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Bereaved relatives' perspectives of the patient's oral intake towards the end of life: A qualitative study

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ABSTRACT

Background: Patients approaching death often have a decreasing oral intake, which can be distressing for relatives. Little is known about the relatives' experiences with and perceptions of oral intake at the end of life.

Aim: This study aims to contribute to a more thorough understanding of relatives' concerns regarding decreased oral intake of the patient at the end of life.

Design: Qualitative interview study: semi-structured interviews were transcribed verbatim and analysed using qualitative content analysis.

Setting/participants: Twenty-three bereaved relatives of patients who had been referred to a New Zealand palliative care service were interviewed.

Results: All relatives experienced significant changes in patients' oral intake at the end of life. Oral intake towards the end of life was considered important and is perceived as meaningful by relatives in different ways, such as nutritional value, enjoyment, social time, daily routine and a way of caring. Relatives responded differently to decreasing oral intake; some accepted it as inherent to the dying process, others continued efforts to support the patient's oral intake. Some relatives perceived decreasing oral intake as the patient's choice, and some viewed maintaining oral intake as part of the battle against the disease.

Relatives recalled limited communication with health-care professionals concerning oral intake at the end of life.

Conclusions: This study revealed the complexity of meaning relatives' experiences with dying patients' decreasing oral intake. Their perceptions and concerns were related to their awareness of the imminent death. These findings can guide staff involved in care delivery to better support relatives.

INTRODUCTION

Patients receiving palliative care often have a decreased oral intake of food and fluids, and anorexia is a frequent problem at the end of life, occurring in 39%–82% of patients receiving palliative care.^{1–3} Furthermore, loss of appetite is one of the most common symptoms in patients when referred to palliative care.² It is known that decreased oral intake of the patient at the end of life causes considerable emotional distress for relatives.^{3,4} Most scientific literature on oral intake at the end of life has focused on artificial (medically assisted) nutrition and hydration (ANH), including descriptions of practices,^{5,6} clinical effects,^{5,7,8} ethical aspects⁹ and attitudes of patients, relatives or health-care professionals.^{10–12}

The impact of decreasing oral intake at the end of life on patients and relatives has been scarcely researched, and there is little insight in underlying mechanisms of related distress. One study on the impact of decreasing oral intake among bereaved relatives has recommended that care aimed at reducing relatives' emotional distress related to a patient's inability to take nourishment orally should include 'relieving the relatives' sense of helplessness and guilt', 'providing up-to-date information about hydration and nutrition at the end of life' and 'understanding relatives' concerns and providing emotional support'.³ Additionally, a qualitative study among relatives has demonstrated that 'doing what's best' is an overarching theme in beliefs and behaviour related to nutritional care for terminally ill patients.¹³ Due to limited in-depth knowledge of the underlying mechanisms of relatives' distress related to the patient's decreased oral intake, there are few clues for health-care providers to support relatives when caring for a terminally ill patient. The main purpose of this study is to contribute to a more thorough understanding of relatives' concerns regarding decreased oral intake of the patient at the end of life.

METHODS

Study design and setting

This qualitative study was conducted in a specialist palliative care service in New Zealand. The service included an inpatient unit, with a 10-bed capacity, a 24/7 community service and a consultation team in the allied hospital. We performed semi-structured interviews with bereaved relatives of patients who died under the care of this specialist palliative care service.

Semi-structured interviews as a method of data collection were appropriate to meet the study objectives.

Recruitment of respondents

Forty-five bereaved relatives of patients who died in November–December 2011 under the service received an information letter about the study. The bereaved relatives, as registered in the patient files as first contact person, were approached

after consultation with the social worker from the service regarding the appropriateness to contact this relative.

All bereaved relatives living within a circle of 100 km of the hospice received the information letter about the study.

After a week, they were contacted by phone by a researcher (N.R.) to further inform them and enquire about their willingness to participate. In total, 23 bereaved relatives participated in an interview. Ten relatives refused to participate, due to emotional concerns (n = 6), lack of time (n = 3) and unknown reasons (n = 1), and 11 relatives were not reached.

The interviews took place in February and March 2012.

Questionnaire

A semi-structured questionnaire, developed in collaboration with health-care professionals (oncologists, palliative care physicians and nurses) was used for the interviews, to ensure consistency of topics addressed in all interviews.

The questionnaire started with an open question 'Can you tell me about the last month of life of your loved one?' to encourage respondents to tell their story and experiences. Subsequently, different topics were addressed to investigate their experiences and perceptions of these topics (Box 1).

[BOX 1]

Process

All interviews were conducted at the location of the participants' choice, that is, respondents' homes (n = 20) or the hospice (n = 3). All respondents gave written consent prior to the interview, and in the introduction, it was made clear to all respondents that they could stop the interview at any time.

During the interview, only the respondent and the researcher were present for all but four interviews where the respondent had invited a support person. All respondents consented to the interview being audiotaped. The interviews were transcribed verbatim by a confidential transcribing service, and all transcripts were checked by the interviewer (N.R.).

Ethical approval

The Central Regional Ethics Committee, Ministry of Health, Wellington, New Zealand approved the study protocol (CEN/11/EXP/076).

Analysis

Data analysis was informed by qualitative methodology.¹⁵ The focus of analyses was the words, meanings and phrases used by interviewees.¹⁶ Each interview was considered in relation to its predecessors. During data collection, general themes arising from the interviews were discussed (N.R. and J.C.). After completing all interviews, all transcripts were reread and annotated for initial coding, using the general themes of the questionnaire (N.R.). A set of transcripts was independently read and analysed to identify specific categories within the general themes (N.R. and J.C.). The themes and categories were discussed until consensus was reached. Subsequently, the remaining interviews were coded (N.R.). The findings were later discussed with other members of the project group (A.v.H. and L.Z.), to support consistency and rigour in the data analysis.¹⁴ Data were coded using ATLAS.ti (version 6.1.1, ATLAS.ti GmbH, Berlin). Verbatim data are included in the research

findings to ensure transparency, to make the data explicitly available and understandable to the reader.15

RESULTS

Characteristics of respondents

The characteristics of bereaved relatives and deceased patients are presented in Tables 1 and 2.

Meaning of oral intake at the end of life for relatives

Almost all bereaved relatives recognized decreased oral intake at the end of life as an important issue. When a patient was still able to eat and drink at the end of life, this was perceived as meaningful by relatives in different ways. One important aspect was the nutritional value of food and fluids.

Relatives perceived oral intake at the end of life as being beneficial for the body, for example, as giving physical strength and energy, and as contributing to the preservation of life. As long as the patients could just eat something, even just a spoonful, relatives interpreted this as the body and therefore the person still going on, which appeased them: I think if she didn't eat she wouldn't have been ... she wouldn't have talked to us the way she did. Talking was a little bit hard but she always managed to keep herself going and I'm sure the food helped in that area. (F, daughter, rest home) While she was doing that [eating and drinking] I gathered she might keep some strength. I don't know, I mean, it's just. It was important for me.

(F, daughter, hospice) The meaning of oral intake at the end of life appeared to hold more importance to relatives than the nutritional value of food. The patient's enjoyment of eating, drinking or tasting meant a great deal to relatives, especially at the end of life where many enjoyments of life have disappeared.

Happy memories of special occasions or when special food had been shared were recalled:

[TABLE 1]

She seemed to enjoy the ice cream and a bit of jelly; I mean, as I say I took her whitebait fritters one night and she did have a smile on her face. She had those so it was good. So she did still appreciate food.

(F, daughter, rest home) My most precious memory is probably the whitebait fritter, yeah that would have been the happiest I've ever seen him, having that whitebait fritter.

(F, daughter, rest home) Partaking of food and drinks was often done together, creating a social activity that legitimized spending time together. Having a meal or having a cup of coffee was perceived as a social event, which facilitated conversations.

Moments of eating or drinking together were often deeply appreciated by relatives. They made many efforts to create such moments, for example, relatives had their meal on a tray, sitting next to the bed of the patient and dressing the patient for the family Christmas dinner: I spent a lot of time with her and we did a lot of talking, especially at that half past six morning cup of coffee. Normally I'd sort of get up, shower, gobble down our breakfast. I'd never have coffee; I'd go straight to work. So it made me sort of sit down and actually take time with people, actually having the

coffee with her and I think probably that was probably the best you know, was just that little time and there was nobody calling in and just the two of us.

[TABLE 2]

(F, daughter, hospice) At the end of life, mealtimes also gave rhythm to the days and could serve as a reason for the patient to get dressed, which was appreciated by the family. Several rituals involving eating and drinking were described, such as having a whisky every night together. These daily routines and habits were important for relatives, also as an attempt to hold on to normal life: I spent as much time as I could with her. I'd go up and have my lunch time with her. I'd come home, my son was at home at that point so I'd feed him, get him sorted even though he was 20 odd.

And then I'd go up to the hospital or hospice for the evening.

(M, partner, hospice) Finally, accommodating patients' wishes, regarding food, was also experienced as a way of caring and expressing love. Being able to do something, such as providing special food, meant a great deal to relatives and made them feel less helpless. Relatives described many different ways they tried to accommodate patients' choices and desires, conveying the significance of oral intake at the end of life for relatives: I'd always ring the night before and talk to her and ask her what she wanted brought over. The first thing was a coffee and the second thing was I think ... but you know she just basically wanted to pick at things.

(M, son, rest home) I'd go up at 8 o'clock in the morning, up at the hospice she like poached egg and toast, but yeah here [at the rest home] it was just cereals and I said, 'Right'. So 8 o'clock in the morning I'd make her poached egg and take it to the rest home.

(M, partner, rest home) Well I used to cook for him, and I'd go out and get whatever. You know he might say, 'I'd like some mushrooms tonight'.

So I'd go and specially get mushrooms for him and cook them up and so forth.

(F, partner, home) It was not easy to accommodate the patients' wishes.

Relatives described occasions in which the patient requested something special, such as whitebait fritters or Indian curry, and the moment relatives offered this, the patient was not able to eat it. This was distressing for relatives, making them feel helpless and thwarted in caring for their loved one. Consequentially, they worked to understand what was happening and to find ways to console themselves: I couldn't say to him, 'Do you want to die?' [...] I just said to him at that time and I could have bitten my tongue after but I said, 'I don't know what you want to eat'. I said, 'I've tried everything, I've moulid', I said, 'That was a roast meal and I've moulid the meat and the vegetables altogether for you'. I said, 'A little baby can eat that'. 'I don't want it'. I said, 'Well, I don't know what the hell you're going to live on'. That was about the only time I sort of said anything to him about things then.

(F, partner, hospice) I had all these things lined up, and my husband went out one night and mum said she wanted a curry and my darling husband went out and brought her curry from one of these places in town, it was really cold, wintery, yuk night and he went out and brought her a curry, and she said, 'Oh you have it boy, I'm not hungry'. [...] But that's what she did, all the time. Just really finicky about stuff and you just couldn't do anything.

(F, daughter, rest home)

Responding to decreasing oral intake

It was difficult for relatives to witness the decrease in oral intake. In addition to their efforts to accommodate the patient's wishes, they also worked to understand what was happening and to find ways to console themselves.

Part of the process

Some relatives interpreted decreasing oral intake as being part of the normal (dying) process and saw it as a sign of approaching death. They phrased it as 'beyond coping with oral intake'. For them, this was directly linked to the stage of illness and to changing bodily needs, and they were aware that the end of life was near: By that stage she didn't really want it anyway and I think people were throwing food at her and she really didn't want it anyway. By that stage I thought we were just forcing her to do something that ... I guess in the last week for me, it was just let's just let this be, let it be.

(F, daughter, rest home) Yeah, because even though I don't have a lot to do with dying people, I actually notice when they start to want to go because their eating gets less and less and less [...] Yeah, so I sort of knew the telltale signs.

(F, partner, hospital) Relatives may also realize that eating and drinking became a struggle for the patient, instead of something beneficial and enjoyable. Physical problems, such as lack of appetite, having no energy to eat, having no or an unpleasant taste, having trouble swallowing or nausea and vomiting impaired their oral intake at the end of life: He had no ... well he didn't have an appetite because he couldn't ... he said he couldn't taste food, the food was horrible and he refused to eat it, and he is a person who loved his food, I mean he loved food. And he just had no appetite, no taste in his mouth, no nothing and he had thrush.

(F, daughter, rest home) He was eating less and less, but he did always try and eat a little bit each time. But you can imagine when you eat and then bring it back you get to the stage you don't want to eat because you don't want to be sick.

(F, partner, hospice) Changes in oral intake were often referenced against the person's earlier preferences and appetite, when he or she was still healthy. What patients used to eat or drink or enjoyed were described as an intrinsic part of the patient's identity. Decreasing oral intake therefore also symbolized losing the patient: I bought little ice blocks, so that she could suck on, just on that.

But she didn't even want to do that, so, which was really quite unusual. For somebody who always loved her food. Such a difference, it was a big difference, yeah, getting used to it, the fact that she didn't have an appetite at all.

(F, daughter, hospice) It was really difficult for her, so she ... anyway I digress. But I'd go into the home and stuff and she just wasn't wanting to go out; she didn't feel like coffee, and her taste buds changed. She couldn't drink her coffee; her coffee was her thing you know ... I used to buy a coffee for her on the way into the home and yeah, she just didn't want it, it tasted awful to her.

(F, daughter, rest home)

Patient's choice

Some relatives thought that a decreased oral intake was the patient's choice. They perceived it as giving up by the patient. The patient had decided that it was enough and therefore deliberately stopped eating and drinking. This could be upsetting for relatives who may feel helpless because they could not do anything anymore for their loved one: I had the feeling that he's starved himself in the end because he didn't like

illness; he couldn't cope with illness and yeah [crying] [...] Nothing we could do to make him eat because, as I said, I kept saying to him, 'I'll go and get you something nice or some fish and chips or Chinese takeaway'. 'No, no, don't bother'. He'd given up.

(F, daughter, rest home) Perceiving decreased oral intake as the person's own choice could allow some relatives to stop trying to persuade the patient to eat something. Efforts by relatives to make the patient eat could upset the patient, who knew best what was happening, what he or she needed and what he or she wanted or not wanted. Perceiving eating and drinking as the patient's own responsibility relieved relatives' distress: I came to the conclusion that it didn't matter how I fretted, all I was doing was making him upset and me getting more stressed. I was as stressed as I could be. So I just decided, I'll give him an offer of such and such, and let him choose and then I'll make it for him and see what happens. [...] and then I almost sort of gave up and thought well, he knows whether he's hungry or not. He knows the repercussions; he knows what's happening in the end; this is his choice of how he wants it; at this stage in his life, let it be.

(F, partner, rest home) However, other relatives perceived maintaining oral intake as part of the battle against the disease and therefore against dying. Central to this perception were efforts to tempt the person with special foods and supplements. Giving up eating was not an option for these relatives: I spent a fortune on special little things [...] One day he said, 'Does [the Oncologist] know you're doing this?' I said, 'I don't give a bugger what he thinks', I said, 'I'm trying to get you some good blimmin' bacteria inside you again'. I said, 'We've gotta fight this damn thing', you know, so he'd do anything to please me.

(F, partner, hospice)

The vicious circle

Some relatives realized, in hindsight, that the patient was trying really hard to eat something because of them. They were caught in a vicious circle, in which the patient and the family did not want each other to worry and both tried hard to maintain the oral intake and avoid talking about its decrease: I think she thought it [eating and drinking] was important for me. I think she wanted me to have this false hope that she would get better just to help me cope I think, at the time. And it went pretty well cause she was you know; I tried to be strong for her and she tried to be strong for me [crying].

(F, daughter, hospice) It [trying to make him eat and drink] upset me, but I was only trying to do it for his good. And then he would feel bad, because he didn't want to upset me. It was a vicious circle. He never complained, he was amazing, he just accepted that it was his lot, and took it all in his stride.

(F, partner, hospice)

Communication and information: talking about it

Relatives recalled few in-depth discussions about decreased oral intake with both health professionals and patients.

Conversations with the patient predominantly concerned if and what the patient preferred to eat or drink. Some relatives avoided talking about the decreasing oral intake because they did not want to upset the patient or considered talking about eating and drinking as futile. Furthermore, some relatives recalled having arguments with the patient when trying to persuade him or her to eat something. These

arguments were perceived as upsetting and a struggle by the relatives, and remained vividly in their memory: Not into any depth because he just ... like he was a very placid man and you could never argue with him. [...] Over this and the food, he did actually get a bit stropy and he'd just say, 'Oh leave me alone for goodness sake I can't eat, I can't eat'. And then that would upset me because he'd been cross with me and he was never cross with me, so I thought, no, this is a fruitless exercise too, so I'm not even going to talk to you about it, if that's the way you're going to talk back to me. No, we didn't do it in depth because he got too ... I think he knew that he should have been; or couldn't be bothered; or didn't have the heart to; or didn't want to; or whatever.

(F, partner, rest home) I was always pumping drinks into him. I used to sit on the bed with a straw in his mouth and say 'Suck!' He would say I was a bossy woman. It was a struggle.

(F, partner, hospice) Conversations with health-care professionals predominantly concerned information for the relatives about oral intake at the end of life and what to expect: 'Just let him eat whatever he wants', and they [nurses] weren't too worried about it. They said 'Just get whatever you can and when you can into him'.

(F, partner, home) Relatives were sometimes given a written pamphlet on food and fluids at the end of life. This information was often perceived as reassuring by the relatives because it lifted some of the weight of responsibility off their shoulders.

DISCUSSION

Decreasing oral intake in patients at the end of life is a meaningful change for relatives. When oral intake was still present at the end of life, relatives attributed multiple positive meanings to it, including nutritional, psychological and social meaning. Furthermore, it gave routine and structure to their daily life in a time of disorder. Relatives responded differently to a decreasing oral intake and also perceived different reasons for this decrease. Some viewed the decrease in oral intake as part of the dying process, related to the stage of illness, lack of appetite and physical inabilities.

Others perceived decreasing oral intake as the patient's choice. Some relatives were able to accept the decrease in oral intake, while others viewed maintaining oral intake as an important part of the battle against the disease and for life. Other relatives realized that the patient and they were keeping each other in the dark through their mutual efforts to maintain oral intake. Relatives recalled limited communication with health-care professionals concerning oral intake at the end of life.

Several findings deserve particular attention. First, the broader meaning of eating is significant and important at the end of life. Some data on the meaning of food in other patient populations resonate with our results, although most did not address the relatives' perspective. For head and neck cancer patients, physical, social and emotional losses related to eating problems have been described.¹⁷ Also in cachexic cardiac patients, the broader meaning of food has been identified.

These patients described a feeling of deprivation due to fatigue and lack of appetite because of missing both eating and the related social environment. This could even lead to a loss of personal identity.¹⁸ These studies illustrate the broader social and relational meaning of eating and drinking, which our study shows also to be present for relatives of patients who are at the end of life. When addressing the issue of oral

intake with patients and relatives, health-care professionals should not only emphasize the nutritional element but also be aware of these other elements. Second, awareness of dying and relatives' perceptions of decreased oral intake at the end of life seems to be related.

McClement et al.¹³ have identified fighting back versus letting nature take its course as two opposite positions, between which relatives may also vacillate. Those fighting back believed that the decreased intake was largely responsible for the patient's declining status instead of disease progression, while those who were letting nature take its course believed that the decreased intake was an expected occurrence as death became imminent. Our results showed similar patterns, and these ways of responding by relatives were not static or exclusive.

Third, our study showed that, despite the significance of decreasing oral intake for relatives, only a few relatives recalled conversations with health-care professionals about what to expect regarding oral intake at the end of life. This lack of attention regarding oral intake at the end of life has been noted before. It has been shown that family call the out-of-hours general practitioner practice often because of problems related to oral intake such as vomiting and dehydration, which resulted in potentially preventable hospital admissions at the end of life.¹⁹ Early communication regarding these problems may contribute to more efficient health-care usage.

Since the primary goal of palliative care is to improve the quality of life of not only patients when facing the problems associated with a life-threatening illness but also of their relatives,²⁰ health-care professionals should adequately address issues regarding patients decreasing oral intake, with family. Overall, more attention for issues regarding oral intake and related problems at the end of life may improve the quality of life of relatives and contribute to better health-care usage.

There is a body of literature describing ANH at the end of life, discussing whether it is appropriate or not to administer ANH during the last weeks of life. To date, this controversy remains, although the positive effects seem limited.^{5,7,8} It has therefore been suggested to make decisions on ANH preference based.²¹ When doing so, healthcare professionals should keep in mind that by administering artificial hydration probably not all issues relating to eating and drinking will be addressed. Health professionals should recognize the need for multiple conversations over the illness trajectory regarding declining oral intake and the broader meaning of eating and drinking at the end of life.

Strengths and limitations

One strength of this study is that perceptions regarding oral intake at the end of life in terminal illness were derived from bereaved relatives of patients dying in different settings. Some caution must be exercised when using our findings in practice because all patients were under the care of one single palliative care service, which might hamper the generalizability of the findings to other bereaved relatives. Furthermore, this study included relatives who had different relationships with the deceased patient, and the patients' diagnoses were not restricted to cancer. Finally, the willingness of the bereaved relatives to participate in this research was noteworthy. Limitations include the following. First, the data collected for the study were generated from families receiving specialist palliative care. This might have led to a selection bias that restricts the generalization of the results to other care settings. Second, ethnic minorities are underrepresented in this study; relatives were mainly of European descent, while in New Zealand, Maori constitute 17% of the population.

The meaning of oral intake at the end of life for Maori and other ethnic groups should be further investigated, as it is known that cultural differences exist.²²

CONCLUSION

Oral intake at the end of life has multiple meanings, going beyond the nutritional value of food and fluids.

Psychological and social aspects of oral intake at the end of life also are significant for relatives and should be addressed when supporting relatives who are caring for a terminally ill patient. Views on decreasing oral intake are interconnected with awareness of dying. Communication with health-care professionals concerning oral intake at the end of life seems limited.

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TABLES AND BOXES:

<p>Box 1.</p> <p>Topics of questionnaire</p> <ul style="list-style-type: none">- Experiences in last month of life- Awareness of dying (patient and relative)- Satisfaction with care- Experiences with food and fluids intake- Perception of food and fluid intake- Communication at the end of life- Quality of Death and Dying Questionnaire (QODD)¹⁴

Table 1. Characteristics of deceased patients.

	Deceased patients (N = 23)
	% (n)
Age	
Mean \pm SD	76 \pm 12
Gender	
Male	57 (13)
Female	43 (10)
Ethnicity	
New Zealand European/Pakeha	96 (22)
Maori	4 (1)
Primary diagnosis	
Cancer	74 (17)
End-stage heart failure	13 (3)
End-stage renal failure	9 (2)
End-stage respiratory disease	4 (1)
Place of death	
Home	13 (3)
Hospital	9 (2)
Hospice	44 (10)
Residential care facility	34 (8)
Months in specialist palliative care	
Mean \pm SD	2 \pm 2

SD: standard deviation.

Table 2. Characteristics of bereaved relatives.

	Relatives (N = 23)
	% (n)
Age	
Mean \pm SD	65 \pm 13
Gender	
Male	22 (5)
Female	78 (18)
Education ^a	
Low	78 (18)
High	22 (5)
Ethnicity	
European/Pakeha	91 (21)
Maori	9 (2)
Relationship to deceased patient	
Partner	65 (15)
Son/daughter	35 (8)

SD: standard deviation; ISCED: International Standard Classification of Education.

^aLow = levels 1–4 according to ISCED guidance (primary school, lower secondary general education, lower vocational education, intermediate vocational or higher secondary general education) and high = levels 5–7 according to ISCED guidance (higher vocational education or university).