

A multi-faceted, family-centred nutrition intervention to optimise nutrition intake of critically ill patients: The OPTICS feasibility study

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Descriptive Title: A multi-faceted, family-centred nutrition intervention to optimise nutrition intake of critically ill patients: The OPTICS feasibility study

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Abstract

Background: Critically ill patients are at risk of developing malnutrition which contributes to functional decline and hospital re-admission. Strategies to promote nutritional intake have had a modest effect on protein-calorie intake. None have addressed the recovery trajectory of critical illness or incorporated family as advocates.

Objectives: We evaluated the feasibility and acceptability of a family-centred intervention designed to optimize nutrition during and following recovery from critical illness.

Design: A prospective cohort study

Setting: Two Australian adult intensive care units

Participants: A convenience sample of 49 patients and their families was recruited. Patients ≥ 18 years of age anticipated to require mechanical ventilation for at least 2 days were eligible, provided their family visited regularly and were able to communicate in English. Health care professionals including doctors (n=4), nurses (n=20) and dietitians (n=2) also participated.

Methods: Demographic data were obtained from participants. Recruitment and retention informed study feasibility. Individual and group interviews informed participant views on the acceptability, perception of and experience with the intervention. Inductive analysis was used to analyse qualitative data.

Results: 187 (15.8%) patients met the eligibility criteria; 49 patients and 51 family members consented to participate for a 20.3% consent failure rate. We interviewed 33 (67.3%) family members and 13 (43.4%) patients, all of whom considered the intervention acceptable and who would participate in a similar intervention again, given the opportunity. Inductive analysis of qualitative data from all participants identified three themes: variability in in-hospital nutrition support, families as advocates for optimal nutrition, and partnering with health care providers.

Conclusion: We described a feasible and acceptable family centred intervention that may be effective in promoting nutrition intake in critically ill patients. Further research is required to examine contextual factors impacting implementation of family-centred interventions, particularly those that involve active family participation and advocacy.

Keywords: nutrition, critical illness, family, partnership

BACKGROUND

Adequate nutrition is required to promote health and recovery from illness yet almost half of all hospitalized patients are malnourished¹ and around a third of patients admitted to hospitals in developed countries may have pre-existing malnutrition.² Critically ill patients are at increased risk for developing hospital acquired malnutrition because of the significant metabolic changes which occur in critical illness that result in hypermetabolism, hypercatabolism, and loss of body energy stores.³ These physiological effects of critical illness underscore the importance of rigorous assessment of nutritional requirements coupled with prompt initiation of nutritional therapy. Failure to provide adequate and timely nutrition therapy has been shown to contribute to protein/energy depletion that results in poorer patient outcomes^{4,5} and may contribute to an increased intensive care unit (ICU) length of stay, increased health care costs and higher rates of mortality.⁵

Enteral nutrition (EN) is the preferred form of nutrition therapy in critical illness recommended in all published evidence-based clinical practice guidelines and is associated with improved patient outcomes, such as reduced mortality⁶ and fewer infectious complications.⁷ Yet, in the setting of critical illness, nutritional adequacy from EN is often poor, with data indicating that some patients receive only 40-50% of their nutritional requirements.⁸ Achieving nutritional goals in critical illness is challenging and may be hampered by gastrointestinal dysfunction and frequent interruptions. Variability contributes to persistent gaps between clinical practice and evidence-based recommendations.^{8,9}

Nutrition intake is also suboptimal during recovery from critical illness when enteric feeding devices are removed and the patient transitioned to oral intake. At this time nutritional needs of the patient may remain high while daily protein and energy intake is reduced. This reduced intake may persist for up to a month following ICU discharge^{10,11} despite improvement in appetite.¹¹ Several factors may be responsible for decreased oral intake in this group of patients including weakness, physical barriers to oral intake, lack of appreciation of nutrition and the importance of nutrition in functional recovery. Recent reports have highlighted nutritional issues during hospitalization contributing to the “post hospital syndrome”, an acquired, transient high risk period of vulnerability of 30 days after hospital discharge.¹² In a study of 684 adults over the age of 70 years, almost half (46.3%) reported functional decline one month post hospital discharge and this functional decline was directly associated with in-hospital nutrition intake.¹³

To date, several strategies have been developed to try and optimize nutritional adequacy of critically ill patients with limited or no impact.^{14,15,16,17} To our knowledge none have incorporated strategies to improve nutrition intake during and following recovery from critical illness. Most interventions have been targeted at health care professionals and system factors. None have incorporated the patient and his/her family despite family involvement in patient care in the ICU being implemented in other contexts^{18,19} and reported as being favourable to patients, families and health care providers.²⁰ We developed a novel intervention designed to educate family members about the importance of nutrition in recovery from critical illness and encourage them to partner with health professionals to optimize nutrition during and following recovery from critical illness. Before evaluating the impact of this intervention on calorie and protein intake, we first wanted to assess the intervention feasibility and perceptions of the intervention from the viewpoint of patients, families and health care providers.

AIMS

The purpose of the study was to evaluate the feasibility and acceptability of an intervention designed to educate family members about the importance of nutrition in recovery from critical illness and encourage them to partner with health professionals to promote optimal nutrition during and following recovery from critical illness.

METHODS

Study Design

This prospective cohort study used qualitative methods to evaluate patient, family and health care provider perspectives of a low- and a moderate-intensity family-centred intervention. We evaluated feasibility of the study by evaluating recruitment and retention rates. Based on previously reported data of consent rates for critically ill patients²¹ we anticipated recruiting 30% of eligible participants and retaining 80% of consenting participants until hospital discharge. Views and perceptions of the intervention were elicited from patients, families and health care providers to assess acceptability of the intervention. The study was approved by the health service's Human Research Ethics Committee (HREC reference number: HREC/12/QGC/46) and the affiliated university's ethics committee (HREC reference

number: NRS/34/12/HREC) before commencement of the study. Informed consent was obtained from all participants.

Setting

To promote data transferability, data were collected at two Australian intensive care units, one located in Queensland and one in New South Wales, Australia. One intensive care unit was located in New South Wales and the other in Queensland. Both were Level 3 adult intensive care units which provided 1:1 nursing care for ventilated patients and provided allied health support including physiotherapy and dietetics. Dietitian resources differed between the two sites; in New South Wales the full-time equivalent for the dietitian was 0.8 and in Queensland was 0.4. Research leads responsible for data collection at each site were familiar with and had adequate understanding of the clinical environments which assisted with establishing data credibility.²²

Sample

We planned to recruit a convenience sample of 30 patients and families at each site within the first 48 hours following ICU admission. Any patient ≥ 18 years of age anticipated to require mechanical ventilation for at least 48 hours was eligible. Patients not expected to survive 48 hours after screening, or in whom there was a lack of commitment to full aggressive care, were excluded. It was expected that the patient would be visited by family members regularly while in hospital. Only those families able to communicate in English were included. Health care professionals including doctors (n=2), nurses (n=14) and dietitians (n=2) were also included in the study sample, with half to come from each study site. Health care professionals who were involved in the care of patients and their families enrolled in the study were eligible to participate.

Intervention

Development of the intervention was informed by family centred theory²³ which originated with Carl Rogers' work in psychiatry²⁴ and subsequently expanded to care of hospitalized children.²⁵ The spread of family-centred care from hospitalized children to hospitalized adults is likely in response to the recognition that treating the patient in the context of the family was recognised as a valuable strategy.²³ This is especially so in the context of recovery from critical illness where functional recovery and health-related quality of life are important

goals²⁶ that require a collaborative approach to health service delivery throughout the trajectory of critical illness to recovery.

While there are many descriptions within the published literature, there are some common key features of family centred care. For example, Briar-Lawson et al.²⁷ developed an interdisciplinary framework for family-centred practice and policy. This framework recognises that families are experts in what helps and hurts them and are indispensable, invaluable partners for health professionals who collaborate with, and are empowered by, health professionals. Using this framework as a guide, we developed two intervention doses, a low- and moderate-intensity intervention, to help us understand the participants' perception of participation requirements and how these may impact intervention acceptability (Figure 1). In keeping with the features of family centred care and consumer engagement,²⁸ both the low- and moderate-intensity interventions were developed with input from families with experience in the ICU environment. Both interventions included an interview with the family to systematically elicit a structured nutritional history of the patient which was subsequently made available to the health care team. We then delivered a short, focused education session supplemented with a printed resource, which conveyed the importance of nutrition and explained nutrition therapies used during and after an episode of critical illness. Guided questions or scripts were provided in the printed resource as prompts to assist families in discussing nutritional goals with health professionals. The intervention was delivered within 72 hours of the patient being admitted to ICU.

The moderate intensity intervention included all aspects of the low intensity intervention and also included a daily nutritional diary which was completed by the family during a two-week period following extubation of the patient and resumption of oral intake. The nutritional diary was developed based on the data collection tool used for the nutritionDay worldwide survey.²⁹ Each day they visited, families were asked to talk with the patient to estimate the amount of food consumed from the hospital meal(s) and any additional food provided. The intent of the diary was to facilitate a conversation about rather than to specifically measure nutrition intake. If during completion of the diaries families were concerned about nutrition intake of the patient they were encouraged to communicate these concerns to the nursing or dietetics staff, thus serving as a patient-level audit and feedback mechanism. Specific information and scripts were provided to families in the education booklet to support families to frame their questions and discussions with health care providers.

Data collection

We obtained demographic data from the patients, families and health care professionals, with participant triangulation helping to establish data credibility.²² At one site we conducted brief interviews with patients to ascertain their support for their family members being involved with advocating for optimal nutrition. Patient interviews were conducted after discharge from intensive care but before hospital discharge. Families and health care professionals were interviewed to obtain their views on the acceptability and feasibility of the intervention and their experience and perception of being involved in the intervention. Families were interviewed two weeks after intensive care discharge or immediately following hospital discharge, whichever came first. Health care providers were interviewed after 15 families received the low-intensity intervention and after the moderate-intensity intervention. Examples of prompts used in the semi-structured interviews are provided in Table 1. Data were collected between September 2012 and December 2013.

Data analysis

Descriptive analysis was used to report demographic characteristics. Interview data was transcribed verbatim. A deductive analysis³⁰ was conducted first to specifically evaluate the nutrition education intervention and was then analysed using a general inductive approach.³¹ Interview transcripts were read through several times to gain a sense of the whole, which allowed large amounts of raw data to be condensed into key ideas. Data were coded by one researcher who used the code-recode technique to increase dependability of the analysis.²² Findings directly arose from the analysis of the raw data rather than from a priori expectations where core meanings relevant to the research objectives were identified which informed development of the key themes.³¹

FINDINGS

Forty-nine patients were enrolled in the study, most of whom were male (n=27; 57.4%). The median (IQR) age was 51.0 years (38.5-70.5). The median (IQR) length of stay in ICU was 10 days (5.5-19.5) and length of ventilation was 6 days (3-15). Reason for admission was predominantly for non-surgical care (n=30; 63.8%) with the most common clinical presentation being for pneumonia (n=7; 14.9%). The mean (SD) Acute Physiology and Chronic Health Evaluation II score was 20.0 (7.7). Of all patients admitted to ICU during the study period, 187 (15.8%) met the eligibility criteria. We obtained consent for 49 patients and

51 family members. Family participant demographic data is provided in Table 2. For eligible patients and families, consent was not obtained for 138 (73.8%). There were a variety of reasons consent was not obtained (Table 3). The overall consent failure rate, which reflected those participants who declined participation, was 20.3%.

Family members of 30 patients received the low intensity intervention with the remaining (n=19) receiving the moderate intensity intervention. We interviewed 33 (67.3%) family members; 18 from the low intensity intervention group and 15 from the moderate intensity intervention group, all of whom were positive about their participation in the intervention and who indicated that they would participate in a similar intervention again, if given the opportunity. Interview data were not obtained for 16 participating families because of loss to follow up (11; 68.7%) or where families were not approached following death of the patient (5;31.3%).

Qualitative data were obtained from 13 (43.3%) patients at one site. Each of these 13 patients indicated their agreement with their family being involved as advocates for nutrition intake and would support similar involvement in the future, if the opportunity arose. We were unable to collect interview data from 17 patients; 3 had died, 9 were confused or had difficulty communicating and 5 were lost to follow up. Twenty-six health care professionals (4 physicians, 2 dietitians, 20 nurses) also participated in individual or group interviews (Table 4).

Through qualitative interviews we were able to explore intervention acceptability, that is, how well the intervention was received by and met the needs of patients, their family and health care provider. Through inductive analysis of the data three additional themes were identified: variability in in-hospital nutrition support, families as advocates for optimal nutrition, and partnering with health care providers. Examples of participant quotes for each theme are provided in Table 5.

Nutrition education intervention

Family participants considered both the low- and moderate-intensity interventions acceptable with few suggestions offered on how the information or its presentation could be improved. The intervention met the needs of family participants who valued the opportunity to learn about nutrition prompting several to share the information with their extended family and friends. Three participating families also described using the information booklet as a point of

discussion with health professionals outside the ICU such as the community dietitian, speech pathologist, general practitioner or diabetes nurse, and commented that the intervention assisted them to plan nutritional support once the patient was discharged home.

Participants in the moderate-intensity group also received the food diary as part of the intervention and differing views of its utility were expressed. For most, the diary was well-received, straight forward and easy to complete, although some commented that they weren't clear about how they were to use the diary. In some cases, completion of the diary was the responsibility of one family member; for others this task was shared between family members and also with nursing staff. Many of the patients in the moderate-intensity intervention group did not resume oral intake once transferred to the ward and at least five patients continued with nasogastric feeds. Patients who were confused or had a cognitive deficit were often unable to recall or report oral intake to family members. Some families also reported that the patient ate so little of their meals that they decided to "ignore" the diary.

Timing of the intervention was highlighted by participants as an important consideration who commented that the first few days following ICU admission was a period of considerable stress for family members and that this may have reduced the ability of some participants to fully comprehend the information provided. One participant described the early period in ICU as being "a pretty crazy moment" where he wasn't thinking much about nutrition but thought the information was something that he would "read a little bit later". Three participants who had previous experience of the ICU environment believed that their familiarity with the ICU environment increased their willingness to be involved in advocating for optimal nutrition.

Variability in in-hospital nutrition support

Families described a range of experiences in relation to the provision of in-hospital nutrition therapy. All families indicated that the nutrition support provided in the intensive care unit was exemplary. Information provided by staff in the ICU meant that they often did not feel it necessary to ask questions about nutrition and felt confident that their family member was receiving the prescribed amount of protein and energy. Through these conversations the perception was that ICU staff placed a high level of importance on nutrition and which, for one family member, echoed the mother's instinct to "feed the kid".

Once the patient was discharged to the ward, some family members commented that the importance of nutrition seemed lost. Although the families continued to use the resources provided as part of the nutrition intervention, they commented that some ward staff “don’t seem to take as much interest in [nutrition]” and concern was expressed that nutrition intake was not closely monitored. One family member commented that “... the same little lady that brought [meal trays] in would whisk them away. Nobody would have known whether [the patient] ate or not.” Consequently some families felt the need to be vigilant about nutrition intake in the period post ICU discharge, to the extent that they would coordinate visiting to coincide with meals to ensure that the patient was eating. Another commented that advocating for nutrition was “useless” because “the hospital itself doesn't follow up...most meals were just thrown in, picked up and taken out.”

Participants recognised that models of care differed between the ICU and ward areas and that lower nurse-to-patient ratios in ICU likely made using the printed nutrition information resource to discuss nutrition with health care professionals easier. The transition from ICU to the ward area was highlighted by many families as being a challenging time and support from dietitians, speech pathologists, and nurses seen as necessary to optimize nutrition intake. Having a “good plan in place” was reassuring and when this plan was communicated to the family, satisfaction with the provision of nutrition improved.

Recognising that the transition period following ICU might contribute to decreased nutrition intake meant that some family members used aspects of the intervention to help them advocate for better nutrition provision for the patient at this time. For example, one family member described “asking for the types [of nutrition supplements] that I knew that he would eat. But they [nurses] didn't take the time to try to find out.” Other family members described asking questions “that weren't really answered”. Offers to find out information to address family member’s questions were sometimes not followed through or there were significant delays where “you don’t hear anything for hours” the consequence which was for family members to “give up asking”.

Families as advocates for optimal nutrition

We interviewed 13 patients in total (43.3%) each of whom considered the intervention acceptable and viewed their family’s involvement positively. Acceptability of the intervention from the patient’s perspective was emphasised by each indicating that they

would like their family member to be involved in a similar way in the future, should the opportunity arise.

Families were also positive about their involvement in the intervention and described feeling comfortable asking questions while the patient was in ICU. Many described their participation in the study as providing them with the “opportunity to ask questions legitimately” even on matters unrelated to nutrition. This perception was echoed by several nurses who also commented that the education intervention and prompts gave families “permission to ask questions” and believed this might have facilitated dialogue between families and health care providers in general, demonstrating that the intervention was meeting the needs of family participants. Most frequently questions were posed to nursing staff because he/she was the person most readily available. Many nurses commented that families who received the intervention asked more specific questions about nutrition provision and were able to recognise the importance of nutrition in the ICU.

However, health care providers consider knowledge of families to be important. It was felt that most families did not have “the medical knowledge required to make some decisions” and in such situations health care providers believed that families needed to be guided by the medical staff. Health care providers’ perception was that knowledge was most lacking in the context of ICU, prompting one dietitian to suggest families might not be able to engage meaningfully with health care providers about nutrition support in this environment. In contrast the same dietitian suggested that once the patient was moved to the ward there was “a very profound role” for families. Ward nurses were supportive of family engagement with improving nutrition intake and commented that providing patients and families with good nutrition information and emphasizing the importance of nutrition in recovery was beneficial and might help prevent readmission after hospital discharge. Family participation at meal times for patients who required assistance or culturally specific food was also considered an important strategy to promote nutrition intake for certain patients.

Partnering with health care providers

The notion that families and health care professionals “have to work in unison and help guide each other to achieve what's absolutely best” was seen as important by families and health professionals alike and most nurses and dietitians supported the notion of family advocacy and partnerships between families and health care professionals. Nurses saw families as being important advocates for the patient in general, particularly in ICU, a time when patients were

unable to advocate for themselves. However, this view was not universally shared. Some nurses did not believe that families had the requisite knowledge to advocate for patients and should leave decisions to “the experts”. The lack of support for families partnering with health care professionals was highlighted by one family member who described being made to feel as though she was “intervening” in the nurses’ work. This paternalistic notion exemplified by a ward nurse who commented that “you can have a family that's really compliant with what you're doing as nursing staff and others who just get in the way”.

Physician’s perceptions of family working with health care professionals differed between the two sites. At one site, the physician group supported the notion of a family-centred nutrition intervention although were not actively involved in its delivery. In contrast, other physicians were opposed to the notion of families advocating for best practice. They viewed the family’s role was as an “important source of information” and one to “provide love and support”. The notion of partnership and teamwork was not considered appropriate and emphasized in the comment that “there are doctors, and nurses and physios....and there is the family. They are not part of the team”. Patient advocacy was considered by some physicians to encourage “adversarial” behaviour that might result in the “challenging” of physician judgement rather than being about a partnership to optimize care for the patient. One physician commented that “I don't see they [families] have a role except in so far as to have what is happening explained to them”. If families were to ask questions dialogue was considered productive as long as the families asked “sensible questions when appropriate.”

It was conceded, however, that if families were fully informed then “they've got a right to expect the best for their family and advocate for it.” However, one nurse commented that there was a public expectation that hospitals deliver what is considered “best practice” and consequently advocating for best practice seemed somewhat redundant. Despite the misgivings of some health professionals about families advocating for optimal nutrition an education intervention about nutrition therapy was “certainly not a bad thing” and “despite initial misgivings [about the intervention], a downside to families being educated about nutrition was not evident”.

DISCUSSION

The provision of adequate nutrition to critically ill patients is recognised as an important therapeutic strategy to improve patient outcomes during hospitalization and following discharge. However nutrition intake in the ICU³² and other hospital settings^{2,33} are often suboptimal and multi-faceted interventions aimed at improving nutrition intake have not always made a strong and sustained impact on calorie and protein intake.³⁴ At the centre of many of these interventions is a nutrition champion, typically a health care professional, whose availability may be inconsistent and where the focus is often at the organizational level.³⁵

We evaluated a novel intervention that involves partnership with families of critically ill patients, where families advocate for optimal nutrition during and following recovery from critical illness. This approach is consistent current approaches to incorporating family-centred care in the ICU³⁶ and supports informed and inclusive decision making for families of critically ill patients.³⁷ Patients at higher nutritional risk are likely to benefit more from nutritional interventions³⁸ so we focused our intervention on those patients anticipated to require mechanical ventilation for at least 48 hours. Of all patients admitted to the ICU 15.8% (n=187) met the eligibility criteria. It is likely that our inclusion criteria excluded some patients at high nutritional risk who did not require mechanical ventilation for this period given that an estimated 43% of patients are malnourished on admission to ICU.³⁹ Using a nutrition risk assessment tool specific for critically ill patients⁴⁰ may have allowed us to identify a broader cohort of patients who may have benefited from the intervention.

Of those patients who did meet the eligibility criteria, we obtained consent from 49 families the overall consent rate was 26.2% slightly lower than the 31% consent rate reported in a multi-centre, cross sectional study of research feasibility.⁴¹ However, consent failure rate, where families declined to participate, was only 20.3%, demonstrating that recruitment is feasible provided other factors impacting the consent rate are addressed.

The main reason consent was not obtained related to operational reasons such as the research coordinator being unavailable or being unable to contact the family, which is consistent with the experience of others.⁴¹ It is possible that recruiting families within the first 48 hours after ICU admission might have decreased the consent rate given that this is a time period when there is likely most uncertainty about the patient's condition and a time when families often feel overwhelmed. This concern was highlighted by some family participants commented that

some families might find making a decision to participate difficult early in the ICU admission. This suggests that the variability with which families might feel prepared to participate in the intervention requires assessment of family readiness and flexibility with timing of intervention delivery which allow more families to participate and have the opportunity to positively influence nutrition care in the ICU.

The recovery trajectory following critical illness is often lengthy and thus presents opportunity for family to continue engagement with nutrition optimization nutrition throughout the hospital stay and following discharge. Ongoing engagement with optimizing nutrition after ICU discharge is warranted with research suggesting there are numerous factors that make nutritional intake post extubation difficult.^{10,42} In our study family participants perceived that there was less emphasis on nutrition once the patient left the ICU with promoting and monitoring of nutrition intake being perceived as a lower priority than other aspects of patient care and management. Whether ward nurses were sufficiently familiar with the nutrition therapy plan for individual patients was unclear as they did not appear to be well equipped to provide information or guidance to family members. While we recognise the opportunity for nurses to become more proactive in promoting nutrition as patients continue to recover after a critical illness, this also suggests that families might play an important role in monitoring nutritional adequacy and communicating their concerns to relevant health care professionals.

Our intervention was directed at families of the critically ill patient who we saw as well-positioned to advocate for optimal nutrition on behalf of their relative. In developing the intervention we made the decision to partner with families as they are the one constant through the patient's hospitalization and recovery at home an approach that is consistent with the direction of many international⁴³ and professional⁴⁴ organisations. Families in our study were positive about undertaking this role. Participating in the study was seen to legitimize asking questions and interacting with staff. The positive interactions with health care professionals is consistent with other positive reports of shared decision⁴⁵ and collaborative patient care^{19,46} in the context of critical care practice.

Recognising the possible disparity in views,²⁰ we also sought the patient's perspective of their family being involved in the intervention. Of the patients we were able to interview, all indicated that they were pleased their family member had participated and would like them to do so again if the opportunity arose. As we collected information from less than half of the

patients enrolled in the study it is possible that this view was not shared across all participants and warrants further exploration.

While the notion of collaboration between families and health care professionals was embraced by patients and their families this was not a concept universally embraced by health care professionals. Nurses and dietitians were generally accepting of the principle that families could work together with health professionals in promoting optimal nutrition but recognised the level of participation and engagement would differ depending on the level of knowledge of individual family members. Conversely doctors demonstrated a more paternalistic approach to care and seemed less able to recognise and accept the range of preferences held by patients and families towards patient and family centred care.⁴⁷

The challenges in adapting a family-centred care approach may be partly due to the origins of family-centred care in paediatric health where the partnership is usually between parents and health care professionals.²³ In our study we were partnering of families of adult critically ill patients so it is possible that health care professionals viewed the family's participation in patient care differently than if the patient were a child. Nevertheless, the elements of patient and family engagement as described by Brown et al.⁴⁴ include collaboration, respect and dignity, activation and participation, information sharing and decision making. Of these principles, it seemed the notion of collaboration, which is described by Kou et al⁴⁸ as 'medically appropriate decisions that best fit the needs, strengths, values, and abilities of all involved are made together by involved parties, including families at the level they choose', was the least likely to be supported by health professionals, specifically doctors.

There is a body of work addressing family-centred care in the ICU however most of this relates to provision of physical care^{19,20,46} and end of life decision making.⁴⁹ Our data suggest that family-centred interventions are a potential way to optimize care for critically ill patients. Implementation of such strategies should be considered within the context of the family-centred care approach within specific clinical contexts, recognising that some health care professionals maybe more ready to incorporate family-centred care into clinical practice.⁴⁹

This study is not without its limitations. Data were collected in two intensive care units and it is not clear whether the issues highlighted here reflect practice more broadly and further exploration of intervention acceptability is planned for additional international sites.

Although our sample size was limited, the data has allowed us to develop a deeper understanding of the complex issue of patient and family focused care in the context of

critical illness that can be used to inform future research. We recognise that socioeconomic status might also influence families' ability to participate and limit their ability to be present in the ICU.

Conclusion

Our intervention specifically focused on partnering with families to promote optimal nutrition for critically ill patients, in the ICU and during recovery from critical illness. From this preliminary data we are confident that patients and families favourably viewed this intervention and the ability to partner with health care professionals. The effectiveness and success future interventions involving family partnership requires an interdisciplinary team that respects and values the principles of family centred care.

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Table 1 Example interview prompts

Patient	Family	Health care provider
Views on family involvement in advocating to best nutrition practice on their behalf	The reason for deciding to participate in the study and how they felt when approached to be involved	The extent to which families should be advocating for best nutrition practice
Willingness for families to be involved again in advocating on their behalf, if the opportunity arose	Clarity of the education session including the education booklet	The role of the family in the context of acute illness
	Ability to provide information about the patient's nutrition history	How families can be incorporated as part of the team where they have involvement in patient care and/or decision making
	The extent to which families asked staff nutrition-related questions and whether these questions were positively received.	The benefits of families receiving nutrition education
	The extent to which they knew whether the patient was receiving adequate nutrition	The impact of participating in the study on the way in which families interacted with staff
	Adequacy of nutrition intake in the ICU and on the ward	
	Potential problems with resumption of oral intake and whether these would continue after hospital	

discharge

Usefulness of the nutrition
diary

Ability of the patient to recall
what food was eaten

Willingness to be actively
involved in strategies aimed
at improving the patients
wellbeing, if the opportunity
arose again

Would participants
encourage others to be
involved in similar
interventions aimed at
improving patient wellbeing?

Table 2 Family participant characteristics (N=51)*

		N(%)	%
Relationship	Spouse	28 (54.9)	54.9
	Child	7(13.7)	13.7
	Parent	11(21.6)	21.6
	Close friend	1(2.0)	2.0
Gender	Male	21(41.2)	41.2
	Female	26(51.0)	51.0
Age (years)	26-30	5(9.8)	9.8
	31-35	4(7.8)	7.8
	36-40	1(2.0)	2.0
	41-45	5(9.8)	9.8
	46-50	7(13.7)	13.7
	51-55	4(7.8)	7.8
	56-60	3(5.9)	5.9
	61-65	5(9.8)	9.8
	65+	10(19.6)	19.6
	Employment	Full time	17(33.3)
Part time		7(13.7)	13.7
Casual		1(2.0)	2.0
Student		3(5.9)	5.9
Not currently working		2(3.9)	3.9
Retired		9(17.6)	17.6
Income (\$)	<20,000	1(2.0)	2.0
	20,001-40,000	10(19.6)	19.6

	40,001-60,000	12(23.5)	23.5
	60,001-80,000	7(13.7)	13.7
	80,001-100,000	3(5.9)	5.9
	100,001-120,000	3(5.9)	5.9
	120,001-140,000	1(2.0)	2.0
	>180,000	2(3.9)	3.9
Highest education level	Some high school	8(15.7)	15.7
	High school	10(19.6)	19.6
	Some college/university	89(15.7)	15.7
	College diploma	5(9.8)	9.8
	Bachelor degree	10(19.6)	19.6
Frequency of anticipated visiting	Daily	42(82.4)	82.4
	Every other day	1(2.0)	2.0

*Not all participants provided data for all categories

Table 3 Reasons consent not obtained for eligible patients (n=138)

	N(%)
Family dynamics	11 (8.0%)
Refused consent	28 (20.3%)
Family member not contactable	24 (17.4%)
Research coordinator unavailable	30 (21.7%)
MD deemed patient ineligible	9 (6.5%)
Participating in other studies	11 (8.0%)
Other	25 (18.1%)

Table 4 Health care provider characteristics (n=26)

		N	%
Discipline	Registered nurse	20	76.9%
	Physician	4	15.4%
	Dietitian	2	7.7%
Gender	Male	14	53.8%
	Female	12	46.2%
Age (years)	<30	11	42.3%
	31-45	9	34.6%
	46-60	6	23.1%
Employment	Full time	16	61.5%
	Part time	9	34.6%
	Casual	1	3.9%
Highest education level	Bachelor degree	11	42.3%
	Postgraduate specialty qualification	13	50.0%
	Master's degree	2	7.7%
Years' experience in intensive care	< 2 years	8	30.8%
	3-5 years	2	7.7%
	6-10 years	5	19.2%
	11-15 years	4	15.4%
	15+ years	7	26.9%

Table 5 Example quotes for identified themes

Theme	Quote
Variability in in-hospital nutrition support	<p>Food-wise, well with the condition [my daughter] was in, in ICU, for what she was getting there, that's fine. But the food in the general ward, she didn't like it. I mean, she didn't have much choice in ICU because that was coming through a tube, where up in the ward she was actually eating the food and didn't - she could hardly eat the meals. (Family)</p>
	<p>Well, it [the nutrition intervention] was pretty useless because the hospital itself doesn't follow up. We weren't there for most meals - well I was there but [the meals] were just thrown in, picked up and taken out. Really the whole thing doesn't seem to be much use. (Family)</p>
	<p>I think he did. I don't know - he got his pureed meat and his veggies. They were going to give him Sustagen and then he didn't end up getting that, like it wasn't sort of followed through. (Family)</p>
	<p>I guess I haven't really asked too much about what she's currently been having. I know that she appears to be well and I think under the circumstances, there was something coming into a tube from her nose. I think overall it's all gone surprisingly well. (Family)</p>
Families as advocates for optimal nutrition	<p>Even reading the booklet was - it gives you the advocacy to I suppose ensure that things are going well like the 30 degree feeding and those kinds of things because I'm an outsider. You want the best for your loved one and there's no way I would ever tell staff what I think should be going but reading that just gave me the confidence to say that 30 degrees, is he there? (Family)</p>
	<p>Oh no, oh no, you wouldn't [speak to the staff about your concerns] because then you're just a complaining mother. No, I wouldn't want to annoy them for fear that they would retaliate. But [my son] lost a lot of weight because he didn't eat [after ICU discharge] in</p>

hospital. Now we're trying to build him up a bit, now that he's home. (Family)

That's all we want - we just want to know details. We're a detail family. We don't like this surface - oh he's fine. Yeah he's eating, no problem. It's like, no but what is he eating? How is he eating? Why is he - we want to know that stuff. (Family)

I think they should be able to advocate for the best practice as possible available to the patient, but I think that we need to look at where the line is drawn where the family members do not have the medical knowledge required to make some decisions. (Registered Nurse)

I think if you think of the average person out there who's family member presents to ICU in a situation where they suddenly have to be ventilated and artificially fed, it's just so foreign to them that I don't think they would feel comfortable talking about it or knowing what to say (Dietitian)

I do not believe families in acute illness can make an informed decision when all the facts and circumstances are not known and it depends on how it's presented to them. (ICU Consultant)

Partnering with health care providers

... John's nutrition was actually switched off at the time you and I were talking. Now firstly I wouldn't have noticed that so that made me more alert to start noticing things. Secondly I would never have asked about one of those bottles that are hanging up because I didn't think I'd get a positive response. But having spoken to you and the dietician, I did ask and found why it was off at that time and the answer was that he wasn't absorbing it and so they had to take it out and reinsert it. (Family)

It is because then you say the dietician suggested I ask this, that kind of thing, so it softens it a little bit without the staff thinking that I'm telling them what to do which I would never do because

I'm not trained in that area. I think it was a nice foot in to say, yes, the dietician's just asked me to ask that kind of thing ... (Family)

I see, certainly from a nutrition point of view, is that family have some knowledge and understanding, if possible, of - or are able to provide some information in terms of things like we need to know people's heights and weights or if people - we need to know what their eating habits or something like that which we can't get from the patient. (Dietitian)

Our job is to support [families] in making a role and just making decisions where their role [is], because I think they're uncertain about what they're capable of doing and how important their presence is. (Registered Nurse)

... apart from being a family member by [the patient's] bedside, providing love and support and asking sensible questions when appropriate, I don't think [family] have a bigger role (ICU Consultant)
