

RESEARCH

Down's syndrome: Good communication by healthcare personnel reduces parents' stress

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Summary

Background: Being told that their child has Down's syndrome in the hospital after giving birth can be a profound and stressful life experience for parents. Parents' experiences of the communication with healthcare personnel can therefore be crucial to how they deal with their emotional responses in the post-natal period and can impact on the parent-child interaction.

Objective: The purpose of the article is to disseminate knowledge about the experiences of parents of children with Down's syndrome in terms of the communication with hospital healthcare personnel in the post-natal period. Furthermore, we want to show how such communication impacts on how parents deal with their own emotional responses.

Method: The study has a qualitative design with a phenomenological and narrative approach. We conducted narrative in-depth interviews with eight biological parents of children with Down's syndrome aged between two and ten years. None of the parents knew that the child had Down's syndrome before giving birth. The collected data was analysed using a narrative analysis method.

Results: Through the main narrative of 'not being seen as a whole person', the parents spoke about their sense of abandonment, feeling excluded from communications, being referred to a computer to find information about the diagnosis of their child, and being talked to by the healthcare personnel in a way they found burdensome. In contrast, the parents recounted through the narrative of 'being a fellow human being' specific situations where the healthcare personnel's attitude helped them to feel that both they and their child were treated as fellow human beings.

Conclusion: The study indicates that the communication with healthcare personnel in the post-natal period has a strong emotional impact on parents. The study also suggests that parents need a style of communication that makes them feel that their child and their own responses are validated and supported.

International research has suggested that children with Down's syndrome and other disabilities have a higher risk of developing an insecure attachment and experiencing abuse and neglect than other children (1, 2). This risk is linked to the child's greater care needs and the parents' emotional resources and ability to accept and respond to the child's needs (1). Contrary to this research, a NOVA report from 2011 shows that children with disabilities are not overrepresented in the Child Welfare Service in Norway (3).

However, Lewis (4) suggests that the moment when parents are told that their child has a disability is a critical time in the long-term development of the parent-child interaction. When receiving the news, parents can find it a major emotional strain. Parents' experience of shock, grief and anger can be linked to concern for the child's future and health challenges, and the stigma attached to the child's 'otherness' (5-9).

«The moment when parents are told that their child has a disability is a critical time in the long-term development of the parent-child interaction.»

Few studies, either nationally or internationally, have explored parents' experiences of interacting with hospital healthcare personnel during the critical period after giving birth to a child with Down's syndrome. The study presented in this article explores parents' specific lived experiences of communication with healthcare personnel. The parents' narratives highlight the role and potential of healthcare personnel in relation to the parents' emotional needs and their interaction with the child in this early stage of parenthood.

Method

The study has a qualitative design with a phenomenological and narrative approach. Phenomenology can be understood as the study of experience as it appears to the subject, in other words, 'what it's like' to experience something (10–12). Phenomenological approaches to embodiment, for instance, emphasise 'lived experience', and that which is felt and sensed in the body and in material space. (11, 12).

The term 'narrative' can be interpreted as 'story' (13). A phenomenologically based narrative approach may be particularly useful for providing rich details about specific, lived experiences of a phenomenon. This approach enables participants to construct a story in which different experiences are given meaning and put in context.

Participants

We interviewed eight biological parents of children with Down's syndrome aged between two and ten years. Six interviews were conducted with mothers, one with a father, and both the mother and father were present in one interview. We conducted the interviews in 2014. The children were born at various hospitals, and none of the parents knew that the child had Down's syndrome before the birth. At the hospital, the point at which the parents were given the news varied from less than six hours (four children), between six and thirteen hours (one child), to more than thirteen hours (two children) after the birth.

In order to recruit participants, we prepared and sent a written information letter to the Norwegian Network for Down's Syndrome and the Ups & Downs associations in Norway, who distributed the letter via e-mail and Facebook. Those who were interested in participating in the study contacted the researcher (first author) by phone or e-mail.

Narrative interviews

We devised an interview guide for the purpose of the study based on the existing literature. By using the guide, the researcher (first author) was able to encourage the parents to explore their own concrete and specific lived experiences, as opposed to asking them to talk about having a child with Down's syndrome in more general terms (12).

The parents were given the opportunity to explore their thoughts and perceptions of their experiences, and were better able to recall and reflect on their feelings and sensations during specific events in the encounter with healthcare personnel ('what the experience was like') (11, 12). Furthermore, they were able to merge the different experiences into a longer narrative. The duration of the interviews ranged from 1.5 to 2 hours.

Narrative analysis method

The interviews were transcribed verbatim and analysed using a narrative analysis method. The analysis process consisted of six overlapping analytical steps developed by Del Busso (13), based on Langdridge's recommendations for critical narrative analysis (14). In the first step of the analysis, we undertook a close reading of all the interviews. We reflected critically on impressions, immediate interpretations, ideas and thoughts about the material as a whole, and the basis for these (14).

In the next step, we identified descriptions of specific lived experiences. These descriptions were analysed according to the details of the description, for example which elements were emphasised by the participant, and the meaning that the participant afforded a particular experience (13). In the third step of the analysis, we coded each of the transcribed interviews for meaning-bearing units. The units were then synthesised into themes. We then identified recurring themes across the participants' accounts.

Using the themes as a starting point, the next step was to identify narratives in each of the interview transcripts. The narratives that recurred across the different participants' accounts were then identified, and resulted in two main narratives being identified. The next step in the analysis entailed identifying how the participants 'construed themselves' in the narratives. We then explored these narratives in light of the existing research on disability.

Ethics

The study was reported to and approved by the Norwegian Social Science Data Services in 2013 (approval number 36355). We obtained informed written consent and notified participants of their right to withdraw from the study at any time during the process without having to give a reason. All identifying data was anonymised, and we gave each participant a pseudonym, which will be used in the publication of the findings of the study.

We used researcher reflexivity as a methodological tool in all stages of the research in order to ensure an ethical, fair and reliable research process (15). Reflexivity included critically evaluating the aspects of the researcher and the research process that contributed to the data produced, and the interpretation of this data material.

Results

The two fathers and six mothers who participated in the study formulated two contrasting main narratives or main stories in relation to their specific experiences of interacting with hospital healthcare personnel in the post-natal period:

- ‘not being seen as a whole person’, and
- ‘being a fellow human being’.

Not being seen as a ‘whole person’

Most of the participants in the study had had several difficult experiences in their encounters with various healthcare staff when their child was born and in the period that immediately followed. Many had experiences in which they felt a sense of exclusion and abandonment. For example, they found that their opinions were not sought or listened to and that the healthcare personnel were unprepared for the situation. The parents described how during these experiences they did not feel they were being seen as a whole person by the healthcare personnel they met.

Kari, mother to a little girl, told of a situation where she felt she was abandoned by the midwife immediately after the birth:

‘The midwife just disappeared, she just left, then I remember her sending a message through someone else: “Contact me if you need to.” When I now look at pictures of my daughter when she was first born, I think she must have seen it, but she didn’t say anything’.

In hindsight, Kari thought it was likely that the midwife suspected that the child had Down's syndrome and that she avoided telling them. If the midwife had seen that Kari's baby had Down's syndrome, the midwife's 'disappearance' and delivery of a message through a third party could be interpreted by Kari as the midwife disclaiming responsibility. It may also be interpreted to mean that Kari, who had just given birth to a disabled child, was given the responsibility of asking for help and support.

Ignored

Lise, mother to a boy, also told of an experience where she felt that the nurses in the maternity ward were talking to each other about the child, but were avoiding talking to her:

'It was like they were unprepared and didn't know what to say or how to deal with the situation. They were uncertain, and were whispering to each other.'

Lise recounted how she felt that the nurses in the maternity ward were uncertain, and that they spoke in hushed tones, whispering to each other instead of talking to her. Lise described how this made her insecure. She felt she was being ignored and that the nurses did not recognise her need to be included and involved in discussions. Both Kari and Lise described experiences where they felt they were not treated as people who deserved and were entitled to care and supportive communication.

Patronising attitudes

Unlike Kari and Lise, who found that the healthcare personnel did not communicate with them, Ina, mother to a boy, found that the communication with the healthcare personnel was diminishing or patronising. Ina described the experience of being hurt by the healthcare personnel's way of communicating, and said that following the birth she was kept separate from her son:

'... I wasn't given the opportunity to look after him or get involved in anything, because they felt sorry for me. Because this was my first child, poor me, and it made me feel so angry. All the others were told, 'he's beautiful', or 'she's so cute', while all I heard was 'is that your child? Poor you.'

Ina told how the maternity staff's attitudes towards her and her son hurt and provoked her. She described the feeling of the maternity staff not seeing her son as a new-born baby, whom it is normal to talk about in a positive way; 'he's so cute', but as something that deviated from the norm. In addition to her sense of being diminished into someone to be pitied, she felt that the child was not treated like a 'regular' baby, but as a burden.

«All the others were told, ‘he’s beautiful’, or ‘she’s so cute’, while all I heard was ‘is that your child? Poor you.’»

Ina, participant

Ina told how her son’s Down’s syndrome was not a great source of sorrow for her. She explained that when she gave birth to a child with Down’s syndrome it forced her to make changes in her life that she had previously wanted but failed to carry out. It was therefore meaningful and positive for Ina that she in particular was now a mother to a child with Down’s syndrome. Ina described how she felt that her child was valuable and helped strengthen her potential to carry things through. This was in contrast to experiencing that both she and her child were perceived as ‘poor things’ and ‘deviant’ by the staff in the maternity ward.

Lack of empathy from the doctor

Many of the participants had found that information was conveyed in a way that lacked sensitivity and empathy. They had also felt that they were not given sufficient information and that the information they did receive was inadequate or outdated. The participants described these experiences as frustrating and burdensome.

Kari recounted an experience when she received information from a doctor:

‘A doctor arrived, a bit of a strange doctor, he used a lot of medical jargon: “Yes, it has to do with the oxygen uptake ...”, but he didn’t make proper eye contact, and he stood like this [the participant demonstrates by partially turning her head away and looking at the ceiling], speaking into the air. “It has to do with the oxygen, so we’ve put her in an incubator.” I remember thinking, “I’m going mad, this is what it’s like going mad [laughs]”’.

In the quote above, Kari said that she found the encounter with the doctor difficult. He was only concerned with imparting medical information, and not with recognising the parents’ situation and meeting their needs. In this context, the doctor had an exclusively medical approach to interacting with the parents and providing them with information. His focus was on identifying the child’s symptoms (insufficient oxygen uptake) and how the child could get better (treatment needs/incubation). The way he communicated (using medical jargon and speaking into the air) and his demeanour (did not make eye contact with the parents when he spoke) gave Kari a feeling of ‘going mad’.

Based on Kari’s description, this situation can be interpreted as meaning that the doctor’s demeanour prevented Kari from being a ‘whole’ person during her interaction with him. The doctor’s demeanour entailed him failing to make eye contact or to address Kari’s need for supportive communication.

«She also reacted strongly to how the doctor referred to her child as belonging to ‘a group of people’, as opposed to being an equal and a person of worth.»

Similar to Kari’s experience, Åse also described the situation when the doctor told her that her son had Down’s syndrome:

‘... so, he said [the doctor]: “I’ve heard rumours that you suspect he has Down’s syndrome, and we’re not in doubt about it.” “Whaaat?” There we sat, you could’ve knocked my husband down with a feather ..., and then the doctor turns to my husband and asks if he has any knowledge about this group of people. “Ehhhh”, my husband said Then the doctor said there were actually opportunities for them, and that was it, end of conversation. Being as good as shoved out of the doctor’s office after getting that news, it was such a slap in the face.’

Åse described how the experience of the doctor giving her the news that her son had Down’s syndrome was characterised by the doctor’s lack of understanding of their emotional and communication needs. She told how the news was not conveyed in a particularly empathic manner and that she and the baby’s father were shocked, both by the news and the way in which it was communicated to them.

Åse clearly described a sense of not being seen as ‘a person with feelings’ in terms of the need for the news to be delivered in a careful and sensitive manner. She described her and her husband’s reaction (‘slap in the face’, ‘shoved out of the doctor’s office’). She also reacted strongly to how the doctor referred to her child as belonging to ‘a group of people’, as opposed to being an equal and a person of worth.

Being a fellow human being

In stark contrast to the parents’ description of feeling ‘less than a whole person’, several of the participants in the study felt they were given the opportunity to be a fellow human being in the encounter with healthcare personnel. They found that both they and their child were treated as fellow human beings, and that the healthcare personnel had a positive disposition, which made them feel like equals. In this main narrative, the participants described experiences where they were met with empathy and humility. They said that the healthcare personnel had time for them and that they received emotional care and support.

Discrete and friendly nurses

As already mentioned, Kari described how she felt abandoned by the midwife in the delivery room and that the doctor in the maternity ward did not recognise her needs. However, Kari also had a positive experience in the encounter with the nurses in the intensive care unit:

‘They asked, “Does she resemble anyone in your family?” “No”, we said ... They were so sweet and friendly – they were very specific, but very discrete and friendly. And then they said, “We think she has Down’s syndrome, and we think that because ...” and then they showed us: because of the ears, because of the toes. “Also because some lines are missing on her hands”, because of this and that.’

«The nurse also gave Åse’s husband time and space to express himself and to talk about the situation with her on his own.»

Kari described an interaction in which the nurses communicated in a careful and supportive manner, ‘discrete and friendly’. When the nurses gave them the news that they suspected their daughter had Down’s syndrome, they specifically explained the reasons for this by showing the parents the baby’s ears and toes. Here the nurses communicated that the child was a fellow human being and probably resembled her parents, like all other children. This was in stark contrast to the doctor who asked Åse’s husband if he had any knowledge about ‘this group of people’.

Åse described how she felt she was treated well by a nurse in the maternity ward. This was in contrast to the description of Åse and her husband’s experience when a doctor told them that their child had Down’s syndrome:

‘She [the nurse] said she needed to talk to him, and they had a long conversation, without me being present.’

Åse said that her husband had a strong reaction and that the nurse recognised his need for care and supportive communication. The nurse also gave Åse’s husband time and space to express himself and to talk about the situation with her on his own.

In this interaction, both Åse and her husband felt that the nurse was a fellow human being. The nurse also made the husband feel like he was a fellow human being with a natural and understandable reaction to receiving the news that his baby had Down’s syndrome.

Discussion

International research shows that parents of children with Down's syndrome receive little follow-up of their emotional needs and, at different times during their son's or daughter's childhood, find that healthcare personnel communicate in a manner they experience as burdensome (7–9, 16, 17). These findings are in line with how the parents in our study described their experiences of the birth and the period immediately after at the hospital.

The parents had several specific experiences in their encounters with healthcare personnel where they felt that they and their child were less than 'a whole person'. The 'whole person' can be understood initially as someone whose new-born child has a health challenge that needs to be taken care of, but who subsequently also needs support for their own worries and feelings. These can be seen as aspects of a holistic approach to the parents' health, which is co-constructed in the encounter with healthcare personnel (18).

Important to feel accepted

When parents have been anticipating and looking forward to having a healthy baby, their emotional response may be characterised by strong feelings of shock, grief and anger. Dealing with their own emotions whilst also communicating with and responding emotionally to their child can be a challenge (5). It is therefore reasonable to assume that when parents' need to be seen as a 'whole person' or as 'a person with feelings' is met by healthcare personnel, it can have a positive impact on the family's future dynamic and quality of life.

For example, when parents have specific experiences of acceptance and validation in their relations with healthcare personnel, it can foster good parent-child interaction. It can also provide a good starting point for the relationship that will be created over time between the main caregivers and the child (4). In this way, supportive communication with healthcare personnel can help parents to construct and communicate positive narratives about the child's birth and the hospital.

Such stories can be of major emotional importance and can counteract the social stigma they may face in their daily lives after returning home from the hospital (16). In line with this, some parents had experiences where healthcare personnel referred to their child in a way that equated them with fellow human beings, and they themselves felt validated, which was of crucial importance to the parents in this study.

In relation to interacting with others in the manner described here, Anderson (19) argues that 'withness' is a way of communicating with other human beings that makes it possible for the person to feel accepted. She describes the healthcare personnel's approach as 'talking with', 'acting with' and 'responding with' the person in need of assistance (19).

Social stigma

Research shows that parents of children with a disability experience 'otherness' and stigma in the social context (16, 17, 20, 21). It may therefore be particularly important in the early stage of parenthood for the healthcare personnel to be 'together with' the parents when they have their first reaction and initial experience.

Healthcare personnel's communication at the very moment parents learn that their child has Down's syndrome, and in the period immediately afterwards, is crucial to the parents being able to cope with the emotional stress they feel there and then. In addition, feeling that they and their child are validated and supported can form a positive basis for the future attachment and interaction that will be created between the parents and the child over time (4).

Weaknesses of the study

We recruited the sample from Ups & Downs associations, and it is possible that the parents who volunteered had had particularly difficult experiences. The study could thus be strengthened by a larger sample and more descriptions of parents' specific experiences, but time constraints did not allow for this. In the context of a narrative approach, it could also be preferable to interview participants several times, particularly with a view to exploring the importance of the initial encounter and communication with healthcare personnel for the family and the child over time.

Conclusion

In this study, we wanted to disseminate knowledge about the specific lived experiences of parents who had a child with Down's syndrome, both at the time of the birth and the period immediately afterward. By doing so, the study shows the healthcare personnel's key role and potential in relation to parents' emotional needs and interaction with their child in this early stage of parenthood.

The study indicates that facilitating communication that makes parents feel they and their child are 'fellow human beings' can be an important resource for dealing with parents' emotional responses at the hospital during the post-birth period.

It is also reasonable to assume that by taking a validating and supportive approach to communication, healthcare personnel can help lay the foundation for the relationship and interaction that will be created between the parents and the child over time.

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