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Gastrostomies Preserve but do not Increase Quality of Life for Patients and Caregivers

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Short Title: Quality of Life after Gastrostomy insertion

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Abbreviations: EQ-5D, EuroQOL-5-Dimensions, HRQoL, health related quality of life, PEG, percutaneous endoscopic gastrostomy; PIG, per-oral image-guided gastrostomy, VAS, visual analogue scale

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ABSTRACT

Background & Aims: Gastrostomies are widely used to provide long-term enteral nutrition to patients with neurological conditions that affect swallowing (such as following a cerebrovascular accident or for patients with motor neuron disease) or with oropharyngeal malignancies. The benefits derived from this intervention are uncertain for patients and caregivers. We conducted a prospective, multicenter cohort study to determine how gastrostomies affect health-related quality of life (HRQoL) in recipients and caregivers.

Methods: We performed a study of 100 patients who received gastrostomies (55% percutaneous endoscopic gastrostomy, 45% radiologically inserted) at 5 centers in the United Kingdom, 100 caregivers, and 200 population controls. We used the EuroQoL-5D (EQ-5D, comprising a questionnaire, index, visual analogue scale) to assess HRQoL for patients and caregivers before the gastrostomy insertion and then 3 months afterward; findings were compared with those from controls. Ten patients and 10 caregivers were also interviewed after the procedure to explore quantitative findings. Findings from the EQ-5D and semi-structured interviews were integrated using a mixed methods matrix.

Results: Six patients died before the 3-month HRQoL reassessments. We observed no significant longitudinal changes in mean EQ-5D index scores for patients (0.70 before vs 0.710 after; $P=.83$) or caregivers (0.95 before vs 0.95 after; $P=.32$) following gastrostomy insertion. The semi-structured interviews revealed problems in managing gastrostomy tubes, social isolation, and psychological and emotional consequences that reduced HRQoL.

Conclusions: We performed a mixed methods prospective study of the effects of gastrostomy feeding on HRQoL. HRQoL did not significantly improve after

gastrostomy insertion for patients or caregivers. The lack of significant decrease in HRQoL after the procedure indicates that gastrostomies may help maintain HRQoL. Findings have relevance to those involved in gastrostomy insertion decisions and indicate the importance of carefully selecting patients for this intervention, despite the relative ease of insertion.

Keywords: Outcome, Decision making, PEG, RIG, Mixed Methods

INTRODUCTION

Gastrostomies are widely used to provide long-term enteral nutrition when oral intake is inadequate. They are most frequently performed in patients with neurological conditions affecting swallowing (e.g., post cerebrovascular accident, motor neurone disease) and in those with oropharyngeal malignancy.¹ 17,000 gastrostomies are estimated to be inserted annually in the United Kingdom, compared to 125,000 procedures in the United States of America.²⁻⁵ These estimate values and paucity of contemporary data internationally, highlight the uncertainty that currently exists in the medical literature regarding the frequency of enteral access placements.⁴

Although these procedures are widely performed, controversies exist regarding the merits of this intervention. These controversies reflect the absence of an evidence base supporting their role in certain patient groups, and the high morbidity and mortality identified in others.⁶⁻⁹ Quality of life is another important health outcome measure, which has been poorly characterized in this group of patients. Improving an understanding of this outcome measure is pertinent to those involved in the decision-making process regarding gastrostomy insertion, as improvements in survival and nutritional status could be perceived to be of limited gains, if no quality of life improvements are achieved for patients.

Health-related quality of life (HRQoL) can be defined as the way illness, pain and motor activity influences daily behavior, social activities, psychological well-being and other aspects of an individual's life.¹⁰ Currently, an understanding of HRQoL in gastrostomy patients has been focused on patients with cancer¹¹⁻¹⁸, despite most gastrostomy insertions occurring in non-cancer individuals.¹⁹⁻²¹ The influence

gastrostomies have on caregivers is also poorly appreciated. A recent British Medical Journal editorial discusses the impact healthcare interventions have on caregivers and raises concerns about the current paucity of knowledge about caregiver outcomes.²² Researchers are now challenged to provide better evidence of the effectiveness and efficiency of healthcare intervention from the perspective of all individuals involved in healthcare decisions (i.e. inclusive of caregivers). Through advancing understanding of caregiver outcomes, the novel concept of “carer-proofing” healthcare decisions can be achieved.²² This need to carer/caregiver -proof healthcare decisions is pertinent to gastrostomy insertion decisions.

Mixed methods research can be used to assesses HRQoL. Mixed methods research combines elements from differing research methods (e.g. quantitative and qualitative methodologies) to produce converging findings in the context of complex research questions.²³ The use of this novel technique has increased over recent years through its ability to enhance understanding, and achieve clinically relevant findings.²⁴ Another merit of this technique is that views from individual patients and caregivers are expressed. Incorporation of individual’s reported outcomes has the potential of helping inform the clinical decision making process, pertinent to gastrostomy insertion decisions.²⁵ This prospective, multicenter study aimed to evaluate how gastrostomies influence HRQoL in both patients and caregivers using mixed methods research.

METHODS

Setting

Adult participants (>16 years old) were enrolled from five hospitals in South Yorkshire and North East Derbyshire, United Kingdom (Royal Hallamshire Hospital, Northern General Hospital, Chesterfield Royal Hospital, Rotherham Hospital, Doncaster Royal Infirmary). These hospitals in combination serve a population of just over 1.5 million people and perform approximately 350 gastrostomies annually.²⁶ At all hospitals percutaneous endoscopic gastrostomy (PEG) and radiologically-inserted gastrostomies (RIG) were available as potential methods of inserting a gastrostomy. No surgically inserted gastrostomies were performed during the study period. Selection as to which procedure was undertaken was left to the discretion of the referring clinician, with similar outcomes following the two techniques (PEG and RIG) reported previously by our group.²⁷

Group 1 – Assessment of HRQoL

An explanatory sequential mixed methods design was used incorporating two differing HRQoL assessment tools.²⁸ The rationale for using a mixed methods approach was to attain a more complete picture of an individual's quality of life, using different forms of complementary data. The two-phase design of this study involved collection and analysis of quantitative data from patients and caregivers, prior to a second phase when qualitative data was collected. This approach enabled exploration and possible explanation of the quantitative findings and was used to assist in sampling.

Participants

Patients referred for a gastrostomy and caregivers of patients with a gastrostomy were eligible for inclusion in this study. Participants were excluded if they were too unwell, unable to communicate or if English was not understood. Caregivers were defined as an adult family member or friend providing unpaid care for an individual with a gastrostomy. Patients were most frequently recruited alongside their own caregivers, although occasionally patients and caregivers were recruited in isolation if their counterpart was ineligible for the study (e.g. unable to communicate).

Nutrition teams within individual hospitals helped identify potential participants for this study, who were then approached by clinical research nurses if they agreed. Information sheets were provided either by direct contact with the participant in hospital or by writing to them personally at home. In both cases, individuals were contacted a few days after the information sheet was provided, to question if they wanted to meet and discuss the study further with a member of the research team or take part. The research team met those who wanted to meet and following informed consent being obtained, participants were enrolled.

Phase 1: Quantitative Assessment

EuroQol-5D (EQ-5D) is the National Institute of Clinical Excellence's (NICE) preferred measure of HRQoL in adults.²⁹ It is a quick and easy bedside tool that takes 2-3 minutes to complete consisting of a questionnaire, index and visual analogue scale (VAS). EQ-5D has previously been evaluated in the area of gastrostomy feeding.¹⁰

Five dimensions (mobility, self-care, usual activity, pain/ discomfort and anxiety/ depression) and three levels (no problems, some problems, extreme problems) in the EQ-5D questionnaire create 243 unique health states. These states can be then converted into a single index value between -0.59 and 1.00, facilitating the calculation of quality-adjusted life years (QALYs). The VAS is a millimeter scale, 20 cm in length, ranging from 0 (worst imaginable HRQoL) to 100 (best imaginable HRQoL). The VAS complements the subject's description of HRQoL within the questionnaire.

In this study, we use EQ-5D to assess HRQoL in both patients and caregivers at baseline (prior to gastrostomy insertion) and then again at 3 months (post insertion). The decision to reassess patients and caregivers at 3 months was pragmatic, allowing sufficient time for gastrostomy feeding to have any potential influence on HRQoL, whilst also considering the high mortality rates identified previously following this intervention. In addition, to assessing longitudinal changes in HRQoL in both patients and caregivers using EQ-5D, findings at 3 months post gastrostomy insertion were compared with a control group drawn from the general population of Sheffield.

Phase 2: Qualitative Assessment

Semi-structured interviews were conducted on a sample of participants who had undergone phase 1. The principle investigator (MK) undertook these interviews, having had no previous involvement in the clinical decision-making process regarding gastrostomy insertion, which could have potentially influenced responses. Purposive sampling was undertaken to ensure assessment of a cross sectional cohort with differing underlying conditions. Findings and variables assessed in Phase 1 study were used to refine interview schedules for the semi-structured interviews, aiming to

gain a richer understanding of results obtained using the quantitative assessment. Most questions asked were open ended and undertaken face-to-face within individual's own homes or if requested in private surroundings within hospitals. Slight differences were made to the interview schedule of the caregivers when compared to the patients, reflecting the impact gastrostomy insertion had on them personally. Most participants were interviewed in isolation, however two patients requested the presence of a relative during the interviews, which was allowed. In patients with dysarthria, written communication was permitted during the course of the interviews. All interviews were undertaken in English, with an average length of 22 minutes. Following informed consent, interviews were tape recorded and transcribed later, with all potentially identifying information excluded or coded. Transcripts were sent to participants to be reviewed afterwards, ensuring accuracy of the transcription and allowing a means of quality control.

Analysis

The phase 1 quantitative data findings were analyzed using statistical packages for the social sciences (SPSS Inc., Chicago, Illinois, USA), version 20.0. Baseline and 3 month post-insertion EQ-5D index and VAS scores were compared using a paired t-test, after Shapiro-Wilk normality testing indicated a good fit (p value >0.05). An independent T-test was used to compare findings between differing groups, with p values <0.05 considered significant. In phase 2 of the study, a thematic interpretive analysis was used, where transcripts were coded in NVivo (QSR International Pty Ltd. Version 10) using a coding structure, based on the interview schedule and findings from Phase 1. These codes were subsequently organized by theme, enabling

comparisons to be made between differing individuals. Integration of the EQ-5D findings and semi-structured interviews was then done using a mixed methods matrix, allowing further exploration and understanding of quantitative findings from the qualitative data³⁰

Ethical Considerations

This study protocol was: approved by the Yorkshire and the Humber Research Ethics committee (REC reference - 11/YH/0152), registered with the Sheffield Research and Development department (reference - STH15871) and included in the National Institute for Health Research Clinical Research Network Portfolio (Portfolio ID - 11090).

RESULTS

A total of 100 gastrostomy patients and 100 caregivers were prospectively recruited during the study period, alongside 200 population controls. Characteristics of these individuals are demonstrated in Table 1. PEGs accounted for 55% of the gastrostomy insertions, with the remaining insertions being performed radiologically (RIGs). All caregivers completed follow up assessment at 3 months, however 6% (6/100) of the patients who underwent a gastrostomy died prior to their 3-month follow up. Of these 6 individuals, 3 had PEG insertion and 3 had RIG insertions.

Phase 1 – Quantitative Data (EQ-5D)

Table 2 shows baseline and 3-month follow up EQ-5D scores for both patients and caregivers, alongside EQ-5D scores for the population controls. When analysing longitudinal changes in HRQoL scores, no significant change in mean EQ-5D index

scores was noted in either the patients (0.70 versus 0.71, $p=0.83$) or the caregivers (0.95 versus 0.95, $p=0.32$) following gastrostomy. These findings were corroborated by the EQ-VAS, with mean scores unchanged at 3 months in either the patient group (67.2 versus 67.4, $p=0.65$) or in the caregivers (96.5 versus 96.7, $p=0.18$).

When compared to population controls, caregivers had comparable HRQoL (mean EQ-5D index score = 0.95 versus 0.93, $p=0.87$) following gastrostomy unlike the patients, who had significantly lower HRQoL at 3 months (mean EQ-5D index score = 0.73 versus 0.94, $p<0.0001$). Outcomes in the gastrostomy patients did differ dependent on the underlying referral indication, with lowest HRQoL at 3 months being in individuals who had a previous cerebrovascular accident (mean EQ-5D index score = 0.513), followed by progressive neurodegenerative conditions (mean EQ-5D index score = 0.657) and then oropharyngeal malignancy (mean EQ-5D index score = 0.835). In the 9 patients who underwent a gastrostomy for alternative indications the mean EQ-5D index score was 0.756.

Phase 2 – Semi-structured Interviews

Ten patients and ten caregivers agreed to participate in the interviews. Of the patients, two had undergone a gastrostomy following a previous cerebrovascular accident, four had oropharyngeal cancer and four had progressive neurological conditions. Six of the caregivers were partners of patients requiring a gastrostomy; two were children of patients and two were siblings. Individually, they cared for six patients with progressive neurological disease, three with oropharyngeal cancer and one who had a previous cerebrovascular accident. The framing of the topics for the semi-structured interviews were informed by the findings from Phase 1 where lower HRQoL in

patients was identified, alongside differences according to referral indication. Questions devised encouraged discussions as to why HRQoL was lower in patients and exploring factors that may have influenced these outcomes. Five main themes were identified from the data analysis: expectations of gastrostomy feeding, gastrostomy management, physical wellbeing, psychological and emotional welfare, and social consequences of gastrostomy feeding. Each theme is discussed below incorporating both patients and caregivers insights.

Expectations of gastrostomy feeding

Both patients and caregivers at the commencement of gastrostomy feeding conveyed high expectations, with aspirations that it would help improve nutrition and help survival. Many felt that information about gastrostomy feeding was well communicated by healthcare professionals at the outset, but some wished to have had more information, particularly pertaining to some of the long term issues and practicalities. Most agreed that after three months, the gastrostomy had met expectations with regards to nutritional benefits (e.g. weight gain, halting previously identified weight loss), however two caregivers questioned this benefit as the patient's underlying medical condition had not significantly improved.

Gastrostomy management

Once at home, caregivers had an integral part in the management of patients' gastrostomy tubes. Many expressed early anxiety and lack of education as barriers to initial success, which were overcome with further experience and support from differing healthcare professionals. Some caregivers expressed a dependence on themselves to provide the feeding regimes to their relatives, which influenced their

own daily routines. Although frequently expressed as being time consuming and sometimes messy, many patients and caregivers were accepting of the need for gastrostomy feeding, and had adopted strategies to maintain daily lifestyles and social interactions.

Physical Wellbeing

A number of patients noted improvement in fatigue levels following gastrostomy insertion, however this did not necessarily reflect improvements in actual physical function, with underlying diseases usually determining capabilities. Two patients commented on improvements in reflux and vomiting symptoms post gastrostomy. No direct influence of gastrostomy feeding was identified on the physical wellbeing of caregivers.

Psychological and emotional welfare

In both patients and caregivers, perceptions of psychological and emotional wellbeing were diverse. Patients frequently expressed long-term health as a concern and the impact this may have on their friends and family. One patient expressed a view that the gastrostomy feeding tube was a burden to them and their partner but that they had no alternative if they wanted to survive. The impact of not being able to eat was also explored in all patients and many missed the sensation of being able to eat and taste in the normal manner, when compared to feeding via a gastrostomy. With regards to the caregivers, concerns most often expressed by them were regarding their loved ones who had undergone gastrostomy placement and their future health. Financial concerns were also of anxiety to some, having previously been managed by their partners.

Social consequences of gastrostomy feeding

Three patients reported that they felt socially excluded because they could not eat meals in a normal manner following gastrostomy. This made it difficult for them to watch other people eat and enjoy food, so they actively avoided mealtimes and often going out. Others felt that exclusion of mealtimes was beneficial to them following gastrostomy, as the pressure and struggle to eat no longer existed. With regards to getting out of the house, some patients and caregivers expressed that the gastrostomy was more discrete than other nutritional support methods, enabling them to do their normal daily activities in public without the perception of others of being unwell.

Integration of Phase 1 and 2

Following identification of differing mean EQ-5D scores in the different gastrostomy referral subgroups a mixed methods matrix was created to explore findings (Table 3). This helped provide a number of potential explanations as to why gastrostomy patients have lower HRQoL when compared to the general population. Interestingly, whilst some of the responses from the interviews were disease specific, most perceptions provided by participants were relevant to all groups with social isolation, complications and management issues of tubes all being pertinent to gastrostomy patients' and caregivers' HRQoL.

DISCUSSION

This is the first mixed-methods study performed in gastrostomy feeding, demonstrating that HRQoL does not significantly improve in either patient recipients or caregivers following gastrostomy insertion. Although improvements were not identified, HRQoL did not significantly change over time in either group. Given that

gastrostomy recipients frequently have chronic progressive illnesses where a deterioration in HRQoL may be expected, the demonstration that HRQoL may be preserved following gastrostomy insertion is important and could be used to inform gastrostomy insertion decisions.

In the first part of this study, quantitative assessment demonstrated that gastrostomy patients had significantly lower HRQoL compared to population controls, which was further explored using semi-structured interviews. This mixed methods approach enabled a better understanding of HRQoL in these individuals, and also provided insights into the impact this had on their caregivers. Findings from this study could be used to support future clinical decisions regarding gastrostomy insertions and potentially “carer-proof” them, by better informing both patients and their caregivers about the merits of this intervention.^{31, 32} This research could also provide an opportunity to co-produce with patients a resource to aid shared decision-making.^{33, 34}

The importance of patient selection and the need to appropriately counsel patients and their caregivers before gastrostomy insertion is emphasized by this research. Although gastrostomies are relatively easy to perform, challenges are frequently encountered regarding gastrostomy insertion decisions in certain patients. Factors considered on an individual basis include survival, healing of pressure sores, reduction of aspiration and the possibility of discharge to a nursing home.³⁵ Ethical and medico-legal issues add to the complexity of this decision making, alongside assessments of risk (both procedural and patient related).³⁶ Our research attempts to better characterize HRQoL. Although this is only 1 facet involved in the complex decision making process, this outcome has advantages over other measures in being a patient and a caregiver

reported outcome. Given the importance of patient autonomy in decision making, we believe that the true merits of our work is in helping endoscopists and healthcare teams provide more accurate and factual, but sensitive, education regarding gastrostomy benefits to both patients and their family.^{35, 36} Given the absence of prospective randomized controlled trials evaluating the alternatives to gastrostomy feeding (e.g. long-term nasogastric feeding, optimizing oral feeding techniques or confining nutritional intake to a patient's own volition), this work could help better inform both patients and their caregivers.

Although this study has strengths in being prospective in design, multicenter, and novel in using mixed methods, there are potential limitations to this work. Firstly, patients who were too unwell or could not participate due to cognitive or communicative problems were not included in the HRQoL assessment. This could have resulted in a selection bias. This may also explain why the mortality was relatively low in this group of patients at 6% at 3 months. In addition, in assessing longitudinal change in HRQoL a longer follow-up of individuals beyond 3 months could have demonstrated different outcomes and potential improvements in HRQoL. The high baseline HRQoL in caregivers (comparable to the general population) may have also limited the opportunity for an improvement in HRQoL over time.

Another limitation of this work is in the analysis of EQ-5D findings. Both patients and caregiver groups showed no statistically significant change in mean index or VAS scores between baseline and 3 months. Whilst this may not represent statistical significance, slight differences in index scores could be deemed to be clinically relevant. Although there is a paucity of work evaluating the smallest change in EQ-

5D index score needed to be important, one study found that the minimally important difference (MID) in EQ-5D index scores was 0.07 in 11 different patient groups (not including gastrostomy patients), which was not achieved in either our patient or caregiver groups at 3 months.³⁷

The validity of our comparator group to assess HRQoL is another potential limitation to our work. In this study we used population controls to compare HRQoL with both patients and caregivers. An alternative and possibly better comparator group could have been patients with similar diagnoses who refused or who were deferred a gastrostomy. Although this issue was considered, our previous study evaluating deferred gastrostomy patients showed that often these individuals were more unwell, limiting their potential to complete our HRQoL assessments, recruitment into the study and potentially raising questions as to their suitability as appropriate comparators.³⁸ Although we recognize this limitation, we feel our study design was pragmatic and addresses a common perception that gastrostomies lead to improvement in outcomes.

Previous published data assessing HRQoL following gastrostomy insertion is conflicting, with some studies suggesting HRQoL benefit following gastrostomy insertions.^{12, 39, 40} This study adds to the literature by being the largest prospective study evaluating a cross sectional cohort of gastrostomy patients, and provides longitudinal outcomes in both gastrostomy patients and their caregivers. What our findings do support from previous work is that HRQoL does vary in gastrostomy patients dependent upon the referral indication.^{10, 40} When our findings are considered in the context of our previous work evaluating mortality and other recently published

prospective mortality studies, it would appear that patients with oropharyngeal cancer have the best outcomes, both with regards to mortality and HRQoL.^{38, 41} Our study also provides insights into why patients with gastrostomy feeding tubes have lower HRQoL when compared to population controls. Whilst underlying conditions did influence HRQoL, the burden associated with managing gastrostomy feeding tubes, the feelings of social isolation and the impact this had on psychological and emotional well-being were cross cutting themes pertinent to most gastrostomy patients and caregivers.

In conclusion, HRQoL does not significantly improve in either patient recipients or caregivers following gastrostomy insertion, although the absence of a significant fall suggests gastrostomies may still confer benefits by maintaining HRQoL. This work emphasizes the importance of patient selection and the need to appropriately counsel patients and their caregivers before gastrostomy insertion.

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Table 1: Characteristics of Patients, Caregivers and the Population Controls

	Patients	Caregivers	Controls
Total Number (n)	100	100	200
Mean Age (SD)	67 (14.7)	65 (12.2)	60 (10.1)
Sex (M: F)	56M: 44F	46M: 54F	89M: 111F
Ethnicity			
- <i>White</i>	100%	99%	96%
- <i>Black</i>	0%	1%	2%
- <i>Asian</i>	0%	0%	2%
<i>Patient's Underlying Diagnosis</i>			
- <i>Cerebrovascular Accident (CVA)</i>	24%	25%	-
- <i>Oropharyngeal Malignancy</i>	33%	30%	-
- <i>Neurodegenerative</i>	34%	35%	-
- <i>Other</i>	9%	10%	-

Table 2: Number (Percentage) of respondents reporting no, moderate and severe problems in EQ-5D dimensions and mean EQ-5D index and EQ VAS scores.

EQ-5d Domains	Patients		Patients		Caregivers		Caregivers		General	
	Baseline		(3months)		Baseline		(3 months)		Population	
	Total n=100		Total n=94		Total n=100		Total n=100		Total n=200	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Mobility										
No problems	40	(40.0)	37	(39.4)	86	(86.0)	86	(86.0)	192	(96.0)
Moderate problems	53	(53.0)	50	(53.2)	13	(13.0)	13	(13.0)	8	(4.0)
Severe problems	7	(7.0)	7	(7.4)	1	(1.0)	1	(1.0)	0	(0.0)
Self-care										
No problems	52	(52.0)	48	(51.1)	95	(95.0)	97	(97.0)	194	(97.0)
Moderate problems	44	(44.0)	41	(43.6)	4	(4.0)	2	(2.0)	6	(3.0)
Severe problems	4	(4.0)	5	(5.3)	1	(1.0)	1	(1.0)	0	(0.0)
Usual Activities										
No problems	35	(35.0)	36	(38.3)	92	(92.0)	93	(93.0)	195	(97.5)
Moderate problems	60	(60.0)	53	(56.4)	7	(7.0)	6	(6.0)	4	(2.0)
Severe problems	5	(5.0)	5	(5.3)	1	(1.0)	1	(1.0)	1	(0.5)
Pain/ Discomfort										
No problems	62	(62.0)	54	(57.4)	93	(93.0)	95	(95.0)	188	(94.0)
Moderate problems	36	(36.0)	39	(41.5)	7	(7.0)	5	(5.0)	9	(4.5)
Severe problems	2	(2.0)	1	(1.1)	0	(0.0)	0	(0.0)	3	(1.5)
Anxiety/ Depression										
No problems	81	(81.0)	76	(80.9)	94	(94.0)	92	(92.0)	190	(95.0)
Moderate problems	19	(19.0)	18	(19.1)	5	(5.0)	8	(8.0)	8	(4.0)
Severe problems	0	(0.0)	0	(0.0)	1	(1.0)	0	(0.0)	2	(1.0)
EQ-5D index mean (±SD)	0.70 (0.27)		0.71 (0.21)		0.95 (0.15)		0.95 (0.14)		0.93 (0.14)	
EQ VAS mean (±SD)	67.2 (14.7)		67.4 (14.6)		96.5 (9.3)		96.7 (8.9)		86.2 (11.8)	

Table 3: Mixed methods matrix exploring potential causes for HRQoL differences between referral indication subgroups

Gastrostomy Indication	Mean EQ-5D index score of Patients	Defining statements made by Patients during Interviews	Defining statements made by Caregivers during Interviews
Cerebrovascular Accident	0.513	"I've had lots of problems with my gastrostomy, particularly with leakage" (B) "The feed is less pleasurable than eating" (E) "The accumulation of saliva in my mouth is a big problem. I constantly need to spit it out" (E)	"I don't like the look of feeding tubes" (D) "The PEG has helped him put on weight" (C)
Progressive Neurodegenerative Conditions	0.657	"I miss eating the things I like" (D) "Feeding via the tube is time consuming" (E) "I wish I had the tube gastrostomy tube inserted earlier" (A)	"I mainly look after the feeding tube and give the feeds" (B) "It took me a while to get used to the tube but once I got the hang of it, it was ok" (B) "The sickness is a lot better and the weight has come back, which is what wanted" (C)
Oropharyngeal Malignancy	0.835	"The PEG helped as I had pain at the back of my throat following the radiotherapy" (C) "The support teams were really important to both of us" (B) "I was really anxious about having the gastrostomy inserted" (D)	"I'm not concerned about the gastrostomy tube, it's the not knowing of cancer itself" (D) "Without family support, the last few months would have been very difficult" (D)

Themes from where the defining statements were derived:

- (A) - Expectations of gastrostomy feeding
- (B) - Gastrostomy management
- (C) - Physical Wellbeing
- (D) - Psychological and emotional welfare
- (E) - Social consequences of gastrostomy feeding