The complexity of food for people with multiple long-term health conditions

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ABSTRACT

INTRODUCTION: The prevalence of long-term health conditions (LTCs) continues to increase and it is normal for people to have several. Lifestyle is a core feature of the self-management support given to people with LTCs, yet it seems to fail to meet their needs. From a larger study exploring the experiences of this group, this paper reports on the role of food and mealtimes, and the effect of the nutritional advice on the lives of people with several LTCs.

METHODS: The experiences of 16 people with several advanced LTCs were explored using multiple qualitative case studies. Over an 18-month period, contact with participants included monthly conversations, two longer, semi-structured interviews and one interview with their primary care clinicians. The data were analysed inductively using thematic analysis.

RESULTS: There was profound social, psychological and cultural significance of food to the participants. These aspects of food were then described using the Whare Tapa Whā model of health. The approach to food and nutrition participants experienced in health care was closely associated with conventional weight management. They found this advice largely irrelevant and therefore ineffective.

DISCUSSION: The pressure people with several LTCs experience during clinical encounters has perverse effects on wellbeing and reinforces an overall sense of failure. This research challenges the assumption that all people have the will, agency and income to follow the advice they receive about nutrition and exercise. Considering people's needs using the Whare Tapa Whā model of health offers clinicians a framework to re-conceptualise the core features of self-management support and provide realistic, compassionate care that will optimise the quality of life for people with multiple LTCs.

KEYWORDS: Long-term conditions; nutrition; self-management

Introduction

The prevalence of long-term conditions (LTCs) and many of their predisposing factors such as hypertension, hyperlipidaemia, inactivity and morbid obesity, continue to increase.[1–3] LTCs tend not to occur in isolation and people often have several concurrent conditions.[4,5] With multiple LTCs, the disadvantages, unpredictability and complexity of living are compounded and people experience a poorer quality of life.[6–8]

Long-term conditions do not respond to established health-care approaches that work well for acute or infectious diseases. Rather, a combination of programmes and approaches that collectively relate to the Chronic Care Model and the self-management approach have been adopted.[9–11] In these models, clinicians support patients and their family to acquire the skills and confidence to self-manage their LTCs.[12,13] Over-consumption or inappropriate food intake and insufficient physical activity are major contributors to LTCs.[14,15] Self-management support, therefore, often centres on lifestyle advice, particularly about weight loss and exercise.[16,17] However, clinical encounters that focus on lifestyle advice goals are

not always appropriate for people with advanced, multiple LTCs.

Based largely on ideas from the social learning theory of Bandura,[18] the focus of the self-management approach is to change an individual's eating behaviour. Success is judged through measurements of weight loss or body mass index. Health policy regards obesity as a public health priority,[15] yet evidence is lacking about the effectiveness of the advice about diet or exercise from clinicians,[19–21] particularly for people with established LTCs.

A multiple case study that followed 16 people with multiple LTCs was undertaken to learn of their experience with the self-management approach to health care.[22] This study found themes described within the four domains of the Whare Tapa Whā holistic model of health. The model, first described by Mason Durie,[23,24] uses the analogy of a whare or house where each of the four walls represents a cornerstone aspect of health. The walls are taha tinana (physical), taha hinengaro (emotional or mental), taha wairua (spiritual or sense of purpose) and taha whānau (family and social) aspects of health, and the model demonstrates the interdependence of these aspects of health. Mealtimes and food are influenced by all four of the walls of the whare in the model. They reflect the friction between eating for pleasure, eating for nutrition, eating as a social practice and eating in the context of poverty and deprivation.

Methods

A qualitative, exploratory, multiple case study design was selected to explore cases over time through detailed, in-depth data collection.[25] Case study allows for a holistic understanding of the phenomenon of self-management by keeping the complex experiences of the participants intact through exploration within the real-life context of those involved.[26] Cultural advice and support throughout the research process was provided by two local Kaumātua who were experienced in the health field. Recruitment occurred via community networks and advertisements in general practices in one provincial area of New Zealand (NZ). Potential participants contacted H. Francis

WHAT GAP THIS FILLS

What is already known: There are an increasing number of people with long-term conditions (LTCs) worldwide, most of whom have multiple LTCs. 'Behavioural risk' is the most significant factor contributing to the development of LTCs. Recommendations for activity and nutrition are core features of self-management approaches.

What this study adds: This research focuses on people with multiple significant LTCs. The focus of much health care on nutritional advice and activity over-simplifies the complex role food has in people's lives and is likely to be unhelpful for people with multiple LTCs. The Whare Tapa Whā model of health offers a framework to re-conceptualise the core features of the self-management approach and provide realistic, compassionate care that will optimise the quality of life for people with multiple LTCs.

directly or through the Kaumātua, and the study was explained and questions answered. Informed consent was obtained in person at the first interview. Ethics Committee approval was received (CEN/12/EXP/007, Multi-region Ethics Committee, Wellington).

Data were collected over 18 months through two semi-structured interviews at the beginning and end of data collection, and monthly visits or telephone calls. Additionally, the participants' primary care clinicians (general practitioner and practice nurse) were interviewed. The data from clinicians were not used for this paper, although they were reported elsewhere.[22,27] These data were combined to provide a picture of the lives of the participants living with LTCs and their experiences of self-management of their health care.

During semi-structured interviews, topics ranged across many aspects of living with LTCs. The role of food in participants' lives was not asked about specifically, but was mentioned by all and it is these data that have been used for this paper.

The first stage of analysis of the transcribed interview recordings explored the individual participants' narratives inductively using thematic analysis as a flexible method that is most appropriate for identifying, analysing and reporting patterns and themes.[28] Themes

generated suggested the relevance of the Whare Tapa Whā model,[23,24] which was then applied as a theoretical overlay to the findings to assist in generating an explanatory framework of particular relevance in NZ.

Results

The characteristics of the 16 patient-participants are described in Table 1. Twelve were from the most socioeconomically disadvantaged population, who experience much higher rates of LTCs.[29] The participants were living with advanced, multiple morbidities, mostly amidst complex and trying social circumstances. We present the aspects of the study relevant to food consumption using the Whare Tapa Whā model as a framework.

Taha tinana

Taha tinana describes the physical aspects of peoples' lives. Participants all volunteered information about clinician advice they had received about their food choices. Their perception of these messages concern missing-out on something desirable, which Losefo describes as

'*I was told by the doctor what food I shouldn't eat.*' The adoption of similar advice received by other participants was sporadic at best; for example, as Wiremu describes:

> Well, I'm supposed to eat healthy foods and she [nurse] just gave me a list of what not to eat. But the things I like are on that list. And I haven't got much else to look forward to.

Most of the advice given about food sat in the tinana domain, and the compulsory goal setting that is a feature of self-care management revolved around the physical aspects of nutrition, alongside physical activity. Although guidance for clinicians has stressed the need for goals to be 'patient-led' and what patients would like to achieve, the examples of goals in policy documentation are weight loss and exercise.[30] Participants indicated that these goals were meaningless in the context of their complex lives, as Rawiri described:

> Originally we set a few goals - but they were more what *they* [clinicians] wanted to see. I achieved a couple so that was that. One I didn't want to achieve, so didn't bother.

Table 1. Patient–participant characteristics

Pseudonym	Age (years)	Sex	Ethnicity	Main long-term conditions
Yvonne	67	F	Samoan	Diabetes, heart failure, gout, COPD, arthritis, sleep apnoea
Losefo	67	M	Samoan	Diabetes, hypertension, gout, IHD
Tane	47	M	Māori	Diabetes, COPD, CVD, chronic cellulitis/leg ulcers, depression, sleep apnoea
Rawiri	68	M	Māori	Heart failure, gout, sleep apnoea
Huia	57	F	Māori	Asthma, diabetes, hypertension, IHD, arthritis
Aroha	56	F	Māori	Diabetes, arthritis, CVD, depression, chronic sinusitis, IHD, sleep apnoea
Tamati	74	M	Māori	Diabetes, transient ischaemic attacks, gout
Wiremu	76	M	Māori	Diabetes, arthritis, IHD, aortic aneurysm
Diane	65	F	NZ European	Diabetes, depression, asthma, eczema, arthritis, cancers
Beth	88	F	NZ European	Diabetes, renal failure, mild cognitive impairment
Eva	56	F	NZ European	Diabetes, depression, arthritis, CVD, irritable bowel syndrome, sleep apnoea
George	69	M	NZ European	Diabetes, arthritis, cancer, atrial fibrillation
Lou	67	F	NZ European	Diabetes, depression, hypertension, chronic anaemia, bullous pemphigoid, cancers
Margaret	56	F	NZ European	Diabetes, hypertension, asthma, depression, cancer, arthritis
Hayley	26	F	NZ European	Renal failure, spina bifida
Paul	51	M	NZ European	Multiple knee surgeries post ruptured ACL, CVD, arthritis, depression

M (male); F (female); COPD (chronic obstructive airways disease); IHD (ischaemic heart disease); CVD (cardiovascular disease); NZ (New Zealand).

Tane summarised his experience of ineffective goal setting:

> I've probably had the same [goals] for years. Lose weight and get fit. And I have done the opposite.

An unintended consequence of the focus of self-management support on the physical aspects of lifestyle change was that patients felt their complex realities were not of interest, nor were they acknowledged or accommodated.

Taha hinengaro

Taha hinengaro refers to the psychosocial context of a person's thoughts and feelings. For participants who live complex, chaotic lives marked by loss and poverty, food represented an aspect of their lives over which they retained some control and it gave some enjoyment. Eva's sense of powerlessness over her life coloured her approach to self-management. She said:

> If I'm feeling hoha [weary], then I usually crave something sweet and I need something to pick me up because I need to keep going. And I know I shouldn't do it, and I sort of feel guilty with doing it.

Eva identified food as an immediate way to deal with stress and when resources were limited, her focus was on resolving the problem closest to hand. Tane explained, '*[food is] all about making myself feel better … and the comfort that it gives you.*'

Despite the rhetoric of the collaborative partnership of the self-management approach, participants reported feelings of guilt if they did not comply with instructions. Tane talked about the early days of his illness when he was told to complete a food diary:

> …which I didn't really do. I said I had a lot of vegetables. A bit of lettuce in the burger - that's all I was having! I mean, sometimes when … you're talking to the doctors .. you feel whakamā [shame or embarrassment] - you know, that some of the things that you're doing are bad, and you don't want to admit it, so you go into denial. And then you just say whatever [you think they want to hear].

Attention was not paid to the effect of feelings of shame, or the part that food plays in making people feel better. Clinicians tended to overestimate the participants' ability to engage with the self-management approach, which led to a persistent sense of failure that eroded the participants' sense of wellbeing and vitality. Eva commented about eventually giving up:

> We did [goal setting] at the beginning – but I'm not much good at that sort of thing. Yes, there are goals I'd really like, like losing weight but it doesn't work. So, the goals are what I'd like to be able to do, but know I really can't. And I feel a bit of a flop when I haven't met them, so we gave up.

Taha wairua

Taha wairua is often summarised as 'spirituality', but also relates to an individual's faith, sense of purpose, vitality and motivation. Attention to spiritual wellbeing or sense of purpose is noticeably absent in the goal setting focus of self-management support. Wairua is discussed here in terms of 'the something' that is life enhancing, the lack of which Diane described as causing the 'daily pain of no longer being able to do or contribute to life, in what were life enhancing ways.'

Tane talked of how food temporarily replaced his loss of vitality. He said:

> sometimes … I'd be exhausted and sore, and the only thing I could think of that would make me feel good .. would be a burger or a pie or something … That was my reward. It's something that made me feel good. Inside and out. It would lift my spirit - give me some oomph back. And then … I'd sit there under those trees … and have something to eat. And then feel crap about it. … because it's like I know it's not good for me, it's not good for my weight loss, but it made me feel good for that small amount of time.

Yvonne, a 67-year-old woman, described herself as 'naughty':

> With me, I just eat whatever … what I feel like eating. I know I'm naughty … But lately I just need it for the lift – it lifts my spirits when I feel that stress.

The place of food and mealtimes in both the hinengaro (emotional or mental) and wairua (sense of purpose) domains intersect to provide something individuals can do to feel better or retain some sense of control in their lives. They were overcome with guilt or shame, aware they were contravening the professional advice they had been given.

Taha whānau

Taha whānau concerns the place of family or social group.[31,32] In this study, it includes the way food and eating are socially enmeshed in culture and religion (rather than just beliefs) and the socioeconomic aspects of the participants' lives. These influences are closely interwoven and affect how participants prioritised their lives and the primacy they do or do not give to their own health status and the associated tasks, which a self-management approach requires.

In the context of taha whānau, family eating practices are integral to family life and are associated with a sense of belonging. Whānau were experienced as both a source of support and of conflict, sometimes simultaneously. Several participants described the emotional energy they gained from eating or preparing food in a group and the collective enjoyment it engendered. However, participants also spoke of their whānau '*leading each other astray.*' Eva explained how the family '*talk each other out of*' both healthy food choices in the supermarket and being active. Huia explained 'I just eat what they want really, it's easier.'

A strong sense of whanaungatanga (interconnectedness or belonging) between individuals related to these family and social roles. Although especially marked in the Māori participants, almost all expressed a sense of interdependence and collective identity. For the Māori participants, manaakitanga [hospitality or kindness] was one of many areas where culture and health overlapped. The sharing of food has traditionally linked hospitality, nurturing and identity, and manaakitanga is a significant part of giving and belonging in participants' lives. It often usurped attempts to eat a healthy diet.

The same traditions are also present in Pasifika cultures and the Mormon church where many Pasifika attend, including two participants in this study. Yvonne gained comfort from her experiences of food and church involvement. She said that cooking was a huge part of her life, with most of her church activities involving gatherings where large quantities of food were prepared and eaten. During several monthly telephone calls, she said she was '*baking up a storm*' for a function, and on one occasion she said, '*I'll forget about my diabetes today.*' Her culture trumped any knowledge she had about the effect of her weight and diabetes on her health. She said:

> My goals are to get my sugar levels down. That doesn't happen. I've been busy cooking for a church friend's birthday celebration this afternoon - and of course I have to try them dear! ((laughs)).

She had good knowledge about the physiology of her diabetes, but the social aspects of her life outweighed this knowledge.

Tane's mother insisted on doing all the cooking and he felt pressured to eat what she gave him despite his genuine yearning for better health. He said she equated caring with food and overfed him, his brother and the cat:

> …when you see her cat, how fat that is. Sometimes I look at the cat and I go, 'Oh my God, you poor thing: You're me!' Every time that cat will cry, mum will feed it.

He felt his mother ultimately sabotaged his best efforts and he felt powerless to stop her. He understood her need to feed her family and that it was a reflection of their culture. He said:

> She's naughty like that .. that's the way she is. She thinks giving love is feeding. She feeds up everyone that steps foot in here. She's been raised in manaakitanga. A lot of mums are like that, especially Māori mums … they smother you with food and love, and that gives them satisfaction.

These findings reveal participants who are caught in a complex web of connections to family, whānau, culture and commitment, which are all important aspects of maintaining a sense of

purpose and identity. Yet, these very connections directly conflicted with or reduced the participants' ability to focus on or engage with the requirements of the self-management approach. For the participants, taha whānau had a powerful impact on their eating practices. It is evident that participants made decisions about activity or meals within a whānau and social context, yet the self-management support framework addresses food in terms of the individual.

Discussion

The study findings reveal participants who received dietary or lifestyle advice that failed to consider the complexities of their holistic selves. They describe their circumstances: living with complex comorbidities while struggling with loss of energy, diminished choices, low income and daily challenges to their survival. They find eating, and the social associations with meals, an area of potential pleasure, connection and a small opportunity for control over their lives.

Three major findings of this study offer the opportunity to critically reflect on the care provided to people with advanced comorbidities. The first consideration is how the self-management approach has confined advice around nutrition and meal times to the tinana or physical domain. This contrasts directly with the voice of participants who clearly revealed that the other three domains were of equal, if not more, importance. The second aspect is how policy and clinician pre-occupation with advice for weight reduction persists despite the emergence of evidence that challenges such advice.[19–21] The third point is the relevance or otherwise of lifestyle advice to people who have advanced disease and whose lives and opportunities for change are significantly constrained.

Focus on the physical (tinana)

Focus on the physical aspects of health care that sit in the tinana domain assumes a simplified role of food in people's lives and overlooks the complex role of food, nutrition and meal times. Within a framework that focuses on the physical aspects of food, to the exclusion of other domains, many important aspects of individuals' lives are overlooked, leading to ineffective health-care advice. The result is that patients are forced into a futile self-management approach that considers only narrow influences on their lives. Programmes aimed at the individual level of eating behaviour often fail because food and eating are social practices and eating patterns form from within groups, relationships and the wider social context.[33,34]

Futility of weight loss advice

Self-management support programmes,[35] health policy[30] and clinician pre-occupation with advice about weight reduction persist, despite little evidence of success for any group of people.[20,36] Even for healthy populations, the efficacy of the weight loss advice traditionally offered has been challenged and found to be a much more complex matter than 'calories in and calories out'.[19,20] Clinical advice has been channelled into an emphasis on personal responsibility, and participants in this study describe their sense of failure about their lack of weight loss. The encouragement to lose weight persists despite the fact that success is highly unlikely, and the small weight loss possible is unlikely to substantively change the outlook for this particular segment of the population with LTCs.

Futility of goal setting

There seems to have been little thought given to the utility of self-management for people who have advanced disease, the very patients for whom self-management is actively funded and supported. Because lifestyle is a major contributor to the cause of LTCs, the goals in the minds of clinicians have inevitably focused on food intake and engagement with exercise. The wording in policy, clinical guidelines and formulaic care plans impose an 'eat less, move more' template on reluctant patients.[30] In contrast, the participants in this study mostly operate in survival mode within severely constrained lives (such as mobility restrictions), with little likelihood of improvement to their health.

Self-management support in New Zealand has been delivered from a theoretically attractive model of shared goal setting between clinician and patient, with the aim of increasing each patient's ability to care for themselves effectively.

However, our findings reveal that goals are, in fact, more likely to be imposed by well-meaning clinicians. Such goals are futile for the person with established, complex LTCs and divert attention from goals that are personally meaningful. The approach to goal setting is not only ineffective, but also harmful, as its unquestioned acceptance prevents consideration of a more effective response while compounding the sense of failure felt by people with LTCs.

Limitations

We report on one aspect of a larger study.[27] The participants were enrolled with mainstream primary care providers and also had significant, complex LTCs. The experiences of people enrolled with Māori health providers, or who have less advanced disease, may differ from this group.

Conclusion

Increasing numbers of people living with multiple advanced LTCs are offered suboptimal care and advice due to a narrow focus on nutrition and activity goal setting. Such goals are appropriate for people with early LTCs when substantial reduction in morbidity remains possible.

Food plays a complex role in people's lives, which is not reflected in the food and nutrition advice given in the self-management support people receive. The ongoing pressure people experience during clinical encounters has perverse effects on wellbeing and reinforces an overall sense of failure. The assumption that everyone has the will, agency and income to follow the advice they receive about nutrition needs to be challenged. The Whare Tapa Whā model of health offers clinicians a framework to re-conceptualise the core features of self-management support and provide more realistic, compassionate care that will optimise the quality of life for people with multiple LTCs.

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