



Approaching practice: Cancer survivorship and family loss influence and inspire

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In Senior Seminar (SS), the capstone course of Acadia University's Nutrition program, Lisa Blundell, BSN (2015) presented a reflection of her experiences with childhood cancer and implications for nutrition counselling and food services. Catherine suggested a reflexive paper integrating Lisa's reflections, and her own work on client-centred nutrition work that incorporates meanings of food, eating, nutrition, and feeding, and complex relationships with and expressed through food particularly during times of illness.

CM: Lisa, your SS paper and presentation brought us a voice in dietetics that we rarely, if ever hear, that of the survivor of a childhood illness who is studying to become a registered dietitian. What was your purpose in taking on that project?

LB: I felt (and feel) that my childhood cancer experience gave me a different perspective on nutrition during illness. The challenges during my treatment affected how I ate, my emotions related to eating that include guilt and shame, and a change in my overall body image (as my weight decreased and then increased). These have had a lasting impact on my relationship with food and my overall health. I hoped that in demonstrating the complexity of a person's relationship with food during illness, and how completely different it is from when a person is well, my peers would learn about treating each client as a unique individual going through their own disrupting experience. I hoped that my classmates would recognize their roles in helping to create supportive environments to truly help people during their illnesses.

CM: You mentioned guilt and shame in relation to eating. As a novice dietitian, I don't think these ideas ever occurred to me. That a child would experience guilt and shame re: food and eating and not say anything about it? It makes my heart ache to think about a child

with that burden. What a gift it is to dietetics to have your voice from which we can learn.

LB: I have always felt that children know much more about what's happening around them than most adults give them credit for. Children going through illness become wise beyond their years and learn much about their health and circumstances. They absorb a lot of what they hear or read, both the truth and falsehoods/deceptions. For example, think of the messages we hear daily that some foods cause cancer, and some are 'cancer-fighting'. My interpretation of what I heard led me to believe that I had caused my own cancer! I recall running to the TV to turn off a show my grandparents were watching about foods that cause cancer because I felt so ashamed of what I had done. Of course, they had no idea why I did what I did.

I was overweight as a child and lost weight when I began to experience symptoms of lymphoma. I was happy to finally fit into clothes just like those that my friends wore, and excited that I could shop somewhere other than the 'big girl' shop. People complimented me on my appearance. Because of this, I insisted I felt fine, and hid symptoms from my parents. I know that this delayed my diagnosis by several months.

CM: That is so much pressure on a child! Your story speaks to the care we need to take in (un)conscious messaging about acceptance of body weight. I recall you encouraging your classmates to be aware of not labelling people by their diagnoses (e.g., calling someone a 'diabetic' rather than someone who lives with that condition). What does labelling do to the person being labelled? I confess that I feel awkward referring to you as a person who survived childhood cancer because that is labelling you as well.

LB: When a person is labelled, many assumptions are made about them and, in turn, this makes it seem as if the 'labeller' believes they know all they need to know about the other based solely on their medical diagnosis. While there may be similarities between people living with cancer, important differences can be overlooked, and these differences can be very important in determining the treatment, care, and bedside manner that best suits that person. Labelling a person can make them feel like they can only identify with people who have the same diagnosis. In reality, while it seems ridiculous to even have to write this, people experiencing illness can relate to all kinds of people - they may, in fact, have more in common with someone who has a different diagnosis. Forming relationships (perhaps with the people they see when they are admitted to hospital or when they go to appointments at a clinic) can help them all cope better. Labelling a person by their diagnosis can lead to that person losing some of their identity, and feeling forced to take on the identity handed to them.

CM: Why do you think this practice (labelling people by their diagnosis) has hung around for so long? I think it might have to do with power over another, or discomfort about witnessing someone's illness that this raises fears for one's own health status. That is, by distancing myself through depersonalization, I protect myself?

LB: I think depersonalization is part of the reason. Health professionals sometimes distance themselves to protect themselves from being hurt. Getting to know someone who then becomes sicker or who dies is painful. It is uncomfortable, and people (health professionals included) don't like to feel uncomfortable. So labelling to treat the condition but not the person is a coping strategy –protection from getting hurt.

CM: Your response reminds me of work I once did with dietetics students on the myth of professional detachment; that our work with people who are seriously ill can/does have emotional consequences. What advice

do you have for nutrition and dietetics professionals about how they refer to people with whom they work?

LB: My advice would be to use words that make people feel valued, and words that do not create distance. While using simple labels may be an easy route, it is important to familiarize yourself with an individual and their experience. Not only do physical symptoms differ from person to person, but individual thoughts and feelings certainly vary. Show compassion for the people you work with and recall that the words we use should not contribute to stripping people of their individuality. Using 'living with' is a good start.

CM: You were brave to tell your story as part of the SS presentation; you could have easily made your presentation a recounting of facts about the nutritional issues of children going through cancer therapy, but you didn't. What inspired you to take the more risky route and share your story? What response did you get from classmates?

LB: I thought that by sharing a real (my) story, I would get the attention of my peers more than if I shared information that they would have been able to find/read in the literature. I couldn't find articles in the literature about what I wanted to share anyway, so rooting my key messages in my personal story was important and a logical choice. None of my classmates knew the extent of my story, and many did not know I had had cancer at all. By telling my story, I think others realized that diseases such as cancer can affect any of us. I also thought that sharing my story may be helpful to provide some insight to the life-altering nature of illness.

I observed that most of my peers were overwhelmed to think that what I shared was my story - that all of those issues I mentioned had happened to me, and that I was still affected by those memories and emotions. My peers were so supportive of me and thankful because it helped them think about how it must feel to be in such a situation. We can be so focused on knowledge of nutrition and health, and getting prescriptive that we forget to think about the complexity of a person and what might be helpful to them at the moment that we are working with them. I think my story helped them see the importance of client-centeredness.

CM: You wrote a narrative asking the class (Appendix I) to put themselves in the place of a child admitted to hospital for chemotherapy. While reading it you projected a photograph of a standard hospital room.

In addition to sharing your personal narrative as part of your presentation, you presented part of your SS using a creative non-fiction approach (fictionalizing one's own story is a form of creative non-fiction). Why did you decide to take that second risky route?

LB: I decided to take what appeared to be a fictional route because I suspected some people might be surprised this had happened to me. It is easy for people to hear a story but think 'this happens to others, but not to me', or that the story is a stretch of the actual truth. The reality is that cancer therapy is hard to get through; at least, it was for me. I wanted to provide a hint of the reality of how complex and challenging it is to live with and survive cancer.

CM: Did you have any worries about how I, as a professor/grader, might respond to you including a creative non-fiction segment in your presentation? Sometime students tell me they are discouraged from doing so in other classes because the professor tells them they won't know how grade it. Did you have any such concern; that is, how I might receive it (how it might affect your grade)?

LB: I had no worries about presenting this segment to you and the class. In fact, I felt encouraged. You were always open to creative approaches to disseminating information ("anything but a PPT"). I think that many times when students take you up on that offer, their presentation is more effective. Students' unique presentations made in your class stand out in my mind. Some were more thought-provoking, and some simply held my attention better.

CM: What about your look into the literature on this topic...the meanings of food and eating for children living with serious illness? You mentioned that you did not find much?

LB: Much of the literature I found related to nutrient needs for treatment of illness. There were some articles about the reasons people eat and the factors leading to their choices. I found books and articles on the illness experience, particularly in terms of identity and emotions. However, I found very little literature that connected these topics.

I felt frustrated because it seemed that no one cared about the things that I did. I wondered if that meant no one really cared/cares about a person's changed relationship with food and how they view food? I hope I'm wrong, but the little I found in the literature made it seem that

these ideas weren't important. The ideas that were dominant were those of health professionals as experts, and of "prescribing a standard 'perfect' diet" based on a condition, diagnosis, or that word again, 'label.' When so much is heard about client-centeredness, and working in a patient's best interest, I found it interesting that the client's/patient's voice was virtually absent in the literature.

CM: As you know, my primary research interest (and the focus of my doctoral research) is meanings of food, nutrition, eating, and feeding for people experiencing serious illness, and how an understanding of these meanings can influence approaches to nutrition counselling. The key difference between my work and your interests is that I haven't experienced serious illness and you have. Although not my own illness, the deaths of my brother and father radically transformed how I approached my work (I worked in cancer care at the time).

LB: I found much of your dissertation relevant to my topic. What was it about the experiences of your brother and father that affected your work in nutrition counselling?

CM: I wrote a piece entitled "Would you give a pork chop to a dying man?" about feeding issues that came up with my brother at the end of his life (Appendix 2). The dietitian telling me that she was afraid to meet my brother because he was so sick and his diet so restrictive was such a shock. I wondered if I had ever given precedence to a diet over a person and their family? And then when my brother died after a lengthy illness, I was embarrassed that I hadn't recognized that the exhaustion and grief I felt was so common among the family members of the people I was working with. I decided, "I need to start again. I don't know how to do this job. I will listen for the meanings of food and eating, and trying to feed a loved one who is sick". I reckoned that in my listening, I would learn how I can offer the kind of help that helps (per Wilbur, 1993).

What kind of writing/research would you like to see appear more often in the dietetics literature?

LB: More literature about a person's relationship with food during illness, and exploration of strategies that help people with ways of eating that work best for them, and about a person's thoughts and emotions related to nutrition counselling. I think the only way we will ever know what is best for someone is if we listen to

them, then write about what we learn to broaden our understandings of these complex issues.

CM: I wonder if the Client Perceptions of Nutrition Counselling (CPNC) instrument (Morley, Hauchecorne, Sork and Barr, 1994) that I developed for my Masters thesis might get at the information to inform practice that you are suggesting? When the CPNC was developed, the thinking was to use anthropometric and biochemical measures to assess effectiveness of nutrition intervention. Logical leaps all over the place. Using these placed the attention on impersonal, detached measures while I was interested in learning about client perspectives about how, if at all, interactions with a dietitian influenced whether and how they changed their diets, how they felt about the use of diet in managing their condition/life circumstances, and recommendations/comments they had about counselling.

I don't know that there is any more important work than to help support people in their use of food and eating to feel that they have some control in what is happening in their lives and that we recognize how difficult this all is. When you imagine your own practice, what do you envision?

LB: Listening to clients and asking how I can best support them is going to be how I will try to help them feel valued and have control in their lives. I want to approach nutrition counselling from the perspective of working with people to learn about their meanings of food, of how food and eating fits into the complexity of their lives, and to better understand why people eat what they do.

CM: Talking with a dietitian is not always about behaviour change. The emphasis that remains on behaviour change related to nutrition education frustrates me because it limits what is possible re: the therapeutic relationship that can develop between dietitian and client. Most of the time, people are seeking reassurance that what and how they are eating is suitable for their situation. You mentioned confusing and contradictory (and guilt inducing) messages about food and eating in the media. These messages also arise from inside a person ...people carry ideas about what is 'good' and 'bad' in terms of eating behaviour, and let's face it, eating during times of illness can get pretty unusual in terms of what one feels like eating and when. Offering reassurance is important.

LB: An example that comes to mind for me was when I was told that my medications may cause bizarre food

cravings. I was prepared for this to happen, and when it did, I felt it was normal. I woke during the middle of the night and asked my Dad for a tuna sandwich; I didn't even like tuna. As strange as it was, I was prepared. It didn't feel weird. I believe people want to feel 'normal', and in control of their bodies and life circumstances, and they need to be reminded that their thoughts and feelings are completely understandable. As a counsellor, by providing a comfortable atmosphere for conversation, I could discuss with clients their thoughts about what they eat and the meanings they attribute to food and eating - knowing it is a place for encouragement, not a place of judgment. To me, this is more helpful than overly simple messages offering diet advice such as 'consume more vegetables'. People already know that. What is helpful is discovering the underlying emotions involved in one's relationship to eating, and reassuring someone that how they feel is okay.

CM: How about food services for children who, as you did when you were young, spend quite a bit of time in hospital?

LB: I think flexibility is key. Often meals are delivered at specific times. Children in hospital may not be hungry or willing to eat, they may have had a procedure and be too upset to eat, or their medication may cause them to feel ill. This was the case for me as my chemotherapy was prior to mealtime. Many hospitals provide children with choices; this is important so children can choose foods familiar to them. Presentation is also important. Hospital trays can appear hostile, and often when food is reheated, the plastic dishware has an unpleasant aroma, especially when one's sense of smell is heightened from medications or with nausea. It is important to work with children to provide food services that kids will trust.

CM: Thank you, Lisa, for sharing your thoughts. I enjoyed our exploring ideas together.

LB: Me too; it would be marvellous to have others pick up this idea – learning together contributes to the 'evidence' that informs practice.

References

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Author Bios

Catherine Morley, PhD, PDt, FDC

Catherine's interests are in how the experience of eating changes with illness and aging, and what these experiences mean for approaches to nutrition counselling, and in innovations in dietetics education and research, particularly the integration of art-based approaches. She holds a PhD in Community Rehabilitation and Disability Studies/Educational Research (University of Calgary), an MA in Adult Education (UBC), a BASc in Human Nutrition (University of Guelph), and a Documentary Film certificate and Textile Arts diploma (Capilano University). She worked for many years in cancer care, then as a consultant in nutrition program development and evaluation prior to joining Acadia University in 2011 is a professor in the School of Nutrition and Dietetics.

Lisa Blundell, BSN, MPH (C).

A proud Newfoundlander and first time author, Lisa is a student in the Master of Public Health program at Memorial University of Newfoundland, soon to begin her dietetic internship practicum in Newfoundland's Eastern Health region. She graduated from Acadia University with a Bachelor of Science in Nutrition. As a student Lisa has taken an interest in diverse research areas. She has pursued research regarding health and aging, client-centered care, and most recently, food security among post-secondary students.

Appendix 1

Lisa's narrative

You are an 11 year old girl. You love to eat, appetite has never been an issue, and you're what the older folks called chubby.

Over time, you notice that eating causes a bellyache. You start to enjoy it less and less. Every day it becomes a little harder to eat as much as you used to.

You begin to lose weight. Your parents start to worry but you reassure them you feel fine. You force yourself to eat so they don't worry and sometimes that causes you to vomit, but you don't tell your parents.

You don't tell your parents because after losing weight you can now fit into your cousin's hand-me-downs and clothes you like, clothes your friends can wear.

You continue to try to eat but it has become too difficult. You are constantly hungry but the minute you eat, you feel satiated. What you don't realize is your spleen is

enlarged and pushing in on your stomach, leaving no room for food.

Your spleen is enlarged because you have cancer. Cancer in your spleen, in your neck, and around your trachea.

You are afraid to eat, it is no longer enjoyable. Hospital food leaves something to be desired, and the smells around you now make you nauseous. Eventually, your treatment begins to work and your stomach can handle food again. Your love for food returns, but treatments make you feel terrible.

Your parents give you any food you like, because you're their sick baby girl. But you miss eating with your friends, you miss recess and lunch in school, because your immune system is not strong enough. While your white blood cell count is low, you cannot eat in public at all. Your family does not go out to restaurants as they used to. Instead they bring you take-out.

Your diet is restricted. Frustration is an understatement. Food cravings happen often because of the steroid treatments. Your likes and dislikes are ever-changing.

Your dad brings you lunch one day at the hospital but just as he does, a nurse comes with 'the red medicine' – doxorubicin. It makes you more nauseous than any other. You spend that night vomiting every 20 minutes and needless to say you don't enjoy the meal your Dad brought.

You lose your long hair you were so proud of, and this is one of the hardest parts for you to go through. You are mistaken for a boy more than once and cancer is changing your identity. Over time you realize, things will never be the same.

Appendix Two

Would You Give a Porkchop To a Dying Man? (My early exposure to meanings imbedded in food and eating)

Would you give a pork chop to a dying man?

April, 1985. I got a call that my brother was very ill and that I should come to see him.

Today, we know the condition he had as Hep C. At the time, the disease was unknown. There was no treatment.

I flew across the country and arrived at the hospital. My brother was emaciated with a large, protracted belly. His once handsome features were gaunt and he looked

old. His teeth were black. His hair, what was left of it, was white. His skeletal hands held mine. The lunch tray arrived. I remember that none of the foods were those that Paul, a lifelong fastidious eater, would have chosen. Among the items were low protein (crumbling) bread, a couple of tablespoons of grapefruit juice, some white rice (he disliked rice), a half a canned pear, and 75 ml of weak tea (he rarely drank tea or coffee). White food, white food, white food, white food. My dietitian self, one that spent workdays collaborating with clients and their families to find solutions to barriers to eating, reasoned that if a fluid restriction was in place, why waste it with weak tea, why not something that contained calories... something my brother desperately needed?

I asked him, "Why did you order those foods. You don't like any of those things?"

"I didn't order them. I haven't seen a menu in the two months since I have been here. Trays show up. I don't like the food I get. I eat a couple of bites. I don't understand why they are starving me."

I could see the menu slip with the heading '*25 g protein, very low sodium, 750 ml fluid restriction.*'

"What would you like, if you could have anything to eat?"

"A pork chop and peas."

I knew that given his lack of appetite, he wouldn't eat more than a bite of pork chop and a bite of peas. What he would eat would provide about four grams of protein and minimal sodium and fluid. I could understand why the dietitian was attempting to follow the physician's diet order. I couldn't understand why she/he was so unimaginative in terms of coming up with foods Paul would eat, why he received foods he didn't like, why he was not involved in marking his menus, or why, given his condition, someone from Food Services was not visiting him to check on his likes and dislikes, and to offer encouragement to eat. These were all basic actions of dietitians/diet techs in hospital practice that I had been taught as an intern and that were part of my daily practice. I decided to make a visit the ward dietitian about nutritional care practice choices for my brother.

I knocked on a door labelled, "Diet Office". The door opened. The dietitian wasn't there. She would call me later.

The phone rang. The dietitian repeated that my brother was on a restricted, physician-ordered diet. "I know this,

but you know how anorexic he is. He isn't going to eat more than a bite of meat. I would be surprised if he ever ate close to 25 grams of protein in a day." I asked why his food preferences weren't being followed. A long pause

"To tell you the truth...I have never met your brother."

Another pause. "He is so sick and his diet is so restricted, I didn't want to upset him with the news of how restricted it is...and his situation intimidates me."

"I meant to go every week and kept putting it off."

"This isn't about you," I thought. I encouraged her to go meet Paul as he was a wonderful person, an excellent conversationalist, and that she would enjoy the opportunity to meet him.

Later, when I got to the hospital during dinner service, Paul had received a chicken leg, peas, and mashed potatoes with extra butter. No coffee or tea. Paul beamed. "This is more like it!" he exclaimed. His roommate looked over and said, "How did you get that?" Paul replied, "Hey, I want you to meet my kid sister...she is a dietitian in Vancouver. She was here this afternoon and went downstairs to give the dietitian shit." "No I didn't," I replied. "I only asked her to pay attention to your food preferences. Did she come to see you?" He nodded. He was slowly and carefully eating a tiny bite of chicken (recall that his teeth were bad). As I looked on, he ate a cube of chicken, two bites of mashed potato, and two forkfuls of peas. He was happy. Total estimated protein intake...4-5 grams.

He finally received individualized nutritional care that was respectful of his preferences. He died on July 10 at age 36. I was 27.

My approach to my practice was forever changed by the experience of supporting my brother at the end of his life, and realizing the very real pain that families feel when their loved one cannot participate in the most basic expressions of love...that of accepting food that is offered.

Respect. Honouring. Patience. Accepting of choices we would not make for ourselves. These all contribute to just approaches to nutrition counselling.

Is there ever a time when a person would not be listened to? Under what conditions would a health professional's desires/preferences/goals for nutrition care outweigh the desires and preferences for the person themselves?