Patients' Experience of Nutrition Therapy During Critical Illness and Recovery

A Narrative Review

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KEYWORDS

• Nutrition • Critical illness • Patient experience • Oral nutrition • Enteral nutrition • Nasogastric tube

KEY POINTS

- Nutrition interventions and symptoms can have strong emotional and psychological implications for patients.
- Hospital food service systems affect patients' nutritional intake and experience of nutrition throughout hospitalization.
- The patient experience of nutrition can be impacted by family involvement, clinician knowledge and communication, and the hospital environment.
- Including the patient experience is crucial to inform clinical practice, research, and hospital food services.
- Further investigation of the patient experience of nutrition in the critically ill may help optimize the delivery of this essential intervention.

INTRODUCTION

Medical nutrition therapy (MNT) is considered a mainstay of supportive treatment for the critically ill.[1,2] This may encompass oral, enteral, and parenteral nutrition support.

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Crit Care Clin 41 (2025) 313–325

https://doi.org/10.1016/j.ccc.2024.09.004 **criticalcare.theclinics.com**

MNT has been associated with benefits during critical illness such as supporting the immune system, promoting gut integrity, and aiding wound healing.[1,2] While many studies have investigated the route, amount, and timing of nutrition, patients' experience of nutrition during critical illness and recovery remains largely uninvestigated.

Clinical practice guidelines recommend that intubated patients commence MNT via enteral nutrition (EN) within 24 to 48 hours of intensive care unit (ICU) admission.[1,2] During this early phase, patients' awareness of medical interventions may be limited due to sedation, brain injury, or delirium, with decisions regarding nutrition directed by clinicians. As patients' conditions stabilize, their awareness of interventions will increase, and their experience of MNT becomes highly relevant to ongoing care.

In the ICU, following the cessation of invasive mechanical ventilation, oral intake may commence. In the absence of ongoing brain illness or sedation, patients may be able to engage in decision-making about MNT by communicating individual preferences and challenges with nutrition; however, this has not been described in the literature. Following extubation, nutrition intake from oral diet alone has been described as well below clinician recommendations.[3–5] Barriers affecting oral intake in the ICU include symptoms which affect oral intake such as poor appetite, altered consciousness, nausea and many others (termed nutrition-impacting symptoms), issues with food service, and clinician-related factors. These experiences also affect patients who do not require intubation and can eat and drink throughout their ICU admission.

Following transfer to the ward, ongoing MNT (including EN or oral nutrition support) is often indicated as intake from oral diet frequently continues to be inadequate, with studies reporting 37% to 54% of energy targets and 48% to 65% of protein targets achieved.[6,7] Providing adequate nutrition for recovery can be challenging and must be balanced with patients' preferences. A lack of understanding by ward clinicians regarding nutritional needs in this patient group may contribute to this challenge.[8]

Following hospital discharge to a rehabilitation setting or home, nutrition-impacting symptoms may last for months, affecting nutritional intake.[9,10] However, little is known about the nutrition experiences of patients following discharge from acute-care hospital settings. After hospital discharge, patients may need to integrate MNT (most commonly oral nutrition support) into everyday life. Therefore, understanding patients' individual preferences and situations is imperative. It is also important to consider that eating and drinking is much more than simply consuming nutrients for the body, and can have complex cultural, emotional, and social implications.[11]

In this narrative review, key aspects of the patient experience, and clinician and hospital-related factors influencing nutrition are summarized. Factors that both directly and indirectly impact the patient's experience of nutrition will be discussed (**Fig. 1**).

DISCUSSION

Patient Experiences of Enteral Nutrition Therapy

Nasogastric feeding tubes

For mechanically ventilated patients, the predominant form of nutrition is EN delivered via a nasogastric tube (NGT), of which there are 2 main types. Larger polyvinylchloride tubes are termed "wide-bore" tubes and are relatively rigid. "Fine-bore" tubes are smaller, more pliable, and usually made of polyurethane. In the early stages of critical illness, when the risk of gastric and enteric dysfunction is high, wide-bore NGTs are commonly used for gastric drainage and checking of gastric residual volumes while also being used to administer EN.[12] Changing to a fine-bore tube may occur,

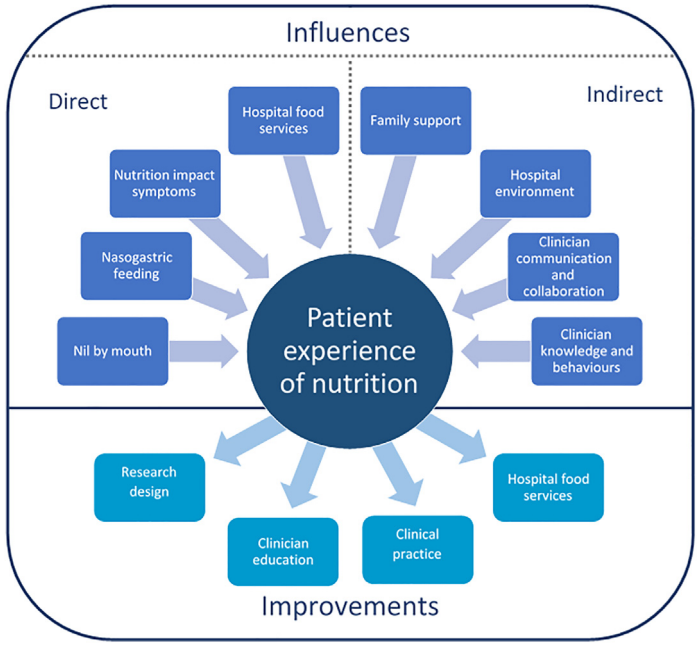

Fig. 1. Influences on the patient experience of nutrition and areas that can be improved with increased understanding of the patient experience.

although when or if this happens varies widely. International critical care nutrition guidelines currently do not make recommendations regarding NGT type or size[1,2]; however, it is plausible that the type of NGT could impact the patient experience. Furthermore, patients may have pre-existing preferences regarding tube feeding before becoming ill.

The patients' experience regarding NGTs is poorly described in patients with critical illness, although there are some reports of discomfort and distress. In a study investigating the experiences of intubated patients within the ICU, NGT insertion was described by one patient as the hardest procedure to endure.[13] Having an NGT has also been briefly described as being unpleasant or repulsive.[14] In a study outside the ICU context, the experiences of patients with malignant small bowel obstruction were explored. In this study, wide-bore NGTs were used for gastric decompression, one patient described the discomfort of the tube: "I hated that up my nose because it was so uncomfortable. It hurt me…it was horrible and uncomfortable in my throat."[15] There is some evidence that NGTs may impact swallowing function in healthy volunteers, though no clear differences between fine-bore and wide-bore tubes have been reported.[16,17] Several authors describe fine-bore tubes as more comfortable for patients[18–20]; however, no data are provided to substantiate these claims. Given a large number of critically ill patients experience NGT use, and it is at times an essential route for nutrition, this is an important gap in the literature and an area of patient experience that should be explored.

Receiving enteral feeds

Divergent experiences of receiving EN in ICU have been reported by Persenius and colleagues.[14] The patients who described positive experiences with EN appeared unphased and reassured. This is evidenced by the quote "I don't really know much

about it, what has come through the tube, but it seems to have worked quite well in my opinion."[14] A sense of convenience and safety at having their nutrition supplied without having to eat and drink was also described.

Conversely, other patients expressed frustration and a sense of helplessness with symptoms related to EN. One patient stated "I think the food you are given through the tube upsets the bowels. That you feel so distended and bloated, I feel it now and it hurts a lot. Nothing seems to help… It's very frustrating."[14] This lived experience of powerlessness was described as changing to relief and hope when gastrointestinal symptoms resolved. This highlights the potential emotional overlay to physical experiences for patients.

Patient Experiences of Oral Nutrition and Impacting Factors

Fasting

The experience of fasting for procedures is common in critically ill patients.[21,22] This experience has been explored in hospital patients, with thirst and xerostomia described as the most difficult aspects, accompanied by a sense of helplessness. Conversely, for patients who were fasting due to gastrointestinal symptoms, fasting was experienced with a sense of relief.[23]

Nil by mouth

Not being allowed to consume food or fluids orally due to dysphagia, mechanical ventilation via a tracheostomy, and illness or injury despite being alert is a challenging experience for patients. Despite receiving EN to meet their nutritional needs, patients have described not being allowed to eat and drink as difficult and contributing to a sense of abnormality.[24] However, it is again often a sensation of thirst that is most distressing,[14] as expressed in the quote, "For a lot of the time I didn't really think about eating, but drinking was very important, much more so than eating. I really wanted to drink but just had no appetite. I wasn't craving food, I wasn't the least bit hungry."[24]

Starting oral diet

Patients describe commencing oral intake as a meaningful symbol of recovery.[24] It can help to bring a sense of normality and routine to an otherwise abnormal environment: "In [the] ICU there is not really any routine or pattern, it's just 12 hours of blur. Whereas, with eating, it breaks this up and makes it more like your normal day. The routine helped as I had a set pattern and knew what to expect. It also really helped me in getting ready to be transferred to the ward."[24] Linking eating and drinking to the next step in recovery gives a sense of hope and optimism.

In contrast, a sense of fear when commencing oral intake when a tracheostomy is in place has been described. This is epitomized by the quote "It had been a long time without taking anything by mouth, also there was fear that it may go down the wrong way. There was concern that if it went down into the lungs it would put the whole process back. This made me feel very apprehensive."[24] Difficulties with swallowing and not meeting goals related to eating have also been linked with feelings of failure.[14,24] Patients also described frustration at restrictions on allowed foods and drinks and needing to slow their eating speed.[24]

Nutrition impacting symptoms

The patients' experience of nutrition may also be shaped by a range of symptoms, most commonly poor appetite.[3,5,10,25] This may be related to changes in appetite hormones, which take several weeks to normalize.[26] Other reported symptoms both in ICU and following transfer to the ward include early satiety, taste changes, nausea and vomiting, dislike of the hospital food, difficulty chewing and swallowing, and

changed levels of consciousness.[3,5,9,10] Given the range of symptoms patients may experience, it is unsurprising that oral intake at this point is consistently reported to be below nutritional needs.[3–5] Ongoing MNT can help patients meet their macro and micronutrient needs during this time[6]; however, the patient's preferred options regarding the mode of MNT are unclear.

Oral intake may also be hindered by difficulty self-feeding due to weakness, injuries, or changes in cognition; feeding assistance is an intervention valued by patients.[27] However, patients may be reluctant to ask for this, as described in this quote "I didn't want to ask them because I knew they were busy and yet they would put my breakfast in front of me and I couldn't take it and I couldn't take my drugs, whatever."[28] This suggests there should be a low threshold to offer patients feeding assistance in the post-ICU period. Whilst this task is usually designated to nurses, it can be difficult to find the time within busy clinical workloads.[29] Nutrition assistants or allied health assistants may be well placed to provide feeding assistance if available; alternatively, trained volunteers have also been shown to provide effective feeding assistance.[30] Family members may also be able to help provide feeding assistance when they are present at meal times.[27,29]

Unsurprisingly, these symptoms influence the patient's experience of nutrition and contribute to the difficulty of consuming enough nutrients from diet alone to support recovery without MNT. These challenges have been described as removing the pleasure from eating and drinking, as exemplified by a quote collected by Merriweather and colleagues: "'I'm eating because I have to. . . I'm eating because it is necessary to live, to eat. You've got to get your dietary stuff, your nutrition, all the stuff you need to get by in life but it's a struggle now."[10] Potential strategies to positively influence the patient's experience of nutrition are outlined in **Table 1**.

Weight and body composition changes

Patients undergo weight and body composition changes throughout their illness, their experience of which could impact patients' feelings about their bodies and self-esteem. This may then affect patient decisions regarding nutrition interventions. Muscle loss is rapid in ICU with patients losing 2% of skeletal muscle per day in the first week of admission[31] and weight and muscle loss continues during the post-ICU hospitalization period.[7,32] Persenius and colleagues[14] found patients experience maintaining weight positively, whereas weight loss was viewed negatively. This may be related to clinicians' focus on weight maintenance and education regarding the harm of unintentional weight and lean tissue loss. However, Johansson and colleagues[33] describe a difference in responses depending on whether the individual was satisfied with their pre-admission weight.

Post-hospital discharge

Limited studies have reported on the nutritional experiences of patients who were critically ill following discharge from acute hospital settings. The prevalence of nutrition-impacting symptoms may decrease in patients following transfer to sub-acute care, with improvements in patients' levels of alertness being a primary improvement and the number of patients requiring enteral nutrition support decreasing.[9] Appetite generally improves with time,[34] with patients at 3 months post ICU discharge having similar self-rated appetite scores compared to healthy volunteers.[35] However, for other patients, poor appetite can persist for months following hospital discharge.[10,36] In a cohort of patients who were critically ill with coronavirus disease 2019 (COVID-19), other nutrition-impacting symptoms that were still present at the time of a post-ICU follow-up clinic included breathlessness, fatigue, taste changes, and dysphagia.[36]

Table 1
Practical bedside interventions that may improve the patient experience of nutrition

Issue	Potential Interventions
Discomfort associated with the feeding tube	• Ensure feeding tubes do not create pressure on the nostril or mucosa • Regularly check for signs of pressure injury • Consider change to a smaller more flexible tube before extubation
Gastrointestinal symptoms attributed to enteral feeds	• Identify and address the root cause of symptoms (ie, medication, anxiety, constipation, slow gastric emptying, administration of cold feed, rapid administration of feed) • Trial a feed with a different composition that is, add or remove fiber, try a more or less dilute feed
Taste changes	• Encourage patients to try different foods that they may not have previously liked • Encourage the use of condiments which counteract the taste change
Poor appetite or early satiety	• Encourage the intake of protein and energy-rich food first • Encourage small frequent intake
Nausea and vomiting	• Administer antiemetics half an hour before meals
Difficulty self-feeding	• Identify patients who require feeding assistance (such as a colored meal tray) • Have designated personnel to provide feeding assistance • Encourage family to provide feeding assistance (where safe and appropriate)
Dislike of eating in a clinical environment	• If clinically appropriate, facilitate the patient to get out of bed and into a chair or wheel the bed to a window • Provide headphones to help block out unit noise
Social isolation at mealtimes	• Encourage visitors at mealtimes • Use volunteers to provide conversation • Facilitate hands-free phone or video calls during meals
Dislike of hospital food or issues with the timing of hospital meals	• Encourage visitors to bring food • Facilitate visits to the cafeteria • Have a stock of snacks available on the ward

Patients may be prescribed nutrition supplement drinks to help meet nutritional needs at home; however, poor compliance has been described.[8] The reasons behind this and the experience of eating and continuing nutrition support following hospital discharge remain areas for further study.

Following discharge home, some patients regain lost weight, whilst others may continue to lose weight,[35] which may change the nutritional advice sought. Changes relating to decreased function of the body as a result of weight loss and decreased lean tissue stores have been described by patients as affecting their mood, with one patient stating "… it's the sheer frustration as well, the sheer frustration of not being able to do what you want to do and obviously the tiredness is a contributory factor to that."[10] Evidence suggests that regained weight may be a higher percentage of adipose tissue compared to lean tissue, with over 70% of regained weight being fat mass.[37] Consistent with this finding, ICU survivors had an average of 6.8 kg more fat mass and 0.96 kg less lean mass compared to matched controls. In a COVID-19 population, reasons for dietitian referral from a post-ICU follow-up clinic included

helping with weight restoration in 43% of patients, but conversely helping with weight loss in 16%.[36] The effect of the complex emotions and societal pressures relating to weight change and body image and how these experiences affect compliance with nutrition recommendations is an area deserving of investigation.

Hospital-Related Factors

The environment

The ICU environment itself can affect some patients' desire to eat. This is exemplified by this quote from research undertaken by Segaran: "Seeing people ill around me really influenced my ability to eat. The lights, the noise, and the people around. It's so horrible to have to eat in the same bed as you've been in all day and even been to the toilet in."[24] Another element of the ICU environment that affects patients' mealtime experiences is the absence of social interaction that is part of a normal meal.[24] This experience may affect how much is eaten and is an area where families may be a key resource to provide a more normalized and social aspect to hospital meals.[24]

Similarly, ward patients have described the clinical aspects of the environment as negatively affecting the mealtime experience.[38] Eating in social isolation was also described as negatively affecting intake, with one patient stating "I think being alone you don't eat as well as if you've got somebody with you."[10] However, some patients prefer to eat alone due to self-consciousness about symptoms at mealtimes, and sharing rooms with patients who may be vomiting, coughing, burping, or yelling is described as affecting appetite and intake.[38] One solution that has been proposed is to provide a communal dining space on the ward.[10] This would allow patients who would like a less clinical and more social environment to enhance their mealtime experience, whilst allowing more privacy for patients in shared rooms who would prefer to eat alone due to their symptoms.

Food service

In ICU, reported food service-related issues include dislike of the hospital meals and difficulty with food packaging.[3,5,9] Altered levels of consciousness are a common barrier to oral intake in ICU.[9] This was also a primary factor in a study of patients' ability to self-report barriers to oral intake, even though these patients were eating and drinking.[3] Given patients are required to select food options from hospital menus, any barrier to the ability to perform this will lead to default meals being served. More in-depth evaluation of food-service issues in the ICU is warranted. Filling out menus for patients who are unable to is a task family members could assist with. Qualitative evidence tells us that critically ill patients value family bringing in preferred food.[10,24,27]

On the post-ICU ward, meal timing, which is system-centric, has been highlighted as a significant problem. Typically, hospital meals are served relatively early and have a set structure. This was strongly highlighted by Merriweather and colleagues[8,10] with quotes relating to both the time and meal patterns in hospital being foreign and out of the patients' control: "You know this sort of breakfast, lunch, supper, I mean that's just not for me you know, I sort of ate when I felt like it."[8]

Changing to a "room service" style hospital meal ordering system, involving patients ordering from a menu at any time within a set period (ie, 6 AM to 7 PM) may help to overcome this issue. Meals are prepared on demand and delivered within 45 minutes and this has been shown to improve energy and protein intake, decrease plate waste, improve patient satisfaction, and lower costs.[39,40]

Other options have been proposed, including having a variety of snacks available on the unit to enable food intake outside of meal times and facilitating food purchasing

from the food outlets in the hospital.[10] This can help accommodate different timings and food preferences. Similarly, a randomized trial in post-ICU patients found that receiving assistance from a rehabilitation assistant to get food from the hospital canteen was valued.[27]

Failures in food service delivery have also been reported to negatively affect patients' nutrition experiences. This relates to oral nutrition supplement drinks and snacks not being delivered from the kitchen.[8] This highlights the importance of auditing hospital meal trays and implies an unmet need in hospitals to help troubleshoot issues and assist with the practical tasks related to nutrition that can make an important difference in the patient's experience. The benefits of similar interventions have been reported. In a population of trauma patients with hip fractures, dietitian assistants helped check patient food preferences and food selection, encouraged intake, and provided meal set-up and feeding assistance. This not only improved nutritional intake but reduced mortality.[41]

Clinician Factors

Education and knowledge

Nutrition has been identified as a shortcoming in medical education across the continuum of training.[42] In a study regarding patients with traumatic brain injuries,[43] doctors described their understanding of the evidence regarding nutrition as either lacking or a belief that studies show no difference in important outcomes. Knowledge was described as being largely influenced by the modeling of senior medical staff, as opposed to being based on published literature or formal teaching.

Huang and colleagues[44] reported that ICU nurses indicated that insufficient education on nutrition was one of the top 3 factors affecting the delivery of EN, and showed that nurses with more frequent education regarding EN reported fewer perceived barriers to enteral feeding.

It should be acknowledged that large randomized control trials investigating nutrition interventions in critically ill patients have failed to show benefits,[45–47] leading to an assumption that nutrition is not important; however, this is not necessarily the case. Methodological issues including the use of primary outcomes such as mortality as opposed to functional or health-related quality of life measures and limited timeframes of nutrition interventions (often 1 week or less) are potential explanations for these results.[48]

A lack of knowledge is hypothesized to underlie the premature removal of feeding tubes,[8] a key barrier to adequate nutrition in critically ill patients following extubation. In post-operative patients, the early removal of NGTs is recommended in enhanced recovery after surgery protocols[49,50]; however, these protocols were not designed for, or tested in critically ill populations. Merriweather and colleagues[10] described close to 70% of feeding tubes being removed within 48 hours of transfer from the ICU to the ward, despite no formal assessment of nutrition intake having taken place. Documented rationale for decisions to remove feeding tubes in patients with poor oral intake included encouraging oral intake[8] or improving appetite.[27] However, oral intake was minimal following NGT removal.[8] Preliminary evidence published as an abstract showed that in ICU, patients receiving oral diet alone, or oral diet plus EN did not have significantly different oral intakes or self-rated appetite scores.[51] This is also supported by observational research showing patients with combined oral and EN have significantly better nutritional adequacy compared to oral diet alone.[3,4,6] This suggests that ceasing EN is not the answer to improving oral intake or helping patients meet their nutritional needs. However, patient wishes and any NGT-related discomfort also need to be considered.

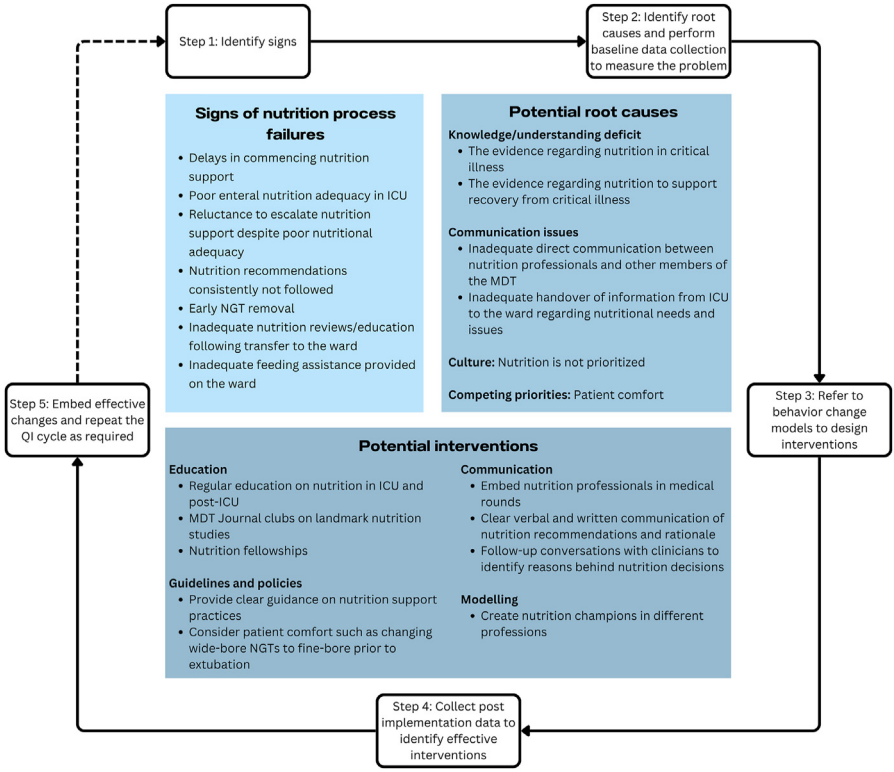

Fig. 2. Ways to improve medical nutrition therapy at a local level. Nutrition process issues can be addressed using quality improvement cycles to optimize multidisciplinary team work.

Insufficient knowledge of factors affecting patients following ICU discharge on the ward may also be an important element. In a study, ward nurses expressed frustration at the high level of care patients require due to ICU-acquired weakness which can affect a patient's ability to self-feed, with patients' dependence seen as demanding.[8] This lack of understanding by ward staff may also extend to dietitians and dietetic support staff. It has been suggested that ward dietitians underestimate the needs of post-ICU patients, as evidenced by limited nutrition reviews, and an unmet need for nutrition education following discharge home.[8]

Communication and collaboration

Nutrition care is acknowledged as a responsibility that intersects with multiple disciplines.[29,43] Despite this, a lack of coordinated and collaborative care has been reported.[10,29] One issue is a lack of integration of the dietitian or other nutrition expert into medical rounds,[43] as well as issues with communication between staff.[10] This may lead to patients experiencing unclear or conflicting messaging regarding their nutrition.

Transfer from ICU to the ward is a key time when communication and handover regarding a patient's nutrition occurs between staff. Patients have described breakdowns in communication as greatly affecting their experience. In a study, a patient was quoted as saying"So when I was discharged from intensive care, the idea was that I would be eating food. I would start off with soup, ice cream, that sort of thing, to get myself back into the habit of eating again. When I got down to the general

ward, there had been no communication from intensive care to the general ward what I should be doing. They could not actually supply the right food for me. So, my wife and son had to bring food in for me to eat."[28] Limited documented handover regarding nutrition information from the ICU to the ward has been described and is postulated to negatively influence nutritional care[8] and can create confusion and frustration for patients.

Fig. 2 outlines potential ways to address knowledge and communication issues at a local hospital level.

FUTURE DIRECTIONS

The patient experience of nutrition should be included across the research process, from design to outcome measures; however, this has not occurred to date. Rectifying this will help ensure interventions are acceptable to patients, and identify if changes are required to improve patient compliance. Evidence gaps identified in this review include patient experiences relating to MNT; feeding tubes, routes of MNT, and nutrition following hospital discharge. Similarly, the impact of family-based interventions and the interaction between clinician knowledge, behaviors, and attitudes regarding nutrition on patient experience of nutrition requires further investigation.

SUMMARY

The patient experience of nutrition throughout the trajectory of critical illness is diverse and can be emotional. Individualized interventions are required along the care journey to address difficulties and enhance the patient experience. Improving clinician knowledge and collaboration and redesigning hospital food services and environments are all potential ways to improve patient care. Resources which may improve nutrition experience and intake in patients include family support, and assistant roles focused on providing additional nutrition-related care such as feeding assistance. Gaining a better understanding of patient experiences is key to unlocking improvements in clinical care, research design, and hospital food service systems.

CLINICS CARE POINTS

- Consideration should be given to the physical as well as emotional and psychological effects of MNT interventions and restrictions.
- Poor appetite is a common and persistent symptom across the recovery trajectory. Strategies to improve intake may be helpful but it takes time for this to resolve.
- Families should be empowered to assist with nutrition where appropriate such as bringing in preferred foods and providing feeding assistance and social interaction at meals.
- Hospital food service systems should be designed to serve various patient preferences, including flexible meal times (such as a room-service style ordering system), readily available snacks, and culturally appropriate options.
- Education to staff regarding the complex nutritional needs of critically ill patients should be embedded into hospital orientation for ICU, wards, and rehabilitation units.
- The decision to remove NGTs should be made in partnership with the multidisciplinary team and the patient.
- Collaborative multidisciplinary work is required to ensure appropriate handover and consistent messaging to patients about nutritional plans and the importance of nutrition.

DISCLOSURES

This work was supported by an Australian Government Research Training Program (RTP) scholarship (G.H.). The Australian Government had no role in the writing of this article.

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