

A qualitative study of dietary discussions as an emerging task for cancer clinicians

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Abstract

Objectives: Improvements in cancer detection and treatment create a need for care that prioritizes acute treatment and ongoing needs. There have been calls to include health promotion in cancer care, but little empirical consideration of the work involved in such an expansion of services. In this article, we adopt a constructionist position to explore clinicians' perspectives on capacity for health promotion, specifically dietary counseling.

Methods: Our data result from 33 semi-structured qualitative interviews with members of cancer care teams. All interviewees were affiliated with one of two contrasting medical systems located in Baltimore, MD, USA. Interviews focused on professional roles and responsibilities around health promotion for cancer survivors. We employed both purposive and snowball sampling. We conducted a thematic analysis informed by the sociology of professions literature of discussions of dietary change by provider type.

Results: We discuss four emergent themes that relate to the work of providing dietary counseling: (1) prioritization of behavior change in survivorship care, (2) evidence base for dietary messaging, (3) available time and clinical priorities and (4) clinical expertise. Interviewees generally expressed support for the importance of diet for healthy cancer survivorship. However, while there was broad support for dietary change and health promotion, we found little evidence of an emerging consensus on how this work should be accomplished, nor an indication of any occupational group expanding their professional remit to prioritize health promotion tasks.

Conclusions: Health promotion is the key to any efficient and effective model of cancer care. Careful attention to the impact of the task on key patient outcomes as well as system capacity for the provision of dietary counseling and its fit with a specific professional remit will be critical for successful integration of health promotion into routine cancer care.

Keywords

Cancer, qualitative methods, health care professionals, health promotion, survivorship, semi-structured interview

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Background

There are approximately 15 million people in the United States living with a history of cancer,¹ about two-thirds of whom will survive 5 or more years post-diagnosis.² Vast improvements in cancer detection and treatment have created the need for an altered approach to caring for survivors as they move beyond acute treatment.³ The protection of the long-term health of cancer survivors has now become a priority issue for cancer control.⁴ The health care needs of long-term survivors include general primary and preventive care and management of comorbidities, as well as encouragement of healthy lifestyle behaviors and attention to ongoing psychosocial issues.^{5,6}

There is currently little clear delineation of responsibilities between the various professionals involved in care provision when it comes to care beyond acute treatment.^{7,8} The

current system for caring for cancer survivors includes numerous providers from both oncology and primary care. In 2005, the landmark Institute of Medicine (IOM) report

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“From Cancer Patient to Cancer Survivor” served to highlight the challenges that cancer survivors face as they transition out of acute treatment.⁵

A cancer diagnosis and the associated treatment can serve as a catalyst for major life changes.^{7,9} As with the general population, many cancer survivors do not adhere to behavioral guidelines (healthy diet, physical activity and not smoking) that could reduce their health risks.^{10,11} Although many cancer survivors report making behavior changes following their diagnosis,^{12,13} establishing and maintaining healthier behaviors is a challenge. The cancer care team might play an important role in communicating the importance of lifestyle behaviors for future health^{13–15} at a “teachable moment” in the course of a patient’s experience of cancer diagnosis and treatment.⁹

Prevention and health promotion have not always been conceptualized as central to the remit of all physicians—particularly oncologists.^{7,16–19} Attitudes toward involvement in preventive activities have, however, changed considerably over the past generation, particularly in general practice.²⁰ As outlined above, there is a rapidly growing population of cancer survivors who are cared for by distinct professionals including medical oncologists, radiation oncologists, surgeons, nurses, nurse practitioners, primary care providers and others. The cancer care “team” might or might not work in explicit and direct consultation with one another. Cancer care work is situated within specific institutional contexts that create both incentives and barriers to changes in practices and roles. Work is structured around the interrelated rewards, incentives and identities of the various professionals involved in the care team, and there is a need for systematic consideration of how these are currently being established, maintained, defended and changed.²¹

The sociology of professions literature provides a valuable lens through which we can view such questions. The “professional project” is central to the sociological conceptualization of task allocation in systems in which professional authority is dominant,²² with changes in work activity being spurred by potential opportunities to redefine “jurisdiction” of one or more set of actors.²¹ Within this literature, the organization of health care work is understood as the product of near constant “jurisdictional disputes, in which occupational vacancies are created and occupied in a competitive, dynamic and inter-related system.”²³ The introduction of new knowledge, technologies or skills often has consequences for the organization and practice of professional work,²⁴ such that professional boundaries are in near constant flux.²⁵ One possible repercussion of such flux is that the construction of professional identities (what one does and what work and areas of knowledge one has control over) is not static or permanent. Even small shifts in a system can create a chance for a high-status profession to delegate tasks to less specialized or lower status group. It might be that the group to whom such tasks are shifted sees this as advantageous,²³ in which case the new technologies or skills might

be integrated into the purview of a professional group such that the professional remit is expanded or fortified. It is also possible that tasks are defined as an unwelcome burden or as not falling within a group’s desired professional remit. In this case, one might assume that tasks that are shifted from one group to another would be left undone or undertaken only minimally.

This study explores clinicians’ perspectives on the importance and feasibility of addressing one behavior change among their cancer survivor patients. We explore how health care providers who care for long-term cancer survivors view diet and dietary change in relation to quality of life, risk of recurrence and comorbidities for long-term cancer survivors.

To what extent are such tasks being brought under the jurisdiction of any of the professional groups who make up the cancer care team? How do the various stakeholders present their capacity to incorporate the work associated with health promotion into their work remit? Understanding how various stakeholders define the value of such work and their own relationship to it is critical to developing feasible and sustainable initiatives for the survivor population.

Methods

In this article, we report on the qualitative phase of a mixed methods study of the promotion of healthy diet among cancer survivors. This analysis is part of a larger study exploring determinants of diet among survivors of breast cancer, prostate cancer and non-Hodgkin lymphoma. All stages of the research were reviewed by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB). The initial stage (reported here) that was based upon semi-structured key informant interviews with members of cancer care teams was determined not to qualify as human subjects research as defined by Department of Health and Human Services regulations 45 CFR 46.102. The IRB made this determination after the research team submitted the research plan on the basis that the research is centered on key informant interviews where data are from individuals, but are not about individuals. Upon completion of the interviews with the cancer care team, we conducted mixed methods research on diet and survivorship with cancer survivors^{26,27} for which IRB approval was sought and granted.

Participants

We constructed a sample of providers who care for people who have been treated for breast cancer, prostate cancer or non-Hodgkin lymphoma.²⁸ We focused on these three cancers because they are associated with large numbers of long-term survivors, and the sample provided heterogeneity in treatment and survivorship care patterns. We conducted 33 semi-structured interviews with 10 oncologists, 6 surgeons (including urologists), 6 primary care physicians (PCPs), 3 nurses, 3 nurse practitioners, 2 social workers, a dietician, a

patient navigator and a survivorship coordinator. All participants were affiliated with either one community or one academic hospital within Baltimore, MD, USA.

Recruitment and data collection

The broad research team includes a medical oncologist, an oncology nurse practitioner and a PCP who are affiliated with the participating hospitals, and these team members provided contact details for the initial clinical contacts. Initial contacts were selected purposively to provide a broad representation of members of the cancer care team in both hospitals. We then used a modified form of snowball sampling²⁹ in which members of the study team and participating providers made recommendations for additional possible respondents so that our sample included various physician specialties and other professional groups from both institutions as well as providers who specialized in different cancer types. Interviews were conducted in person by the study principal investigator or a doctoral research assistant; both interviewers had extensive familiarity with the study aims, experience conducting and analyzing qualitative data and a background in cancer prevention and control. Interviews were held at a convenient location for the interviewee, typically their office; they lasted between 30 and 60 min and focused on how interviewees perceived their roles and responsibilities in caring for long-term cancer survivors. We asked a series of questions about perceived barriers and facilitators to behavior change interventions within clinical settings, and questions regarding the relevance of health promotion and lifestyle behaviors to the work of each respondent (See Appendix 1 for Interview Guide).

Analysis

Interviews were audio-recorded, transcribed verbatim, initially coded inductively to apply topical codes and then subsequently analyzed thematically. The thematic analysis was informed (but not driven) by the sociology of professions literature.

Initial identification of emergent codes. The initial stage of analysis consisted of two of the authors (K.S. and K.C.) independently reviewing and open-coding a subset of the transcripts for emergent topics. We then compared our coding and collaborated to develop a draft coding scheme which we applied and revised (See Table 1). Once the coding scheme was finalized, the transcripts were coded using this scheme by K.C. using ATLAS.ti qualitative analysis software.

Thematic analysis. The output from ATLAS.ti was used to organize data to facilitate and focus the subsequent thematic analysis³⁰ of discussions of dietary change that forms the basis of the results presented. The methodological orientation

taken in this analysis was that of social constructionism; we sought to outline how various practitioners conceptualize dietary counseling as internal or external to their professional role. K.S. applied additional concepts derived from the sociology of professions literature to construct an analytic framework pertaining to boundary definition and expansion, professional identity and authority. Our analysis was informed by the concepts outlined by Powell and Davies.²¹ Namely, we sought to identify and understand the incentives and conflicts of various stakeholders when taking on the work associated with promoting healthy diet in clinical sessions with cancer survivors. We were specifically interested in how work changes were understood in relation to professional identity. We present key emergent themes, giving explicit consideration to outlier cases and possible alternative explanations.

In the “Discussion” section, we sometimes group oncologists, urologists and surgeons together and describe them as “cancer specialists.” For our purposes, this term is used to distinguish between physicians who take a leadership role in the treatment of cancer and those who provide generalized (not specialized) care. Thus, it does not include nurses, nurse practitioners, social workers, patient navigators or other key members of the acute cancer care team nor does it include PCPs.

Findings

Our interviews with cancer care team members were fruitful; patients’ dietary change was a topic for which respondents had considerable experiences and perspectives that they were willing to discuss. We have organized our consideration of the discussion of inclusion of dietary behaviors and behavior change in care provision for cancer survivors into four related, emergent themes: (1) *the prioritization of behavior change in the care of cancer survivors*, (2) *evidence base for dietary messaging*, (3) *relating work to available time and clinical priorities* and (4) *constructing dietary counseling in relation to professional expertise*. We explore the content related to each theme in turn, before relating data to the sociological literature on the “professional project” of physicians.

Prioritization of behavior change in the care of cancer survivors

Most interviewees expressed considerable support for encouraging healthy diet among survivor patients as part of their professional remit. One nurse practitioner summed up her perspective and her notion of her colleagues’ current work practice as follows:

I think most of us, doctors included, are spending a little bit more time talking about that [diet]. You know, we used to not really bug people about their weights at all. We really didn’t say much about it, but I mean I pretty much do at every visit. I get

Table 1. Coding scheme for cancer care team interviews about dietary change for cancer survivors.

Code	Description
Diagnosis	Patient reactions, concerns at time of diagnosis
Treatment	Discussion of the course of treatment, what treatment entails, possible treatment regimens
Follow up	Discussion of post-treatment follow-up protocol, the nature of follow-up appointments, why follow up is important/necessary
Diet as a priority	How is diet/lifestyle issues prioritized in the follow-up care of survivors, providers perceptions of the importance/effectiveness of dietary changes; specific subgroups for which dietary change is particularly relevant
Own role	How the key informant views their role in taking care of long-term cancer survivors
Others' roles	How the key informant describes the role of other health care professionals in caring for long-term cancer survivors
Professional boundaries	Discussions of the "appropriate" type of provider who should be providing specific types of care
Communication	Communication, or lack thereof, between different types of providers
Transition	Discussion of how patients transition out of oncology care (e.g. formal transition visit versus informal), if and when patients are transitioned, perceptions of patients' reactions to being transitioned
Changes in care	Discussion of ways in which the care of cancer survivors has changed overtime
Survivorship	Discussions of when a person becomes a survivor, perceptions of the term "survivor"
Survivor care plan	Discussion of the use of survivor care plans in the transitions of survivors
Survivor concerns	Typical questions that cancer survivors ask providers
Survivor resources	Discussion of resources (or lack thereof) available to address the needs of post-treatment cancer survivors
Family	Discussion of the role of family and friends
Quality of evidence	Discussion of scientific evidence regarding the association between diet and cancer recurrence/prognosis
Diet in treatment	Discussion of side-effects during treatment that either influence diet in some way or can be improved by dietary changes
Reasons for dietary change	Discussion of rationales for promoting dietary changes among patients (e.g. lose weight, reduce risk of recurrence and overall health); relevance of cancer in dietary or weight loss advice
Message timing	Discussion of times during the care continuum when the need for healthy eating/dietary changes should be discussed, initiated
Diet questions	Types of diet related questions that patients ask
Diet provider	Discussion of the type(s) of provider that should or should not be involved in promoting dietary change, ideal provider types, assertions about whether or not the promotion of dietary change falls into the key informant's responsibilities, ability of provider to address dietary concerns
Receptivity	Provider's perceptions of patients' readiness/interest in engaging in behavior change
Type of change	The types of changes patients actually make; whether or not patients actually make changes
Survivor capacity	Discussion of barriers that cancer survivors face that inhibit their ability to make dietary changes; discussion of facilitators that enable cancer survivors to make dietary changes
Barriers to weight loss	Discussion of factors that inhibit weight loss in patients
Maintenance	Discussion of whether survivors maintain changes overtime
Teachable moment	Cancer as a teachable moment where patients are primed to make changes
Personal experience	Discussions of providers personal experience with cancer
Patient characteristics	Characteristics of patient population, how the doctors talk about their patient population (e.g. demographically, personality wise and existence of comorbidities)
Obesity	Discussion of the extent to which obesity impacts either treatment or prognosis
Tobacco use	Comparisons between tobacco use prevention and obesity prevention

the sense that ... it's being talked about much more than it, than it was say two years ago. (Nurse Practitioner, Breast, Academic)

The issue of diet and dietary information was sometimes presented as very straightforward, as in the case of this urologist's description of how he includes dietary information in the clinical visit without it becoming burdensome:

The overview I give them is they need to do three things. They need to learn what a healthy diet is, they need to learn about what a normal portion size is, and they need to learn about

exercise, so those are the three things I talk to them about, so ... it takes a minute to do that, so I don't spend hours doing that. (Urologist, Academic)

Interviewees also described dietary discussions as prompted by patients' enquiries and interests in possible actions to reduce recurrence risk:

People often ask "What can I do to reduce my risk of the cancer coming back?" and I tell them, "Once you've done all your treatments you're on you know whatever medication, the only

other things that we know about is to lose weight because obesity increases the risk of breast cancer recurrence for sure.” (Surgical Oncologist, Breast, Community)

Our data revealed considerable capacity and willingness on the part of providers to engage at least minimally with dietary counseling in routine practice. In contrast, interviewees tended to provide a variety of rationales for their clinical practice in cases where they did not integrate health promotion into their practices of care.

Evidence base for dietary messaging

The evidence base linking diet and healthy survivorship was key to the way in which physicians presented their decision about whether to include dietary messaging in visits with survivor patients. Cancer specialists who described an active role for themselves in promoting dietary change tended to also present a positive perspective of the association between diet/weight and cancer recurrence:

The science clearly points to the fact that lifestyle and behavior change in the areas of diet, exercise, maintaining healthy weight, minimizing alcohol does have a strong scientific basis for reducing the risk of recurrence ... So, I think we need to do an even better, stronger educational job for our patients by reinforcing to them that this isn't just you know pretty sounding pink ribbon language. This is real science that has been shown that these things work. (Medical Oncologist, Breast, Academic)

I think the conversation I have with people about the evidence that people who have chosen unhealthy lifestyles are more likely to die of prostate cancer is a very motivating conversation. (Urologist, Academic)

The above quote from a medical oncologist is illustrative of how some physicians accounted for their motivation to act or not to act within a clinical encounter on the basis of the evidence of the efficacy of an intervention (such as diet) for the patient's health. In addition, the urologist quoted above framed motivation for action in relation to what will potentially impact patient behavior. Not everyone, however, expressed confidence in the nature of the evidence linking diet to cancer recurrence. Rather, opinions ranged from near certainty of relevance of dietary behaviors to considerable skepticism. Some oncologists pointed to the lack of strong evidence about the relationship between diet and cancer recurrence as an explanation for why they do not prioritize dietary discussions with their patients:

We don't have a lot of data on it [dietary impact on recurrence]. I personally don't volunteer because ... whatever they ask me I'm not going to make comment on it because it's not going to be scientific. (Surgical Oncologist Breast, Academic)

The data did not reveal any clear consensus as to how the interviewees viewed the strength of the evidence base about diet and cancer outcomes. The following quote is illustrative

of how some interviewees felt that a more holistic notion of dietary benefits is sufficient to warrant recommendations for dietary change within the context of cancer care:

I do it only because it's mom and apple pie, and only because it might help their heart and may as well help their health while we're at it, but you know I'm skeptical about all of the potential benefits for prevention [of cancer]. (PCP/Medical Oncologist, Academic)

In general, the strength of the evidence base between recurrence and diet tended to be less central to how PCPs described their rationale for including dietary messaging in clinical sessions. There were some instances in which PCPs referenced the evidence base as motivational for the patient, rather than for them as the physician. The following quote from a PCP is illustrative of this perspective, “I know there's some link between obesity and recurrence but I don't think I've used that in the sense ... either as a motivation or a scare tactic” (PCP, Academic).

Whereas oncologists and surgeons seemed to view patients through a cancer lens, the PCP interviewees made reference to whether or not they viewed the patient primarily in relation to their cancer history in emphasizing or discounting the relevance of dietary messaging. Primary care providers described approaching cancer survivors as they would “any other patient” soon after completion of active treatment. One PCP commented, “I guess in my mind when you're that far out I'm probably going to give you the same recommendations that I would if you didn't have cancer. That's the reality.” In several instances, PCPs presented other chronic conditions (such as heart disease, diabetes and obesity) as more pressing in relation to diet/weight than cancer, thus creating an obvious need to address diet in the visit, with or without any explicit link to cancer recurrence or sequelae:

If they have a history of cancer I typically don't talk to them any differently [about diet]. High blood pressure give me a low salt diet, okay. If you have diabetes, I'll go into the, “You can do a low carb, less, if they have high triglycerides, less alcohol, less red meat, pasta.” I'll treat them as if the cancer was not influencing how I do it. (PCP, Community)

Interviewees generally presented evidence regarding the health impact of diet as motivational, but the extent to which evidence related to cancer outcomes was prioritized over health more generally was a point of considerable difference between oncologists and PCPs.

Relating work to available time and clinical priorities

In addition to references to the nature of the evidence base, the actual time allocated for the visit was frequently prioritized in accounts of inclusion or exclusion of diet in professional activities, as in the following extract:

For the most part, it's a 20minute visit during which we see them, examine them, dictate a note on them. There's not a lot of time to do much of counseling, so it's usually just saying, "You should lose weight. You should exercise." That's you know a very common thing we repeat, but we don't have the time or the expertise to go into it any further than that. (Surgical Oncologist, Breast, Community)

The previous extract is representative of many comments made about the impact of time pressures on inclusion of dietary counseling in oncology visits. There was, however, one contrasting case regarding the issue of time made by an interviewee whose position bridged primary care and oncology:

Promoting good health and focusing on that is just the right thing to do and somebody should do it, and you know I feel obligated to do it ... because oncology subsidizes a 30minute visit, so I have time to explore and do that. (PCP/Medical Oncologist, Academic)

Time constraints were one way that interviewees articulated the need for more resources and specialized expertise in this area:

If we had more resources to turn them to, just as you know right we've got multiple other patients we have to see and so to spend the extra 30minutes that you probably need with that patient when there's two others who still need your help then you have to cut short that discussion. So, being able to turn them over to some other professional, I think would be fantastic. (Radiation Oncologist Prostate, Academic)

Some clinicians presented the relevance of dietary issues as being limited in relation to their core tasks or professional role. One urologist (Academic) interviewee neither called into question the evidence base around diet and cancer nor his capacity to address this issue. Rather, he presented a limited way in which this issue is relevant for his professional consideration. His description demonstrated the limited the way in which he viewed the influence of diet (and presumably weight) in relation to a patient's readiness and candidacy for surgery. "As surgeons we discuss some of this [lifestyle] too, but perhaps not as heavily. We're much more focused about are they a candidate for us to do the surgery or not."

Many of the specialists described dietary concerns as somewhat tangential to their primary role as it pertains to cancer surveillance. They also framed their limited (if any) engagement with dietary behaviors in the visit in relation to what is expected and desired of them from their patients:

When I'm seeing someone two maybe three times a year for a 30minute visit where the primary focus is going to be on surveillance because the reality is that's what they want to see me for ... Most of my patients are happy that I'm talking about their lifestyle stuff too I think but what they really want to hear from me is there's no sign of cancer, so we'll spend 15 of the

30minutes on "there's not sign of cancer" and "don't worry" and we just don't have time to do the other stuff. (Medical Oncologist, Breast, Academic)

Nurses were, however, an exception to this "distancing" from dietary tasks by clinicians:

I think maybe it should be introduced throughout treatment because you might, you see the patient every week and you might be able to do some more teaching as they ask questions - then you can continue it. (Nurse, Prostate, Academic)

Constructing dietary counseling in relation to professional expertise

Both cancer specialists and primary care providers tended to describe a lack of time and lack of expertise as barriers to including dietary messaging in clinic visits. A common way to frame discussions of one group's inability to include such services was in reference to the greater potential or capacity of another professional group to deliver information about dietary change. Cancer specialists often referenced PCPs as having the appropriate professional perspective from which to address dietary issues. This capacity was presented in terms of both patient practices and preferences and professional skills and expertise, as summarized by one surgical oncologist (specializing in breast cancer) in the following statement, "I think they [cancer survivors] may talk to their primary care providers." A urologist (Academic) provided the metaphor of the PCP as a patient's quarterback in reflecting on professional capacity in relation to health promotion:

I think the appropriate person might be the primary care doctor. I think probably they have a big role cause that's been their quarterback for years, and hopefully their quarterback for years to come, so that sort of person I think would be the best facilitator. (Urologist, Academic)

It is, however, worth noting that PCPs were not uniform in portraying confidence and comfort with counseling for dietary change, as illustrated by the following quote from a PCP [community] comparing readiness for dietary messaging to smoking cessation counseling, "I do have to say in terms of behavioral modification, I have more of a game plan when it comes to smoking cessation than when it comes to anything else" (PCP, Community).

Setting aside the resource constraints, PCPs did tend to present some form of engagement with delivery of dietary messaging, and one interviewee provided a clear articulation of how this fits into their management of chronic disease:

We probably should be the vantage point for a lot of this anyway ... it goes along with healthy attitudes and you know all the other chronic care conditions that we worry about, obesity and diabetes and hypertension and heart disease ... I kind of look at it as healthy living, healthy dieting, the care of the whole

individual. There is so much overlap in a lot of the chronic illnesses we take care of, so it is kind of making cancer survivors another chronic illness domain. (PCP, Academic)

On the other hand, this PCP also presented oncologists as having an important role to play in delivering dietary information because of their influence and authority with their patients:

So when they hear from oncology, “We need to have you eat healthy. It’s important to eat these kinds of food.” When I have a conversation with them and reinforce that, they hear it better as opposed to me being the only one giving them the message. Because somehow the oncologist has blessed it as important and I’m reiterating it as opposed to me saying this and they’ll sort of look at me and kind of go, “okay.” (PCP, Academic)

We noted expressions of general support for nutritionists as important for addressing the dietary concerns of patients because of both nutritionists’ specific expertise and their focus on the issue of diet:

I’m pretty sure that the other docs also don’t have the time to go into a diet. We do feel that we are not the experts in that area, and that if anyone wants to, if anyone talks to these patients it should be the dietician, the person that has the expertise in doing that. (Nurse Practitioner, Prostate, Academic)

Some interviewees presented nutritionists as having the capacity to address a deficit (time or expertise) in the current cancer care team. In contrast, for others, visits with nutritionists were constructed as a supplemental benefit to both the patient and the clinician in question:

I’ll often have them see a nutritionist if they have diabetes ... I think it’s often we don’t have time in a visit to sort of you know do a dietary recall for you know an extensive period of time ... but you know I don’t have the, often the time in an appointment to really like you know unpack all of what they’re eating, so I’ll have them see a nutritionist if I’m you know worried about it. (PCP, Community)

I just kind of have them, have this general concept of balance your eating, try not to eat unhealthy things that you know like pizza, things that are not healthy for you, and then if they still have questions about what diet plan they should follow and how many calories they should ingest for weight loss, even my non-cancer patients, I refer them to the nutritionist, and she kind of sits down and goes through a plan with, so I’m kind of spoiled. (Medical Oncologist, Community)

These extracts indicate ways in which stakeholders’ expertise and time were woven into conceptualizations of the potential value of a nutritionist consult. In any case, it was not clear that either hospital had access to nutritionists or a mechanism for reimbursement for consultations with such individuals:

The alternative or holistic usually is not covered by insurance, so with the ACS [American Cancer Society] dietician on call they can call them over the telephone, set up a diet plan and cover whatever issues, concerns, go over that, mail the information to the patient, so usually I make referrals out and just let the patients know what, what is available in the community through, for them. (Patient Navigator, Community)

The presentation of the nutritionists’ expertise can be contrasted with discussion of chemotherapy nurses as possible lifestyle behavioral interventionists based seemingly less on their topical expertise than on their ability and integration into the current system such that the amount of time that chemotherapy nurses spend with patients is viewed as the most fruitful opportunity to present additional information:

I think that even chemo nurses are the ones who are kind of in the trenches doing everything. They spend a lot of time with these patients and sitting with these patients and getting to know them and their family. I think there are times that you could intervene with a patient that may not be the scheduled 15-minute nutrition consult, but there are ways to kind of drop things in when patients are receptive to hearing health information. (Survivorship Coordinator, Academic)

Discussion

The capacity of cancer survivors to live a long life after completion of cancer treatment, but to potentially be in poorer health, has created a growing recognition of the need to incorporate health promotion, specifically in relation to behaviors such as diet and exercise, into systems of care for cancer survivors.^{9,18} In terms of system capacity, the projected shortage of oncology providers in the United States,³¹ and the rising costs of cancer care^{31,32} are such that there is considerable momentum within the health policy and health care system levels for organizational changes that result in more effective and efficient models of survivorship care.⁷ Although there are numerous studies calling for more clinical engagement with health promotion,^{9,33} there has been little empirical consideration of the factors that shape uptake and implementation of suggested changes as well as the actual work involved with such efforts, and the capacity for change within the current clinical structures.

Our conclusions should be considered in light of the limitations of the study conducted. The data considered here are from one small, qualitative study of the perspectives of the professionals who care for cancer patients and work in one of two health systems within a single US city. Not all members of the cancer care team in either system were able to participate, and as with all interview data, social desirability may have shaped responses provided. We constructed our sample to provide variation in the types of patients cared for, the professional roles undertaken and operating practices employed at the systems level. As with all such qualitative studies, it is possible (although we would argue somewhat

unlikely) that the perspectives offered here are somehow unique to the small set of respondents, and not in any way more widely applicable. Our goal is not to provide easily generalizable findings, but to learn from a detailed engagement with the complexities of accounts provided by purposefully selected professionals on one aspect of care provision (dietary health promotion for cancer survivors).

In interviewing members of cancer care teams, we found a general tendency to articulate support for the importance of dietary messaging for cancer survivors, but little evidence of any overarching consensus on how this should be provided, nor any strong indication of a boundary shift such that any group is expanding their own professional remit to clearly include the provision of counseling on dietary change.^{21,34} One area of considerable agreement was on the value of nutritionists and other professionals with specific dietary expertise as resources for clinicians and patients. At the same time, interviews revealed a recognition on the part of team members of considerable structural limitations (including lack of personnel and insurance reimbursement), such that “work-arounds” were also proposed such as chemo-nurses being charged with providing dietary counseling during treatment sessions. Our data suggest that awareness of healthy diet is not a sufficient predisposing factor for the modification of professional practice to include dietary counseling as a routine element of care for survivor patients. Innovation in models of health care provision can be understood to result from of a set of actors (such as nurses or PCPs) challenging existing boundaries around work remits and disputing current practices so as to move themselves into new fields of work.³⁵ Alternatively, reorganization can result from the reallocation of a less desirable task (“dirty work”) from a more powerful professional group to a less powerful one.³⁶ Neither process, however, appears to be much in play in relation to dietary messaging in clinical encounters with cancer survivors from these accounts from various members of cancer care teams – even though dietary messaging is generally supported.

The sociological literature describes boundaries^{21,24,34,37} within work remits that provide a shared understanding of professional responsibility and control. To the extent that boundaries are shared concepts across professions, they serve to facilitate professional identity development and collaboration. The IOM’s call for a reorganization of survivorship care⁵ seemingly opened the door to a new field of work (health promotion for cancer survivors), but as yet, it would seem that professional groups are not moving to claim this “space” as their own. In this article, we focus on the positions adopted by oncologists, surgeons and PCPs because these are the groups who, as the system, is currently organized, continue to have contact with cancer survivors beyond the time of acute treatment. Our analysis suggests considerable potential and even need for inclusion of more diverse professional contributors, such as dietitians, nutritionists, health educators and social workers, particularly given that

the various physician groups represented seem to be expanding their remit to include dietary messaging.

The boundary regarding engagement with lifestyle behaviors as part of survivorship care is shifting; the IOM report and resource pressures are making this work more prominent. Our data suggest that the various clinical stakeholder groups do not share a common sense of any new boundary on this issue and area of work. These tasks have *not* historically been the remit of oncologists and cannot therefore be passed from oncology to other stakeholders in the cancer care team. Nor is this new work that is being readily embraced by oncologists or others. Rather, there is currently something of a “no man’s land” where health promotion tasks such as dietary messaging are commonly recognized as important but are generally going unclaimed and undone (or minimally undertaken) by any occupational group. Mizrachi and Shuval²⁵ outline a care/cure boundary in medicine, such that professional power and status are more associated with cure, rather than with care. If health promotion is being conceptualized as “care” rather than “cure” work in relation to cancer, then this might explain the lack of movement by any group to expand their remit in this area. It is possible that such tasks will only become central to the work of the cancer care team when they are clearly and unquestionably linked with “cure” as well as “care.” Our data suggest that if we utilize a “cancer lens” through which to view diet and health, the evidence for such a link might not yet be fully established or widely accepted.

Our findings are consistent with what has long been discussed about the challenges in implementing health promotion activities within the clinical setting, including physician disagreement as to the importance of various behaviors, followed by disagreements over specific recommendations and concerns about patient compliance and the effectiveness of physician recommendations and activities.¹⁷ Green et al.¹⁶ identified the weight and acceptance of scientific evidence linking behaviors with health outcomes as key to physicians’ willingness to take on preventive roles. Over 25 years later, it seems that the nature of the evidence base regarding the relevance of lifestyle behaviors for cancer recurrence is still a key barrier to the uptake of health promotional work. Several oncologists in our study referenced the nature of the existing evidence base around diet and cancer recurrence in their account of why messages about diet were not part of the care that they provided.

Professional power has knowledge as its foundation, and the distinction between science and non-science is the key to biomedical authority.²⁵ Scientific evidence is an important consideration in health care providers’ decisions to make specific recommendations and embrace changes to clinical practice. In our study, those who described strong evidence between diet and health outcomes under their purview often linked this with attempts to incorporate dietary messages into their clinic, while those who were more skeptical expressed reluctance to making such a change.

As described by Mann and Putnam,²⁰ our data also reveal the role of context and conditions in which the activities would/should occur in the implementation process such that, “Many factors, both independently and interactively, affect the extent to which a behaviour is implemented; these factors can have a different relative importance in different situations and in different specific activities.”²⁰ The actions and interactions of actors operating within a specific set of local conditions are the dynamic through which concepts of idealized care become what actually transpires in practice.³³ Interviewees presented structural factors as playing a critical role in preventing potentially desirable changes in practice, including having neither the training nor the time to undertake activities related to promoting healthy diet. They also described no easy way to link patients to identified resources (namely dietitians and nutritionists) within the current system.

Changing environmental demands and local forces often result in shifts in the boundaries between the work practices of various professional stakeholders.²⁵ To the extent that lifestyle behaviors and health promotion are now a “demand” being placed on the cancer care team, it is critical that consideration be given to ways to ensure that various members of the team become aware of and engaged with strengthening evidence of the importance of diet, activity and healthy weight for cancer outcomes.

We suggest that expanding the oncologist’s professional remit is unlikely to be an effective solution to providing important health promotion work (such as dietary counseling). The current status of the evidence regarding the association between diet and improved outcomes in cancer survivors is that dietary recommendations are best guided by recommendations pertaining to other health outcomes and general cancer prevention.¹⁸ Once a holistic perspective on survivorship is applied, the relevance of dietary behaviors is unmistakable. Adding nutritional capacity to the cancer care team would be one way to address the gap in capacity, but our data reveal that this will be challenging both in terms of available personnel and models for reimbursement. Oncology nurses were identified as potentially having the opportunity to discuss diet, but not necessarily at an ideal time during the treatment trajectory. Alternatively, yet another model is for primary care providers to be trained and explicitly charged with dietary messaging given their identity as all-around care “quarterbacks” and the fact that they already routinely manage complex sets of comorbid conditions. If health promotion tasks are central to caring for cancer patients and PCPs are to take a leadership role in this area, then it is critical to better understand how patients view the role of their PCP and non-oncologists in their post-cancer care.³ The question becomes, what is the best way to create room and support for other professionals into authoritative positions in relation to long-term survivorship? The distinction between cure and care is not straightforward as cancer comes to be conceptualized as a survivable, yet chronic condition.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

Ethical approval for this study was reviewed by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board, and it was determined that the research does not qualify as human subjects research as defined by the Department of Health and Human Services regulations 45 CFR 46.102 as it involves key informant interviews where data are from individuals, but are not about individuals.

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Informed consent

Verbal informed consent was obtained from all subjects before the study.

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Appendix I

Key informant interview guide

The key informant interview guide will have a common foundation, but with adaptations for the various providers (oncologists, primary care doctors, nutritionists, social works and oncology nurses)

Key domains

1. Care for long-term cancer survivors within work role/responsibilities;
2. The importance of behavior change and healthy diet for survivors;
3. Barriers and facilitators to behavior change for survivors;
4. Barriers and facilitators to behavior change interventions within clinical setting.

Domain I

Q. In your practice, do you care for many long-term cancer survivors—that is, people who are 2 years post-diagnosis and finished with active treatment?

Q. Can you think of a “typical” long-term cancer survivor in terms of their care needs?

Prompt: In other words, in what capacity are you seeing most survivors?

Prompt: What are they asking or expecting of you?

Q. How, if at all, has your practice relating to long-term survivors changed in recent years?

Prompt: Do you see more or fewer survivors in a typical month?

Prompt: Are you focusing on different aspects of their health?

Prompt: Are you focusing more or less on health promotion or other comorbidities with survivors now than previously?

Domain 2

Q. What do you think of as the most important elements to promoting health and quality of life among long-term cancer survivors?

Q. What role do you think that lifestyle factors such as diet and physical activity play in health and quality of life for survivors?

Prompt: To the extent that diet is important, what do you think are the key issues?

Q. Do you assess diet among your long-term survivor patients as part of routine care?

Prompt: If so, how do you do this, and at what point/s?

Q. Do you discuss dietary change with your long-term survivor patients as part of routine care?

Prompt: If so, when does this come up?

Domain 3

Q. For your long-term survivor patients, what do you think might prevent them from eating a healthy diet?

Prompt: Do you think that most of these patients are physically able to access and prepare healthy food – or have someone to do this for them?

Prompt: What about the cost of eating a healthy diet? Do you think that this might be a factor for many of your survivor patients?

Prompt: What about their general outlook – do you think that most of your survivor patients think that they are able to influence their health – and their cancer recurrence, specifically?

Q. What about making a change in diet – do you feel that this is something that most of your survivor patients would be prepared and able to undertake?

Prompt: Do you think that there is a particular time point in terms of their cancer history at which engaging in a behavior change initiative would be most effective?

Domain 4

Q. If we were to design a dietary intervention for long-term cancer survivors, do you think that this might fit well with the care/services that you provide?

Prompt: Do you see this as consistent with the work that you do?

Prompt: Do patients and/or their family members bring up issues about health promotion?

Prompt: Are most of your patients also being seen by another health care provider on a regular basis?

Q. In thinking about designing dietary interventions for long-term cancer survivors that could be introduced or even implemented within a clinical setting, what would we need to know about how you do your work – how your practice is structured – to design an appropriate approach?

Prompt: How long do you typically spend with a patient?

Prompt: How regularly do you see most patients?

Prompt: Do patients tend to come by themselves or with family members?