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Parents' experiences of carrying out distressing nursing and healthcare procedures as part of supporting children with complex or long-term conditions at home

RESEARCH SUMMARY

Background

Parents of children with long-term or complex health conditions often assume responsibility for aspects of their child's ongoing nursing care at home. Sometimes this involves procedures that can cause distress for the child. For example, care and changing of naso-gastric, gastrostomy or tracheostomy tubes, giving injections and thumb/finger pricks. This exploratory study, funded by WellChild, sought to understand parents' experiences of this, including how they would like to be supported in this role.

Overview of the findings

Assuming responsibility for carrying out the procedures

Parents became responsible for taking on these procedures in a range of circumstances. Some proactively chose to assume this responsibility. Others took on the procedures as a condition for going home from hospital with their child. For some, this responsibility was assumed reluctantly in the absence of any alternative.



I didn't want to be the one to do it, but we kept ending up with no NG tube, nobody able to come out and constant trips to the hospital"

Mother, on being trained to re-pass her child's naso-gastric tube

In taking on these procedures, some parents made trade-offs between the emotional discomfort they felt in causing their child distress, and the wider benefits it would bring to the child or family (eg being able to stay at home).



If we can do this at home, you know, it's done within a second, he's more relaxed, we're more relaxed and he just learns to just get on with it, basically. So definitely, you know, the more time they're at home the better"

Mother, on choosing to learn how to re-pass her child's naso-gastric tube

The challenges parents faced

The procedures themselves were a technical process which parents had to carefully orchestrate (e.g. preparing equipment). However, it was not just the administration of the procedures that parents managed. These procedures caused some form of distress for the child (typically this was perceived to be because the child was experiencing pain or discomfort, but other sources of the child's distress included being held in a particular position for a procedure and to a lesser extent, being taken away from a preferred activity). This meant there were additional issues and challenges that parents had to contend with. These included managing their child's distress and resistance (physical and/or verbal), their own emotional response, and the reactions of siblings present in the home.



[We] just tried to stay calm and keep it kind of a calm voice and talk slowly and kind of trying to explain what we were doing and show him the machine and show him, help him to press buttons and make him involved in it"

Mother, on preparing her child for finger pricks



you just stay tunnel visioned because the more emotion you show the more then it's upsetting for her, cos if she would see her mum upset then it's only gonna make her worse"

Mother, on managing her own emotional response when giving her child injections



You've got a squirming baby, a toddler that wants your attention, and you're trying to pass this tube"

Mother, on re-passing her child's naso-gastric tube

Parents also had concerns about the implications of incorrectly administering the procedures (eg misplacement of nasogastric tubes) in terms of their child's health.

Managing their child's distress and resistance

Being able to prevent and/or minimise the distress their child experienced was a core part of parents' experiences, with a range of techniques developed, tried and used. Sometimes this was guided by input from professionals, but in most cases parents were directing their own efforts in this. Some parents did not feel confident about this and a need for professional advice about managing their child's distress was highlighted.



we tried to encourage him... we tried to bribe him... But he knows his own mind and even from a young age he knew, he was not having it, it didn't work."

Mother, on the challenges of preparing her child when attaching cannulas



[practitioners could observe and] see how you do it, and see if there's any other way we could advise you. So if you think, if we're not distracting the child when we're doing the procedure, 'oh well we've observed you doing it, perhaps if you could distract them next time or try this way or try that other way', and give us just some coping strategies, then perhaps it would have made it easier instead of us having to learn it ourselves, cos that's, obviously, been the worst bit"

Mother, on ways practitioners could advise her about managing her child's distress

How did being responsible for carrying out distressing procedures affect parents?

We found that in most cases, carrying out the procedures was, to vary degrees, an emotional experience for parents. However, this did not appear to translate into an ongoing emotional burden for most. The majority expressed either a sense of acceptance for their responsibility, or a view that it had become easier over time.

“ Now it's normal for me; before it was like; when she was younger I knew I had to do it, it's you, you know you've got to do it because that's your job now, but you sort of think why should I have to do it? So you question that, and then you think well obviously I have to do it because there's nobody else here to do it.”

Mother, on how her views on carrying out various procedures for her child had changed over time

Where the emotional burden was more prominent and ongoing, this was situated in experiences of poor professional support, struggles to manage their child's distress, concerns about how their child viewed them and/or a perceived absence of choice in being responsible for the procedures.

How did parents think that being responsible for carrying out distressing procedures affected their relationship with their child?

Most felt that their relationship with their child was unaffected by their involvement in the procedures, with any conflict being limited to the moments in which the procedure was carried out.

“ it's not had an impact, you know, I mean obviously at the time she's not very happy with me but it doesn't, she doesn't hold a grudge”

Mother, giving finger pricks, on the relationship with her child

However, a small minority were concerned about how their child viewed them (eg being seen as the 'bad' parent) or that there might be a loss of trust in the parent-child relationship.

Being trained and supported

Experiences of training in the procedures and ongoing support from healthcare professionals varied among those we spoke to. Training received ranged from extensive and thorough to minimal and rushed. In a small number of cases parents received advice about managing distress and resistance. Other parents reported that this and their own emotional discomfort were given little consideration. Similarly, once at home, ongoing training and support ranged from being “left to get on with it”, with no monitoring or input from health staff, to having a network of support from ward and community nurses.

Ways of supporting parents

Parents identified a number of ways that they would like to be supported with this responsibility, including:

- Advice about managing the child's distress and resistance.
- Psychosocial support from nurses and peers (ie other parents) with respect to the emotional aspects of the role.
- Assistance with the procedures (eg to manage the child's resistance or give parents a break).
- Recognition from health professionals of the responsibility that parents have assumed.
- Occasional supervision and observation from nurses to feel reassured and informed about the procedures.

What are the implications of the research findings?

This study has shown that, at least in the early days, parents have to learn to manage a number of issues beyond the technical delivery of the procedure. These may include the child's distress and resistance, their own emotional responses, and the presence and reactions of siblings. Importantly, these issues may not always be visible or obvious to health staff once parents take on the procedures at home. This has implications in the way parents are trained and supported in this role.

The study has also revealed parents' emotional, practical and informational support needs. Addressing some of these needs may have resource implications (such as increased provision of outreach/children's community nursing teams). Other needs, such as improving training and greater recognition of the impact on parents, could be incorporated into existing practice. Furthermore, whilst some support needs are clearly the domain of nurses or other healthcare professionals, it is important to also note that some parents highlighted the value of, or called for opportunities for, peer support.

Recommendations and considerations for practice

- ✔ **Good training** when taking on responsibility for a procedure is paced, not rushed, involves sufficient practice and gives parents enough time to become confident. It allows them to talk through their anxieties and includes written information to refer to later. It also includes advice about managing distress and resistance, and allows parents to take time out of training if it becomes too emotionally uncomfortable for them. The contact details of nurses to call for help and advice are provided.
- ✔ Parents need to feel able and confident to **manage their child's distress** when they carry out nursing and healthcare procedures at home. Some develop techniques to do this on their own whilst others want advice and help with this. This could be explored with parents during the training period. Play therapists may be a good source of advice.
- ✔ Parents value **recognition** (from health staff) of what they are doing, **emotional support**, and **reassurance** (or checking) they are administering procedures correctly. Provision of emotional support may have implications for costs. However, the ability of nurses to provide recognition and reassurance may be one simple and immediate way of supporting parents.
- ✔ Carrying out procedures in the hospital environment is different to doing them in the home environment. Only one parent may be present and thus there is **no one else to assist** if a second pair of hands is needed. There may be **young siblings present** whilst procedures are being carried out. Thus, any advice to parents about the best ways to manage procedures their child finds distressing should explore and take into account these individual, and **potentially 'hidden', circumstances**.
- ✔ When parents carry out these procedures at home, they can have concerns about the **safety** of what they are doing, and anxieties about **correctly administering the procedures**. Parents believed this could be eased by having access to a nurse to call for **advice and reassurance**, or having a nurse to visit occasionally to **refresh training and/or observe** the parent carrying out the procedure.

Summary of methods

- We carried out in-depth interviews with 19 parents who were responsible for carrying out procedures they believed caused distress for their child
- In five cases, we also interviewed their partners/spouses.
- Procedures carried out by parents recruited to the study included: inserting naso-gastric tubes, inserting gastrostomy tubes, changing tracheostomy tubes, giving injections, finger/thumb pricks, oral suctioning, nasal suctioning/prongs/other nasopharyngeal procedures, changing dressings, administering suppositories, colostomy care and bladder manipulation.
- A thematic analysis of the interview data was used to understand parents' experiences of carrying out these procedures.

The full research report is available at: <http://eprints.whiterose.ac.uk/100454>

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