uses the findings from this study and any follow on studies to lobby the development of complementary policy to ensure that DDN training becomes part of mandatory training for relevant NHS staff. This infrastructure would support large scale rolling out of the training to all staff. We also recommend the establishment of local protocols and policies for effectively DDN in NHS trusts to ensure consistent, safe and balanced practice. These protocols and policies will address the variation in practice which was reported by various study participants.

Following on from this definitive study, we recommend that the training is rolled out on a large scale in order to address the unmet need for training in DDN. There were several suggestions from participants about rolling out the training to HCPs who DDN on a large scale. This suggests that the HCPs felt that the training addressed an unmet need for training. We recommend a cascade model of training which involves the appointment and development of local DDN champions to ensure that there is ongoing up-to-date evidenced based local support for HCPs who deliver different news. A similar model had been used by the iHVT for its award-winning perinatal mental health training.

The DDN training has the potential to provide essential skills to HCPs who deliver DN to parents. Equipping HCPs with the necessary skills to effectively deliver DN may reduce the negative impact of
the news on parents, families, and HCPs. If delivered well, there is potential to minimise the distress, anxiety, and depression associated with receiving different news. The improved mental wellbeing and adjustment of parents will also affect the mental health of their children which represents a key aspect of the prevention of mental ill health across the life course.

REFERENCES

6. RCN, Breaking bad news: supporting parents when they are told of their child’s diagnosis RCN guidance for nurses, midwives and health visitors. 2013.