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The Research Informing "Who Cares?"

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This article is about the research that informed the development of the ethnodrama, Who Cares?.

For over 25 years I have been researching meanings of eating, how these are affected by changes in health status, and how this can/should influence dietitians' approaches to nutrition education. My interest in this topic began when I worked as a dietitian in cancer care. One day a man who was living with lung cancer said something that so shook my understanding of what I thought I was supposed to be doing (offering nutrition advice to maintain nutritional status during therapy) that I began to wonder what kind of help would actually help. The man, about 70 years old, said, "I've been thinking, you tell me what to do, I'll do it, and God will reward me and take away my tumour...if that doesn't work, at least I'll go to Heaven when I die".

When I trained as a dietitian, I had learned about nutrients, how the body uses them, and how these needs change depending on one's medical condition. I was instructed to provide nutrient-based advice - so I did not know how to respond when this man started talking about beliefs about eating behaviour and 'being good'. I was fortunate that this fellow was willing to have a conversation about what he thought his request for help meant, and what I might offer in terms of help. He was as surprised as I about what he had said for, as he shared, "I am not a religious person; what is this about?" That was the start of a journey of inquiry that led to my doctoral studies to better understand the meanings imbedded in eating when one experiences changed health status. I interviewed 11 women (who had the primary feeding role in their families) who were experiencing/had experienced illness or disability. I asked what eating was like at that moment, what eating have been like before their health status changed, and emotions associated with any differences between the two. Analysis of these interviews yielded four findings that profoundly influenced my approaches to nutrition counselling, all subsequent research, and how I work with students and dietitians in nutrition counselling skill-building.

The experience of eating, already complex, is made more so with illness or disability. When asked to describe 'what eating is like now', informants could only recount what they ate and any associated emotions when they had described the context in which they were eating. They situated their food intakes in narratives about their changing views of their bodies and appearance, their relationships with household members expressed through food and feeding, and how their health status affected their abilities to eat away from home or to entertain at home. 'Nutrition narratives' provide greater insight into feeding relationships and routines than does 'taking a diet history' (an account of what and how much one eats). One listens for aspects of the narrative that relate to the individual, the household, and all eating away from home, and associated values/beliefs, actions, and reflections/emotions in addition the sharing of facts/events.

The importance of ascertaining the health status on household feeding relationships and rituals. Those whose lives were radically altered by their health status ('life-altered' or LA) described that they no longer trusted their bodies to function, they mostly stayed home (going out for medical appointments), and could no longer work, vacation, or entertain. All informants in the LA group described tenaciously hanging on to their feeding roles because all else in their lives had changed. Those whose lives were minimally affected ('life-the-same' or LS) had adjusted their diets, medications, and physical activity to manage their conditions and otherwise lived as before. Those in the LS group expected family members to adopt their new 'healthier' diets and to share feeding responsibilities.

Offering food as an expression of love and caring that is altered with illness/disability. Offering food/feeding commonly expresses (although not always) love and the desire to give life to another. Receiving food is the unspoken acknowledgement and appreciation of that love; consuming what is offered conveys trust in the offerer. With illness, this ritual and feeding relationship comes under strain. Issues that are worked through during nutrition counselling often relate to what happens when a 'feeder' cannot feed, or when a recipient cannot consume what is offered.

Coping strategies (taken from psychology) **apply to questions of food, nutrition, eating, and feeding.** These are:

- **social comparison:** because eating and feeding during illness can be so different or 'weird', people value learning 'what is normal?' given their health status/situation
- **create new normal:** new feeding rituals and routines are developed within households to adjust to changes in how the person experiencing changed health status can tolerate food
- **garner social support:** conferring with health professionals about the appropriateness of the 'new normal' reduces anxiety and enhances quality of life.

Having this longstanding interest in eating/feeding and illness/disability, when I facilitated a *Nutrition and Aging* course during the 2015 term, the growing issues with seniors' malnutrition rates, and the feeding difficulties seniors and their families encounter in efforts to prevent hospitalization/institutionalization became evident. I wanted to undertake a study to complement and provide context for the statistics about malnutrition rates, 'mealtime challenges', the effects of dementia on nutritional status, and the incidence of food-borne illness in aging Canadians, and to learn about seniors' and family members' needs and preferences for nutrition education. With funding from the Acadia University Research Fund, I conducted a pilot study with seven informants (supporting spouses (2), in-laws (2), and parents (3)) (three who were living with dementia) to learn about the experiences of feeding aging family members, and to learn where to direct nutrition resource development, and to inform future research.

The challenges reported were consistent with the literature on seniors' malnutrition risk (swallowing challenges; poor appetite; mealtime resentment, unable to feed self). An array of emotions/thoughts associated with feeding emerged including grief, anxiety, frustration, love, resentment, feeling taken for granted, exhaustion, worry, confusion, feeling pulled in multiple directions (had children at home; making household meals as well as those for aging parents and in-laws), needing but not wanting to ask for help, loneliness, isolation, sadness, too tired to be creative finding food/feeding solutions, and a

sense of duty. The findings about needs and preferences for nutrition education were consistent with findings from earlier findings (MacLellan et al., 2011). Learning needs differed depending on the life circumstances of the respondents, their familiarity with food, provisioning, preparation, and how food/nutrition needs change with illness or disability. An important finding was about the challenges and confusion related to managing multiple and conflicting dietary requirements. For example, one informant's mother was over 90 years old; she had lived with celiac disease and lactose intolerance (avoided gluten-containing and dairy foods), and then had a stroke that affected her swallowing ability. Combining texture modifications (pureed foods) with an already restricted diet limited the variety of foods the respondent could make; she wanted meal suggestions because she "had run out of ideas". Informants reported differences in how they wanted to learn about nutrition and food-related topics including in-person consultations with a dietitian (face-to-face or via Skype), food skilling/cooking groups, and the use of online videos, downloadable recipes, and one-page 'three things you need to know'.

Concurrent to wanting to develop insight into the challenges families experience when feeding aging family members and their preferences for nutrition education, inspired by *Sundowner*, an Australian documentary on the use of theatre to raise awareness of caregiver experiences of supporting loved ones living with Alzheimer's disease, and based on my studies in documentary film to extend the reach of research findings (Morley, 2011), I approached Cheryl McLean about using ethnodrama to present the findings about the research I was doing on feeding aging family members. I sponsored Cheryl's application for a Harrison McCain Foundation Award as a Visiting Scholar at Acadia University to present an ethnodrama based on the interviews that could:

1. raise awareness about feeding challenges for the public and for students aspiring to work in the health professions including nutrition/dietetics,
2. reassure family members that they were not alone,
3. provide an opportunity to assess audience reception of using theatre in knowledge mobilization (KM).

Excerpts from the interviews (for which informants had given permission to be used in KM) and findings about the nature and experience of feeding aging family members were woven into the script of *Who Cares?*.

Catherine Morley PhD, Pdt, FDC, Assistant Professor in the School of Nutrition and Dietetics at Acadia University works in the field of dietetics and nutrition and has written extensively about *Meanings of Eating and Changes with Illness*. She is also an educator who engages in research to raise awareness about the causes, prevention and management of malnutrition in aging Canadians and those living with dementia or changed health status. In her work she hopes to reduce caregiver burden and the frequency and duration of hospitalization and institutionalization of older persons. She has also studied documentary filmmaking and textile arts at Capilano University and is excited by the possibilities of fusing health education, adult education principles and the arts to raise awareness and to promote social justice.

Works Cited

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