

# Indications, medical conditions and services related to gastrostomy placement in infants and children at a tertiary hospital in South Africa

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**Objectives.** To describe South African infants and children requiring gastrostomies in a tertiary hospital, including the indications, medical conditions and health services, during a 5-year period (2005 - 2009).

**Design.** The research design was a retrospective descriptive survey of medical records.

**Setting.** A tertiary paediatric state hospital in South Africa.

**Subjects.** One hundred and forty-two patients between the ages of 0 and 17 years.

**Results.** Dysphagia ( $N=80$ , 56%), aspiration ( $N=70$ , 49%) and need for nutritional support ( $N=63$ , 44%) were the most common indicators for gastrostomy placement. Most participants ( $N=85$ , 75% of the subset of 114 with feeding and swallowing difficulties) presented with multiple medical conditions, and neurological impairment ( $N=94$ , 82%) and gastro-intestinal problems ( $N=96$ , 84%) were the most prominent. Services were required from a variety of health care professionals for a period ranging from 6 to 103 months (mean 18 months). The speech-language therapist was consulted most frequently before gastrostomy placement (85%), while the stoma sister (97%) and dietician (97%) were consulted after placement.

**Conclusions.** South African infants and children requiring gastrostomies frequently present with multiple medical conditions and dysphagia. These children are likely to benefit from extended services provided by a specialised team of health care professionals.

Feeding via gastrostomy tubes, including percutaneous endoscopic gastrostomy, is used in paediatric patients when long-term enteral feeding is required.<sup>1</sup> This form of alternative feeding may be indicated in infants and children with feeding and swallowing difficulties (dysphagia), particularly when these difficulties result in aspiration (entry of food or liquid into the trachea) and/or growth faltering.<sup>2,3</sup> Gastrostomy feeding may also be indicated in paediatric patients with structural abnormalities, or those who require unpalatable diets or medications.<sup>4</sup> Dysphagia has been reported as the primary indicator for gastrostomy placement in a number of studies.<sup>4,6</sup>

Gastrostomy placement appears to be reported more frequently in certain populations, such as those with neurological impairment,<sup>4,7,8</sup> gastro-intestinal tract (GIT) abnormalities<sup>4</sup> and cardiac defects.<sup>4,9</sup> The reported prevalence of feeding and swallowing difficulties in infants and children with neurological impairment ranges from 30%<sup>10</sup> to over 90%,<sup>11</sup> which may explain the need for gastrostomy placement. Infants with cardiac defects may have difficulty with feeding endurance, resulting in poor weight gain and the need for alternative feeding.<sup>9</sup>

Infants and children who require gastrostomy feeding will require management by a multidisciplinary team to provide optimal care, including pre-operative assessment, postoperative care and on-going intervention.<sup>12,13</sup> A multidisciplinary team approach has been associated with a reduction in complications and morbidity after gastrostomy placement.<sup>14</sup> This team should include a speech-language therapist (SLT), a dietician, a doctor (paediatrician, surgeon, gastro-enterologist) and a nurse practitioner (specifically trained in gastrostomy care).<sup>12</sup> The SLT conducts a comprehensive assessment of oropharyngeal swallowing to determine the cause of the feeding and swallowing difficulties, and whether non-surgical interventions are possible. The assessment usually includes a clinical and a videofluoroscopic evaluation of swallowing (also known as a modified barium swallow study), which focuses on oropharyngeal swallowing of different consistencies and volumes. After gastrostomy placement, follow-up management by the team includes monitoring of weight gain<sup>8</sup> as well as feeding and swallowing skills to determine if and when the infant/child can be weaned from gastrostomy feeding. Early intervention for dysphagia, which may include gastrostomy placement, is warranted because growth and respiratory health may

be negatively affected.<sup>4,7</sup> When considering the paediatric population with gastrostomies, it is necessary to identify the medical conditions that place infants and children at risk, as well as the services that are required. There are very few South African data, with only one study reporting on the indications, patient characteristics and complications in patients with gastrostomies.<sup>6</sup> The purpose of this study was therefore to identify the medical conditions and indications associated with gastrostomy placement and the health care services required for optimal intervention.

## Methodology

### Aim

To describe the paediatric population requiring gastrostomies for feeding and swallowing difficulties and their service delivery needs.

### Objectives

In the paediatric population who received gastrostomies at a tertiary hospital in a 5-year period (2005 - 2009), the following will be described:

- Indications for gastrostomy placement
- In participants with feeding and swallowing difficulties:
  - the medical conditions
  - the health services related to feeding and swallowing difficulties and gastrostomy placement.

The research design was a retrospective descriptive survey of medical records.

### Participants

Individuals had to be between the ages of 0 and 18 years, and to have had an initial gastrostomy inserted during January 2005 - December 2009.

Participants' folders were identified from the gastro-enterology and surgical databases. Non-probability purposive sampling was used. Two hundred and nine children had gastrostomies during the study period, of whom 142 met the inclusion criteria. Those who were excluded had gastrostomies placed at other institutions, had a replacement gastrostomy, or records were missing.

Fifty-four per cent of the participants were female and 46% were male; 93% lived in the Western Cape province, while 7% were from the Eastern Cape. The median age at gastrostomy placement was 15 months, with a range of 4 days - 17 years.

A standard data collection protocol was developed based on the current literature to address content validity (protocol and references available on request). The following data were collected as part of a larger study: biographical information, general medical information, underlying medical conditions, indications for gastrostomy and health care services received. Three professionals (2 SLTs experienced with paediatric dysphagia and gastrostomy placement and a paediatric surgical

consultant who manages gastrostomy patients) reviewed the protocol to ascertain face validity. Construct validity was assessed during the pilot study following which amendments were made to the protocol.

Intra-rater reliability was addressed by each research assistant completing the data collection protocol at two separate times, on at least two participants, and blinded to the original data set. A 95% level of agreement was accepted. To establish inter-rater reliability, 10% of each research assistants' records were reviewed by an external researcher, who was blinded to the original results. A 90% level of agreement was set and failure to meet these criteria resulted in consultations to address the discrepancies, following which an average of 97% was obtained.

Ethics approval was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (REC REF 052/2010), and permission from the hospital was requested. Participants' records were identified and the protocol was used to record the data. The coded data were statistically analysed using SPSS for Windows version 18. Where data were missing, the participants were excluded from the analysis of the specific variable.

## Results

### Indications for gastrostomy placement

As can be seen from Table I, dysphagia, aspiration and need for nutritional support were the most common indicators for gastrostomy placement in the total sample ( $N=142$ ) as well as in those participants with feeding and swallowing difficulties ( $N=114$ ). Participants frequently had more than one indication documented (therefore  $N$  does not add up to 100%).

### Medical conditions in participants with feeding and swallowing difficulties ( $N=114$ )

Twenty-five per cent of participants had a single medical condition, while 75% had multiple diagnoses. GIT and neurological conditions were the most frequently occurring medical conditions (Table II). Eighty-four per cent of the participants had GIT conditions, of whom 92% had gastro-oesophageal reflux (GOR). A neurological condition was documented in 82% of participants, with more than half (53%) having a diagnosis of cerebral palsy.

### Health services related to feeding and swallowing difficulties and gastrostomy placement

The median waiting time for gastrostomy placement was 1.25 months, with a range from 1 day to 127 months (mean 5.5 months). Ninety-one per cent of the participants received their gastrostomy within 6 months of identification, with a mean of 1.4 months and a median of 1 month. In the remaining participants, the range was 7 - 127 months. SLTs were the predominant (64%) referral source for gastrostomy placement in participants with feeding and swallowing difficulties, followed by doctors (32%) including paediatricians, gastro-enterologists and surgeons, and dieticians (4%).

TABLE I. INDICATIONS FOR GASTROSTOMY PLACEMENT

Indicator	Number in total sample ( $N=142$ ) ( $N$ (%))	Number in sample with feeding and swallowing difficulties ( $N=114$ ) ( $N$ (%))
Dysphagia	80 (56)	80 (70)
Aspiration	70 (49)	70 (61)
Need for nutritional support	63 (44)	52 (46)
Oesophageal stricture/atresia	13 (9)	5 (4)
Medication	6 (4)	1 (1)
Increased feeding time	6 (4)	5 (4)
Reduced endurance	1 (1)	1 (1)
Reduced level of consciousness	1 (1)	1 (1)
Nissen fundoplication	1 (1)	0 (0)
Other	3 (2)	3 (3)
None recorded	6 (4)	0 (0)

**TABLE II. MEDICAL CONDITIONS IN PARTICIPANTS WITH FEEDING AND SWALLOWING DIFFICULTIES (N=114)**

Medical condition	Participants with feeding and swallowing difficulties (N (%))
GIT	96 (84)
Neurological	94 (82)
Respiratory	37 (32)
Cardiac	16 (14)
Syndromes	13 (11)
Craniofacial	6 (5)
HIV/AIDS	5 (4)
Renal	5 (4)

Assessments conducted before gastrostomy placement included radiological contrast swallow studies (57%), videofluoroscopic swallow studies (VFSSs) (51%) and clinical feeding and swallowing assessments (52%). The data suggest that the majority of the participants (89%) had either a radiological contrast swallow study or a VFSS.

The range of professional services related to feeding and swallowing before and after gastrostomy placement are reflected in Table III.

### Discussion

The most frequently documented indications for gastrostomy placement were dysphagia, aspiration and need for nutritional support, suggesting that safety and nutritional requirements were key factors/considerations in managing these patients. Dysphagia has similarly been reported as the main indication in other studies.<sup>4-6</sup> While aspiration was the second most common indicator in this study, other studies<sup>15,16</sup> reported aspiration as the most prominent indication. The results for need for nutritional support as an indication are similar to those of other studies, which reported nutrition as the second most common indication for gastrostomy placement.<sup>4,15</sup> Fortunato *et al.*<sup>17</sup> reported that 49% of their participants received a gastrostomy for growth faltering.

The results of this study suggest that South African infants and children requiring gastrostomies for feeding and swallowing difficulties were likely to present with multiple diagnoses, of which neurological and/or GIT impairments were the most prominent medical conditions. Neurological impairment has been associated with gastrostomy placement in the paediatric population.<sup>4,6-10</sup> Cerebral palsy was the main neurological diagnosis, which is similar to other studies reporting on gastrostomy placement.<sup>3,6</sup> Children with cerebral palsy frequently have dysphagia<sup>3,4,7,8</sup> and therefore may require gastrostomy feeding.

In the present study, the large proportion of participants with neurological impairment may account for the high occurrence of GIT diagnoses that were mostly attributed to GOR. GOR is known to occur together with neurological conditions.<sup>8</sup> The co-occurrence of GOR in the paediatric population with gastrostomies has been discussed,<sup>3-6,18</sup> but GOR is not an indication for gastrostomy placement on its own.

Respiratory illnesses were present in a third of the study population, and may have been caused by aspiration in participants with feeding and swallowing difficulties.<sup>19</sup> Aspiration frequently occurs in children with neurological impairment,<sup>8,20</sup> which may explain why it was the second most common indication for gastrostomy placement in this study.

The median time from identification of a problem to gastrostomy placement was 1.25 months, which could not be compared with waiting times elsewhere as there is no other literature on this aspect. Surgical waiting lists, participant illness and delayed consent may influence waiting times; this period should, however, be minimised for optimal health (respiratory and nutritional) outcomes and costs.

The majority of referrals were made by SLTs, followed by doctors and dietitians. This study focused on participants who had feeding and swallowing difficulties, which may explain why the SLTs made the most referrals. Half of the participants had a clinical feeding and swallowing evaluation, while 89% had radiological contrast swallow studies or VFSSs indicating the services required prior to gastrostomy placement.

A range of health care professionals provided services to the participants in the study both before and after gastrostomy placement. The multidisciplinary team included the SLT, dietitian, surgeon, GIT specialist and nurse practitioner, which is similar to teams recommended in other studies.<sup>6,12,13</sup>

The majority of participants consulted the SLT before gastrostomy placement for assessment and intervention of feeding and swallowing difficulties. SLT management was provided to a smaller number of participants for a further 18 months after gastrostomy placement. Loss to SLT follow-up after gastrostomy warrants further investigation, especially as these participants had feeding and swallowing difficulties and attended other services at the hospital. The SLT usually provides therapy and re-evaluates feeding and swallowing to determine the need for ongoing gastrostomy feeding.<sup>2,6-8</sup> The dietitian and stoma sister were both consulted by 97% of the study population after gastrostomy placement, demonstrating good post-surgical support in terms of nutritional and gastrostomy care, which improve health after gastrostomy.<sup>6,13</sup> However, less than

**TABLE III. PROFESSIONALS RENDERING SERVICES BEFORE AND AFTER GASTROSTOMY PLACEMENT (N=114)**

Professional	Services before (N (%))	Services after (N (%))	Mean duration of services (mo.)	Maximum duration of services (mo.)
SLT	97 (85)	68 (60)	18	100
Dietician	87 (76)	111 (97)	18	103
Surgeon	74 (65)	45 (40)	10	33
Gastro-enterologist	50 (44)	24 (21)	6	21
Stoma sister	17 (15)	111 (97)	10	31



*Infants and children requiring gastrostomies for feeding and swallowing difficulties were likely to present with multiple diagnoses.*

15% of the participants received services from the stoma sister before gastrostomy placement. Health care professionals working with infants and children with gastrostomies should be aware of the role of the SLT in ongoing management, and particularly the pre-operative role of the stoma sister, as parents report a lack of knowledge and understanding about gastrostomy that needs to be addressed pre-operatively.<sup>21,22</sup>

These results confirm that this population requires assessment and ongoing management by a team of health care professionals. However, these services may not be available at all levels of health care in South Africa, which may affect access.

### Conclusion

There are inherent limitations in retrospective studies, such as missing data and diversity of data. However, the results of this study provide a starting point for specific information on gastrostomy placement in the South African paediatric population. Dysphagia was the most frequent indicator for gastrostomy placement in the study population. Most of the participants presented with multiple medical diagnoses, of which neurological impairment was the most prominent. They required services from a number of health care professionals both before and after gastrostomy placement. The results of the study suggest that children with gastrostomies for feeding and swallowing difficulties did not receive ongoing SLT management after gastrostomy, which needs to be addressed by the health care team.

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