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**Author/s:**

Woodhouse, S;Hebbard, G;Knowles, SR

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MISS SALLY WOODHOUSE (Orcid ID : 0000-0003-3129-645X)

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## **ABSTRACT**

### **Aims and objectives**

To build on the understanding of how individuals experience gastroparesis, how gastroparesis impacts on their lives, and how they adapt to living with gastroparesis.

### **Background**

Gastroparesis is a neurogastroenterological disorder associated with increased psychological distress and reduced quality of life. Research shows that gastroparesis poses a significant burden across many facets of life, however less is known about how individuals cope and adapt to living with the condition.

### **Design**

The study employed an interpretive phenomenological approach with semi-structured interviews and thematic analysis.

### **Methods**

Ten gastroparesis patients were interviewed over the telephone (n=8), Skype (n=1), or face-to-face (n=1). All interviews were audio-recorded and transcribed.

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## **Results**

Key themes identified: 1) Frustration, 2) Identity, and 3) Coping and adaptation. Gastroparesis patients experience significant frustration around their diagnostic journey, being misunderstood, and the burden of living with the illness. Patients differed in how they identified with the illness, and this appeared to be associated with adaptation and whether they remained socially engaged.

## **Conclusions**

Gastroparesis is associated with significant frustration and burden, however some patients adapt to living with the condition more effectively than others. Identity appears to play an important role in this relationship. Support aimed at fostering a health-focused and resilient identity may assist gastroparesis patients in adaptation.

## **Relevance to clinical practice**

The findings of this study can help nurses and other health professionals better understand the experience of living with gastroparesis and the factors that help patients best adapt to living with the condition. Nurses can help promote resilience in patients by discussing the importance of being health-focused rather than illness-focused. Nurses can also support patients by helping them problem solve issues that may arise around social eating and remaining socially engaged.

**Keywords:** gastroparesis, quality of life, anxiety, depression, identity, coping, adaptation, distress, frustration, burden.

## **What does this paper contribute to the wider global clinical community?**

- Gastroparesis patients experience significant frustration around their diagnostic journey, feeling misunderstood, and the general burdens associated with the condition.
- Patients who identify as being resilient tend to adapt more effectively to living with gastroparesis.

- Remaining socially engaged is an important aspect of adapting effectively to life with gastroparesis.

## INTRODUCTION

Gastroparesis is a neurogastroenterological disorder involving delayed gastric emptying in the absence of a mechanical obstruction of the stomach (Tack 2005). Typical gastroparesis symptoms include chronic nausea, vomiting, early satiety, postprandial fullness, bloating, and abdominal pain (Camilleri *et al.* 2013) The incidence of definite gastroparesis per 100,000 person years is 9.8 in women and 2.4 in men (Jung *et al.* 2009), with approximately one third of patients being admitted to hospital for the condition (Dudekula *et al.* 2011), and a disease burden likened to that of Inflammatory Bowel Disease (Jung *et al.* 2009). The treatment options currently available for this chronic and debilitating condition are limited and in many cases lack efficacy (Abell *et al.* 2006, Bielefeldt 2012, Camilleri *et al.* 2013).

## BACKGROUND

Research involving gastroparesis cohorts has identified that psychological distress is common, with greater symptom severity linked to increased psychological distress (Bielefeldt *et al.* 2009, Hasler *et al.* 2010, Parkman *et al.* 2011, Hasler *et al.* 2013). Similarly, individuals with gastroparesis have demonstrated decreased quality of life (QoL) compared to population norms (Harrell *et al.* 2008, Bielefeldt *et al.* 2009, Hasler *et al.* 2011, Jaffe *et al.* 2011), where greater gastroparesis symptom severity is associated with poorer QoL (Harrell *et al.* 2008, Bielefeldt *et al.* 2009, Cherian *et al.* 2010, Hasler *et al.* 2011, Jaffe *et al.* 2011, Cherian *et al.* 2012, Friedenber *et al.* 2013, Hasler *et al.* 2013, Cutts *et al.* 2016).

At present, two qualitative studies have been conducted to provide further insight into how an individual experiences gastroparesis. After in-depth interviews with nine gastroparesis patients, Bennell and Taylor (2013) concluded that gastroparesis can affect every aspect of the patient's life. Patients reported undesirable experiences with medical professionals who often didn't understand gastroparesis and its impact on the individual. Patients also described feeling accused of fabricating their illness, significant difficulty in managing social settings, as well as changes to sense of identity and security. Consistent with Bennell and Taylor (2013), based upon 55 interviews with gastroparesis patients, Bielefeldt *et al.* (2009) also found that primary concerns related to attending social events and eating out, as well as frustration with healthcare providers. Other issues raised included fatigue, strain placed on relationships by the illness, and the influence that the condition had on professional activity.

The literature demonstrates that gastroparesis poses a significant burden across many facets of life, however less is known about how individuals cope and adapt to living with the chronic condition. Beyond standard treatment approaches to symptom management (e.g., dietary therapy, medication), Bielefeldt *et al.* (2009) observed that a small number of patients were aided by using relaxation techniques, however no details about the techniques were offered. Bennell and Taylor (2013) delved further into the topic and found that common coping strategies included comparing the condition to that of people perceived to be less fortunate (e.g., "I haven't got cancer"), and preparing for the likelihood of nausea by planning food intake and carrying vomit bags. Importantly, the authors identified that a key step toward coping with gastroparesis was for patients to accept the limitations of the illness. Bennell and Taylor (2013) also noted that participants managed social situations in varying ways. Some individuals completely withdrew in order to avoid the stigma and difficulties associated with gastroparesis, while others played down the impact of gastroparesis and engaged in 'normal' activities in order to prove to themselves and others that they were well.

Clearly, the impact of gastroparesis reaches far beyond the physical symptoms. In order to develop more holistic management of gastroparesis and improve QoL in this cohort, further insight into patient experience is needed. The current study sought to build on the understanding of how individuals experience gastroparesis, how gastroparesis impacts on their lives, and how they adapt to living with gastroparesis.

## **METHODS**

The study employed an interpretive phenomenological approach (IPA) with semi-structured interviews and thematic analysis. The phenomenological perspective is ideal for examining the lived-experience of individuals, allowing rich description of personal accounts (Giorgi 1997). At the same time the IPA recognizes that the researcher plays an active role in interpreting the interviewee's experience, acknowledging that the researcher's perspective, and the interaction between the researcher and the interviewee, will influence the research outcomes (Willig 2001).

### **Sample**

Ten adults with gastroparesis participated in this study (mean age: 40.2 years). Inclusion criteria were: 1) aged 18 years or older, 2) diagnosed with gastroparesis and currently under the care of a gastroenterologist, and 3) English as a first language or able to read English. Exclusion criterion: 1) currently experiencing severe mental illness.

### **Data collection**

Ethics approval was attained through the local University Human Research Ethics Committee (protocol number: 2013/261).

Participants were recruited either through online advertising, or through personal invitation from private gastroenterologists. All participants were presented with a detailed information form about the study and gave signed consent to be interviewed and audio-recorded. Each participant gave one interview which was conducted either over the telephone (n=8), Skype (n=1), or face-to-face (n=1) depending on the participant's preference.

The interviews were conducted by one research team member, were semi-structured, and were partially directed by the information that the participant wanted to share. Example interview questions and prompts are listed in Table 1, and were developed in consultation with all members of the research team who provided expert advice based on their experience working with the cohort. Questions were generally open-ended and addressed the experience of living with gastroparesis, and how to cope with the illness.

Participants were recruited until data saturation was met. The average interview duration was 48 minutes (range: 20-80 minutes). After transcribing was complete, all audio-recordings were deleted and transcripts were stored on a password-protected computer. Transcripts were de-identified and each participant given a pseudonym.

### **Data analysis**

Thematic analysis was conducted based on the steps recommended by Braun and Clarke (2006):

Step 1: Interviews were transcribed verbatim, with names changed to protect anonymity. A copy of the transcript was emailed to the interviewee for review, after which they could inform the researcher (by phone or email) of any changes they would like to make to the record. A number of participants were able to clarify words and sentences that were not comprehensible on the recording, and two participants requested that certain information be deleted from the

transcript. Once these changes were made, the transcripts were read a number of times, with initial reflections noted in a separate document.

Step 2: Transcripts were re-read with meaningful or interesting features marked in the document and coded. Data relevant to each code was collected in a separate document.

Step 3: Codes and transcripts were evaluated to establish broader level themes. A separate document was created for each theme, with all relevant data collected in this file.

Step 4: The effectiveness of the selected themes was assessed by re-reading transcripts and coded data to ensure that key information was reflected in the themes and that important features had not been overlooked. A visual map of the themes was created to examine possible relationships between themes, including the hierarchical structure.

Step 5: Themes were reviewed and refined to ensure that each was essential to describe the experience of the participants. Themes were labeled and defined by appropriate exemplars.

## **RESULTS**

All 10 participants were female, with the average duration of gastroparesis being 6.61 years (range: 0.5-21 years), and the majority of participants experiencing idiopathic gastroparesis (n=8) (see Table 2 for demographic information). Eight participants were married, five were unemployed, and seven were receiving tube feedings to meet their nutrition requirements.

Three themes were identified through analysis of the qualitative data: frustration, identity, and coping and adaptation. See Table 3 for overview of themes.

## Theme one: Frustration

Frustration was the main theme that was evident throughout the interviews, pervading many of the experiences associated with having gastroparesis. The frustration stemmed from negative experiences with the medical profession and in social settings, as well as the physical and social limitations imposed on them by gastroparesis.

### *Frustration with the diagnostic journey and being misunderstood by others*

All participants reported frustration regarding the lack of awareness around gastroparesis. *"It's a horrible disease and I feel really sorry for people that are diagnosed because there's no awareness. And it's not just the awareness amongst patients, it's an awareness from doctors knowing how to treat it, and what to do, and what options are available"* (p3). Participants repeatedly spoke about the challenges of getting an initial diagnosis. *"The biggest thing that everybody finds the most frustrating is that you have to run around to a lot of different people before you eventually get the diagnosis and the help and that just delays the help and you get even sicker and sicker"* (p10). There was a feeling of being blamed and misunderstood. *"I'd seen lots of different specialists and lots of doctors sort of told me 'oh, it's in your head', 'there's nothing wrong with you' that sort of thing"* (p6). In addition to finding little awareness of the illness, participants strongly felt that doctors did not listen to them. One participant described her desperation:

*"You get so frustrated and down that no one's listening to you and that no one will do anything to help. It's very very overwhelming. I got very very upset. I was pretty much sitting in doctors' offices saying 'I'm not coping and I'm begging for help', and they were just telling me to go away"* (p10).

Another common experience for participants was that their illness was mistaken for an eating disorder. *"For many years I was told that it must be an eating disorder because it had no medical name...that for some reason I must be in my*

*head psychologically making myself feel sick and that I had to just push through it....”* (p3). At times, the lack of understanding led some to question their own experience of the illness. *“Not knowing whether you’re imagining it because they couldn’t find anything that was wrong”* (p5).

Participants also reported feeling judged and misunderstood in social situations. *“Some people say to you ‘just get over it, you’ll be fine, get over it’. And you think, you just don’t know what I’ve been through”* (p8). Some reported discomfort going out in public due to their feeding tubes. *“You’re sitting there just going about your own business and people just stand around and stare. Or they’ll be sitting at a table near where I’m sitting with friends and they’ll just sit there and stare at you”* (p4). There were also reports of being challenged by others to eat certain foods. *“There’s been times where she’s said ‘come on, what if you just ate that party pie, what would happen?’”* (p5).

As a result of the limited understanding relating to gastroparesis, participants also expressed frustration over not knowing what their future would look like. *“Just not knowing if you’re going to get any better. If you’re going to be like this forever, or if it’s going to get worse. Yeah, not knowing if you’re ever going to be able to eat normally again. That’s pretty hard”* (p6). This contributed to difficulty in social situations: *“I guess it’s frustrating and aggravating for me, because they don’t have any answers to give me, and then when my family and friends ask, I don’t have any answers to give them”* (p7).

#### *Frustration with the burden of gastroparesis*

Participants commented on the stress caused by the limitations associated with gastroparesis. At times, participants felt as if their lives had been reduced to an intrapersonal battle with their stomach: *“Well, usually in the morning I’m woke up with nausea. And then the rest of the day is a mixture of trying to figure out how to eat so I won’t throw up and not eating so I won’t throw up”* (p9). In many ways the illness had prevented them from being the person they wanted to be:

*"I mentally want to be able to go and work or study or, you know, be able to go out and see people and do all these different things but even though I'm so much better than I was, my body still can't cope with all of that at the moment. And I think that's, you know, the most frustrating thing."* (p10)

Participants also raised many concerns about the interpersonal burden of gastroparesis. In particular, they expressed anguish about burdening friends and family. *"I really feel like I've held everyone back..."* (p5). A participant spoke of the guilt she felt about not being able to help around the house. *"When one can't do it the other one is pulling more of the weight and it's just hard to, to swallow that, for want of a better word. That you're doing that to someone you love"* (p9). The concern also contributed to feelings of isolation:

*"I don't ever want to be one of those friends or one of those family members that's constantly whining and complaining... and I guess that can leave you very alone, because there are times where it can be hard and you need someone to talk to"* (p7)

The illness also led to isolation for other reasons. Some participants spoke about losing friends due to gastroparesis. *"I lost quite a few friends when I was in hospital. Just because they taper off, because they think that hospitals are going to give you the magic pill and you're all better, but it doesn't always occur like that"* (p4). Another commented that being chronically unwell has *"basically taken away your whole social life"* (p5). There was also an emphasis on the way that social situations tend to revolve around food and drinking and the problems this raises when an individual cannot eat or drink in the 'normal' way.

*"Everything you tend to do with your friends is like we'll meet for dinner, we'll meet for lunch, like all that has stopped. You know, you can't do that so, I guess like your whole dynamic, your everything changes. Like, it's the weirdest thing, it's not just an illness, and I guess people don't understand that"* (p7).

The relationship between gastroparesis and social engagement was also highlighted in theme three – coping and adaptation. However, as will be outlined, this relationship appeared to be moderated by the role of identity.

### **Theme two: Identity**

Participants varied in how they felt about living with the effects and demands of gastroparesis. Some participants demonstrated remarkable resilience and a determination to maintain the identity of being a 'healthy' person. *"I will not let this make an invalid out of me"* (p2). Similarly: *"I'm fine, I'm healthy, that's the main thing"* (p8). Participants viewed themselves as being able to recover from medical and social setbacks. *"But most of the time I'll bounce back. I'm pretty good at bouncing back from those kind of things"* (p4). Participants also considered themselves to be persevering when confronted by difficulties:

*"I'm not one to just give up and say I'm not going to do the shopping, I'm not going to do this, I'm not going to do that...because I don't want to be that person that just can't do anything. That's when I just think I'll get really depressed."* (p5)

Participants who identified as being resilient were also likely to report that having gastroparesis had positively affected their sense of self in some way. *"I think it has made me stronger"* (p6), and *"I've been able to learn just how strong and resilient I can be, you know, given something massive, you know, you learn about yourself as well"* (p10).

However, it was clear that at times the burden of gastroparesis was too much to bear. For some, there was a feeling that the illness had completely taken control of their lives. *"Honestly, I feel like my gut rules my world, and I try not to let it rule my world, but it does"* (p3). For these participants there was a focus on the limitations associated with gastroparesis (Theme 1), and on what gastroparesis had taken away from them: *"it stops me from eating, it stops me from drinking, stops me from having the social life that..."* (p5); *"It makes you homebound"* (p9).

In some cases, participants felt they could no longer be themselves and that gastroparesis had consumed their identity:

*"I'm not the person I am, I can't be, I'm emaciated, and I'm malnourished, and I don't think right. All of those things are because I can't eat food and drink and without those things I'm not a normal person because I'm not a healthy person. For me, I'm constantly living in a state of grief over who I know I am, and what I show the world, and my symptoms and what I have to feel every day is unbearable. That's the worst for me."* (p3)

In most cases, patients identified times in their journey where they had given up, and times where they had approached gastroparesis with positivity and resilience. Here one participant explains her experience of both responses and the interplay between them:

*"I think anybody with any chronic illness goes through the point where 'ok, I'm gonna fight this, I can do this' and then you just keep getting beat down and beat down and beat down and you're like 'I can't do this', and you give up. And then something kicks in and it's like 'no, I'm not going to give up'. When you start fighting back, it makes you realise how strong you can be as a person"* (p7).

As will be discussed in Theme 3, the way an individual identified themselves in relation to gastroparesis appeared to be associated with how they coped and adapted to living with the condition.

### **Theme three: Coping and adaptation**

Participants acknowledged the importance of finding coping strategies to help manage symptoms and get through difficult times. One participant commented: *"You have to find something, and I think if I could tell anyone, it's like you have to find what works for you to get you through it because if you don't you could drive yourself crazy"* (p7). For many participants, keeping busy and finding distractions from symptom flares was an important coping strategy.

*"Distractions are often the best. Anything from playing board games with a friend, or boyfriend. Just any kind of distraction... Talking" (p4); "I might just put on my favourite movie and just relax and watch that and try not to think about missing out on my favourite foods and stuff. I might just go shopping and try to cheer myself up a bit" (p6).*

Cultivating a positive attitude appeared to be an intrinsic element in coping with the illness. One participant expressed: *"a positive attitude towards anything will help you feel better"* (p7). When asked about advice she would give to someone managing gastroparesis, another participant stated: *"Well, just be positive. Very positive. Think about what you're going to eat and yeah, just be positive"* (p8). Acknowledging that gastroparesis can present in varying degrees of severity, another participant commented: *"there's always a way of living to your best, within it"* (p3). Another participant shared the importance of keeping a positive attitude to her:

*"I know if I stayed in bed all day and didn't get up, I'd bury myself in a hole I think. I'd just spiral down. So, just got to look at the positives... You've got to look at the other things in life that are good and not just all bad to help you get through each day I think."* (p1)

The results demonstrated that individuals who were able to maintain a more positive attitude and a health-focused identity tended to be more proactive in adapting to their current health situation. In particular, this was demonstrated by making an effort to remain active and engaged in their social life. In most cases, this involved thinking of ways to socialize that did not involve food:

*"I sort of like just go to the movies now. Try and find something that doesn't involve food. Going bowling or..."* (p6)

*"I learnt to find other things, like yoga and Pilates was something that I found that I could do in small moderation."* (p4)

*"I've definitely been trying to think of things that don't involve food that I can catch up with friends. So, one of my friends, we will go for a walk together, and I've got another bunch of friends that come over and there's like a TV show that we're all a bit obsessed with and so every once in a while we'll kind of all sit down and watch that together. Had to get a bit creative, but we've gotten there."*  
(p10)

*"I go for a walk every day. I walk about 3 kilometres every day Monday to Friday with my friend and I've done that for about 3-4 years now."* (p8)

Participants reported arranging their activities around feeding routines and symptoms in order to stay engaged:

*"So night times, evening time things, we can't generally do, and we don't generally do. We go to the theatre and we go to a matinee, we go to the cinema - we go during the day. We still do all of those sorts of things, but we have to fine-tune it a bit, if you know what I mean. So that it fits in with my feeding regime."*  
(p2)

*"I try and get out of the house and go for a walk, or I started running which has been really fun. Yeah, I need to make sure I don't run too much though because otherwise I end up in hospital. But, yeah, I try. Even if I'm not, like if I'm feeling terrible I won't go out running, but even if I'm, like, if I'm feeling sort of slightly not great I'll try and push myself to go out because I often do feel better afterwards. Especially, like, yeah if I'm slightly nauseous or I've got a stomach ache that kind of moving around I find helps calm it, so..."* (p10)

Patients also took the time to explain their situation so that friends and family would feel comfortable eating around them, and continue inviting them to gatherings:

*"They feel guilty, almost. That they eat things and they feel guilty sitting and eating a meal if I'm there and not eating and things. And I think a lot of my*

*friends still have that guilt but then some of them know, 'cause like, I've spoken to them and said 'it doesn't bother me, it's ok, you're allowed to eat', so yeah, it's been a bit of a learning curve with that."* (p10)

*"My circle of friends have been very supportive. What I've had to say to them, the sort of thing that would happen, people would say 'oh, it's awful that you can't eat and we don't like sitting here eating all this stuff while you can't eat'. In the finish, I said to them all 'that's your problem, don't put that one on me, it's your problem. I'm quite happy to sit here and drink my latte while you eat whatever you want to eat'."* (p2)

Participants with a more positive identity regarding gastroparesis were also more likely to use the internet to create beneficial connections with other gastroparesis patients. Online communities gave patients an outlet to express their frustrations with gastroparesis and compare experiences:

*"I just made my own Instagram the other day about it to get my feelings out a bit, when you have a bad day. I found a few, most of them overseas, a few other ones that suffer from it. Sort of seeing what their journey...sort of similar to your journey. And you see some of them are really bad, and I'm a bit grateful I'm not that bad."* (p1)

In addition, the online gastroparesis communities provided an opportunity to support others:

*"I sort of made friends with people who have gastroparesis, and I think it's good for them to be able to talk to someone about it."* (p6)

*"Being able to have a reciprocal friendship with someone who understands what you're going through has been a massive massive help for me, for myself. And then I've also been able to support other people and that kind of gives you a bit of purpose back in life and helps you feel like you're doing something to help*

*someone else, and so, you don't kind of dwell on your own situation as much. "*  
(p10)

In contrast, individuals who had a more illness-focused identity tended to be less active: *"Yeah, it's been really hard for me to maintain anything. I do everything from home, from my armchair, and that's what I do."* (p3). Often unable to perform basic home duties or attend medical appointments: *"I can barely go to the doctor. That kind of thing. I haven't been to the grocery store in months."* (p9), and *"I've cancelled so many appointments with my gastroenterologist, not because I can't be bothered to go, but because I'm too sick to even go"* (p3).

These participants reported that the symptoms of gastroparesis made it difficult, and sometimes impossible, to maintain social connections:

*"My husband wanted to ask the neighbours down the road for a swim, and I just said 'you do what you want but I'm staying inside'. I just feel that awful I can't even come outside and talk to them."* (p5)

*"I've lost count of the times that I've picked up the phone to my mum or dad who've called and I've just said "I can't talk to you at the moment" and put the phone down. I don't even want to talk to someone when I feel that sick. Taking my kids out is impossible."* (p3)

One participant reported that attending social functions was often not worth the effort:

*"Quite often (my husband) and my girls go out together to family functions or lunches or whatever, and I stay home because it's either too hard or I'm not well or sometimes it's not worth the effort if I've got to go there and watch them all eat and I can't eat anyway then it's more detrimental."* (p5)

While, another reported that having gastroparesis had completely eliminated her social life: *"I have none. Literally."* (p9)

Despite having a more illness-focused identity, two participants did continue to socialize when they could. However, for these participants, the social events were often followed by feelings of distress. For example, one of the participants felt that she was wearing a social mask around her friends, which she thought contributed to her feeling isolated and misunderstood:

*"I put a front on for all my friends, really. Because, you know, everyone will say 'oh she's still the same, always the joke of the party', like I always have a smart-ass comment for everybody. I always have an answer for everyone and have everyone laughing but then that's how everyone would see me and I don't think that has changed."* (p7)

For the other participant, social occasions seemed to remind her of the person she was before she had gastroparesis, and how the illness had changed her:

*"So Sunday night after the people left I actually just burst out crying because I hate being antisocial, I used to be the life of the party, I used to be the one that drunk too much and offended my mother-in-law and everything. But now, I just can't, and I'm just so worn out all the time."* (p5).

See Figure 1 for an illustration of the relationship between identity and adaptation.

## **DISCUSSION**

The results of the present study provide insight into the experience of living with gastroparesis. While the physical symptoms of gastroparesis were clearly a significant issue, patients tended to place a greater emphasis on their frustration with the journey of reaching a gastroparesis diagnosis, being misunderstood and judged by healthcare professionals, friends and family, as well as the general burden of living with the condition. Identity was another clear theme in the present study, specifically relating to whether the individual identified as being

resilient (health-focused) or less resilient (illness-focused). How an individual identified herself in relation to the illness appeared to be associated with how well she adapted to living with the condition, and particularly whether she remained engaged in social activities.

Consistent with previous qualitative studies (i.e., Bielefeldt *et al.* 2009, Bennell & Taylor 2013), the results of the present study found that the impact of gastroparesis was not limited to physical wellbeing, but was instead pervasive throughout the individual's life. Some predominant concerns for gastroparesis patients that were reiterated by the present study included frustration regarding medical experiences, and feelings of being burdened by the condition, including loss of wellbeing, loss of relationships, and difficulty attending social occasions. Consistent with Bennell and Taylor (2013), the present study also found that gastroparesis had an impact on an individual's identity, significantly influencing how some individuals perceived themselves. Additionally, several participants reported that the intrapersonal and interpersonal burdens associated with gastroparesis led to psychological distress, which is generally consistent with previous research identifying an association between psychological factors and gastroparesis (e.g., Harrell *et al.* 2008, Bielefeldt *et al.* 2009, Hasler *et al.* 2010, Hasler *et al.* 2011, Jaffe *et al.* 2011, Parkman *et al.* 2011, Hasler *et al.* 2013).

With regard to coping and adaptive strategies used by gastroparesis patients, there was some disparity between previous findings and the current study. Although approaches such as the use of relaxation techniques (Bielefeldt *et al.* 2009), comparing self to others, and diligent planning around symptoms (Bennell & Taylor 2013) were brought up throughout the interviews, they were not the main strategies reported by the present sample. Rather, patients identified the importance of utilizing distraction techniques, working to maintain a positive attitude, and making an effort to remain engaged in social activities as integral to coping with, and adapting to, gastroparesis. This finding suggests that the benefit of particular coping techniques may be individual specific.

The findings of this study demonstrate that the impact of gastroparesis is far-reaching, with patients reporting a significant impact across all areas of life. As there appears to be limited understanding of gastroparesis in the medical community, it is likely that patients are not being informed about the widespread impact that gastroparesis can have and may not be prepared for the tremendous influence on QoL. The impact of gastroparesis on social connections was particularly evident throughout the interviews, with participants highlighting the strong links between socialising, eating, and drinking. Being unable to eat and drink was associated with social isolation and distress, however some participants were able to adapt to the demands of gastroparesis more effectively than others. Participants who identified as being more resilient and health-focused tended to find ways to restructure their social life in order to accommodate gastroparesis symptoms. For example, going for a walk with friends rather than meeting for lunch/dinner, connecting with other gastroparesis patients online, or meeting friends at a café and being comfortable with not ordering food. Remaining socially engaged appeared to be an important factor in adapting to life with gastroparesis.

Before discussing the implications of these findings, it is important to note the methodological limitations of the present research. Firstly, as with all interview-based studies, it is possible that participants may not have been comfortable divulging personal information to the interviewer. The interviewer had no previous contact with participants other than to arrange interviews, and had no prior experience with the gastroparesis cohort. While these factors may have created a barrier between interviewer and participant, efforts were made to establish rapport and participants did not appear to be holding back. It may have been influential that the interviewer was female, had a background in psychology and mental health, and was not a health professional. As recognized by the IPA, the unique experiences of the interviewer, who was also the primary data analyst, would have had an inherent influence on data collection and data interpretation in the present study. Therefore, future studies by other researchers may identify alternative themes.

In addition, this study utilized an all female sample, and while gastroparesis is more prevalent in females than males, key concerns relating to gastroparesis may differ between the sexes. Finally, while the qualitative nature of the present study provided a depth of understanding that could not be attained through other methodologies, there are limitations associated with it. For example, and as mentioned by Bennell and Taylor (2013), the impact of symptom severity on the key interview themes of frustration, identity, and coping and adaptation is not yet understood. Similarly, the relationships between these factors and levels of psychological distress or QoL cannot be directly assessed through a qualitative methodology.

The results of this study have clear implications for future gastroparesis research and for the healthcare needs of individuals with gastroparesis. It is evident that gastroparesis patients require treatment and support that stretches beyond physical symptom intervention and dietary advice. As highlighted by Bennell and Taylor (2013), gastroparesis patients must be provided with more holistic support. Based on the findings of the present study, a psychological support program aimed at fostering a health-focused and resilient identity may assist gastroparesis patients in adaptation. While current research provides some insight into the mechanisms that could be targeted in a psychological intervention, further research is required to build on this understanding, and to assess the effectiveness of such a program at maintaining, or improving, psychological wellbeing and QoL.

## **Conclusion**

In summary, the present study has shown that gastroparesis patients experience significant frustration around their diagnostic journey, being misunderstood, and the burden of living with the illness. However, some patients adapt to living with the condition more effectively than others. Identity appears to play an important role in this relationship, with participants who identify as being health-focused and resilient tending to adapt more effectively and remaining more socially engaged. In order to provide the best possible support for

gastroparesis patients, it is important that a more holistic approach to treatment is embraced. The results of the present study suggest that fostering a health-focused and resilient identity in gastroparesis patients may be an important component of a targeted psychological support program for this cohort.

### **Relevance to clinical practice**

The findings of this study can help nurses and other health professionals better understand the experience of living with gastroparesis and the factors that help patients best adapt to living with the condition. Nurses play an essential role in gastroparesis care and are in a position to offer support and understanding throughout the difficult diagnostic journey that patients experience. Nurses can also help promote resilience in patients by discussing the importance of being health-focused rather than illness-focused. In addition, nurses can also support patients by helping them problem solve issues that may arise around social eating and remaining socially engaged. Finally, nurses can also help to identify patients requiring further psychological support, and direct them to the appropriate services.

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Table 1. *Examples of interview questions and prompts used*

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Please tell me about your experience of gastroparesis.

How does gastroparesis impact on your relationships?

How does gastroparesis impact on your personal and social life?

How does gastroparesis impact on your mental health?

What strategies help you to manage your gastroparesis symptoms?

Please describe any positive aspects to your experience with gastroparesis.

What advice would you give others managing gastroparesis?

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Table 2. *Demographic information for sample*

Demographic information	Sample ( $n = 10$ )
Sex	
Female	10
Age	
21-30	4
31-40	2
41-50	2
61-70	2
Marital status	
Single	1
In a relationship	1
Married	8
Employment status	
Full time work	1
Part time work	1
Part time study	1
Unemployed	5
Retired	2
Aetiology	
Idiopathic	8
Post-surgical	1

Post-viral	1
Nutrition	
Modified oral diet	3
Tube feeding	7
Treatment	
Botox	2
Gastric electrical stimulation	1
Medication	7
Non-medically approved marijuana	1
Allied health	
Clinical nutrition	2
Counselling/psychological therapy	3
Exercise physiology	1
Naturopathy	1
Osteopathy	1
Rheumatology	1

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Table 3. *Main themes and subthemes*

Theme one:	Frustration
	- Diagnostic journey and being misunderstood by others
	- Burden of gastroparesis
Theme two:	Identity
Theme three:	Coping and adaptation

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*Figure 1.* The relationship between illness burden, identity, and coping and adaptation in gastroparesis patients.

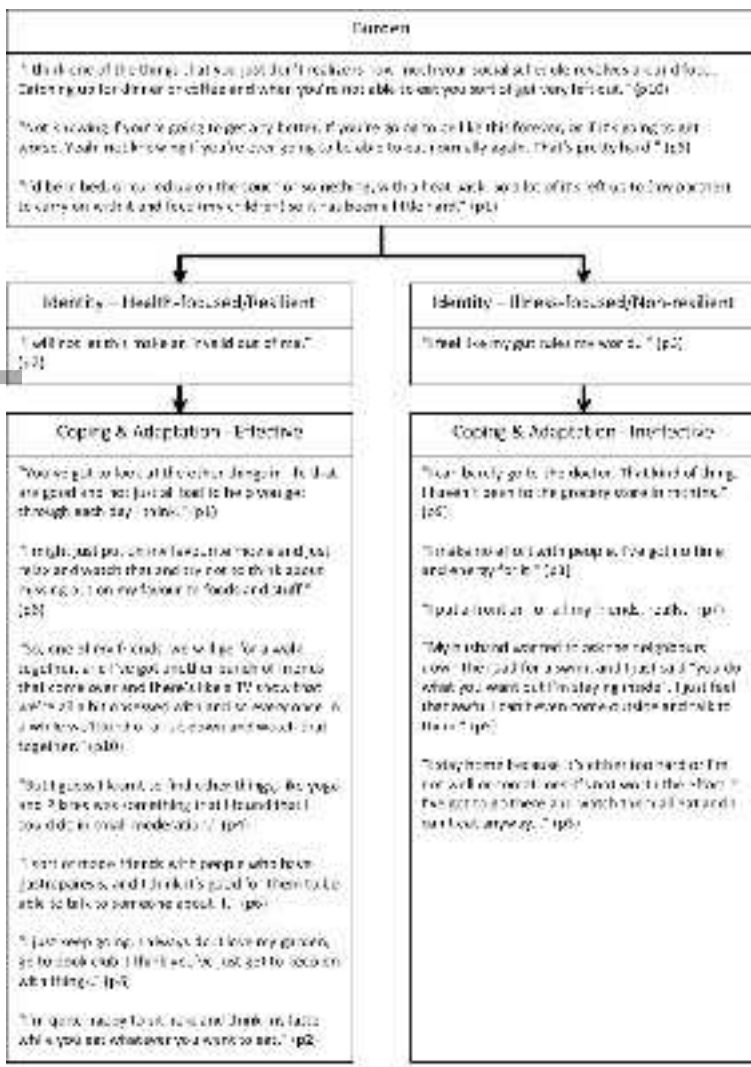


Figure 1. The relationship between illness burden, identity, and coping and adaptation in gastroparesis patients.

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