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- Infants and children
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# Journal of Human Nutrition and Dietetics

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## CANCER

# The impact of home enteral feeding on the daily lives of people with head and neck cancer: a metasynthesis of qualitative studies

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### Keywords

daily life, feeding tube, head and neck cancer, home enteral feeding, impact.

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### Introduction

Malnutrition is a major concern in people with head and neck cancer, with up to 80% of such patients suffering significant weight loss during treatment<sup>(1,2)</sup>. Enteral feeding is often indicated if they are unable to meet their nutritional requirements orally<sup>(3)</sup>. It can reduce weight loss both during and after treatment for head and neck cancer, as well as reduce treatment interruptions and

### Abstract

**Background:** Home enteral feeding (HEF) may have a wider impact on peoples' daily lives beyond influencing their nutritional and clinical status. This metasynthesis aimed to determine the impact of HEF on peoples' daily lives.

**Methods:** Qualitative studies were included with adults, who had been diagnosed with head and neck cancer and had finished their cancer treatment, with a feeding tube in place. Medline, PubMed and Cinahl were searched (August 2009 to August 2019). Thematic synthesis was conducted to interpret findings from the included studies. The 'Confidence in the Evidence from Reviews of Qualitative research' (GRADE-CERQual) approach was used to assess the level of confidence associated with each review finding.

**Results:** Seven qualitative studies met the eligibility criteria. Four overarching themes were identified. 'Loss of life as they once knew it' encompassed loss of normality. 'Developing personal coping strategies works towards restoring a sense of normality' encapsulated active adjustment and acceptance of the feeding tube. 'Navigating the hurdles when transitioning back to eating' comprised the trials and tribulations of returning to oral intake. Overall, participants recognised that they could not have managed without the feeding tube and this is encapsulated in 'Feeding tube valued'.

**Conclusions:** In many cases, initial feelings of change and loss as a result of HEF were replaced with empowerment, adaptation and acceptance following a period of adjustment. Despite the challenges associated with HEF, participants acknowledged its purpose as being functional, as well as reassuring. Future research should explore barriers and facilitators to self-management and patient empowerment amongst those receiving HEF.

nutrition-related hospital admissions<sup>(4,5)</sup>. Enteral feeding is often used in these patients to support longer-term nutritional requirements in the community setting<sup>(6–9)</sup>.

Despite the potential for home enteral feeding (HEF) to positively impact on patients' nutritional and clinical status, living with HEF can constitute an additional burden<sup>(10–12)</sup>. Quantitative studies have found that people with head and neck cancer on HEF report a poorer quality of life compared to those who have never had HEF or

those who have had a feeding tube removed<sup>(13–17)</sup>. Furthermore, previous quantitative studies have found that HEF can negatively impact on social eating<sup>(18)</sup>, social functioning<sup>(13,14)</sup>, daily activities<sup>(13,14,19)</sup> and relationships<sup>(14)</sup>. There is however a lack of agreement between quantitative studies regarding the extent to which HEF impacts on peoples' daily lives. For example, one cohort study<sup>(15)</sup> found that HEF did not impact on socialising, whereas two cross-sectional studies identified that 22–44% of participants found HEF to negatively impact on their family or social life<sup>(14,19)</sup>.

Because the impact of HEF can vary day-to-day and week-to-week, restricting participants' responses to a single answer on a questionnaire can be difficult to interpret and of limited value<sup>(20)</sup>. The use of set questions with predefined options may have miss some aspects of the HEF experience<sup>(21)</sup>. Knowing how often a HEF issue occurs or knowing whether an issue is 'very much' or 'a bit' of a problem, as reported in the quantitative studies, does not provide an understanding of why participants perceive this as a problem or what this problem means to participants.

The use of qualitative methodology facilitates an in-depth exploration of the impact of HEF by allowing participants to provide open and detailed responses on their entire HEF experience<sup>(22)</sup>. Participants have greater freedom in their responses to discuss areas of importance to them<sup>(23)</sup>. Investigating the daily impact of HEF amongst people with head and neck cancer would aid clinicians in supporting an ever-growing cohort of people by facilitating holistic, individualised and patient-centred care<sup>(24,25)</sup>. Additionally, having a greater appreciation of the impact of HEF would facilitate the development of coping strategies and initiatives to better support this patient group.

The current evidence-base lacks a systematic review that focuses on qualitative literature. Therefore, we conducted a metasynthesis of qualitative studies aiming to determine what impact HEF has on the daily lives of adults following treatment for head and neck cancer.

## Materials and methods

The systematic review protocol was registered on the PROSPERO database on 14 November 2017 (Registration Number: CRD42017079632), although the inclusion criteria have subsequently been amended to solely include qualitative studies. As discussed above, qualitative studies were considered to provide a richer, more patient-centred understanding of the lived HEF experience<sup>(22)</sup>. This systematic review is reported in line with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines<sup>(26)</sup>.

## Searches

The PICO (population, intervention, comparator and outcome) framework was used to determine a comprehensive search strategy (Fig. 1)<sup>(27)</sup>. Full search strategies are in the Supporting information (Appendix S1). Inclusion criteria were adults, with a diagnosis of head and neck cancer who received curative or palliative treatment, with a feeding tube in place during and following their cancer treatment, and utilising a qualitative study design. Studies were excluded if they did not meet the inclusion criteria, were dated prior to August 2009 or were not reported in English. Studies including participants receiving HEF and oral nutrition were included if findings related to those receiving HEF could be identified.

Changes in clinical practice and advancements in technologies associated with enteral feeding over time meant that it was appropriate to exclude studies that were more than 10 years old<sup>(3,28)</sup>. The impact of HEF may be specific to people with head and neck cancer as a result of the specificity of cancer treatment and subsequent side-effects<sup>(29)</sup>. Studies were therefore restricted to those including people with this diagnosis. Studies including people receiving palliative care were included to reflect clinical practice.

Databases searched included Medline (via the Ovid platform), PubMed and Cinahl (via the Healthcare Databases Advanced Search platform). The date ranges for each of the searches comprised August 2009 to August 2019. Reference and citation lists were also searched. No limits were placed on publication status.

## Study selection and data extraction

Two researchers independently screened studies based on their title and abstract. Full articles were then accessed for studies deemed eligible based on title and abstract screening. Full articles were independently reviewed by two researchers to assess eligibility. The researchers were not blinded.

Data extraction was initially undertaken by a single researcher (AT) and the data were tabulated (see Supporting information, Table S1). The second researcher (AMS) checked the data extraction tables by cross-referencing with data in the original studies. Data extraction tables were piloted.

The outcome of interest was the experience or impact of HEF, with impact including physical, psychological or social impact. Experience or impact indicators were not specified a priori. This was because there is not a gold-standard measurement to determine impact or experience in this patient group.

<p><b>P (Population):</b></p> <ul style="list-style-type: none"> <li>- Adults, people with head and neck cancer, people who are tube fed</li> </ul>
<p><b>I (Phenomenon of Interest):</b></p> <ul style="list-style-type: none"> <li>-The impact of home enteral feeding in this participant group which may include physical, psychological or social impact</li> </ul>
<p><b>Co (Context):</b></p> <ul style="list-style-type: none"> <li>- Any country and any healthcare setting (acute or community based)</li> <li>- Finished cancer treatment</li> <li>- Studies more than 10 years old not included (earlier than August 2009)</li> <li>- Only studies in the English language included</li> <li>- Published and unpublished studies included</li> </ul>

**Figure 1** PICO framework used to determine the search strategy.

### Data synthesis

The metasynthesis aimed to analyse and interpret the findings of the included studies to generate further insights<sup>(30)</sup>. First, the following data were extracted: participant quotations (first-order interpretations), the authors' interpretations of findings (second-order interpretations) and descriptive information on the research context<sup>(31)</sup>. Analysis of first-order and second-order interpretations across all eligible studies resulted in the generation of new sub-themes and overarching themes (third-order interpretations)<sup>(31)</sup>.

A constant comparison technique was used to develop third-order interpretations with each study being analysed in turn<sup>(31)</sup>. Moving through subsequent studies and by comparing with previously analysed studies, similar first-order and second-order constructs were grouped together to generate new sub-themes (third-order interpretations)<sup>(31)</sup>. New or divergent data were also added to the data analysis table. Overarching themes linked similar sub-themes together. Despite this, contrasting accounts were viewed with equal importance to accounts that showed similarities<sup>(30)</sup>. The data synthesis table is provided in the Supporting information (Table S2).

The researchers recognised that third-order interpretations were influenced by both the first-order and second-order constructs available to them, as well as their own underlying assumptions, perspectives and experiences<sup>(32)</sup>.

AT generated the sub-themes and overarching themes, which AMS checked against data from the original studies. AT and AMS then discussed and agreed the sub-themes and overarching themes.

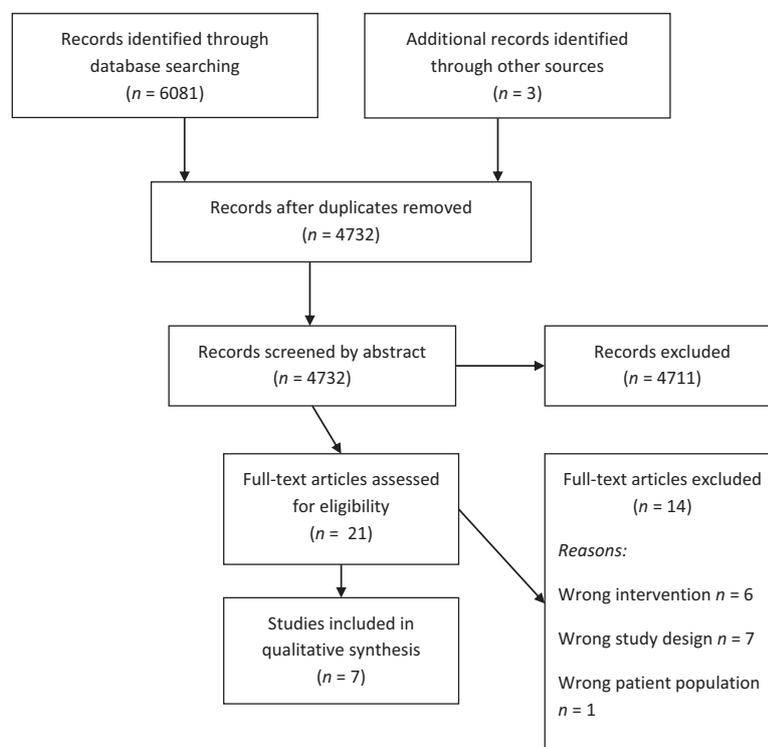
### GRADE-CERQual

The 'Confidence in the Evidence from Reviews of Qualitative research' (GRADE-CERQual) approach was used to assess the level of confidence associated with each finding from the metasynthesis<sup>(33)</sup>. GRADE-CERQual provides a transparent and structured method for reviewing findings from metasyntheses, and has undergone rigorous testing and refining through a consensus approach<sup>(33)</sup>. Methodological limitations were assessed using the CASP critical appraisal tool for qualitative studies as this is the tool suggested in the GRADE-CERQual literature<sup>(34)</sup>. Full GRADE-CERQual methods are described elsewhere<sup>(33–38)</sup>. AT and AMS conducted the GRADE-CERQual assessment (see Supporting information, Tables S3–S8).

### Results

#### Study characteristics

Seven qualitative studies met the eligibility criteria (Fig. 2)<sup>(39–45)</sup>. Many studies lacked member checking<sup>(39,40,43,45)</sup>, method triangulation<sup>(39–44)</sup>, multiple coders<sup>(39,45)</sup> or a



**Figure 2** PRISMA flowchart.

detailed description of the data analysis <sup>(40,42,43,45)</sup>. The completed CASP tool is provided in the Supporting information (Table S3).

Study characteristics are provided in the Supporting information (Table S1). Four studies were located in Britain <sup>(39,42,44,45)</sup>, and the remaining studies were based in Sweden <sup>(41,43)</sup> or Canada <sup>(40)</sup>. Five were single-centre studies <sup>(39–43)</sup>. The number of included participants ranged from six to 135. Participants in all studies had finished treatment for head and neck cancer. Five studies utilised qualitative interviews <sup>(40–44)</sup>, one study undertook a focus group <sup>(39)</sup>, and one study undertook observations and semi-structured interviews <sup>(45)</sup>. Varied methodologies were drawn upon: Thematic Analysis <sup>(42)</sup>, Ethnography <sup>(45)</sup>, Inductive Qualitative Content Analysis <sup>(41)</sup> and Interpretative Phenomenological Analysis <sup>(44)</sup>. Three studies did not specify the methodology used <sup>(39,40,43)</sup>.

### Overarching themes

Four overarching themes were identified: ‘Loss of life as they once knew it’, ‘Developing personal coping strategies works towards restoring a sense of normality’, ‘Navigating the hurdles when transitioning back to eating’ and ‘Feeding tube valued’. Each overarching theme and sub-theme is described below.

### Loss of life as they once knew it

#### *Admitting defeat*

Participants initially struggled to accept the feeding tube. Many participants reluctantly used it as a last resort when side-effects of the treatment made eating unbearable or when they became concerned with weight loss. Participants now saw eating as a relentless battle or chore <sup>(39–45)</sup>: ‘You’ve taken away the pleasure aspect of food. Food then just becomes fuel and not a leisure or pleasure activity’ (H) <sup>(39)</sup>. In some cases, the initiation of tube feeding lead to feelings of failure as using the feeding tube was seen as an admission of defeat <sup>(40,42,43,45)</sup>:

‘... And then I finally gave in and consented to have the tube placed in. I got to the point where I couldn’t eat liquids ... and certainly not solid foods, that was out of the question’ (003) <sup>(40)</sup>

#### *Confined by the feeding tube*

Some participants felt physically trapped as a result of the time taken for feeding and tube maintenance <sup>(40–44)</sup>: ‘There is work with it. It’s not a plug-in, play operation’ (004) <sup>(40)</sup>. Some lived in constant fear of accidentally damaging the feeding tube. As a result, participants set

self-imposed restrictions on activities deemed potentially hazardous including physical work, taking public transport and exercise<sup>(41,42,44)</sup>. These participants struggled to see life beyond the feeding tube and could never fully forget its presence: 'I'm always aware that the [NG] tube is there, you know and what could happen ... while I'm asleep I could actually pull the tube straight out...' (M6)<sup>(42)</sup>.

Some physically confined themselves and limited daily activities in case they experienced feed-related side-effects: 'I've kept certain people away from the house because of being sick ... so I didn't want people to see me' (Connor)<sup>(44)</sup>.

#### *Distancing of relationships*

Prior to their illness mealtimes were seen as a way of developing and maintaining relationships<sup>(39,44,45)</sup>. This was disrupted by HEF<sup>(39,44,45)</sup>. Many felt that they could not integrate with others at meal times as a result of difficulties with eating or because they struggled watching others eat<sup>(39,44,45)</sup>. This leads to them feeling emotionally distanced from others: 'Very difficult to get a girlfriend ... so much relationship building revolves around eating and drinking ... the idea of having sexual encounters with a new person is an obstacle' (H)<sup>(39)</sup>.

Relationships could be strained if family or friends did not understand the challenges participants faced when eating<sup>(44)</sup>:

'People say, do you want another one, and I say, no, I'm alright thanks. Are you sure? And you say, yeah. And I am. People can't understand you don't need to have a load' (Frank)<sup>(44)</sup>

Additionally, some participants saw the feeding tube as a physical barrier hindering relationships and intimacy<sup>(39,42,44)</sup>: 'He couldn't cuddle me [Husband]' (F1)<sup>(42)</sup>.

#### *Perceived social stigma*

Some participants felt the feeding tube highlighted their sense of being different and made them feel marginalised<sup>(39,40,42,44)</sup>. Some were anxious about receiving negative reactions as they felt other people would perceive their feeding tube as not normal. In some cases, anxiety and embarrassment about others' perceptions prevented them from undertaking usual daily activities<sup>(39-42,44)</sup>:

'I went shopping once, and a little one, he were about three, "Oh look mummy, that lady's got a worm out of her mouth, out of her nose and she's got a hole in her neck" ... It were upsetting, I couldn't wait to get home' (F1)<sup>(42)</sup>

### **Developing personal coping strategies works towards restoring a sense of normality**

#### *Restoring a sense of agency*

Here, participants actively made decisions and took positive steps to regain control over the feeding tube and feeding regimen. Being empowered meant they were able to successfully fit HEF around their daily lives and no longer felt confined by HEF.

First, participants adjusted the method of feed administration to facilitate integration of the feeding regimen into their daily life<sup>(40,42-44)</sup>: 'I preferred to have the syringe because it was a lot faster. I could feed myself within 10 min and be done' (013)<sup>(40)</sup>. Einarsson *et al.*<sup>(40)</sup> described how the feeding backpack gave greater freedom by enabling one participant to feed when out of the home.

Second, some actively adjusted their hobbies, socialising patterns or mealtime habits around HEF so they could partake in these activities<sup>(39,40,44,45)</sup>:

'Like my wife's thing with me when she has breakfast, I have two bottles of feed. And then we both have lunch in the afternoon. And then when she has dinner, I have two bottles of feed. So I'm living with her like a normal person ...' (Nicholas)<sup>(44)</sup>

Third, some participants described taking the decision to opt for a G-tube rather than a nasogastric feeding tube. The discreet nature of G-tubes enabled participants to feel more confident in undertaking their usual daily activities and socialising<sup>(40-42)</sup>: 'It didn't bother me at all. As I said, it wasn't visible at all unless you wear a tight shirt or whatever' (014)<sup>(40)</sup>.

Finally, participants took active steps to achieve what they felt was the appropriate level of support from family, friends and the public<sup>(39,40,42,44)</sup>. Support gave many participants additional confidence and feelings of security, empowering them to socialise and conduct daily activities<sup>(39,40,44)</sup>. By contrast, being able to manage HEF independently was important for some participants to cope with the perceived burden of HEF: 'I could have had [support], but I didn't, you know, I just did it on my own, I just wanted some time on me own to work it out' (M5)<sup>(42)</sup>.

#### *Acceptance*

Participants became accustomed to the feeding tube over time and in many cases came to see the feeding tube and its associated challenges as their new, accepted normal<sup>(40,41,44)</sup>: 'It's part of me' (Francesca; Lilian; Frank)<sup>(44)</sup>. Creating this new normal was important for participants and enabled them to cope better with HEF<sup>(42,44)</sup>: 'I wanted it done [G-tube] ... and then I could start living again ... I go to the cafe now, to t'pub, play bingo' (F1)<sup>(42)</sup>.

## Navigating the hurdles when transitioning back to eating

### *Learning to eat again*

The transition back to oral eating was a gradual process and involved participants having to learn to eat again<sup>(39,40,42,43)</sup>. Many were anxious because they could not know for certain which foods they would tolerate before trying them. Learning to eat again was therefore seen as a daunting process of experimentation:

‘That’s the way I feel yes, [trial and error]. You just, try this and if it won’t work, it won’t work. And 80% of the foods you try at first do not work so, you just don’t give up...’ (007)<sup>(40)</sup>

### *Home enteral feeding as a barrier*

Some recognised that having the feeding tube meant their nutritional requirements were met and so this made them less motivated to progress with oral intake<sup>(39,40,44,45)</sup>. They had become dependent on the feeding tube: ‘Although I want to eat, I want to eat normally and I would love to be able to eat I feel like I am tending to rely on the PEG and used the PEG as a, rather than and force to eat normally ...’ (A)<sup>(39)</sup>.

Patterson *et al.*<sup>(45)</sup> described the struggles participants faced when trying to fit eating around the enteral feed. If not well timed the combination of food and enteral feed could lead to bloating.

## Feeding tube valued

### *Feeding tube is a lifeline*

Many participants felt that the feeding tube was a necessity because it had kept them alive<sup>(39,40,42)</sup>: ‘Well it saved my life ... but think it was absolutely marvellous really’ (E)<sup>(39)</sup>. For others, the feeding tube was a support mechanism and provided much-needed security and reassurance<sup>(39,40,42)</sup>. Participants gained comfort knowing that the feeding tube was there should they come to need the tube: ‘Gives you hope already, right? It’s like a security blanket. Your ace in the hole sort of thing that if all goes sour, I still have my life support system here’ (004)<sup>(40)</sup>.

### *Regaining control over body weight and treatment side effects*

Here, tube feeding had taken the pressure off eating, and was seen by some participants as a positive step in taking back control of their nutritional status and treatment-related side effects<sup>(39–43)</sup>:

‘My tongue was so sensitive it was like eating raw chillies ... my gums were all white, my tongue was white, anything that touched it, it was just

stinging ... I thought “no I’m not gonna do this anymore, I’m gonna do what xxxx said and use the tube”’ (M4)<sup>(42)</sup>

### *Internal conflict*

Many participants described tube feeding as being both a positive and a negative experience, although, overall, they recognised that they could not have managed without the feeding tube<sup>(40,42,44)</sup>: ‘My initial reaction was, no (laughs), but I thought about it and, probably a blessing in disguise, right? Anyone who goes through that needs to have the tube’ (015)<sup>(40)</sup>.

## Divergent data

A further concept found by Ehrsson *et al.*<sup>(40)</sup> was how the feeding tube can reduce participants’ self-esteem as a result of them perceiving the feeding tube as malodorous and unhygienic.

Williams *et al.*<sup>(42)</sup> found additional ways in which participants coped with HEF. First, participants compared themselves to others in a worse situation: ‘Without being disrespectful I don’t know how an older person might’ve coped with it’ (M2). Second, participants hoped they would not need to use the feeding tube: ‘Dr X advised that at least 80% of patients do have to use it [gastrostomy], I thought I may be in the lucky 20% but I wasn’t’ (M1)<sup>(42)</sup>.

## GRADE-CERQual assessment

Overall, there was moderate confidence in most of the review findings (Table 1). ‘Admitting defeat’ and ‘Regaining control over body weight or treatment side effects’ were assigned low-to-moderate confidence as a result of the methodological limitations of the studies contributing to these review findings. There was high confidence in the sub-theme ‘Internal conflict’.

## Discussion

### *Discussion of review findings*

Many participants initially felt that they had lost control over their daily lives because their lives were now defined by HEF. Mourning the loss of one’s previous life and self when coping with change has been previously identified in the literature<sup>(46–51)</sup>. HEF was found to have initially imposed considerable restrictions that lead to a perceived loss of freedom and independence. Feeling confined by limited horizons is mirrored in the literature on living with long-term conditions<sup>(46–48)</sup>. As we found, during the initial stages of coping with change, patients tend to focus on how they are different to others and perceived

**Table 1** GRADE-CERQual evidence profile

Summary of review finding	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence in the evidence
Loss of life as they once knew it						
Admitting defeat	Ehrsson <i>et al.</i> <sup>41</sup> Einarsson <i>et al.</i> <sup>43</sup> Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Patterson <i>et al.</i> <sup>45</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate-to-serious concerns	No or very minor concerns	Minor concerns	Minor concerns	Low-to-moderate confidence
Confined by the feeding tube	Ehrsson <i>et al.</i> <sup>41</sup> Einarsson <i>et al.</i> <sup>43</sup> Kwong <i>et al.</i> <sup>40</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Distancing of relationships	Mayre-Chilton <i>et al.</i> <sup>39</sup> Patterson <i>et al.</i> <sup>45</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Perceived social stigma	Ehrsson <i>et al.</i> <sup>41</sup> Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Developing personal coping strategies works towards restoring a sense of normality						
Restoring a sense of agency	Einarsson <i>et al.</i> <sup>43</sup> Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Patterson <i>et al.</i> <sup>45</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Acceptance	Ehrsson <i>et al.</i> <sup>41</sup> Kwong <i>et al.</i> <sup>40</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Navigating the hurdles when transitioning back to eating						
Learning to eat again	Einarsson <i>et al.</i> <sup>43</sup> Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence

Table 1 Continued

Summary of review finding	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence in the evidence
Home enteral feeding as a barrier	Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Patterson <i>et al.</i> <sup>45</sup> Thomas <i>et al.</i> <sup>44</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Feeding tube valued						
Feeding tube is a lifeline	Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate concerns	No or very minor concerns	Minor concerns	Minor concerns	Moderate confidence
Regaining control over body weight or treatment side effects	Ehrsson <i>et al.</i> <sup>41</sup> Einarsson <i>et al.</i> <sup>43</sup> Kwong <i>et al.</i> <sup>40</sup> Mayre-Chilton <i>et al.</i> <sup>39</sup> Williams <i>et al.</i> <sup>42</sup>	Moderate-to-serious concerns	No or very minor concerns	Minor concerns	Minor concerns	Low-to-moderate confidence
Internal conflict	Kwong <i>et al.</i> <sup>40</sup> Thomas <i>et al.</i> <sup>44</sup> Williams <i>et al.</i> <sup>42</sup>	Minor concerns	No or very minor concerns	Minor concerns	Minor concerns	High confidence

GRADE-CERQual. Confidence in the Evidence from Reviews of Qualitative research.

societal norms, and this can give rise to feelings of exclusion and marginalisation<sup>(46,47)</sup>. Acknowledgement and understanding of the emotional vulnerability of patients during the initiation of HEF is fundamental to ameliorating feelings of defeat, fear, isolation and embarrassment.

Despite HEF initially causing considerable disruption, many undergo a journey of adjusting to HEF by actively making decisions and taking positive steps to regain control over their daily lives. Adaptation encompassed the transition to a state in which their life was no longer dominated by HEF. In accordance with our findings, the wider literature on living with a long-term condition also recognises the importance of finding ways to enable participation and inclusion through integrating with others and continuing to engage in valued activities<sup>(46–48,52,53)</sup>. This may involve negotiating new ways of participating according to current circumstances and abilities<sup>(46,47)</sup>.

Enabling patients to feel empowered to make these positive steps is crucial<sup>(46)</sup>. Support networks can be reassuring and provide much-needed feelings of worth, security and self-esteem, which are fundamental in harnessing the confidence to make positive changes<sup>(46–48,53)</sup>. Furthermore, certain personality traits, such as optimism, resilience, a solution-based mentality or high residual self-esteem, have been found to encourage adjustment to change<sup>(54,55)</sup>. Understanding barriers and facilitators to the development of coping strategies is fundamental to supporting patients adjusting to HEF.

We found that many participants coped better with the changes associated with HEF if they felt that they had created a new, accepted normal. Being in acceptance with life and oneself was a key coping mechanism. The desire for restoring a sense of normality is well-recognised in the literature for those coping with change<sup>(46,47,52,53)</sup>. In line with our findings, seeing the change become routine and part of daily life can encourage acceptance<sup>(46,56)</sup>. Reaching acceptance of one's current circumstances is crucial because this can increase an individual's perceived quality of life<sup>(57–60)</sup>. Acknowledging and supporting patients during their journey to acceptance can therefore enable them to cope better with the life changes associated with HEF.

The benefits of HEF amongst people with a diagnosis of head and neck cancer have been reported previously and include reducing weight loss, treatment interruptions and nutrition-related hospital admissions<sup>(4,5)</sup>. However, we found HEF to have positive implications beyond influencing participants' nutritional and clinical status. HEF provided much-needed reassurance and security at a time of substantial uncertainty and difficulties around eating. Furthermore, participants felt empowered because HEF had enabled them to regain control over their body weight and nutritional provision. Despite its perceived burden, overall participants viewed HEF as saving their

life and something that they could not have lived without. This finding is also reported in the wider literature on enteral feeding<sup>(12,19,61–63)</sup>. When making the decision around feeding tube placement, it is important that patients are aware of the emotional benefits of HEF so that they can make a fully informed decision.

As we have found, feeding tube dependency has also been reported in previous literature<sup>(64–66)</sup>. Setting expectations and encouraging patients to progress with oral intake as soon as able may reduce their reliance on the feeding tube. However, additional methods to facilitate tube weaning in this patient group is an area that requires further exploration.

### Confidence in the evidence

The review findings are likely to be a reasonable representation of the phenomenon of interest as there was moderate confidence in most of the findings<sup>(33)</sup>. Confidence was mainly downgraded as a result of the methodological limitations of the included studies<sup>(34)</sup>. Many studies did not draw upon member checking<sup>(39,40,43,45)</sup>, method triangulation<sup>(39–44)</sup> or multiple coders<sup>(39,45)</sup>, or lacked a detailed description of data analysis<sup>(40,42,43,45)</sup> (see Supporting information, Table S3). Only Thomas *et al.*<sup>(37)</sup> had considered researcher influence and showed evidence of reflexivity. Data adequacy was of concern for Ehrsson *et al.*<sup>(40)</sup> and Einarsson *et al.*<sup>(40)</sup> because semi-structured interviews were not audio-recorded, data saturation was not discussed and there were limited participant quotations<sup>(37)</sup>.

Relevance was of concern for Patterson *et al.*<sup>(45)</sup> and Einarsson *et al.*<sup>(40)</sup> because their primary focus comprised swallowing and eating, respectively<sup>(38)</sup>. Mayre-Chilton *et al.*<sup>(38)</sup> may have inadvertently included more highly functioning patients because seven participants withdrew as a result of being too unwell to attend the focus group. Additionally, many studies excluded those with a palliative diagnosis which is not reflective of clinical practice<sup>(40–43,45)</sup>.

### Appraisal of the metasynthesis

Eligibility criteria were predefined, unambiguous and well-justified. Searches were comprehensive as a result of searching multiple databases, reference lists and citations, and placing no limits on publication status. However, hand-searching of journals and contacting key authors may have increased retrieval of additional studies<sup>(67,68)</sup>.

Further strengths comprised the utilisation of two researchers throughout screening, data extraction, data synthesis and the GRADE-CERQual assessment. The researchers were not blinded, although there is no consensus on whether this is necessary<sup>(69)</sup>. Synthesis methods were appropriate based on the type of studies that

were included, and an audit trail for the generation of third-order interpretations is provided (see Supporting information, Appendix S1). Overall, multiple steps were put in place to enhance rigour and increase the robustness of the methodology used in this metasynthesis<sup>(35,70)</sup>.

### Conclusions

Living with HEF has practical, social and emotional implications amongst people with a diagnosis of head and neck cancer. When supporting these patients, a 'biopsychosocial' approach is therefore needed to facilitate holistic, patient-centred care<sup>(46)</sup>. Appreciating the challenges faced and advising on coping mechanisms can support patients in their adaptation to create a new, accepted normal. Practical advice on how to adjust feeding around daily activities and socialising can restore inclusion and participation, which in turn encourages empowerment and increased freedom.

Many steps were taken to promote rigorous methods in the metasynthesis; however, caution should be taken regarding the review findings associated with low-to-moderate confidence. Future research should explore barriers and facilitators to self-management and patient empowerment amongst those receiving HEF.

### Transparency declaration

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with PRISMA guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

### Conflict of interests, sources of funding and authorship

The authors declare that they have no conflicts of interest.

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AT was the lead author and undertook the systematic review. AMS supported the review with searches, data extraction, data synthesis, GRADE-CERQual assessment, drafting and proof reading. SB was the academic supervisor, supporting the study by proof reading and advising on methods.

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### Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1.** Supplementary material.

**Table S1.** Overview of studies.

**Table S2.** Data synthesis.

**Table S3.** CASP critical appraisal tool.

**Table S4.** GRADE-CERQual evidence profile.

**Table S5.** GRADE-CERQual assessment: methodological limitations.

**Table S6.** GRADE-CERQual assessment: coherence.

**Table S7.** GRADE-CERQual assessment: adequacy.

**Table S8.** GRADE-CERQual assessment: relevance.

## CANCER

# Dealing with loss: food and eating in women with ovarian cancer on parenteral nutrition

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### Keywords

eating, food, home parenteral nutrition, ovarian cancer, phenomenology, qualitative.

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### Introduction

Ovarian cancer is the sixth most prevalent cancer in the UK in women and most cases are diagnosed at an advanced stage<sup>(1,2)</sup>. Malignant bowel obstruction (MBO) is a common complication of advanced ovarian cancer occurring in between 20% to 50% of patients<sup>(3–6)</sup>.

### Abstract

**Background:** Malignant bowel obstruction is a common complication of ovarian cancer, resulting in limited oral intake. Home parenteral nutrition (HPN) may be offered to patients in this condition to meet nutritional requirements. However, it is not known how they experience being unable to eat. The present study reports how patients related to food when receiving HPN.

**Methods:** The investigation was a qualitative study underpinned by phenomenology with women with advanced ovarian cancer in bowel obstruction receiving parenteral nutrition. Interview transcripts were analysed thematically guided by the techniques of Van Manen.

**Results:** We recruited 20 women to the study. Participants were interviewed a maximum of four times and a total of 39 in-depth longitudinal interviews were conducted. Participants could tolerate minimal amounts of food, if they had a venting gastrostomy. Not being able to eat engendered a sense of sadness and loss, and most women found it challenging to be in the presence of others eating. They adopted strategies to cope, which included fantasising about food and watching cookery programmes. These approaches were not a long-term solution; either participants came to terms with their loss or the strategies became less effective in providing relief.

**Conclusions:** Home parenteral nutrition meets the nutritional requirements of patients with malignant bowel obstruction but cannot replace the non-nutritive functions of food. Healthcare professionals can offer a patient-centred approach by acknowledging the difficulties that patients may face and, wherever possible, encourage them to focus on the positive benefits of interacting with people rather than the loss of eating on social occasions.

Patients with this condition are not able to eat normally. They may be fitted with a venting gastrostomy to enable them to have small amounts of soft food and fluids for taste and comfort. In addition, they may be treated with home parenteral nutrition (HPN)<sup>(7)</sup>.

Home parenteral nutrition is used in patients with intestinal insufficiency both from benign and cancerous

causes. Although HPN has been found to be a safe and efficient procedure, it does carry risks of complications such as line infections<sup>(8)</sup>. The benefit of HPN is that it can be administered outside of hospital, allowing patients to be in their own environment. Although median survival lengths quoted in the literature vary from as little as 15 days for patients with cancer and palliative needs, it can be for substantial periods of time<sup>(9)</sup>. Some studies have reported these patients surviving on average more than 200 days on HPN<sup>(10)</sup>. Artificial feeding means that patients' nutritional and hydration requirements can be met and, for patients with MBO, it is replacing food that they cannot eat.

Food, however, is not only a means of delivering nutrition. Food provides rhythm and structure to days, weeks, months and seasons<sup>(11)</sup>. As well as punctuating the ordinary, food is key in special occasions, which are often focused around celebratory meals. It can be perceived that involvement in the social experience includes being able to eat a shared meal. In addition, food can play a fundamental role in quality of life because the act of eating in itself provides enjoyment<sup>(12)</sup>. Therefore, as well as its nutritive function, food is invested with social, emotional and cultural meaning<sup>(13)</sup>.

Patients in MBO are unable to eat normally for an extended period of time and the non-nutritive functions of food are denied to them. Little is known how these patients feel and behave around food when receiving artificial feeding because previous research has focused on supplementary HPN that has been added to oral intake and not replaced it completely<sup>(14,15)</sup>. However, the numbers of patients in MBO receiving HPN are increasing as people with advanced cancer on HPN increase and healthcare professionals need to be able to support these patients throughout this time<sup>(16)</sup>. The present study aimed to report patients' experiences of losing the non-nutritive aspects of food over a protracted period of time.

## Materials and methods

The present study is part of a larger project investigating HPN in women with ovarian cancer, which involved interviewing patients, relatives and healthcare professionals<sup>(9,17–20)</sup>. Here, the focus is on patients' relationship with food when on parenteral nutrition. Participants had advanced ovarian cancer ( $\geq$  stage III) and were admitted to an oncology hospital with inoperable malignant bowel obstruction between October 2016 and December 2017. They were introduced to the study by an oncologist or dietitian and all provided their written informed consent. The study was approved by East of England Cambridge Central Research Ethics Committee on behalf of the

Health Research Authority National Research Ethics Service.

## Data collection

The aim was to interview patients up to four times; once in hospital and up to three times at home. A topic guide was used to structure the interview but was employed flexibly so that the interviewer (a university-based researcher, who was not a member of the multidisciplinary team) could investigate topics raised by the interviewee (see Supporting information, Appendix S1). With participant permission, all interviews were audio-recorded and encrypted at source; interviews lasted up to 1 h.

## Data analysis

NVIVO, version 11 (QSR International Pty Ltd, Doncaster, VIC, Australia) was used to manage the interviews. Transcripts were analysed using the techniques of Van Manen<sup>(21)</sup>. Initially, the transcript was read to gain an understanding of the interview as a whole, particularly regarding the patients' feelings regarding food and eating whilst receiving HPN. The analysis then moved on to a detailed line by line coding. Themes were formulated from reflection on the codes, with similar ideas being grouped together to highlight the essence of the experience of having a restricted intake when on HPN. Particular attention was given to how patient's experience in relation to food and eating evolved over time.

Rigour was introduced by having two authors (AMS and SB) discuss and agree the coding framework. The interviewer (AMS) kept field notes and a reflective diary during the process of data collection and analysis. The longitudinal nature of the interviews allowed an opportunity for participants to reflect on previous interviews. This meant that changes in attitude that patients had to food and eating could be documented over time.

Quotations have been used to illustrate the themes. All names are pseudonyms and the ages of patients at the first interviews are given.

## Results

Home parenteral nutrition was considered with 26 patients and all were invited to participate in the study; of these, 20 patients agreed to be interviewed. The intention was that patients would be interviewed four times; however, there was attrition at each stage as a result of patients dying or becoming too unwell to take part. In total 39 interviews were conducted; with 20 patients being interviewed initially, nine being interviewed twice, seven being interviewed three times and three

participating in a fourth interview. Four patients were not discharged on HPN. One was discharged to hospice care, another decided to go home without HPN and two were assessed as unsuitable by the medical team.

Median survival for patients was 156 days (range 46–156 days) measured from admission with bowel obstruction.

Four themes were identified, moving from what the participants were eating to how patients felt being in the context of food and not being able to eat normally and the strategies they employed to deal with the loss of eating (for further quotations, see Supporting information, Appendix S2).

### Patients' oral intake

Participants discussed what they were taking orally and most ate very little. Some patients would take a forkful of food from other people plates: 'If anybody is eating something ... I just pick' (Charlotte, 60); sometimes chewing food and spitting it out: 'I've had pineapple and spit it back out. Just so long as I get the flavour' (Sally, 63). However, others were fearful of the venting gastrostomy tube becoming blocked.

One woman was so concerned about this she limited herself to food that would melt in her mouth, even though she missed food terribly and did not like what she was eating.

Katherine: I'm making sure I go for stuff that's going to melt type of thing. I mean, I can have a bit of chocolate, you know.

Interviewer: But do you like chocolate?

Katherine: No, but I do try a bit now and again (Katherine, 56)

Others did not have anything more than sips of fluid and, for one patient, this was all she could have because it was not possible to fit a venting gastrostomy.

By contrast, one patient reported she was eating small varied meals: cod in parsley sauce, casserole and mash. However, she had on-going problems with nausea and vomiting and, at one point, her venting gastrostomy tube blocked necessitating an in-patient stay for replacement. She had been told by healthcare professionals not to eat so much to alleviate her vomiting, although she did not appear to take this on-board. It was only when she had been on HPN for around 6 months that she stopped eating, having only juice to drink and occasionally sucking on the segment of a tangerine. Her nausea and vomiting subsided and she became much stronger. She then commented that she had 'just very, very little

[sickness]. And I can go days [without being sick]' (Maureen, 72).

### Being in the context of food

In general, participants found being in the vicinity of food challenging, and mealtimes in hospital were particularly difficult. There was no escape from people eating around them; if they stayed in bed or if they went to the day room, they would encounter other patients eating. The impact was exaggerated by a protected mealtime policy that required anyone who was not based on the ward or serving food to leave. Thus, the whole focus of everyone on the ward was on meals. Patients dealt with this situation differently, using various distraction techniques: One woman closed her eyes: 'I had to shut my eyes while they were eating their lunches ... but I could still hear the knives and forks clinking thinking, oh, hurry up and finish' (Susan, 73). Another woman distracted herself with a book and another somewhat surprisingly looked at recipes on the Internet.

Interviewer: How do you feel when everybody else is eating around you?

Louise: It's extremely frustrating, but there's not a lot you can do, is there, it's not their fault, is it? They've got to eat to get better. It's torture ...

Interviewer: And do you do anything to [deal with] that?

Louise: I tend to look at recipes on the Internet (Louise, 57)

Other patients used humour to get them through: 'I just say, [to other patients] oh go on and feed your ... fat face. I suppose you're having a packet of Hula Hoops now. You know, just make a joke of it' (Sally, 63).

When at home, some women could not tolerate people eating in front of them. So, relatives would eat in another room if there was space in the house: 'B. has his meals in the kitchen so I don't go in there while he's [eating]' (Susan, 73). One woman's house was small with only two rooms downstairs so the only place for her husband to sit down and eat his meals was in the lounge besides her, which she found difficult. Other women were less disturbed by others eating around them, with one occasionally cooking for her husband: 'He's had a full cooked breakfast I did this morning' (Sally, 63). Her husband, however, felt guilty eating around his wife:

'He didn't feel comfortable eating it while I couldn't eat ... Sitting at a table and you think ... look at

her sitting in that room can't have [anything] and look at me shovelling all this in ... it's mental strain on him ... He's lost a bit of weight' (Sally, 63)

Women could feel differently about being in the presence of others eating, depending on the function that food was playing at the particular time. One woman, who did not mind if her daughter ate a sandwich when she visited, did not want to be at the table at Christmas time. Rather than join in with the conversation, she preferred to sit separately with her back to the table:

'I'll be going [to daughter's house] on Christmas Day for a few hours. It's not easy because I can't eat, but I'll have a little glass of champagne or something like that ... But I won't have a plate. I said [to daughter], don't please put me at the table. ... she's got a nice comfortable sofa there, so I'll have a drink ... And the living room is actually facing the back garden, which is quite nice to look out' (Maureen, 72)

### Sense of loss

The loss of being able to eat was profound for the patients: 'I just miss food. Yeah, you find yourself dreaming about daft things, you know, bits of food, ooh I fancy that' (Charlotte, 60). The women realised that they were receiving all the nutrition they needed from the HPN, but they expressed an emotional loss, as eating is associated with normality. One patient who retained the hope that she might return to eating commented: 'I mean I know I'm getting my vitamins and everything, but it's the actual food going in your stomach ... it's just wanting to get back to normal, if you see what I mean, whatever normal is these days' (Katherine, 56). This patient felt: 'like an empty shell' (Katherine, 56) because she did not have food inside of her to fight the cancer.

Eating is an important part of daily living, which is enjoyed almost without thinking and the women voiced sadness that this had been taken away from them:

'I'm not hungry, I don't feel hungry and yet when I see it I'm thinking but I ... I don't say it sometimes because they're just sitting there and eating, normally, not even having to think about it. I thought I'll never eat anything' (Susan, 73)

This lack of normality made the women feel isolated: 'It really annoys me that I can't join in things' (Louise, 57). They felt excluded from the activity of eating but also socially isolated as it was difficult for others to understand their situation: 'you can't expect anybody to understand who's not got to do it. It's like one of them things, unless you've done it you don't fully understand' (Katherine, 56).

As well as being a loss for the patients, it was also a loss for their families. One woman who found it problematic to be around food was sad about the impact that this had on her family who she perceived had lost their traditional way of celebrating Christmas because they had arranged an alternative Christmas dinner without the patient present: 'They are not even cooking a Christmas dinner ... And that upsets me for them' (Bella, 70).

### Strategies to cope with loss

Women used different strategies to cope with this loss; some, as might be predicted, sought to avoid food and eating as much as possible. A number of them took the surprising step of looking at recipes, as mentioned above, or watching cookery programmes. Others would fantasise about food, thinking about different foods for the appropriate time of day, or about meals they had previously enjoyed on holiday when receiving the HPN: 'I've a vivid imagination so Sunday breakfast is scrambled egg and smoked salmon and my roast at lunchtime' (Melissa, 69).

It was interesting to see how the strategies adopted evolved over time; following discharge home, one patient started watching cookery programmes and would think what the food tasted like when the presenters tasted the food at the end: 'I like watching [cookery programmes] because I think, when it's going in I think, oh their tasting that then ... I think, look at that going in now, they're tasting that bacon' (Katherine, 56). At her next interview, she was still watching cookery programmes but she reported: 'I'm looking at stuff and I thought well I can't really remember what it tastes like anymore' (Katherine, 56). By her final interview, she found watching such programmes difficult:

'I did watch MasterChef ... last night ... when they plate it all up and then they're cutting it and they're eating, it's when it goes in their mouth that annoys me. It's not too bad watching them cook it, but it's when ... they start eating it, I just think, look at that. Because I think back to what I liked ... I think, oh, I used to love that' (Katherine, 56)

The patient who looked up recipes online when she was in the hospital also watched cookery programmes at home. However, during a follow up interview, she commented she was finding it challenging to watch them. 'I do [watch cookery programmes]. I always have done, anyway, because I do like my food. And I do cook. So, it's a bit of torture, really' (Louise, 57). By her third interview, she was avoiding watching them. The reminder of her losses was too much for her that she could not eat and, if the programme was set in another country, that she could no longer travel far and go on holiday.

'Well I used to watch all the cooking programmes so I'm definitely avoiding them now ... It upsets me sometimes so I'm best off not watching them ... Gino D'Acampo's on next week ... I'm not watching them ... That'll be like a double kick in the stomach 'cause he's going around the Italian coast cooking. What can I say? I'm never going to get there now' (Louise, 57)

Another patient illustrated a different experience than the other two patients discussed above. At first, she thought about meals on holiday whilst receiving HPN.

'What I do, I pretend when it goes on my feed, I say, I'm starting my soup ... I imagine it ... I've had lobster thermidor ... I think about the holidays we've been on, and restaurants that we've been to' (Pearl, 72)

She became less interested in doing this for herself as time progressed. However, the nurses who administered the HPN and her husband started to ask her what she was having.

Pearl: Oh, and one of the nurses asked me, she said, what are you having tonight, Pearl? I said, well, my big fillet's steak here in peppercorn sauce definitely ... And I used to make light of it like that, it's just I'm not really missing it.

Interviewer: So it doesn't sound to me like food is a big miss in your life, is that right or not right?

Pearl: I think it was in the beginning but it's not now, no (Pearl, 72)

She said that she would think of something to try to make her husband and the nurses laugh. So, it seemed like she was at that point doing it for others. She hosted a family party enjoying people's company and was unconcerned about being around food, even ensuring everyone's favourite food was provided:

'I want to have all the family around for lunch ... my sister in law [said] can we have those prawns that we had at Christmas ... I said you can definitely have them ... we're hoping it'll be at the end of this month so that everybody can get together and just a laugh, that's what I like, conversation and laughing, yeah, I like that' (Pearl, 72)

## Discussion

This is the first study to interview patients with MBO receiving HPN longitudinally so that it was possible to track patients' responses to not being able to eat over

time. They found losing the non-nutritive aspects of food difficult and some found it challenging to be in the presence of other people eating. This invoked a sense of loss in patients and various strategies were used to overcome these feelings, such as watching cookery programmes or fantasising about food. For some, their sense of loss dissipated over time, although this was not the case for all.

Previous research focused on patients' experience of food and eating where HPN is supplementary to oral nutrition<sup>(14,15)</sup>. One study investigated patients with benign intestinal failure and found that food and eating remained an important facet of quality of life<sup>(15)</sup>. Although patient's eating was circumscribed by their illness, they were still able to join in the social aspect of eating, such as going out to restaurants and celebratory meals. Another study focused on patients with advanced cancer, who did not have MBO<sup>(14)</sup>. For these patients, HPN meant that mealtimes became less pressured and more enjoyable as they could eat what appealed to them rather than focusing on meeting their nutritional requirements. This can be contrasted with the women who were interviewed in the present study where the social aspect of eating with others was denied to them and they felt isolated.

Although the method of artificial feeding differs, the findings of the present study more closely mirrored those of Walker *et al.*<sup>(22)</sup> These researchers analysed open-ended survey questions of patients fitted with percutaneous endoscopic gastrostomy (PEG) feeding tubes who had minimal oral intake. Similar to the participants in the present study, the patients with a PEG experienced being unable to eat a social loss because they were could not participate in social situations that involved eating, particularly around special occasions. Walker *et al.*<sup>(22)</sup> concur with our findings and other research reporting that patients not being able to eat had an impact on family members who avoided eating in front of them<sup>(23)</sup>. Food and mealtimes, rather than acting as a social glue in relationships, became a point of separation and isolation as family members ate in different rooms.

There were a plethora of ways that patients dealt with the losses they faced. Some took to fantasising about food, a technique also used by patients with head and neck cancer regarding foods they could no longer eat<sup>(24)</sup>. Other patients avoided social situations involving food. Some did this at the same time as continuing to watch cookery programmes, which might appear to be a counterintuitive way of dealing with the loss of eating. However, it addresses the social isolation caused by being unable to eat. Patients could interact with food in the same way as everyone else, watching food being prepared and eaten, but unable to taste it themselves.

These strategies were only effective in the short term. For two of the patients, watching cookery programmes

became less successful as time progressed. Eventually, this tactic appeared to heighten their sense of loss rather than provide a release or outlet as it had done previously.

Strategies such as fantasising about food were also dropped because they were no longer necessary to deal with the loss as patients moved beyond having problems with eating around food. For one patient in the present study, the emotional loss of not being able to eat appeared to dissipate. It could be that some reached what has been described as a sense of acceptance<sup>(25–27)</sup>, where the person comes to a sense of peace about what has been lost and accepts the situation.

The present study focused on HPN in ovarian cancer patients, which, although giving a comprehensive insight into how this group of patients felt about the loss of eating over time, could also be seen as one of its limitations; because the patients had ovarian cancer, all the participants were women. It may be that, in this situation, men would cope differently from the women. Also, as with all qualitative research, the sample size was small and there was a drop off of participants at each stage as a result of the nature of the disease. However, given the longitudinal in-depth methodology, with some patients undertaking four interviews, it is likely that the results would resonate with patients in similar contexts.

Dietitians dealing with patients with cancer or starting them on parenteral nutrition are appropriately focused on ensuring patient's nutritional requirements are met<sup>(28)</sup>. However, when dealing with patients who will not recover the ability to eat, it is important that they also keep in mind the symbolic and social nature of food, as well as its nutritive function. Healthcare professionals can offer a patient-centred approach, using good communication skills, listening to patients and acknowledging the problems they may face<sup>(29)</sup>. Also, wherever possible, they could encourage them to focus on the positive benefits of being with family and friends in social situations rather than on the food they cannot eat.

## Conclusions

Parenteral nutrition is the only method of providing nutrition to patients with malignant bowel obstruction. However, it cannot replace the non-nutritive aspects of food and some patients are more successful at adapting to this loss than others. Healthcare professionals need to be aware of this and offer appropriate patient-centred support.

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SB, SL, AC, LH and AMR obtained the funding for the study and were involved in the initial conception of the study. AMS conducted the interviews. AMS and SB analysed the data. All authors interpreted the data. AMS wrote the original draft of the paper. All authors reviewed, revised and edited the paper. All authors read and approved the final manuscript submitted for publication.

## Transparency declaration

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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## Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1.** Ovarian cancer and feeding into a vein: views of patients, carers and staff Interview Topic Guide (Patient).

**Appendix S2.** Additional patient quotations.

## CLINICAL PRACTICE

# A longitudinal ethnographic study of hospital staff attitudes and experiences of change in nutrition care

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### Keywords

change, experience, hospital staff, nutrition care, qualitative research.

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### Abstract

**Background:** Change promotes quality in healthcare, yet adopting change can be challenging. Understanding how change in nutrition care is adopted may support better design and implementation of interventions that aim to address inadequate food intake in hospital. The present study followed the process of change in a healthcare organisation, exploring staff attitudes, beliefs and experiences of the implementation of a mealtime intervention.

**Methods:** In total, 103 h of fieldwork were conducted in this longitudinal ethnographic study over a 4-month period. Over 170 staff participated, with data captured using observation, interviews and focus groups. Data were analysed using an inductive, thematic approach, informed by implementation theory.

**Results:** Attitudes and experiences of change in nutrition care are described by three themes: (i) staff recognised the inevitability of change; (ii) staff cooperated with the intervention, recognising potential value in the intervention to support patient care, where increased awareness of their mealtime behaviours supported adopting practice changes; and (iii) some staff were able to reflect on their practice after implementing the intervention, whereas others could not. A model illustrating the interconnectedness of factors influencing implementation emerged from the research, guiding future nutrition care intervention design and supporting change.

**Conclusions:** The requirement to address the underlying perceptions of staff about the need to change should not be underestimated. Increased efforts to market the change message to specific staff groups and physical behavioural reinforcement strategies are needed. Nutrition care in the future should focus on helping staff feel positive about making practice changes.

### Introduction

Change is inevitable in healthcare, with new knowledge continually generated through scientific inquiry. Change can promote healthcare quality through the refinement of systems, processes and practices relating to all aspects of patient care<sup>(1)</sup>. Knowing which interventions work is important to support quality patient care, as well as effective use of the healthcare dollar. But perhaps more important than knowing which interventions work is an understanding of why they do or do not work. We know

from implementation theory that adopting change can be challenging in healthcare settings<sup>(2,3)</sup>. Numerous conceptual frameworks have organised the factors at structural (e.g. political, social or economic climate), organisational (e.g. leadership, culture), provider (e.g. knowledge and confidence of healthcare professionals), patient (e.g. attitudes, adherence) and innovation (e.g. relative advantage of the innovation) levels that are known to influence implementation success<sup>(2,4,5)</sup>. The complex system in which healthcare is delivered is key to influencing change to practice.

Nutrition care is an important part of healthcare in hospital and its delivery by dietetic professionals has changed considerably in recent times. This includes, for example, implementation of extended and advanced scope of practice models to improve efficiency within the public healthcare system,<sup>(6,7)</sup> as well as nutrition care process and standardised terminology for quality care and clear communication<sup>(8,9)</sup>. New approaches in nutrition care have also impacted other healthcare staff. This has been in recognition of the need for shared responsibility to address complex nutrition-related problems, like malnutrition<sup>(10–12)</sup>. This includes, for example, nutrition screening by nurses to identify at-risk patients,<sup>(13)</sup> as well as patient-centred foodservice models and trained feeding assistants to improve food intake and satisfaction<sup>(14,15)</sup>. Indeed, the whole healthcare team may be called upon to support interventions that tackle multiple barriers to adequate nutritional intake<sup>(10,16)</sup>.

Surprisingly, there is little evidence on how change in nutrition care in hospital is adopted. This knowledge is important when implementing multifaceted interventions within complex healthcare systems that require input from numerous clinical and support service staff. Protected Mealtimes is one such intervention that seeks to improve the food intake and mealtime experience of patients through a range of strategies relating to mealtime practice and environment<sup>(17)</sup>. These include limiting non-urgent ward activities at mealtimes, reducing unnecessary interruptions to patients, creating a relaxed mealtime atmosphere and providing mealtime assistance. Understanding how staff think about and cope with change in nutrition care is important, so that researchers, clinicians and policy-makers may design and implement interventions targeting mealtime practice and environment that are more likely to succeed in combatting unresolved problems, like malnutrition<sup>(18)</sup>.

The present study is part of a broader research project exploring hospital mealtimes before, during and after a mealtime intervention (Protected Mealtimes) was implemented as part of a clinical trial<sup>(19)</sup>. The 4-week trial across three wards determined the effect of the mealtime intervention on nutritional outcomes. Implementation strategies included staff education (three 1-h sessions per ward), changes to the physical environment and meal delivery schedules, and executive oversight. Intervention implementation followed published guidelines<sup>(17)</sup>, with staff asked to make practice changes to support the food intake and mealtime experience of patients, including closing ward doors, clearing tray tables, positioning patients before meal service and prioritising food at mealtimes. Tasks such as medication administration, observations and bed-making were to be avoided at mealtimes. Trial data collectors stationed around the ward monitored

implementation fidelity. Studies describing mealtime culture and environment, staff practices and relationships, and volunteer and visitor contributions before intervention implementation are reported elsewhere<sup>(11,20,21)</sup>. Findings of the ethnographic investigation during intervention implementation have not been published to date. The present study was conducted alongside the trial and aimed to follow the process of change in a healthcare organisation, exploring staff attitudes, beliefs and experiences of the implementation of a mealtime intervention.

## Materials and methods

### Study design

This longitudinal ethnographic study draws upon data collected over a 4-month period before and during the implementation of a mealtime intervention, referred to as datasets 1 and 2, respectively. Situated within the interpretivist paradigm, the present study aimed to find meaning in staff perspectives and experiences of mealtimes and the mealtime intervention, building an appreciation for why changing nutrition care practice is difficult in hospital<sup>(22,23)</sup>. The ethnographic approach supported the development of rapport with participants, promoting a nuanced understanding of attitudes, practices and the experience of change during intervention implementation<sup>(24,25)</sup>. The longitudinal design enabled changes over time to be seen and alternative explanations to be explored.

### Participants and setting

Two 32-bed subacute care wards from one Australian healthcare network were selected. Both wards were part of the trial where the mealtime intervention was implemented<sup>(19)</sup>. Meals were plated in the kitchen, then taken to the ward and passed to patients by foodservice staff. Nurses and/or volunteers provided mealtime assistance. The trial found modest improvements in mealtime assistance and encouragement with the intervention, although no significant difference in patients' energy or protein intake<sup>(19)</sup>.

Participants were over 170 staff present at mealtimes or involved in nutrition care. All professions (nursing, dietetics, foodservices and others) and levels of experience (student through to manager) were included. Convenience, purposive and snowball sampling were used to recruit staff involved in or impacted by intervention implementation.

### Data collection

In total, 103 h of fieldwork were conducted by the first author, a dietitian with qualitative research experience and interest in improving nutrition care. The author was

not previously known to participants. A combination of data collection techniques was used to capture observed and reported data, promoting an in-depth understanding of mealtime practice and intervention implementation. Data were collected by the first author over a 4-month period using observation and interviews for datasets 1 and 2. Additionally, focus groups contributed to dataset 2 (Table 1).

Observation focused on the mealtime behaviours and practices of more than 165 staff. Observation was conducted across breakfast, lunch and dinner on weekdays and weekends, from different positions on the ward, such as the nurses' station, corridor and dining room. Observation began prior to meal service, usually concluding when meal trays were collected. Repeated observation supported immersion on the ward, pattern identification (e.g. activities, interactions) and to check evolving interpretations. Data were recorded as handwritten fieldnotes in an A4 notebook, then reconstructed into 188 pages of single-spaced, typed fieldnotes.

Interviews with individual and groups of staff focused on hospital and mealtime roles, mealtime environment, and the impact of the mealtime intervention. Interviews were conversational or semi-structured in nature, depending on interviewee availability and interview purpose. Potential interviewees were identified using convenience, purposive and snowball sampling and verbally consented, with data recorded using an audio-recorder or as handwritten fieldnotes (e.g. at the participant's request or spontaneous conversation)<sup>(11,20,21)</sup>. Key points were relayed back to interviewees to check understanding and obtain further insight. Follow-up interviews served to clarify understanding or for interviewees to provide further information.

Focus groups were conducted with staff in the 2 weeks following trial conclusion. This allowed staff to experience and then reflect on intervention implementation. A moderator's guide was used, with questions designed to elicit different accounts of the implementation experience (Fig. 1). Focus groups enabled discussion and debate amongst participants<sup>(26)</sup>, who were grouped by profession

(nurses, foodservice staff), or combined where there were fewer numbers (allied health and medical staff). Recruitment was through e-mail and verbal invitation, with refreshments offered as incentive to participate. Focus groups were conducted in the workplace, often between shifts or during breaks to fit in with staff availability. Informed consent was obtained prior to participation, with data audio-recorded and transcribed verbatim. Additional interviews were conducted to supplement focus group data, where voices were not adequately captured during focus groups. Approximately one-half of the participants contributed to both datasets, either through observation, interview and/or focus group.

### Data analysis

An inductive, thematic approach was used to analyse both datasets, concentrating on staff attitudes and beliefs towards change in nutrition care and experience of intervention implementation. Development of the code list for dataset 1 followed published literature<sup>(27)</sup> and is described elsewhere<sup>(11,20,21)</sup>. Two authors independently checked suitability of the code list for dataset 2, coding a sample of interview and focus group transcripts and fieldnotes collected during implementation. Consensus was achieved through discussion. Each dataset was analysed together, sequentially, then compared and contrasted, as were data from different professions. Using the same code list for both datasets enabled changes to be seen within and between codes over time. Focus groups were additionally analysed using techniques described by Barbour<sup>(26)</sup>, Krueger and Casey<sup>(28)</sup>, and Willis *et al.*<sup>(29)</sup>, including matrix development, constant comparison and attending to individual voices, as well as participant interactions. Data analysis was supported by use of NVIVO, Version 11 (QSR International, Melbourne, VIC, Australia), memo writing and reflective journaling, with emergent themes related to the experience of change discussed amongst the research team. Implementation theory was used to make sense of the findings after the completion of coding, in the context of mealtime interventions and nutrition care<sup>(2,4,5)</sup>.

**Table 1** Summary of data collected for the longitudinal ethnographic study

	Dataset 1	Dataset 2	Total
Fieldwork	67 h	36 h	103 h
Observation	35 episodes (55–255 min)	33 episodes (45–105 min)	68 episodes (45–255 min)
Interviews (individual and group)	62 interviews (3–84 min <sup>†</sup> )	16 interviews (5–44 min <sup>†</sup> )	78 interviews (3–84 min <sup>†</sup> )
Focus groups	–	8 focus groups with 39 participants (4–7 participants per group; 16–38 min, mean 29 min)	8 focus groups with 39 participants (4–7 participants per group; 16–38 min, mean 29 min)

<sup>†</sup>Length is reported for audio-recorded interviews only.

**Figure 1** Focus group questions to explore staff experiences of implementing the mealtime intervention.

- How did you find the experience of Protected Mealtimes on the ward? Prompts: what was easy/difficult about the intervention or its implementation?
- How did Protected Mealtimes affect you? Prompts: role, morale, behaviour, work patterns, interaction with patients/visitors/other staff.
- Can you describe any changes to the mealtime environment or the way things work that was brought about by Protected Mealtimes? Prompts: changes felt by patients/visitors/other staff.
- What would make future foodservice system changes easier to adopt?

### Ethical approval

Ethical approval was obtained from the university (CF15/2929–2015001205) and healthcare network (LR76/2015) human research and ethics committees. Both wards were granted a waiver of consent for the trial. Posters about the ethnographic study were displayed and staff information sessions held prior to data collection. The author was identified using university name badge and lanyard, and explained the nature and purpose of attending the ward when asked. Consent was not sought for observation, reducing the likelihood of changed behaviour<sup>(24)</sup>. Participant identities were protected by use of unique identifiers instead of names.

### Results

Over 170 staff participated across both datasets, representing professions of nursing, medicine, allied health (dietitians, speech pathologists and others), food and support services, and administration. Perspectives and experiences were attained from 81 staff through interview and/or focus group participation.

Attitudes and beliefs towards change in nutrition care and the experience of change when a mealtime intervention was implemented are described by three themes: (i) inevitability of change; (ii) cooperation with and experience of change; and (iii) reflecting on change. We propose a model based on our findings, drawing on implementation theory<sup>(2,4,5)</sup>, to illustrate the interconnectedness of intervention, individual, organisational and structural factors influencing mealtime intervention implementation in hospital (Fig. 2), and describe the detail within each theme below.

#### Theme 1: Inevitability of change

The constantly evolving nature of the nursing profession meant that nurses frequently experienced change in workforce, leadership and practice. Nurses understood they must adopt change to improve patient care. They saw themselves as adaptive and open-minded towards change,

willing to embrace change if it was a ‘positive change’ and something their colleagues supported.

‘You cannot be stuck in one area or trend. [There are] always going to be changes, which is a matter of adapting and adjusting, and of course if the focus is for patients, then we have to make the change’ (MIC, associate nurse unit manager)

Dietitians also reflected on workforce and leadership changes, describing how staff turnover impacts efforts to improve nutrition care. For example, by hampering change progress and requiring continued attention to sustain change.

‘... your ‘change person’ might leave, and so you have to – not start right from scratch – but it’s a constant evolving process’ (DT6, dietitian)

Nurses met the change that was implementing the mealtime intervention with apprehension. They explained how it would be a logistical challenge to enact the requested practice changes, especially in the morning, where there were already considerable time pressures to wake and ready patients, and give medications.

Interviewer: Can you remember how you felt about Protected Mealtimes when you first heard about it?

SGN: That it was going to be really difficult.

Interviewer: [Thinking] how is this going to work in practice?

SH: I don’t think it did, did it?

SGN: No.

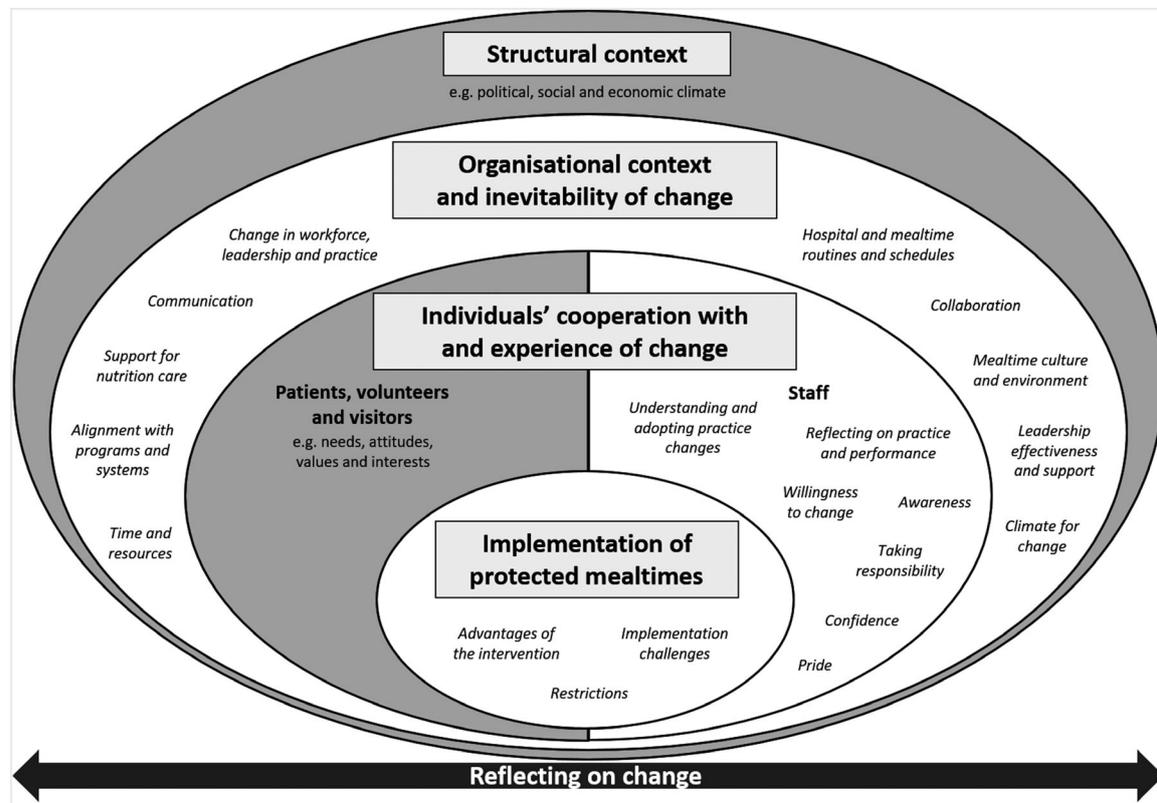
SH: It couldn’t.

SGN: Not in the mornings.

SH: No.

FA: We can’t stop in the mornings (Nurses, Focus Group 5)

Foodservice staff at one site also held reservations about the intervention, where implementation as part of the trial required breakfast service be delayed by 15 min. Foodservice staff explained how this would have ‘huge ramifications’ for foodservice operations, which ran to a tight schedule, evoking a sense of panic amongst foodservice staff.



**Figure 2** Model constructed using implementation theory to illustrate the interconnectedness of intervention, individual, organisational and structural factors influencing mealtime intervention implementation in hospital <sup>(2,4,5)</sup>. Factors presented in the unshaded segments (implementation of Protected Mealtimes; individuals' cooperation with and experience of change – staff; organisational context and inevitability of change) reflect the findings of this study. Intervention factors are presented at the core; for example, perceptions that Protected Mealtimes would improve patient care, and expectations that implementation would be a logistical challenge. Individual factors, for example, include staff confidence to change their practice, and taking personal responsibility for their actions. Organisational factors, for example, include compatibility of Protected Mealtimes with existing hospital and mealtime routines and schedules, and communication about the change. Shaded segments (individuals' cooperation with and experience of change – patients, volunteers and visitors; structural context) were beyond the scope of the present study, highlighting areas for future research. Reflecting on change extends across multiple levels of the model.

By contrast, allied health staff advised that the intervention should be part of standard practice and that it was a 'strange idea' that it needed to be enforced.

## Theme 2: Cooperation with and experience of change

Some staff changed their practice to support the intervention. For example, nurses conducted observations before rather than during breakfast, and doctors tried to finish ward rounds before lunch. However, overall, the intervention had little observable impact on staff mealtime activities. Dietitians and speech pathologists continued meal-related tasks (meal rounds, swallow assessments) that were considered positive interruptions. Social workers and occupational therapists continued to focus on administrative tasks, rather than assessments, during meal periods. Nurses continued to assist patients with both meal-related (positioning, encouragement, feeding) and

non-meal-related tasks (medications, observations, personal hygiene).

'She [NNK, nurse] moves to Room 3, "How are we going over here?" The elderly female patient complains there is too much food on the meal tray. NNK suggests ordering a smaller meal at dinner. NNK, "Then it's not too much for you." [Thoughtful, sympathetic tone]. NNK enters Room 4, "Are we right in here? [Notices the patient has eaten most of their meal]. Oh, you've eaten well! Good on you!" (Fieldnote extract, 27 October 2015, 5.25 PM)

Nurses justified the lack of change in some nursing practices during implementation, perceiving they were already protecting mealtimes. Other nurses commented to patients how they would see them after the meal, revealing attempts to avoid any patient contact (positive or negative) at mealtimes. There were no observed attempts

from doctors to chart medications away from mealtimes. The mealtime role of foodservice staff was largely unchanged (meal delivery, opening packaging). However, improvements in their workflow efficiency were realised, with fewer people obstructing the meal trolley's path during implementation.

Administration and support service staff found it difficult to cooperate with the intervention, as they did not understand the requested practice changes. They conceded they did not attend an information session about the trial, and that news of the intervention was not communicated to them. Administration and support service staff were confused about what they should tell visiting family members and which tasks they could complete and when, relying on direction and clarification from nurses and colleagues.

'[The intervention was a] big surprise for me, because nobody said anything to me' (OM, support service staff)

Closing ward doors to reduce noise during mealtimes also confused maintenance and support service staff and visitors, who did not know why the doors were closed and whether they could enter. This was corroborated by nurses, who noted that it was quieter and less frenetic with the doors closed, with fewer people coming and going.

Changes that were made during implementation were not reported to be sustained beyond the trial. Allied health staff observed mealtime interruptions by nurses creeping back in towards the end of the trial, and doctors admitted reverting to 'business as usual' post-trial, with ward rounds overlapping lunch. Some participants were disappointed at this, unable to fathom why other staff would not want to continue supporting the mealtime intervention.

DT1: [Another staff member] said, "Oh, it's all over. You can go in [to patients' rooms] anytime now. It's all finished ..." I actually reminded them, "No, just because the study's over, we still need to make sure that meals aren't interrupted, and that we do make sure that it's a positive experience for them [patients]." We shouldn't be just going in anytime ...

FGB: A bit awkward, wasn't it?

DT1: It was almost like a reversal ... "The study's over, so let's keep interrupting patients." (Dietitian and social worker, Focus Group 4)

Allied health, medical and nursing staff explained how the presence of trial data collectors reminded them to support the intervention. This was particularly important for allied health and medical staff, who were more aware of their non-meal-related activities, such as delivering application forms or completing assessments.

'I didn't actually realise how much I was interrupting the patients until people [trial data collectors] watched me like a hawk!' (DD, doctor, Focus Group 4)

Although foodservice staff were uncomfortable being watched by trial data collectors, they did not report this leading to change in mealtime practice.

Patient utilisation of the dining room was identified as another reminder to avoid negative interruptions. Doctors explained how it was inconvenient and inappropriate to conduct assessments in this social and public environment, and, as such, avoided this at mealtimes. This was corroborated by a physiotherapist, who admitted it was easier to forget that it was time to eat when patients received meals in their room. Nurses acknowledged how the ward architecture at one site contributed to the sense of concealment, with room layout designed for privacy.

Being held to account by colleagues supported practice change. The intervention gave staff confidence to approach other staff at mealtimes, encouraging them to stop negatively interrupting patients. Nurses admitted how change would be easier with greater patient and family engagement. For example, if patients prioritised meals and eating, rather than just taking medications.

### Theme 3: Reflecting on change

Staff feedback on the experience of intervention implementation tended to focus on other professions, rather than looking at their own practice and profession, and taking personal responsibility for their actions. For example, some nurses explained that their mealtime activities did not interrupt patients, negating the need to change their practice.

'The patients are with us one hundred percent of the time at mealtimes. They're more likely to get interrupted by ancillary staff, not nursing staff, because we're, you know, doing their meds or taking them to the toilet. We're tending to their actual needs. The interruptions often are external, from other disciplines' (FGL, nurse, Focus Group 1)

Occasions of doctors not adhering to the intervention were recounted:

'I noticed one of the doctors was admitting a patient at a mealtime. Like their [the patient's] meal had arrived, and they went in and admitted them' (NK, nurse, Focus Group 2)

By contrast, managers from different departments readily reflected on their team's practice and performance. They identified opportunities to improve patient care and service delivery, both within their team and in

collaboration with other teams. Managers highlighted the importance of viewing projects (e.g. falls prevention, Protected Mealtimes) as a collective and aligning programme priorities, so that the delivery of one project did not negatively impact the outcomes of another.

Time was identified as a factor influencing change. For nurses, it was about needing time to practice the new approach, finding a way to make it work. By contrast, allied health staff applauded the abrupt nature of intervention implementation for the trial, explaining that this was a good way to approach change.

Reflections on intervention implementation centred on the inconveniences of restrictions and what failed. For example, nurses recounted being held up in team meetings, unable to maintain their usual mealtime routine. There were exceptions, however, where medical and allied health staff, and nurses to a lesser extent, described feeling proud of the positive changes they had made to support patients at mealtimes.

## Discussion

The present study has identified the contextual factors that are important to address when implementing change in complex environments. The findings highlight the interplay between individual (staff) and organisational factors relating to the implementation of the intervention, Protected Mealtimes.

Research has shown that intervention implementation is influenced by staff engagement, which is underpinned by their understanding of the need for change, communication and collaboration<sup>(30)</sup>. Although information sessions were conducted for the trial,<sup>(19)</sup> the findings of the present study indicate that some staff were unaware of how and why they needed to change their practice. This highlights how a lack of information can limit the ability of staff to adapt to change, as well as how novel ways to engage those who do not follow standard communication methods are needed. Difference in opinion on what constituted a negative interruption also contributed, with some staff continuing their usual practice, believing that their non-meal-related activities did not detract from nutrition care. This shows an opportunity for greater leadership support and communication to ensure the message around the need to change is understood by staff<sup>(31)</sup>. Intervention ownership and implementation engagement may have been stronger had staff conceived the idea of intervention implementation, as in action research approaches<sup>(32)</sup>. There is a need for the interprofessional healthcare team, together with managers, to take ownership of change to improve nutrition care in hospital.

The findings of the present study show how being watched can powerfully impact the practice of some staff.

The presence of trial data collectors stationed around the ward reminded medical and allied health staff to avoid negative interruptions at mealtimes, appealing to their desire to be well-meaning<sup>(4,5)</sup>. Being watched had less of an impact on nurses who, although acknowledging the importance of nutrition and inevitability of change, made fewer practice changes during implementation.

The underlying influence of staff attitudes towards change on their practice should not be discounted. It was evident that some but not all nurses were committed to changing their practice to support the intervention that had the potential to improve nutrition care. Historical approaches to nursing practice and the focus on patient safety have led to a routine and structured approach at mealtimes, where sequencing involves observations and medications, before mealtime assistance and encouragement. Nurses may have felt conflicted to diverge from this traditional method,<sup>(33)</sup> for fear of compromising patient care. Our findings demonstrate variation in staff cooperation with and experience of change, highlighting how much more needs to be accomplished to help nurses feel positive about changing their mealtime practice<sup>(34)</sup>. Dietitians need to take a leadership role within interprofessional teams when changing nutrition care, understanding and supporting their teams through implementation challenges<sup>(35)</sup>. Efforts need to focus on building staff confidence to change their mealtime practice based on current evidence of what works, as well as recognising and rewarding achievements,<sup>(33,34)</sup> with acknowledgment for the complex system in which the change is occurring<sup>(36)</sup>. Uptake of leadership training opportunities may help build capacity for dietitians to drive effective change within healthcare systems<sup>(37–39)</sup>. The findings of the present study suggest that the focus should be on developing the change agenda, increasing awareness, reducing resistance to change, and helping staff cope with and accept change<sup>(40)</sup>. Securing executive support is important, promoting the success and sustainability of change<sup>(41)</sup>. Leading and coordinating teams of staff to address complex health issues may help to extend the reach, influence, and impact of the nutrition and dietetics profession in the future<sup>(37–39)</sup>.

Greater attention and investment in change may require dietitians to shift focus from direct patient care to system-level intervention, to address the underlying factors impacting food intake<sup>(42,43)</sup>. The present study draws upon implementation theory to highlight the interconnectedness of intervention, individual and organisational factors influencing the success of mealtime intervention implementation in hospital (Fig. 2). Interventions designed to improve nutrition care will need to draw upon complexity theory to understand the interaction of these factors, targeting multiple factors at multiple levels within foodservice and healthcare systems<sup>(18,41)</sup>.

Interventions that fail to consider how they influence and are influenced by other system components, including programmes, personnel and practices, may be less likely to succeed<sup>(21,37)</sup>. Factors at the patient/volunteer/visitor and structural levels should be explored further, such as early and increased patient engagement,<sup>(44)</sup> as well as political and socio-economic drivers of policy and practice in nutrition care<sup>(45)</sup>.

Employing an ethnographic approach was a notable strength of the present study, enabling the implementation experience to be explored as it unfolded<sup>(46)</sup>. Extended fieldwork and multiple data collection techniques captured diverse reported and observed data, enabling comparison of attitudes and behaviours. Including different professions provided a comprehensive view on how change in nutrition care is received by the broader healthcare system.

The limitations of the present study are that data were collected by one researcher with a dietetics background. Collaborating with researchers from other professions may have enriched insight into the impact of change on different staff groups<sup>(47,48)</sup>. Understanding of the implementation experience may have been limited by the researcher's positioning as an observer, rather than a participant delivering the intervention,<sup>(49)</sup> as well as the limited availability of staff for extended focus groups. Future research should investigate staff experience of change in nutrition care, where changes are initiated by staff themselves, as in action research approaches. Additionally, whether these co-design approaches support more effective change<sup>(32)</sup>.

## Conclusions

Interventions designed to improve nutrition care should target multiple barriers to adequate food intake, with consideration for foodservice and healthcare system integration. Approaches to change nutrition care in hospital should not underestimate the requirement to address the underlying perceptions of staff about the need to change, promoting commitment from the outset. Increased efforts to market the change message to specific staff groups and physical behavioural reinforcement strategies are needed to support the successful adoption of change. Nutrition care in the future should focus on ways to help staff feel positive about making practice changes to nurture continued engagement and foster a sense of pride in achievements, as well as acknowledge the complex system in which change in nutrition care occurs.

## Transparency declaration

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being

reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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All authors contributed to the study design. EO collected the data. EO and CP analysed the data, with contributions from CEH and JP. EO wrote the first draft. All authors reviewed and commented on subsequent drafts, and approved the final version of the manuscript submitted for publication.

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