

EATING AND NUTRITION

## A loss of social eating: the experience of individuals living with gastroparesis

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**Aims and objectives.** To report the experience of patients living with gastroparesis.

**Background.** The complex illness of gastroparesis is a condition of delayed gastric emptying associated with a range of different symptoms, including nausea, vomiting and depression, resulting in altered eating patterns. Patients are often over-investigated, treatments are not always successful, and quality of life is often impaired.

**Design.** A descriptive phenomenology study was undertaken to examine the experience of living with gastroparesis. Nine gastroparesis patients gave in-depth interviews. The interviews were transcribed, and framework analysis methods applied.

**Methods.** A descriptive phenomenology study was undertaken. Nine gastroparesis patients gave in-depth interviews. The interviews were transcribed, and framework analysis methods applied.

**Results.** Four main themes emerged: the first described their experiences and opinions of medical professionals, the second their understanding of mental health and mental illness, the third how they managed social settings and the fourth their identity and security. Their behaviour around food and mealtimes was often associated with feelings of loss, isolation and rejection, which influenced their reported quality of life. These factors resulted in their personal struggle to understand how this chronic, stigmatising illness affects their identity and their need for security.

**Conclusions.** The complex illness of gastroparesis affects every aspect of patients' lives. As treatments for gastroparesis continue to evolve, therapies to help these patients address the psychological impact and the feelings of loss they report must not be overlooked.

**Relevance to clinical practice.** A better understanding of these patients' sense of loss of normal eating behaviour and the associated psychological distress needs to inform gastroparesis service provision with a view to developing a more holistic service for this patient group.

**Key words:** chronic illness, eating, gastroparesis, psychological distress, symptom experience

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### Introduction

Gastroparesis is a condition of delayed gastric emptying in the absence of any mechanical obstruction (Abell *et al.* 2006). There are no data on the number of gastroparesis patients in the UK; however, the prevalence of gastroparesis in USA has been estimated at 0.01% for men and 0.04% for women (Jung *et al.* 2009), with a mean age for onset of 33.7 years (range, 15–72) (Soykan *et al.* 1998). The American Gastroenterology

Association report an increase of 138% over 10 years in the number of patients being diagnosed and hospitalised with gastroparesis (Parkman *et al.* 2004) and highlight these patients undergo more investigations than other gastroenterology patients and have longer hospital admissions (Wang *et al.* 2008).

The condition results in retention of food and fluids in the stomach, causing nausea, bloating, abdominal distension, vomiting, early satiety and pain, which can dramatically

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affect quality of life (Hoogerwerf *et al.* 1999, American Gastroenterological Association 2004). Forty-two per cent of these patients are unable to maintain their nutrition orally and will require supplementary feeding: jejunal tube feeding (15%) initially and parenteral nutrition (27% of the jejunal group) if the former is not tolerated (Abell *et al.* 2003). It is generally accepted that patients who have gastroparesis will suffer from a range of other symptoms that cannot be fully explained by their diagnosis (Keld *et al.* 2011). There is an association between psychological dysfunction and symptom severity but not between aetiology and degree of gastric retention (Hasler *et al.* 2010).

The aetiology is multifactorial, and the main categories are idiopathic (35.6%), diabetic (29%) and postgastric surgery (13%) (Soykan *et al.* 1998). Treatments aim to correct the underlying aetiology as far as possible and improve gastric emptying (e.g. prokinetics), as well as managing associated symptoms (e.g. antiemetics, proton pump inhibitors and analgesia). They have frequent hospital admissions and often undergo surgery (Kuo *et al.* 2007).

These patients are referred to one of the seven specialist centres across England and Scotland (Medtronic Ltd, pers. comm.). No nationally agreed diagnosis and treatment pathways exist, and care is currently delivered by either a gastroenterologist who manages medical interventions or a surgeon who can place a gastric stimulator.

The lack of consensus in care across the UK has resulted in uncoordinated, ineffective care pathways, and as a consequence, patients report feeling abandoned (Gregory 2012, Looney 2012). This results in health-seeking behaviours, inappropriate use of healthcare resource and possibly adverse health outcomes for the patients.

## Background

A literature search using the search terms gastroparesis, stomach paresis, gastric stasis and psych\* did not find any qualitative or phenomenology papers. There were four articles that investigated psychological illness and the link with altered gastrointestinal (GI) motility. A study of patients with major depressive diseases found a significantly increased incidence of tachygastria, arrhythmia, decreased slow wave activity and increased gastric symptoms (Ruhland *et al.* 2008). The link between affect and GI motility was also found by Bielefeldt *et al.* (2009) who found significant correlation between symptom scores and depression ( $n = 55$ ), and these scores determined disease severity better than gastric emptying. The third study identified aimed to determine the demographic and psychological predictors for functional gastrointestinal disorders (Bennett *et al.* 2000).

They took four psychometric measures (emotional distress/mood state, personality, coping style, emotional suppression) and demographic details to compare against GI transit time. Depression, hypochondriasis and anger suppression scores were higher in group with delayed transit in two or more GI regions. These studies make a strong case for the psychological influences of gastroparesis.

The fourth and final study of relevance was a longitudinal study to evaluate the psychological adjustment of idiopathic gastroparesis patients receiving gastric electric stimulation therapy as compared to diabetic and postsurgical groups (Parenteau *et al.* 2006). Gastroparesis patients rated themselves as having a significantly greater degree of hope and less anxiety at 6-month follow-up compared with diabetic patients, and the postsurgical patients had more anxiety than the idiopathic patients. They concluded that hope played a role in the psychological adjustment of patients receiving gastric electric stimulation.

The numerous studies that have investigated effectiveness of treatments are reviewed by Hejazi and McCallum (2009), who found that many patients did not respond to medical management and nutrition support options did not always significantly improve quality of life. Fifty per cent of patients who have had gastric electric stimulators placed reported no clinical improvement (Maranki *et al.* 2008). If gut-directed treatments are proving ineffective, then a biopsychosocial construct needs to be used (Madhusudan & Drossman 2010). Whilst it is imperative to develop evidence to further evaluate these treatments, research examining patient experience whilst on treatment is equally important. Phenomenological methods can complement prevailing biomedical enquiries by capturing the experience of life as it is lived by individuals with gastroparesis (Oiler 1982).

The aim of this study was to discover how patients with gastroparesis experience their disease and what does having the disease mean to them. A descriptive phenomenology study to develop understanding was designed to answer these questions.

## Methods

A descriptive phenomenological methodology using qualitative interviewing and thematic framework analysis was used. Phenomenology, as used in nursing research, is concerned with understanding the patients' own perspectives on ill health, suffering and nursing care (Oiler 1982, Jasper 1994). An interpretative approach was taken due to the unpredictability and complexity of the phenomenon within an individual context.

## Sample

The target sample was all patients attending the gastroparesis clinic (n80) to represent the full range of possible cases and support conceptual generalisation (Mays & Pope 2000). Fifteen patients were purposively sampled over a period of 2 months. The inclusion criterion (Table 1) was verified by the clinic consultant. Nine patients consented to participate and were contacted by the researcher to make an appointment for the interview. The other six patients did not reply.

## Interview guide

Each participant gave one interview conducted in a meeting room set-up to maximise a sense of privacy and security. Date and time was set to coincide with a clinic appointment, and interviews took place within 2 months of returning the signed consent form.

The opening question was:

You have been told that you have gastroparesis. How did this come about and what is it like for you?

Prompt questions were used by the researcher based on the question types identified by Patton (1990, p. 346) and provided the researcher with a broad range of enquiry to meet the research objectives (see Table 2). The question design was intended to access the meaning of the experience being described.

The research had an interview guide that was used intuitively to guide the discussion and keep it focused on the participant. The interviewer developed rapport with each participant, which facilitated open and frank disclosure. The researcher allowed the participant to lead the discussion whilst taking every opportunity to discuss their interpretation of described events. Closed questions were not used unless it was to clarify factual knowledge, such as 'How old were you then?' In this way, the participant chose what was important to include. The researcher used strategies to bracket her prior understanding of the phenomenon by asking clarification questions such as 'What

**Table 1** Inclusion criteria

Definitive diagnosis of gastroparesis
Receiving either medication only or medication plus gastric pacing treatment
Over 18 years of age
Can communicate verbally in English
Can read and write English
Attending the outpatient department within 4 months.

did you mean by ...' or 'Tell me more about the time when ...'. Use of bracketing brought the participants' experiences into clearer focus and allowed the researcher to understand what it meant to live this condition (Oiler 1982).

The recorded interview lasted from 0:42 hours long to 1:23 hours long (mean interview length being 0:59 hours).

## Ethical issues

This study protocol was approved by the Local Research Ethics Committee (REC reference number: 10/H0717/2) and Trust Research Unit. The analysis and report identify each participant by a number only. Identifiable symptoms and life situations (e.g. cyclic vomiting and in full-time education) were kept separate and not linked to sensitive clinical information as far as the analysis allowed and in this was confidentiality could be maintained.

The selected patients were sent a participant information sheet and consent form. They were asked to return the signed consent form if they wanted to participate. All those who consented to be interviewed also agreed to being recorded with a digital voice recorder (Philips Voice Tracer LFH0622). The participants were given the opportunity to complete a postinterview comment sheet. On its completion, the researcher ensured all participants were thanked and the benefit of their contribution emphasised. The interviews were transcribed within 48 hours of the interview, and each was coded so that they could not be identified and kept on a password-protected computer.

**Table 2** Examples of questions employed during the interviews based on Patton's (1990) question types

Questions to elicit descriptions of experiences, behaviour, actions and activities. For example, <i>How did your illness affect you at first?</i>
Opinion or value questions to inform about people's goals, intentions, desires and values. For example, <i>What is your view of the treatments you are having?</i>
Questions about feelings to obtain an understanding of emotional responses. For example, <i>How do you feel when you vomit and how does it affect your social life?</i>
Questions about knowledge and factual information. For example, <i>How old were you when this happened?</i>
Questions that determine which sensory stimuli – sight, sound, touch, taste or smell – the respondents are sensitive to. For example, <i>What do you do at mealtimes when food is cooking and you know you cannot eat?</i>
Background questions that aim to understand the respondents' previous experiences. For example, <i>Has your life changed since your diagnosis? If so, how?</i>

(Patton 1990, p. 346) Examples authors own

## Data analysis

The documented framework analysis process described by Ritchie and Spencer (1994) was used. The steps include familiarisation with the data, thematic analysis to develop a coding theme, indexing, charting and finally mapping and interpretation.

All the data on each theme were collated in separate documents to make the range of data across each theme visible. Each participant's comments on the themes were also collected in separate documents, and in this way, the range of data across cases was also easy to identify. This made it easy to find all comments about one topic; for example, all descriptions of coping were in one document. And because individual participants' comments on all the themes were also collated, it was easy to compare their perspective of experiencing these symptoms and description of how they managed them.

The researcher was interested in what position the participants took when faced with their symptoms, not as much in what their symptoms were. Recurring themes emerged almost immediately; for example, all the patients mentioned altered behaviour at mealtimes. Within this theme, different codes were identified, one of which was 'society's reaction to abnormal eating behaviour'. Another code within this theme was labelled as 'I am different from people who eat'. Both codes described aspects of altered eating behaviour. Discussion with the second author helped identify the nuances between participant statements.

A reflexive and iterative process was used to handle these data. This process makes the researcher's beliefs, attitudes and wishes clear so that they can be distinguished from the participants' experiences. It was this process that helped uncover the reasons why the researcher was surprised that the participants who had feeding tubes did not discuss them in their interviews. They were relevant to the researcher in her clinical role, but they did not reflect the reality of everyday life for the participants.

All data remained connected to their index code, so their source could easily be located so that the researcher could regularly check the original participant statements in context. In addition, a log was maintained of how each interview was conducted and how decisions were made in the data analysis and reporting stages. This was discussed with the second author at regular intervals.

Finally, the relationships between the themes and codes were explored using diagrams and flowcharts. This tested and clarified relationships between concepts and typologies and described associations between the concepts.

## Results

Nine patients were recruited to the study, and their demographic and medical characteristics can be viewed in Table 3. All the responders were patients who had been diagnosed for more than 1 year and had been stable on their treatment for several months. The nonresponders were mainly those who had a recent diagnosis and/or were undergoing new investigations and treatments. Most (7) had idiopathic gastroparesis, one diabetic gastroparesis and one postsurgery gastroparesis. All were receiving prokinetics, and 7 had gastric electric stimulation. Five had a jejunostomy tube to supplement their oral intake, and the other 4 were managing to maintain their weight with a modified oral diet. Most (7) were in the 31–40 age range, eight were female, six were married, and 7 did not have paid employment.

Four themes were identified as they discussed their experiences before diagnosis, which linked to their understanding of mental health concerns. They described social settings involving food and the challenges of managing the risk of vomiting in public, which led to feelings of insecurity and strategies to cope with their changing identity (Table 4).

**Table 3** Sample demographics and characteristics

	Sample ( <i>n</i> = 9)
Aetiology	
Diabetic	1
Idiopathic	7
Other	1
Treatment	
Medication only	2
Medication and gastric stimulation	7
Nutrition	
Modified oral diet	4
Jejunal feeding	5
Age	
21–30	1
31–40	6
41–50	2
Sex	
Male	1
Female	8
Marital status	
Single	2
Married	6
Divorced	1
Employment status	
Full time work	1
Part time work	1
Unemployed	6
Long term sick leave	1

**Table 4** Main themes

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Theme one: experiences and opinion of medical profession (before diagnosis)
Lack of trust in medical profession
Positive experiences with doctors
The effect of not having a diagnosis
The search for answers
Theme two: understanding of mental health/illness
Participants' opinion of mental health/illness
Medical professionals' opinion of mental illness
Theme three: managing social settings
I am different from people who eat
Society's reaction to abnormal eating behaviour
Avoid or participate – what do I do now?
Theme four: identity and security
Opinion and effect of having this disease
Who I am in relation to others who have this disease?
My life plans
My future

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**Theme one: experiences and opinion of medical profession**

There were some positive reports of doctors they had encountered. *'She was really nice but she got to the point where she did not know what to do with me'* (P4). *'My consultant was brilliant but there was no more that she could really do'* (P5). What they valued was their empathy, understanding and patience. *'Somebody who actually don't just give you lip service, but actually shows I've done something about this, I've looked into it myself, sort of thing, to try and help. And I think that makes a big difference to me ... to have someone there who I know I can go to'* (P5). Assessing the medical profession by their attitude rather than by their skill has been noted elsewhere (Shaw *et al.* 2007).

This contrasted with accounts of doctors who responded in negative ways:

Awful. It is so embarrassing because people don't know that there's anything wrong with you... I don't actually think that people can comprehend what gastroparesis is... shortly after I was diagnosed a couple of years ago, eemm, I was being really, really sick and my GP in the end actually sent me with a letter to our local casualty department and I actually argued with the nurse, in, no ... with the doctor in casualty because she told me there was no such illness. (P6)

The anxiety this caused was described graphically as follows:

It's like being in a sink full of water and you take the plug out and the water is going round and round ... I was at that point and I was about to go in that plug hole, fighting and swimming. (P8)

**Theme two: understanding of mental health/illness**

They described confusing and conflicting ideas and described mental and physical health as completely separate: *'Am I really ill or is it in my head?'* (P1), and having a mental cause for the symptoms means you are *'somebody making a stupid choice'* (P7). They felt accused of fabrication if no physical causes were found: *'It's not in my head, I'm not lying'* (P2). *'It's not something I've brought on myself to be ill'* (P9). There was a sense that mental illness was something that patients did to themselves, but gastroparesis was something that you had no control over. *'[Bulimics are] making themselves retch where mine was just coming up'* (P5). This belief seemed to be shared by relatives who ask *'why are you doing that to yourself?'* (P7) when they vomit. The participants interpreted the doctors' behaviour as suggesting that if a physical cause for the symptoms could not be found, then the source of the symptoms was not physical but mental, and this meant it was in their heads and under their control. These confusing messages from doctors, friends and family caused much anxiety.

**Theme three: managing social settings**

All the participants shared experiences that revolved around food and meals with family or friends. There was a feeling of loss and sadness as they thought about the things they missed: *'Am I going to be able to walk down the street eating?'* (P1) There were descriptions of favourite meals, steak with all the trimmings and roast dinners. But they also accepted they might never *'get back the ability back to eat as I was'* (P3) and acknowledged that even though *'Starbucks was a big part of my life'* (P8), it was now gone and the social contact it represented went with it. The abnormality of participant 8's situation was highlighted by the admission that she had stopped watching cookery programmes. But still, it was *'very difficult ... it's not normal, you know?'* (P8).

One participant describes how her family were uncomfortable when she does not eat or when she does eat and then vomits. So she chooses not to socialise for their sake:

When it comes to eating out, no. I just couldn't. I think that that in itself sometimes is a nightmare because you want to go out and it's like, friends birthdays and that, ... because we were quite close with the neighbours and we used to go out. But I just won't now. I think it's when I eat at home and I want to be sick, I know I am in a safe environment. I've got somewhere to run to quite quickly, but

But I think it's the thought when you are out, cause like, [sucks breath in through her teeth] Ooh, I could vomit any time. (P4)

She eats only when she is alone because there is no risk of disclosure. This makes it sound as if she chooses not to socialise because society does not like it, but she has had opportunities to join in whilst on holiday but found that *'It was hard to watch everyone else eat'* (P4). Now it is *her* discomfort in social settings that is determining her behaviour.

The reactions of people around them were divided between people who understand and accept their abnormal behaviour and those who did not. They were able to describe times when they could relax and be themselves in a social setting: *'they are sitting there with a meal ... quite happy ... don't comment'* (P7). But it was more common for them to talk about the difficulties they encountered: the family member who asks *'What are you ordering?'* (P3) so that she can monitor your intake, the mother who says, *'You're crazy!'* (P) when you eat a biscuit and risk vomiting, verbal challenges from waiters in restaurants about why you are not ordering, which leaves you with *'shaking and sweaty hands'*. (P5)

Study participants' abnormal eating patterns affected all their aspects, including any and all of the following: perceptions – *'Social life is centered around meals'* (P7); memories – *'Now everything tastes so different'* (P5); emotions – *'and they were just eating a banana. I completely just go mad'* (P8); content of thoughts – *'And there's always this mental anguish; what do I eat?'* (P9).

Several struggled with food cravings and a fundamental need to eat and *'physically having to chew something'* (P4). Eating had meaning for them, and this was at times more important than avoiding symptoms. *'It's like having smoothies. Oh, I can taste smoothies! I keep it down. As soon as I did that I was on the phone and saying, I've taken a smoothie down! And my mum and they are all going 'yea! Well done!' [laugh]'* P6. They remained hyper-vigilant about their food intake and its effects. As a result, they found socialising a burden especially when focused around food. Most socialising does revolve around food, but participants strove to find events (like sewing classes) that did not involve food.

The way the participants coped with these stresses was varied, but they all described some actions they took to make life tolerable. They had to accept that they had a problem: there was no point in pretending everything was ok. *'Now saying all of that doesn't mean you necessarily immediately accept it. It takes a long time to assimilate that and accept it and find other outlets, if you like, for your intellectual creativity, all of those things that we all need as people'* (P7). Once they had accepted their limitations, they were able to move on: *'It makes you feel more a part of*

*life. If you're in with a chance of doing something and keeping yourself positive, for me it's having goals. I will go out on my bike, I will go and do this, or go and do that. And even when I'm sick I will say to myself, my goal is to get out of bed and sit downstairs. To every day person that may not seem much, but when you feel really ill and feel absolutely awful, to manage to get out of bed and sit down stairs, even if you are still being sick, is quite a big thing. It just proves that I can do it'* (P9).

They put much thought and effort into managing short-term control of symptoms usually by being overly prepared. One participant always carried plastic bags to vomit in; several timed their food intake very carefully so as not to risk vomiting in awkward places; one participant lobbied her boss for just the right desk at work so that she could vomit unobserved. They also compared themselves with others who were more unfortunate; *'I could be a lot worse off ... I haven't got cancer'* (P5).

They were resourceful and creative, and they deliberately chose ways to stay involved and busy because if they did not, they risked depression: *'So you could completely fall into what is happening and you could go down like to, I don't know, I call it the depression route. So, you know, you are very like, you are very like ... engrossed in like what's happening, like the illnesses, they sort of eat you up?'* (P8). This ability to cope with was repeatedly described as starting when they accepted: *'I know things aren't as they should be. And that has taken me long to accept. That was a real turning point for me this time to understand that it is not working, you've got to accept it, you're going to have to get on with it. So it's, that's a big thing'* (P3).

#### Theme four: identity and security

They struggled as they compared themselves against society's idea of normal or their prediagnosis abilities: desiring to be the *'all singing all dancing, wonder mum you always aspired to be'* (P7). All the participants measured their illness in relation to what they were or were not able to do: *'I just want to be someone that is fit and healthy and is not constrained by an illness or a disability, who can actually do what they want to do'* (P9), *'I can't do the things normal people do, so I feel ill'* (P2). But they varied in how they related to the illness. Some described themselves as being ill as if the illness was a part of them, and they judged how people related to them based on this:

They look after me because they (friends) know I'm ill ... so I sit down and they look after me. My friend looks after me, she

controls my health and all my tablets, everything for me ... she does everything for me really ... my cleaning, she used to bathe me and she used to remind me to eat. (P2)

Others felt very strongly that they were not the illness. They avoided activities that focused on their illness and deliberately engaged in normal activities that affirm their sense of self, otherwise '*you are just the illness*' (P7). Some '*learnt to put on this public face*' (P7). They did not want to be identified with the illness and wanted to 'fool' others and even themselves into thinking they were OK: '*You almost overcompensate in terms of what you will do in a day because I'm not going to be defeated by this*' (P7). Others in this study sought social acceptance and yet at the same time needed the people around them to acknowledge their symptoms and remember that they had an illness. Whichever way they played it, they had to cope with not only their symptoms and the possible consequences of eating but also the stigmatising effects of this condition.

### Study limitations

All the patients who consented to participate had been diagnosed for more than a year and had been stable in their treatment for a while. The nonresponders were in a stage of transition, and it was theorised that they opted out of participating because they felt unable to describe or discuss something that was very new in their experience. It may be a period of stability and time to reflect that enabled the responders to put their experiences into words. It is not clear how this potential bias influenced the data. Each participant gave only one interview, so experiences over time are not captured.

This sample was a heterogenous group of participants. The sample size was small (9) but adequate for this type of qualitative research question. The rich data produced revealed strong similarities between participants and the same themes, and phenomena kept recurring.

The researcher was able to establish rapport with the participants as indicated by open and frank disclosures. This was in part due to prior knowledge and contact with the participants. This could also have influenced the interviews negatively, and the researcher was challenged to separate her nursing role (concern about a participant's low blood sugars) from her researcher role. One participant seemed to be reluctant to criticise the service and backtracked from what could have been a critical statement. It was not possible to get this participant to disclose their concerns, but the realisation that an independent interviewed might have received different data must be accepted.

### Discussion

Living with gastroparesis led to loss of social eating, which precipitated much individual distress and disrupted many social activities. What we consume, how we acquire it, who prepares it and who is at the table are forms of communication that is rich with meaning. Beyond merely providing nutrition for the body, what we eat and who we eat with can create and strengthen the bonds between individuals and communities. These participants' descriptions illustrate how food plays a large part in defining family roles, rules and traditions (Warde & Martens 2000). By choosing to join in social occasions involving eating, they may have gained pleasure from being with others, and yet, they were set apart from them by not eating with them and/or by others' difficulty in accepting their unusual eating habits. The participants in this study clearly valued social interaction at mealtimes but, because of these challenges, thought carefully about whether to participate or not in these important events.

Winkler *et al.* (2010) studied the meaning of food for patients on home parenteral nutrition (HPN), and comparisons can be made. The HPN patients also had no specific patterns of food restriction, and whilst the adverse effects on gastrointestinal symptoms were different in nature, they were similarly varied and individual. To manage this, both groups controlled their portion size: they all ate smaller portions than usual. They had a choice to make every time food or drinks were offered, which went far beyond just a preference. The consequences of making choices in stigmatising situations have been well described in the work by Joachim and Acorn (2000).

The HPN patients got great satisfaction from eating, and this outweighed the need to restrict food intake. The gastroparesis patients also described satisfaction when eating and that at times, they chose to eat in spite of the symptoms that would occur, but strove to do this in private or around people who demonstrated acceptance and understanding of their situation. There was great fear that if they ate, they might vomit, but if they avoided eating to avoid vomiting, this was also seen as unnatural and stigmatising. As a result, both groups found socialising a burden especially when focused around food.

The gastroparesis patients in this study described a variety of coping strategies, including minimising the importance of the events they were living through by playing down its impact and comparing themselves with other people who were in worse situations, thereby reassuring themselves that things could be worse. Those who strove to maintain a part of their normal lives linked this very

strongly to their sense of identity and worth. They found it difficult to accept the type of person they would be if they gave in to the symptoms. They expended much energy on avoiding action.

However, there were a couple of participants who had given in to the difficulties their symptoms presented when eating in public and had withdrawn from socialising. They were resigned to their situation and felt they had no control and influence over their symptoms. This response was noted in a study by Larsson *et al.* (2007) who undertook a qualitative study with patients diagnosed with head and neck cancer. Their sample also report the challenges of eating and the psychological consequences of not knowing from 1 day to the next what food they might manage to get down and keep down.

Gastroparesis patients (Bielefeldt *et al.* 2009) describe how their altered eating adversely affects their daily routines, their professional obligations around food and drinking, dining out with friends and many other regular reminders of how the disease had robbed them of these pleasures. Healthcare professionals often give simplistic answers about nutritional content of foods without acknowledging the true impact on the patient. In this study, the participants also reported a lack of knowledge and understanding amongst healthcare professionals, and very few stopped to ask about the impact of the symptoms on their quality of life.

They had a choice to make every time food or drinks were offered. They felt pressure from those around them to conform to normal eating and drinking behaviour. They balanced this against the knowledge that they might vomit. How participants behave in those situations depends on whether they valued inclusion and integration and suppressed their desire to eat or whether eating and meeting their own needs to behave as others took precedence. Either decision could result in unwanted attention and comment from those around them. Robinson *et al.* (2011) suggest that mimicking occurs to gain social acceptance. This may mean that these patients try to eat more in social settings where it matters to be eating the same as those around them so as not to feel that they do not belong and avoid the discordant social interactions reported in this study.

The participants' loss of social eating highlighted their need to eat on a more fundamental human level. If they were receiving tube feeding, their nutrition requirements were being met, but they recognised another need to eat. They described this as a craving and '*physically having to chew something*' (P4). Missing out on the basic human function of eating felt artificial to them.

It is apparent from the published studies reviewed that an illness that results in a chronic alteration of how food is eaten has a profound impact on the sufferers' experiences. Establishing whether there is a social reality that can be clearly described would make this knowledge applicable in many care settings. There is a great opportunity to explore the experience and meaning of eating in chronic illness.

### Relevance to clinical practice

These results highlight that it is not possible to separate the needs of the stomach from the needs of the whole person (Maslow 1954). Study participants described how their altered eating habits affected their perceptions of what a social life is, their connections with others and their emotions. Whilst we need to attend to their nutritional intake, we also need to think how this is affecting them socially and emotionally. The patient needs to know that the healthcare professional acknowledges their struggles, and this can be done by asking simple questions to introduce the topic, allowing the patient time to answer and open up and being prepared to listen. Formal assessments can also be used to help the patient explore how affect and anxiety influence their quality of life. Most of these complex problems will not be fixed in one clinic appointment, but acknowledging that they are an integral part of the gastroparesis experience allows them to be included in the management and treatment plans.

Any new service needs to include therapies that facilitate holistic assessment. Helping patients develop their ideas of self as they live with an unpredictable and chronic condition needs professional support. The patients need to be able to clearly define who they are based on a solid foundation that is not dependent on external forces. From that secure, stable place, they can look back at who they were, who they are now and all the skills and qualities they have access to that they can use to develop their own sense of self-worth, security and identity. We have little evidence to date on how well available interventions can ameliorate these daily struggles, but we might assume that traditional cognitive behavioural approaches could prove helpful when managing this illness.

Nursing is ideally placed to facilitate and support this type of care, especially when established as an integral part of the multidisciplinary team. The gastroenterology service requires specialist nurses to work autonomously and provide expert knowledge to work at the centre of a web of services, referring to and from other providers and coordinating between all health professionals (Ball 2005). In this way, patients' complex and often frag-

mented care can be efficiently and effectively delivered. These are invaluable lessons from the descriptions participants were able to share. The treatments we instigate, such as gastric electric stimulation and jejunostomy tubes, do have an impact on patients' lives, but they are not their biggest concern. Understanding how we can help patients address these issues is a much neglected part of gastroparesis care.

## Conclusion

This complex illness affects every aspect of the patients' lives. Their behaviour around food and mealtimes had a detrimental effect on their reported quality of life, feelings of isolation and rejection, heightened food cravings and stigmatisation.

The cause of their debilitating symptoms is still to be definitively proved, and the resultant assortment of treatment options causes confusion and frustration for the

patients. More studies are required to understand the full impact of this disease and how the psychological burden reported relates to the symptoms. The treatments available are developing quickly, but management strategies must include therapies to help these patients address the psychological impact of this disease.

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## Contributions

Study design: JB, CT; data collection and analysis: JB and manuscript preparation: JB, CT.

## Conflict of interest

The authors declare that they have no competing interests.

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