

Psychosocial support for families of children with neurodisability who have or are considering a gastrostomy: the G-PATH mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Scientific summary

The G-PATH mixed-methods study

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Scientific summary

Background

Children with neurodisability, for example those with severe cerebral palsy and complex feeding needs, can experience poor growth and undernutrition associated, in part, with high rates of oromotor difficulty, dysphagia and oropharyngeal aspiration. These factors can affect children's ability to achieve an adequate nutritional intake by mouth. Parents, usually mothers, can spend several hours each day feeding children, which can be experienced as stressful, with implications for parental, child and family well-being. A gastrostomy feeding tube (surgically placed in the stomach) is recommended along with commercially prepared feeds delivered via the gastrostomy feeding tube. However, the suggestion of a gastrostomy feeding tube can generate parental opposition owing to the values and social meanings that caregivers attach to feeding children orally. Conflicts may arise between caregivers and professionals about the child's need for a gastrostomy feeding tube, and parents may also experience difficulty and a sense of loss in adjusting to new roles following gastrostomy feeding tube placement. Evidence reviews recommend that professionals attend to the non-clinical factors when recommending a gastrostomy feeding tube and ensure that there is consistent and structured support in care pathways to improve the quality of decision-making and post-operative quality of life.

Aims

The overall aims of the study were to explore how services were implementing the recommendations from evidence reviews given that the provision of psychosocial support is an under-researched area. We aimed to (1) identify different models of psychosocial support, (2) compare the implementation and operation of models of psychosocial support and key resource differences and (3) provide an estimate of the costs and preferences (i.e. willingness to pay) for support.

Methods

We adopted an explanatory, sequential, mixed-methods approach with a qualitative, collective case study as the dominant methodology, which included the following:

- A web-based survey, distributed through professional networks and NHS research and development departments to map concepts and exemplar models of psychosocial support, including involvement of peers, perceived barriers to and facilitators of delivering psychosocial support, and how services manage conflict. Data were presented in percentage responses and open-ended questions analysed thematically in relation to the study aims.
- A multisite collective case study of four local service configurations involving health care, educational and social care agencies selected from our survey using initially purposive, and later theoretical, sampling to provide insight into how support is embedded in a range of contrasting contexts. We conducted interviews and focus group discussions with caregivers and a theoretical sample of managers, staff, children, parents, teaching assistants and others involved in children's care to analyse their experiences of providing or receiving psychosocial support; observations of care processes; and a review of service documents. Interviews were audio-recorded, transcribed and uploaded into NVivo version 11 (QSR International, Warrington, UK). Data were analysed thematically, drawing on approaches described by Braun and Clarke (Braun V, Clarke V. Thematic Analysis. In Cooper H, Camic PM, Long DL, Panter AT, Rindskopf D, Sher KJ, editors. *APA Handbook of Research Methods in Psychology, Volume 2: Research Designs – Quantitative, Qualitative, Neuropsychological*,

and *Biological*. Washington, DC: American Psychological Association; 2012. pp. 57–71). Text was organised into meaningful categories, compared across all responses and labelled using principles borrowed from constant comparative analysis. The analysis was informed by Mahant's model of decisional conflict, which was incorporated into the Donabedian conceptual framework as a rationale for the synthesis and presentation of data.

- A survey of the cost of psychosocial support and associated resource use across the four case study sites, using questionnaires disseminated to parents and professionals by the local research nurse. Requested information included demographic data and details of appointments in the previous 12 months related to feeding and gastrostomy, including length of appointment, staffing, reason for appointment, whether or not psychosocial support was given and, if so, an estimate of how much time was spent discussing these issues. Further questions for parents addressed whether or not their problem was resolved, and asked if they would have liked specific appointments to discuss psychosocial support or were offered the opportunity to talk to other parents or families, and, if not, if they would have liked the opportunity to do so. The questionnaire also asked how satisfied parents were overall with the support they had received (on a scale of 1–5). Economic descriptive data on the cost of support were analysed using Personal Social Services Research Unit data.
- A willingness-to-pay survey, which required professionals and parents to rate two services based on our case study findings: a hypothetical model of care that reflected usual practice and an enhanced care package of psychosocial support involving a psychologist and parental peers. These varied slightly in terms of professional support, frequency and type of psychological and peer support offered. Respondents were required to rate their preference for each service using a scale with a hypothetical 'purchasing price' as a measure of the value of support offered. We also collected demographic data about respondents. The questionnaire was distributed online via Qualtrics XM (Provo, UT, USA) via professional and parental networks, third-sector organisations and social media [Facebook (Facebook, Inc., Menlo Park, CA, USA; www.facebook.com) and Twitter (Twitter, Inc., San Francisco, CA, USA; www.twitter.com)].

Results

Web-based provider survey

We received 64 questionnaires between July 2016 and May 2017 with varying degrees of completion. The majority of respondents were based in services in England (52/63). Questionnaires were completed by consultant paediatricians (10/49), those with a dietetic background (14/49), children's community nurses (7/49), nurse specialists (4/49), speech and language therapists (3/49) and those in other professional groupings (11/49). Respondents reported that psychosocial support (according to the provided definition) was provided to caregivers (20/45), children (24/45) and young people (22/45) but that in two-thirds of cases (28/43) this was not formalised or documented and that there was no process in place to measure the outcome of psychosocial support (31/38). In a small number of cases (7/25), children had to reach a threshold before receiving support. A majority (38/43) reported that they would like to do things differently with regard to the provision of psychosocial support and a majority (29/44) felt that there was room for improvement in current practice. Most reported that they put parents considering a gastrostomy feeding tube in contact with others with prior experience (23/39) and that this was formalised (19/23). Few services (8/39) had written guidance on managing conflict when parents disagreed with the recommendation of a gastrostomy feeding tube and just under half (16/34) reported having used safeguarding legislation in relation to an aspect of children's weight or growth in the previous 12 months, although it is likely that feeding was only one aspect.

Collective case study

Participants included children ($n = 3$), parents ($n = 26$) and professionals ($n = 58$). Just over half of parents did not consent to their child participating in the research. Four exemplars were chosen from different geographical regions of England and Scotland, including rural and city-based services, generalist and specialist, and with contrasting service configurations. In these services, six mechanisms

for integrating psychosocial support were identified: (1) a lead professional, (2) integrated health and education through pooled budgets, (3) Meeting Around the Child processes, (4) a joint surgical clinic that linked the tertiary and community health services, (5) a surgical nurse assessment model that linked the tertiary and community health services and (6) a multidisciplinary children's home enteral feeding clinic. Psychosocial support was provided by any member of the multidisciplinary team, rather than by designated staff, and integrated into appointments often dominated by clinical care. Few professionals had received specialist training to provide psychosocial support. Although professionals reported spending time and effort providing psychosocial support, it was rarely documented in a way that could be evaluated or costed. Parents expressed various needs for support, including managing feeding and equipment, becoming technically proficient, developing expertise in 'nursing' skills, negotiating maternal identities around new feeding practices, managing emotions and relationships and managing feeding in everyday contexts. They reported little opportunity to discuss emotional aspects of decision-making in appointments, although in two cases the importance of emotional support for children and families was underwritten by policy. Technical care post gastrostomy (gastrostomy feeding tube management and stoma care) was also raised as a particular issue, with ongoing problems in obtaining and managing supplies of equipment being reported.

Professionals constructed families' need for psychosocial support in terms of their own roles and the management of risk. Although generally valued by both staff and parents, peer-to-peer parent support was not consistently offered. Barriers included concerns about confidentiality and matching parents. The involvement of psychologists was not usual practice; perceived barriers were resource constraints and beliefs that psychosocial support was already provided by the multidisciplinary team, although this was not always supported in parental interviews. Parents valued relationship continuity and support that minimised the number of appointments. Medical models of working were less effective in involving parents and ensuring psychosocial support was integrated routinely in care. Parental roles were stronger in cases typified by strong leadership and where health care and education were integrated. Nurse-led models appeared to be effective in ensuring that support was integrated provided that they were adequately resourced. Three analytical constructs described the provision of psychosocial support: 'hidden work', opportunity to express emotional vulnerability and negotiations around risks and values.

Resource utilisation and costs

Caregivers returned 21 out of 103 (20%) questionnaires disseminated through our case study sites and 8 out of these 21 questionnaires provided information on appointments, with five reporting that psychosocial support was received in the previous 12 months. Professionals returned 31 out of 109 (28%) questionnaires. Just under one-quarter of parents and 30% of staff did not consent to participate in one or both costings studies.

The mean number of appointments over the previous 12 months was reported as 2.25. None of these had been arranged to discuss psychosocial support specifically. The cost of health-care professionals' time spent on psychosocial support ranged from £0.00 to £317.37 per child per year, with an average of £76.42 per family for the year, at 2017 prices. Only one respondent reported being offered the opportunity to speak to another parent, and 12 out of 21 respondents said that they would have liked such an opportunity. Few health-care professionals (7/31) reported having received specialist training to provide psychosocial support and fewer (4/31) reported feeling 'very confident' to do this. The willingness-to-pay study comparing the median ranks of the two services, usual care (mean 259.90, 95% confidence interval 227.73 to 292.05) and enhanced support involving parental peers and an appointment with a psychologist (mean 374.48, 95% confidence interval 344.14 to 404.82), showed that the median rank of the service with enhanced support was significantly higher ($p < 0.001$; $n = 96$).

A two-sample *t*-test (unequal variances assumed) was used to assess whether or not there was a significant difference in willingness to pay between parents and health-care professionals. There was no significant difference in mean willingness to pay for usual care (carers, £252.17; health-care

professionals, £262.33; $p = 0.8090$) and enhanced care (carers, £306.52; health-care professionals, £395.89; $p = 0.0519$). There was also no significant difference in mean willingness to pay by household income group between usual care ($p = 0.5550$) and enhanced care ($p = 0.6852$) using a one-way analysis of variance.

Conclusions

It proved difficult to disseminate a web-based survey; there was a poor response rate. The survey results may not represent the experiences of all services given the number of questionnaires received and incomplete data. Children's views were not well represented owing to the severity of their communication impairment (between 42% and 60% are estimated to have a communication impairment in this population of children) and because parents did not consent to their participation.

The results demonstrated that parents had different needs for psychosocial support, which was provided by various team members in appointments integrated into children's clinical care. Hence, it proved difficult to highlight or cost the provision of psychosocial support, which we designate as 'hidden work', owing to the lack of recording in clinical systems. The estimates of the cost of provision of psychosocial support should be interpreted with caution owing to the small number of data. The fact that a number of parents and professionals did not agree to participate in the costing survey in our case study sites is worthy of further investigation but may have been linked to concerns about health policy and service privatisation.

The willingness-to-pay study demonstrated a preference for enhanced psychosocial support involving parent peers and an appointment with a psychologist. In general, families were underserved by the psychosocial services compared with families attending because of other childhood disabilities, and few staff members had received specialist training, highlighting a gap in professional team development. The study suggests that services should formally assess families' needs for psychosocial support and record the use of resources to estimate costs. Personalised interventions may assist with the appropriate targeting of resources. The mechanisms of care we have identified could provide a focus for strengthening the provision of psychosocial support before and after the placement of a gastrostomy feeding tube. There may be a role for psychologists in advising and supporting other professionals to integrate psychosocial support, which may be a more feasible and effective use of resources than aiming to refer all parents routinely to psychologists.

Although there is an established literature describing the support needs of parents, there has been little focus on the organisation and delivery of psychosocial support. This study will be of interest to those who commission or manage services and parent organisations. The methodological limitations of the study, barriers to participation in the research (including the effect of gatekeeping) and the challenges of conducting research with small populations are discussed.

Implications for practice

- Our study suggests that parents/caregivers vary in their need for psychosocial support. A formal assessment of need, including those of other family members, could help to effectively target resources.
- Appointments where the primary focus is support may help to create spaces in which emotional aspects can be discussed and support needs documented, audited and evaluated.
- Pathways to access a psychologist were often unclear, including for staff members; these could be clarified, including the provision of information about what parents can expect and the timescale involved. Where available, input from a psychologist is probably best when integrated into the team to minimise the burden of appointments and relationship burden.

- The provision of psychosocial support could be strengthened through multidisciplinary team training to ensure a systems-based psychological approach to feeding rather than an approach based on the initiative, skills or interests of individual practitioners.
- Establishing a formal register of parents willing to talk to others may overcome professional concerns about confidentiality.
- Standards of support, such as those developed in this study, could be used to reinforce the importance of psychosocial support and shared with parent groups and organisations, such that parents come to expect that psychosocial support is part of their care package.

Recommendations for future research

- A study to develop, pilot and validate an instrument to assess psychosocial support needs co-produced with families.
- The development and evaluation of peer-to-peer parent support initiatives for families considering a gastrostomy feeding tube for their child involving formal quality-of-life outcome measures.
- An exploration of professional and parental attitudes towards costing studies and barriers to participation.
- A study to develop and evaluate the role of parent trainers in training packages for health-care and social care professionals.

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