

Complex Feeding Decisions: Perceptions of Staff, Patients, and Their Families in the Inpatient Hospital Setting

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Abstract

Objective: Where swallowing difficulties are chronic or progressive, or a patient is palliative, tube feeding is often not deemed appropriate. Instead, patients continue to eat and drink despite the risks of pneumonia and death. There is currently little evidence to guide clinical practice in this field often termed “risk feeding.” This qualitative study investigated staff, patient, and family member perceptions of risk feeding practices in one New Zealand hospital. **Method:** Twenty-nine staff members and six patients and/or their family were interviewed. **Results:** Thematic analysis revealed four global themes: supporting practice, communication, complexity of feeding decisions, and patient and family-centered care. Staff described limited education and organizational policy around risk feeding decisions. Communication was considered a major factor in the success. **Conclusion:** Feeding decisions are complex in the hospital environment. The themes identified in this study provide a foundation for hospital guideline development and implementation.

Keywords

risk feeding, dysphagia, PEG, interprofessional team, shared decision making

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Introduction

When swallowing disorders (dysphagia) become severe, it is often deemed unsafe to continue eating and drinking due to the high risk of aspiration pneumonia and choking (Logemann, 1998). *Risk feeding* is the term used when a patient continues to eat and drink orally despite risks (Royal College of Speech & Language Therapists [RCSLT], 2005). A risk feeding approach may be deemed appropriate for a multitude of reasons. Alternative feeding options (nasogastric, gastrostomy, total parenteral nutrition) may be limited by the patient’s medical condition or the risks of alternative feeding options (such as gastrostomy placement) may be too high (Royal College of Physicians, 2010). The person may be at the end of his or her life and a palliative approach deemed more appropriate by the team, patient, and family (Chakladar, 2012; McCann, Hall, & Groth-Juncker, 1994; Sherman, 2003). The team may not believe alternative feeding will prolong or improve quality of life, for example, in advanced dementia (Finucane, Christmas, & Travis, 1999; General Medical Council, 2012; Hinson, Goldsmith, & Murray, 2014). An informed, competent person may not be prepared to give up the pleasure of eating and drinking, or

they may not wish to have an invasive procedure such as tube feeding (Medical Council of New Zealand, 2008).

Despite the ethical challenges and the complexities of risk feeding management faced by the interprofessional team, a review of the literature suggests that research from the staff, patient, or family perspective is limited (Hinson et al., 2014; McCann et al., 1994; Palecek et al., 2010; Pollens, 2012; Sherman, 2003). Although palliation and advanced dementia have received some attention, there is little research exploring risk feeding management in hospitalized patients with chronic, progressive, or life-limiting conditions, who are not yet end of life. This qualitative study investigated staff, patient, and family member perceptions of complex feeding decisions across the breadth of conditions leading to chronic dysphagia in the inpatient setting.

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Method

This study complied with the ethical rules for human experimentation that are stated in the Declaration of Helsinki, gained ethical approval from an appropriate regional ethics committee (5/NTA/49), and all participants provided written, informed consent.

Participants

Recruitment occurred at one medium-sized metropolitan hospital. Recruitment was multifaceted. All senior medical officers were invited at a weekly medical meeting. All junior doctors and allied health staff were emailed the flyer directly. All nurse managers were emailed the flyer and asked to circulate to their nursing teams. Potential patient and family participants were taken from a concurrent clinical audit at the same hospital. Twenty-five patients identified at ward round as being involved in risk feeding decisions during their inpatient admission between November 2014 and July 2015 were included. Patients were invited by post. Patients were offered individual or family group interviews.

Twenty-nine staff members consented to participate: one nurse manager, one stroke ward nurse specialist, one palliative care nurse, one social worker, six registered nurses, three dietitians, four speech-language pathologists, three house officers, four registrars, and five consultants representing geriatrics, rehabilitation, rheumatology, burns, plastics, maxillofacial, palliative care, stroke, and gastroenterology. Three patients and three family members also consented to participate representing five episodes of care. These five patients represented the range of causes of dysphagia (two stroke, one Parkinson's disease, one motor neuron disease, one pharyngeal pouch). One patient had severe dysarthria and conducted her interview using pen and paper.

Data Collection

The method of data collection was face-to-face ($n = 30$) or telephone ($n = 4$) semistructured interviews. Staff interviews were conducted at the interviewees' workplace and patient and family interviews were conducted at their place of residence. Three university-based researchers carried out interviews ranging between 20 and 60 min. Questions for staff covered their experience of the decision-making process when managing patients with severe swallowing difficulties in the inpatient setting. The interview guide included questions such as "Tell us about your experience working with patients and their family where complex feeding decisions have needed to be made," and "Thinking of a specific case you have worked with, tell us about the process taken." Questions for patients and their families covered areas regarding experiences of feeding decisions during their hospital stay. The interview guide included questions such as "Tell us about your experience of being in

hospital with swallowing difficulties." Consent was gained from participants to audiotape all the interviews. Following completion of the interviews, the audiotape recordings were transcribed, and sent back to those participants who had requested them to check accuracy.

Data Analysis

This research utilized a qualitative descriptive interpretive approach to "hear the voices of people" and "present a thoughtful overview of the results" (Smythe, 2012, p. 5). Thematic analysis was used to analyze the transcripts with the support of NVivo 9 qualitative data analysis software using the process described by Braun and Clarke: Phase 1, familiarization with the data; Phase 2, generating initial codes; Phase 3, searching for themes; Phase 4, reviewing themes; Phase 5, defining and naming themes; and Phase 6, producing the report (Braun & Clarke, 2006). Themes were initially independently identified, defined, and named by two of the interviewing researchers. These two sets of independent themes were reviewed and finalized by the five authors including the three interviewers and two additional researchers from the wider research program who had not participated in any of the interviews.

Results

Four global themes emerged from the data: supporting practice, communication, complexity of feeding decisions, and patient and family-centered care (Table 1).

Supporting Practice

Staff reported a lack of education and operational policy around complex feeding. Two organizing themes emerged from the supporting practice theme: education and guiding documents.

Education. A lack of formal education in complex feeding decisions was described across professions: "I'm not too clear on it . . . I've never had it explained to me or written down to me." They described difficulties among the team around role definition: "sometimes you wonder whether they actually understand what our role is." Staff, patients, and their families verbalized confusion around terminology highlighted by differing definitions of risk feeding: "lots of people had lots of different ideas about what feeding at risk meant and who's role was what . . . and everyone seemed to have a bit of a different take on it" (staff member). Finally, staff indicated the value of supervision within the workplace: "a lot of my knowledge and the way I would approach a situation now has come from my supervisors that I had and my team at the time," "we did a lot of case reviews of complex cases," and "I was lucky to be able to share patients with another colleague who was much more experienced so I could learn from her."

Table 1. Global, Organizing, and Subthemes.

Global themes	Organizing themes	Subthemes
Supporting practice	Education Guiding documents	Undergraduate and on-the-job training Role definition Shared terminology Supervision Keyworker
Communication	Communication within the team Communication with patient and family Transfer of information	Information sharing Accessibility of information Timing of information Consistency of information Continuity
Complexity of feeding decisions	Patient variables Logistics Ethical decisions	Capacity Communication difficulty Medical condition Family influences Differing wards and the interprofessional teams Afterhours and shifts Time Withdrawing treatment Responsibility of decisions
Patient and family-centered care	Quality of life Rights	Shared decisions Culture and family values Informed consent

Guiding documents. Staff described inconsistent processes due to lack of policy: “there’s not an actual written protocol it’s very much kind of therapist-based in the team.” They also described their perception of the challenges of implementing a guideline: “I do wonder whether you *can’t* have guidelines in these situations because they are so complex by very nature” and “a checklist or something to make sure that you’ve considered everything.” Staff indicated the potential value of having a key worker to help coordinate the team: “who’s sort of involved in all these patients,” “key worker to link . . . coordinating the care for all disciplines so even if we don’t have the meeting there’s regular communication,” and “I think it would be helpful to have someone . . . a key worker . . . not necessarily the same person for each patient.”

Communication

Participants voiced how vital good communication was in achieving successful outcomes. Three organizing themes emerged from the communication theme: communication within the team, communication with patient and family, and transfer of information.

Communication within the team. The importance of information sharing between all interprofessional team members was discussed: “having open communication is the most important thing . . . formal situations where that happens like a MDT is really helpful but also just having the capacity to bump into people” (staff member). Staff indicated how successful outcomes are achieved when the interprofessional team

is working toward a common goal: “it’s empowering to see that when you’re . . . everyone’s got a common goal ‘cause it’s discussed in MDT,” and “it’s actually coordinated and there isn’t just little chunks of information everywhere . . . so everyone’s on the same page.” Family described how issues can be avoided through clear communication between the interprofessional team:

well the staff the different um disciplines did seem to communicate well with each other you know . . . there was reasonable good communication going and that’s usually where there’s problems if there’s not . . . there were no stuff ups.

Communication with patient and family. Staff, patients, and their families emphasized the importance of sharing information about options, benefits, and risks with patients and their families: “I wish we had done a bit more kind of joint meetings and I pushed a bit harder to have those” (family member), “information is power . . . every time you’re meeting with the patient or the family it’s a good opportunity to educate and inform” (staff member), and “we have to remember that it’s the patient that’s in the middle of this and if they can make decisions then they definitely need to be included but they can’t make decisions unless they’ve got all the information” (staff member). Providing this information in an accessible manner was deemed important: “people came at that patient’s level so he did understand and he could make decisions” (staff member) and “she gave us the list everything was very clear . . . if I had been trying to follow the original information which was very wordy . . .

and you know it wasn't easy to read" (patient). Staff, patients, and their families indicated the need for the interprofessional team to provide consistent information: "there was a difference between the information from the SLT and the information from the dietitian about what foods he could and couldn't have" (family member) and "the last thing the family needs right now is to get little bits of scrappy information from the different team members" (staff member). Differences between team members led to families making up their own decisions: "he followed what he wanted to follow I don't know what the answer to that is because different people have different points of view and SLT have a different point of view to the dietitian" (family member).

The importance of clear communication with patient and family about risk feeding was highlighted through the confusion of patients and their families in regard to recommendations: "He was there for about 7 weeks he was nil by mouth although he was getting weat-bix and stuff" and "yes although they were feeding him at that time it was a wee bit confusing aye, it was a wee bit contradictory." One patient on a risk feeding plan did not realize that he was allowed to eat and drink as he pleased: "I think I will have this tube in my stomach probably for the rest of my life so I don't think I'll be eating any more lovely food again" (patient).

Continuity and timing of information sharing allowing time for informed decisions to be made were also considered to be important: "the patient had time to ask questions the patient had time to think about it that actually they weren't being rushed into a decision" (staff member) and "I guess as health professionals . . . we don't have to make decisions straight away" (staff member). Family indicated the need for staff to consider how information is processed given the emotional toll of their loved ones hospital stay: "my memory of things is, you know, it's all over the place because of the emotional difficulty of dealing with my father declining you know . . . you sort of forget dates and times and who said what."

Transfer of information. Staff described how there is often a breakdown in the transfer of documentation from the hospital to the place of discharge: "there's not always great communication between what's happened on the ward and what's happened in the outpatients or what's happened in the community it doesn't actually always follow through very well," "clearly the information that's gone out from the hospital isn't clear enough," and "the documentation would really help the care staff there because they feel like they're being asked to feed somebody who's not safe to feed so they need that kind of legal backup." Staff also described how clear documentation would facilitate the process of the patients' potential readmission into hospital: "things can be expressed on an advanced care planning document and we can also put them in a discharge summary and so that can be something that the patient brings in" and "it's clearly stated and documented every time he comes into hospital."

Complexity of Feeding Decisions

Staff described the various factors that make feeding decisions complex in hospital. Family described the complexity of making a decision for their loved ones from their perspective. Three organizing themes were found: patient variables, logistics, and ethical decisions.

Patient variables. Both staff and family reported the increasing complexity of decision making when the patient lacks capacity to make informed decisions: "it gets a little bit blurry I guess if people have significant cognitive impairment . . . and aren't able to communicate whether they want things" (staff member), "if we need to evoke an enduring power of attorney to make that decision for them to make or to consent on their behalf" (staff member), "if they don't have power of attorney personal welfare through the courts . . . it's a long process . . . it can make things complex" (staff member), and "the problem is now . . . I think he's losing the ability to make his own decisions" (family member). A family member reflected on realizing their father no longer had the capacity to make decisions around oral intake: "I just think we should have intervened earlier as a family earlier joined together and said 'look dad' you know but then you can't because you know the Code of Rights and everything you know." Communication difficulty also added to the complexity of management: "the difficult ones are people who can't communicate" (staff member) and "he was aphasic quite severely and we were not sure that he could reliably understand and make an informed choice for himself" (staff member).

Staff also described the uncertainty raised in making decisions when the patient's condition is unknown or has a variable prognosis: "if we don't have the diagnosis we don't know the prognosis it makes it very difficult" and "I think it's hard to make decisions about what sort of feeding we should do you know it ends up kind of a bit of guess work." Staff verbalized the difficulty in managing different family dynamics within the decision-making process: "I think it's harder if you've got a lot of family members that have a lot of different personal views."

Logistics. Many staff indicated that it is the medical team's responsibility to make final decisions for a patient. However, they described varying decision-making processes depending on the ward and the interprofessional team: "as a medical person it usually is ultimately up to myself to make a decision 'cause it is at the end of the day usually the patient is under my care," "you have to take the leadership role to actually say this is what we're going to do because there may be different decisions but I think generally we work as a team," "I'm sure if you go to another medical team the medical consultant will probably take a hands off approach and say you know and just simply let the consensus do what they think is right and that's probably not an unreasonable

thing to do . . . if they're under my care, I'd probably take more active decision making," and "even within a team it's like one registrar was going to be like right let's send him for a PEG right away whereas the other registrar for the same team for the same patient was like we'll go back as a team and actually work out what's going to be right for this man."

Staff described concerns around changes in shifts and having skeleton crew during afterhours and the impact that this can have on patient care: "When a patient comes in afterhours, weekends, that's, that's usually when problems start, especially when you've got family who come in with the patient say 'oh she hasn't eaten since yesterday, what are you going to do? Are you going to feed them?' that's when the pressure starts to happen" and "it's that after hours period if there isn't a plan as an individual it's quite scary with what to do."

Time was considered a barrier for successful outcomes: "If you've got a lot of patients to look after it's very difficult you don't necessarily have time to have all these discussions and this makes it a little bit more complex down the line" and "just sort of just you know sheer volume so you know if you've got 20 patients to see by lunch time stuff gets missed."

Ethical decisions. Staff described the difficulties surrounding the ethical decision of withdrawing treatment: "the issues have usually been more fraught when feeding has started and the patient is deteriorating or the patient is choosing not to continue with feeding and there is a need to withdraw treatment or feeding" and "the hardest decision is doing nothing cause it's so much easier to do something but it's really hard once you've started to stop." The ethical responsibility of the decision was described by both family and staff: "we cannot give him any food because he's getting weaker and weaker and he can't make up his own mind really, and if we give him something now and he chokes um that's you know we could be had for" (family member) and "you know it's the patients decision and they have decided to do this, despite the recommendation you still feel like they're putting themselves at risk and you're standing there watching so it's like a huge burden on you" (staff member).

Patient and Family-Centered Care

Participants described how keeping the patient and his or her family at the center of all complex feeding decisions is paramount to achieving successful outcomes. Patient and family-centered care consisted of two organizing themes: quality of life and rights.

Quality of life. Staff, patients, and their families highlighted the need to undertake a holistic approach when considering feeding options for the patient. The patient's quality of life was considered to be a key consideration for staff: "this man should only have . . . thickened

drinks and that was just unacceptable to him from a quality of life and he hated it and his mood was severely affected," "was the risk worth taking and for some of them for quality of life," and "we adopted the feeding at risk we were confident that he was making informed decisions and his family were informed that we were doing this more from a quality of life perspective."

Rights. Staff, patients, and their families discussed the ultimate rights of the patient and the need to respect patient and family informed choices even if it is against recommendations of the interprofessional team: "it's about the multidisciplinary team ensuring that the patient and the family having that informed consent and understanding all the different options and risks," "I mean at the end of the day if someone's cognitively okay which not all our patients are then actually it's their decision as to whether they want to keep eating or drinking," and "I mean if people understand the consequences it's their life." At times, family felt they had needed to stand up for themselves and go against hospital "orders": "we were glad that we fed him because for us we felt that well . . . she (the speech-language therapist) wasn't by our side making those decisions."

Staff, patients, and their families highlighted the importance of collaboration in decision making between staff, the patient, and family to provide the best individualistic care for the patient: "so explain to the patient and whanau what you're doing but also involving them in the actual decision-making process right from the start" (staff member), "we made sure that we got knowledgeable so we could understand him better because we didn't want to be a family that was like just let the doctors and nurses tell us what to do," and "it's not about working against each other it's about trying to find the best for my dad" (family member). The importance of culturally safe practice when providing services was described by staff, patients, and family: "that whole quality of life stuff just takes on a different kind of flavor depending on the culture of the person" (staff member) and "I think any different culture, you know the importance of eating . . . that would sometimes . . . impact the decision" (staff member).

Discussion

To the authors' knowledge, this is the first study to investigate staff, patient, and family member perceptions of complex feeding decisions in an inpatient setting. Participants described a lack of education and policy supporting interprofessional management of complex feeding. Recently, the British Geriatrics Society published a best practice guideline on dysphagia management in older people toward the end of life (Chakladar, 2012). It highlights several policies and guidelines related to dysphagia management in dementia and stroke end-of-life situations including the Royal College of Physician's advice for oral feeding difficulties and dilemmas (Chakladar, 2012;

Finucane et al., 1999; Hinson et al., 2014). Interprofessional graduate teaching, workplace teaching, and guideline implementation are clearly needed.

Participants in this study described how interprofessional information sharing is essential to ensure the team is working toward a common goal (Vesey, 2013). The importance of accessible information, ongoing discussions, and transfer of information at discharge was emphasized. Yet, patients and their families voiced confusion regarding decisions made in hospital and their consequences. Difficulties in information sharing were heightened when communication and/or cognitive difficulties occurred. Patients with aphasia have been shown to play a passive role in their health care (Hemsley, Werninck, & Worrall, 2013; Knight, Worrall, & Rose, 2006). Patients with communication disabilities have more communication breakdowns and have an increased risk of preventable and harmful adverse events while in hospital compared with patients with intact communication skills (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; Hemsley et al., 2013; Knight et al., 2006). Effective provision of information to patients following stroke has been linked to improved satisfaction of health care with positive outcomes for patient motivation, anxiety levels, compliance with treatment, and empowerment for patients in health-related decisions (Mold, McKevitt, & Wolfe, 2003; O'Mahony, Rodgers, Thomson, Dobson, & James, 1997; Wiles, Pain, Buckland, & McLellan, 1998). Key information shared in a timely, compassionate, accessible manner has been associated with positive perspectives of end-of-life care (Royak-Schaler et al., 2006). Regardless of the condition, patients and family members consider receiving key information as being important to quality care, including discussions about prognosis and future treatment options (Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Royak-Schaler et al., 2006). Clear communication is essential between patients, their family, and the interprofessional team involved in complex feeding decisions.

The complexity of feeding decisions in the hospital environment was evident throughout the data. Both staff and family verbalized the complexity of decision making when the patient lacks capacity. In situations where the patient does not have capacity, an appointed decision maker will make decisions on the patient's behalf while involving the patient as much as possible (Clarke, Galbraith, Woodward, Holland, & Barclay, 2015). Time constraints on effective information sharing has been reported previously (Eames, Hoffmann, Worrall, & Read, 2010; Morris, Payne, & Lambert, 2007). Ethical decisions of treatment, in particular withdrawing treatment, as well as the responsibility of decision making again have been previously described (Leslie & Casper, 2015). Leslie and Casper (2015) proposed that ethical challenges in decision making arise when there is tension between the ethical principle of autonomy and the duty of beneficence, for example, when an autonomous patient wants to go against the recommendations of the beneficent clinician. In these situations, they encourage the interprofessional team to consider the patient holistically and to consider how beneficence is limited not only to

medical aspects of care but also to the patient's perceived quality of life. In this study, staff, patients, and their families described the importance of shared decision making with the cultural and family values of the patient at the center. Yet worryingly, Heyland and colleagues (2003) found 87 patients, in a sample of 135 patients, felt that they had not been involved in end-of-life decisions despite 72% being willing to do so. Patients who actively participate in end-of-life decisions often had positive experiences during the latter stages of life (Carter et al., 2006; Friedrichsen, Strang, & Carlsson, 2000; Royak-Schaler et al., 2006; Smith, 2000). Patients and their whanau in this study were clearly not always informed of the feeding risks being taken.

Limitations and Future Directions

This cohort consisted of staff, patients, and families from one New Zealand hospital and may not be representative of other hospitals nationally and internationally. Staff participants represented a range of disciplines from both rehabilitation and acute wards. Patients and their families represented the Māori and Pakeha populations of New Zealand. However, the small sample size and the limited range of conditions may reduce generalizability of findings. No families from non-English-speaking backgrounds were represented despite the high representation of other ethnic groups in chronic health conditions. Investigating the perspectives of health care professionals in the community regarding transfer of information would provide insights into current practice. One patient with a communication difficulty participated in this study. Given the impact of communication disorders on exchange of information, it would be beneficial to examine perspectives regarding complex feeding decisions from a larger sample of patients with communication disorders and their families. A clinical audit is underway as part of the wider research program and this will provide further evidence of the written documentation provided by the interprofessional team.

Conclusion

This study provides insights into the experiences of staff, patients, and their families involved in complex feeding decisions in hospital. It shows the importance of collaboration and communication between the interprofessional team, patients, and their families to ensure collaborative decision making. It describes the perceived necessity of keeping the patient and his or her family in the center of all clinical decisions. This study highlights the complexity and challenges surrounding these decisions for staff, patients, and their families. Finally, the four global themes identified in this study provide a foundation for future research and the development and implementation of guidelines to help support clinical practice in this field.

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