

# Cancer Care From the Perspectives of Older Women

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**Purpose/Objectives:** To understand how older age affects cancer care, from the perspectives of older women.

**Research Approach:** Qualitative, participatory.

**Setting:** Urban southern region of Ontario, Canada.

**Participants:** Purposive sample (age groups and income) of 15 women diagnosed with cancer at age 70 or older; 10 women were diagnosed with breast cancer, 5 with gynecologic cancer.

**Methodologic Approach:** Two face-to-face interviews, with data analysis in collaboration with the project team based on constructivist grounded theory, including negative case analysis.

**Main Research Variables:** Age, experience of cancer care.

**Findings:** Age-related life and health circumstances intersect with professional practice and wider social contexts and are implicated in treatment decision making, including decisions against treatment, as well as in the day-to-day “getting around” that cancer care requires.

**Conclusions:** The nursing history should be holistic in scope, attending to the supportive care domains to elicit older women’s physical, social, practical, informational, psychological, and spiritual needs after a diagnosis of cancer. History taking should draw forward older women’s life contexts and examine these contexts in relation to cancer care, including treatment decision making.

**Interpretation:** Individual-level care and systems advocacy are required to ensure that older women’s worries about sustaining independence, including worries generated by inadequacies in home-based care, do not act as determinants of treatment choices.

The effect of age on patterns of cancer care and treatment is a subject of considerable debate. Controversy abounds, for instance, regarding appropriate medical investigation and treatment for older people (Balducci, 2001; Lickley, 1997; Turner, Haward, Mulley, & Selby, 1999; Yarbrough, 2004). Some investigators have characterized older patients’ generally more conservative treatment as “less than ideal” (Wanebo et al., 1997). Silliman (2003) explicitly linked patterns of treatment for older women with breast cancer to higher rates of recurrence and mortality. Others, however, report that less aggressive treatment appropriately reflects the diminished efficacy of adjuvant systemic therapy in older people (Guadagnoli et al., 1997). Treatment decision making among older people is an area of similarly contested terrain. According to some studies, physicians are less likely to involve older patients in decision making (Lickley; Silliman, Balducci, Goodwin, Holmes, & Leventhal, 1993). Although such findings generally are assumed to reflect inappropriate and inequitable professional practice, some literature on this subject suggests that older people prefer to assign the decision-making responsibility to others (Degner et al., 1997; Ende, Kazis, Ash, & Moskowitz, 1989). More broadly, the

## Key Points . . .

- ▶ Debates about how older age affects cancer care usually are undertaken from the perspective of healthcare professionals and framed in medical terms.
- ▶ Older women’s life and health circumstances are relevant to their cancer care in complex—and little understood—ways.
- ▶ Age-related life and health circumstances are implicated in treatment decision making, including decisions against treatment.

link between age and decision role preference appears to be weak (Ende et al.), and some authors question the utility of sociodemographic variables in predicting an individual’s desire to engage in the decision-making process (Degner & Sloan, 1992; Ende et al.).

Debates about how older age affects cancer care generally are undertaken from the perspective of healthcare professionals and commonly framed in medical terms. The research presented in this article builds on a small body of literature that foregrounds older women’s own accounts of receiving care and treatment for cancer. Studies in this domain tend to highlight how gendered social and family contexts, including memories of caregiving, shape older women’s treatment decisions (Cameron & Horsburgh, 1998) and often point to the subjective salience for older women, for instance, of feeling rushed in medical encounters (Crooks, 2001).

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The current study focused on the experiences of women aged 70 and older who received cancer treatment in Hamilton, a mid-sized city in urban southern Ontario, Canada. The study employed qualitative and participatory methods: qualitative to illuminate older women's social contexts and the subjective meanings they assign to cancer and cancer care (Popay & Williams, 1998) and participatory to recognize the "standpoint expertise" (Stanley & Wise, 1993) of older women, cancer survivors, community workers, and healthcare professionals.

Broadly speaking, study participants assessed their care as extremely positive, rarely perceiving barriers related to age or generation. Statements praising oncology professionals echoed through the transcripts, in some contrast with participants' assessment of hospital and community care. The study also highlighted ways that living many years affects the experience and evaluation of cancer care. On the whole, age and generation seemed to lend a certain perspective to participants' experiences of cancer care. This finding is not without its own complexity, however, as the investigators discussed elsewhere (Sinding & Wiernikowski, 2005).

In this article, the investigators focused on elements of the study findings most salient to healthcare professionals working in cancer care settings, considering, in particular, how age-related health and life circumstances intersect with key features of cancer care and professional practice to shape older women's experiences.

## Methods

The 70+ Women and Cancer Study is part of the Intersecting Vulnerabilities research program, which asks groups of older women, low-income women, and Aboriginal women to speak about their experiences with breast and gynecologic cancers. The program was designed to examine how women's social locations act as determinants of health and quality of life in the cancer care context. This article reports findings from one study within the larger research program, the study with older women.

Each study within the Intersecting Vulnerabilities research program employs a participatory research framework. In participatory studies, researchers are positioned not as "separate, neutral academics theorizing about others," but rather as "co-researchers or collaborators with people working towards social equality" (Gatenby & Humphries, 2000, p. 90).

In keeping with participatory commitments, the 70+ Women and Cancer Study was undertaken by a project team that includes women in their late 60s and early 70s, cancer survivors, representatives of agencies serving older women and women with breast cancer, healthcare professionals, and researchers.

## Recruitment

Ethics approval for the study was obtained from the Hamilton Health Sciences and McMaster University Faculty of Health Sciences Research Ethics Board. Participants were recruited from the Juravinski Regional Cancer Centre in Hamilton, Canada. Eligible patients were women diagnosed with breast or gynecologic cancer older than the age of 70, not currently receiving radiation or chemotherapy, with no evidence of metastatic disease, and living in the Hamilton-Wentworth or Halton regions of Ontario, Canada; 1,817 cases met the criteria for inclusion.

Recruitment was purposive (Mason, 2002), designed to select for social characteristics known to shape health and health care. For example, drawing on research that highlights the significant effects of low income on many older women's lives (Ontario Community Support Association, 2001), the investigators deliberately oversampled low-income women. The sampling frame was as follows.

- **Age:** One-third in each age bracket: 70–74, 75–79, 80+
- **Income:** Half of sample low-income, as defined by Statistics Canada's low-income cutoff. Canadian low-income cutoffs vary by size of family and community; households falling below the low-income cutoff are "substantially worse off than the average" (Statistics Canada, 1999, p. 6).
- **Ethnicity:** One-third self-identify as members of visible minority ethnic groups.

The charts were reviewed 100 at a time, starting with the most recently diagnosed patients. Patients who met the criteria were mailed a letter explaining the study and told that they would receive a phone call regarding their possible participation. As patients agreed to be interviewed, their names were entered into the sampling frame. As each section of the frame was filled, additional patients who met these particular criteria were not pursued for participation. For instance, the 70–74 age range was filled quickly; further chart review focused only on those patients older than age 74.

In total, 300 charts were reviewed, 43 women were contacted, 26 (60%) declined to participate, and 2 could not be reached by telephone. Of interest, women who declined to participate often said that they had "nothing to say." They attributed this to three circumstances: successful treatment (one woman, for instance, said, "It's completely gone, I don't have cancer now. They check me a few times a year, but I don't have any problems with cancer, so I don't think I can help you."), limited contact with the system (several women compared their few encounters with the cancer care system for surgery with other women's regular visits for adjuvant therapy), and not having encountered problems with cancer care. Despite clear statements during the phone call that all stories were welcome and that good experiences were as valuable as difficult experiences, the women maintained that their input would be of no use to the investigators.

Patients diagnosed older than age 80 were especially difficult to accrue. Advanced disease at presentation made many ineligible, and the remaining number was small. When contacted by phone, women were asked whether they identified as a visible minority, and none did.

## Interviews

Semistructured interviews (usually one to two hours in duration) were conducted with each participant; second interviews (between one to two-and-a-half hours in length) followed several weeks later. With permission, the interviews were audiotaped.

The three interviewers—two of whom are cancer survivors and all three in their late 60s or early 70s—were drawn from the project team. The project team developed the interview guide with input from four additional older cancer survivors. The guide began with questions about how the participants found out about their cancer, who they told (and why and why not), and what happened in terms of their health care. The interviewers continued to ask "What happened next?" to

get a sense of the path of care and followed up on participant comments related to the research questions, such as comments that suggested a barrier to care, comments about what had worked especially well, and comments about age. The interviewers asked about times that participants felt comfortable in meetings with healthcare professionals and times when they felt less comfortable or less strong. They also posed questions about the women's wider life context: their relationships and general health, housing and financial situations, and thoughts and feelings about their age.

Second interviews clarified and expanded on the initial interviews and explicitly asked women about any links that they perceived between their age and experiences with cancer and cancer care. In keeping with qualitative research principles for establishing or improving the credibility of research reports (Lincoln & Guba, 1985; Seale, 1999), participants were asked in second interviews to comment on emerging themes.

Interviews took place at locations amenable to participants, most often in their homes and occasionally at Breast Cancer Support Services, the cancer support center collaborating in this study. A \$30 honorarium was provided for each interview.

### Analysis

In keeping with a participatory approach, all of the project team members reviewed each interview transcript. At team meetings (usually half a day, approximately every two months), the project team shared reflections on what was striking, puzzling, unexpected, or moving about the narratives. Interviewers' interpretations and perspectives were especially important in this process because they drew forward insights gathered from gestures and interactions not captured in the transcripts.

The project team's analysis followed key grounded theory methods, both naturally and by design. Proponents of grounded theory call for constant comparison within and between accounts; attention to the conditions under which phenomena arise and the consequences associated with the phenomena (Charmaz, 2000; Strauss & Corbin, 1990). As each interviewer presented an interview she had done, members of the team were prompted to recall aspects of other participants' narratives, noting similarities and differences among them. The investigators proceeded to more formal conversations about what seemed to make a difference (both for better and for worse) in women's experiences of cancer care and then spent focused time sorting through which features of women's experiences and commentary could be linked particularly with older age, attempting, in grounded theory terms, to discern whether older age was a condition of the phenomenon under discussion.

In keeping with the team's commitment to avoid stereotyping older women and adhere to principles of qualitative analysis (Seale, 1999), the investigators deliberately read for and discussed negative cases (i.e., instances where participants' experiences or commentary departed from or challenged an emerging theme). Drawing from detailed minutes taken at these meetings, a coding framework was developed and transcripts were coded using the qualitative software program NVivo (Bazeley & Richards, 2000).

## Findings

Table 1 presents information about the characteristics of the final sample. Further details of the chart review and participant demographics can be obtained from the investigators.

**Table 1. Demographic Characteristics of the Research Participants**

Characteristic	n
<b>Age at diagnosis (years)</b>	
70–74	6
75–79	4
≥ 80	5
<b>Time since diagnosis (years)</b>	
One	10
Two	4
Three	1
<b>Cancer site</b>	
Breast	10
Gynecologic	5
<b>Total annual household income (\$)</b>	
10,000 or less	1
10,000–20,999	6
21,000–29,999	2
30,000–39,999	2
40,000 or more	3
Unknown	1
<b>Education level</b>	
Grade 8 or less	2
High school	9
Postsecondary	–
University	1
College	3
<b>Household status</b>	
Live alone	8
Live with one other person	6
Live in a seniors' residence	1

N = 15

In the sections that follow, aspects of participants' narratives in which the cancer care experience was linked particularly with age are considered. Ways that age-related life and health circumstances are implicated in treatment decision making and contribute to challenges in "getting around" cancer care are discussed.

### Treatment Decisions, Experiences, and Contexts

Participants' narratives revealed how age-related health and life circumstances, intersecting with key features of cancer care and broader social structures affecting older people, shaped treatment decisions and experiences of treatment. For example, one 71-year-old participant spoke about the health conditions she had to take into account when considering hormone treatment and her feelings about the decision.

I remember [the physician] telling me, like, with the hormone treatment, if you do have them, you have a percentage of having a stroke or a heart attack. And this frightened me because I said, with me, with diabetes and everything, I said it worried me because it's enough worry knowing that you've got diabetes and you could have a stroke or heart attack without asking for something else that's going to cause a heart attack. . . . And they say to you, "We leave it up to you—this is your decision." Well [chuckling], we don't know as much about it as what they know, and when they say, "We leave it up to you," I thought, no, I certainly don't want a stroke, and I don't want a heart attack.

Another woman, who was 87 years old, worried that hormone treatments were exacerbating her heart condition.

You feel awful some days, and I know that a lot of the things that I have—at least I think I know—are caused from the tamoxifen that I take, the medication for the cancer. Now, whether it does or not, I don't know . . . see, I've never really asked them at the cancer clinic, and that's maybe something I should do. Ask them if that makes the dizziness worse or . . . I did ask the doctor about something that I had, and she said, "You have to ask your family doctor."

The women quoted here point to the individual-level struggles of treatment decisions—both in making them and living with their consequences—in light of comorbid conditions. Yet their narratives also point to the influence of cancer care professionals and systems. In one case, the woman's invitation to make a treatment decision, given her multiple health problems, may have been more burdensome than empowering; the woman found it ironic that such a complex decision was left to a patient, despite the physician's clearly superior knowledge. The tiredness and dizziness that another woman experienced are layered with confusion about whether and to what extent the symptoms can be attributed to cancer treatment and by the shifting of responsibility between oncologists and family physicians. The latter feature of cancer care was a persistent problem for women who participated in the research; many felt that family physicians were either reluctant or ill-equipped to handle their follow-up care.

Four women chose to forego treatment (either particular treatments or treatment altogether) explicitly in the context of their age or age-related health problems and social circumstances. Two women (both 87 at diagnosis) felt well supported by healthcare professionals in their decisions. For another 86-year-old and an 81-year-old, however, decisions against treatment led to awkward interactions with healthcare professionals and negative consequences for care.

When one woman was asked if she would have chosen aggressive treatment 20 or 30 years prior, she said, "Oh, sure! Oh, sure! Because, I mean, 86 years old—you're not going to live forever!" She described feeling quite clear in her decision against a hysterectomy. Yet she felt pulled by cancer care professionals' judgment that a hysterectomy was in her best interests.

It upset me because I knew basically what I should do, but I didn't want to. Knowing that, I mean . . . you see, [my physician] had said I should have a hysterectomy. . . . I mean, naturally, they're going to say it would be the best thing for my health to do, but . . . they were kind and certainly told me the facts. . . .

She expressed her decision against surgery to her cancer care team. A nurse from the cancer center followed up with her by phone, setting up a second appointment with the oncologist. The woman was puzzled and ambivalent about the meeting: "I just wondered why he'd want to see me . . . I mean, I've made up my mind, I'm letting Mother Nature look after it and that's it." She felt the "should" of the physician's recommendation for surgery, the sense of obligation to his counsel. She also perceived that this second meeting would require her to assert her decision again, against the physician's advice. She cancelled the meeting.

Another patient's decision to forego chemotherapy was driven by concern that side effects would jeopardize her ability to continue living at home independently, which, for her, as well as for most older people (Rubinstein, Kilbride, & Nagy, 1992), was an overriding priority. She described a difficult interaction with a physician when she expressed her decision to forego chemotherapy.

*Interviewer: When you said you were choosing not to have chemotherapy, what did the doctor say?*

He didn't agree with that; he didn't say so of course, but I got the impression that he didn't think that was a wise idea . . . I felt that he didn't understand where I was coming from, so that's when I explained that I lived alone and I like it, and I knew what chemotherapy does to you . . . he didn't seem to really understand, so I said to him, "This is not a decision that I made right this minute; this is a decision I've given much thought to."

*Interviewer: Did he ever explain why he thought it would be a good idea having radiation or chemo?*

No. When I said that I had given it much thought, it wasn't just a decision at that instant and that I had made up my mind and no . . . he immediately left . . . I don't think he was too pleased.

*Interviewer: So, did you feel sort of on your own in making that decision?*

Yes, and if I hadn't given it thought well before, I might not have been strong enough to say, "I don't need it."

Later, this patient had back pain investigated. Although she was worried, she did not call her oncologist to ask for results of a bone scan. She speculated that her reluctance "was partly because of refusing the chemo. And with sort of that bit of tension with that doctor."

These two women's narratives highlight the factors that older women take into account when making treatment decisions, the thought that goes into such decisions, and the strength it takes to express a choice against treatment. Furthermore, their narratives point to the consequences—unwelcome to the patients and no doubt also to their caregivers—of women feeling unsupported in their decisions against treatment: damaged or severed connections with cancer care professionals.

In addition, participants' appraisals of their options and their worries about the effects of hospitalization or cancer treatment unfold in a social context. The link between treatment and the desire to preserve independence—and, perhaps more accurately, to avoid dependence on family members—was a persistent theme in participants' narratives. Most older people are reluctant to turn to family, particularly for personal rather than more circumscribed practical help (Daatland, 1994). In Ontario, worries about depending on relatives for personal care are heightened by the steady erosion of state-funded supportive home care (Aronson, 2002). Of course, the availability of sufficient and reliable home care would not mean that all women in their 70s and 80s would pursue more aggressive treatment. As one woman indicated, she may have decided against chemotherapy even if professional healthcare support had been available. The point, however, remains: The erosion of hospital and home-based care is one of the contexts in which older women make decisions against treatment.

## Getting Around

A concern with “getting around” (i.e., getting to the cancer center and getting around while there) threaded through participants’ accounts and drew attention to important practical aspects of cancer care associated with older age. Only two study participants regularly drove themselves to the cancer center; the majority relied on family members for transportation. In most cases, the involvement of family members was welcome or neutrally received. Other participants, however, felt mixed about accepting help from relatives. A 75-year-old woman’s sister and brother-in-law, for instance, supported her during treatment. It was “comfortable,” she said, to ride with them, “other than I felt, you know, it was imposing a bit on them, coming in every day when they live out of town.” An 81-year-old participant said, “My son always took the time off work, which bothered me.”

The Canadian Cancer Society (CCS) volunteer drivers played a vital role for participants unable or unwilling to rely on family (or whose families are unable or unwilling to be relied upon). One woman highlighted how the availability of transportation can affect treatment decisions.

I doubt I’d have had radiation if I hadn’t had transportation . . . I had no other means, and there’s no way I could get a bus and get up there. Some of the appointments were for, what, 7:30. I got up very early, and there’d be no way that I could . . .

The importance of transportation services organized specifically to accommodate healthcare appointments (to accommodate, that is, unpredictable and sometimes lengthy waiting times) was made all the more apparent in contrast with other stories that participants told. One woman, for instance, described the mounting anxiety of sitting in a family physician’s waiting room, knowing that her transportation service (a service for people with disabilities) soon would arrive and not wait for her if the appointment ran late.

As a free service, CCS drivers also ease the financial burden of cancer, which can be considerable (Longo, 2002), particularly for people who live on low incomes as so many older women do. A 77-year-old participant confirmed this point. Initially unaware of the CCS service, she took a taxi (at a cost of \$8) for her first appointment at the cancer center. When asked if arranging the CCS service was difficult or easy, she said, “I kept thinking of my eight dollars—it was very easy!”

Several participants in this study also commented on the challenges of getting around the cancer center itself. These women, particularly those who use walkers, appreciated volunteers and staff at the center who directed them to the appropriate areas, thus reducing time and energy spent searching when mobility is compromised.

A 74-year-old participant commented as well on the particular difficulty of radiation treatments for women who are not so agile.

I was never on such a narrow little table. I don’t know how some women manage. You sort of had to get up, and you can’t just turn over. You have to sit up. You have to sit up and then put your feet over on this footstool and then get up on the floor, and you’re sort of a little staggy—of course, my age, too . . . you’re struggling to get up on that narrow, little table, and the footstool isn’t too large either. If you stepped on the side of it, maybe it

would tip. . . . You know, some of [the healthcare professionals] would just take you under the arm and bring you right up. Well, it’s so easy, but some people maybe don’t know how to automatically just bring yourself up, which I do. If somebody just touched me, I’m able to get myself up . . . would be nice if the people . . . but, of course, if they did that with everybody all day they’d be pretty well tired out at night.

This woman pointed to the problem of a not so agile body trying to sit up on a narrow table and negotiate a small footstool and offered a practical solution: a steadying hand from a healthcare professional. Yet she also echoed a concern commonly expressed by research participants: the burden on healthcare professionals of the sheer numbers of patients and the implied statement that such support may be beyond what healthcare professionals can reasonably offer. Participants in this study were aware of the wider context of health care, where healthcare professionals’ workloads are significant. Findings from this study and previous research (Sinding, 2003) suggested that with this knowledge, patients may be particularly unlikely to assert their care needs or challenge inadequate care.

Although a steadying hand makes eminent sense for one woman, the experience of another 77-year-old participant serves as a cautionary reminder of the variability in health and mobility among women older than age 70: “I’m fairly agile, and they’d go to help me on the table, and I didn’t need any help on and off [laughs].” Women’s different capacities point to the challenges of making any standard recommendations for support. For the moment, a distinction can be drawn between the offer of a steadying hand and the assumption that one is required.

## Discussion

The narratives of participants in this study offer an important and rarely sought perspective on the ways that older age shapes cancer care. Participants’ experiences point to the importance of the initial health history and gathering the psychosocial information that enables understanding of the patient’s life and health context and constraints. For the older women who took part in this study (and for many older women), these contexts and constraints included living alone, not driving, mobility and vision problems, and a resolve to sustain independence, each of which affected the cancer care experience.

In addition, multiple health problems make decision making especially difficult for some older women. Oncology nurses must recognize the importance of the psychosocial aspect of their history taking, for, in this domain, older women have an opportunity to express their strengths and vulnerabilities, including vulnerabilities related to health problems other than cancer. Only when this information is available can the oncology team provide patient-centered care that addresses worries about the effects of cancer treatment on other health conditions, both at the time of treatment decisions and during follow-up visits.

In light of older women’s concerns about independence and their greater likelihood of living alone, information about how treatment effects will be monitored and addressed require careful attention by nurses. Beyond the attention that such issues merit in the clinical encounter, however, is the

consideration they require at a policy level. As noted previously, although reports of problems at the treatment center were relatively few in this study, difficulties were identified in community care and hospitals and in the links between the cancer treatment center and other care systems. In a literature review on the investigation and treatment of cancer in older populations, Turner et al. (1999) drew attention to mounting evidence that a certain organization of cancer care—delivery by specialists working in designated cancer units and centers—improves outcomes. Until recently, cancer care in Ontario has been organized in just this way. Recent changes, however, have seen specialist cancer care centers administratively and financially integrated with their host hospitals. Cancer care professionals and advocates must remain alert to the ways this new organization of cancer care may erode the features that have made it especially effective and so valued by the study participants.

This research highlights some of the reasons that older women decide against cancer treatment and points to the importance of healthcare teams understanding and actively supporting such decisions. It draws attention to older women's own "standards of care" that do not always equate increasingly more aggressive treatment with equity or high-quality care. In this regard, the study findings counter the premise of much current research on older women's cancer care. Yet even studies that construct equity in terms of more treatment options and less conservative treatments (see Adler, McGraw, & McKinlay, 1998, and Krupat et al., 1999) highlight the difficulty—and importance—of older women asserting their values about treatment to oncology professionals and of oncology professionals listening for and responding to these values. Oncology nurses are especially well positioned to elicit patients' treatment-related values.

More broadly, results from this study call for history taking that draws forward a complete account of the health and life circumstances that affect older women's sense of their options for cancer treatment. Findings suggest that oncology nurses should assess the extent to which decisions are being made according to the actual anticipated benefits and costs and the degree to which worries about coping with treatment effects are assuming priority. Certainly, this study

draws attention to the ways that older women's decisions against treatment (or against particular treatments) may be influenced by the quality and availability of health services beyond the cancer center. Adequately resourced and skilled hospital care and sufficient, consistent, and reliable community care must be readily available such that the risk of unnecessary suffering and dependence does not act as a determinant of treatment choices. Oncology nurses have a critical advocacy role in this regard.

Transportation was a feature of "getting around" that frequently posed a problem for study participants, echoing findings from a study by Goodwin, Hunt, and Samet (1993) in which patients who drove or who lived with a driver were four times more likely to receive radiation. Attention to transportation is clearly merited for many older people. Yet although results of this study affirm the value of oncology nurses taking age into account, they also make clear that highly standardized practices are both unwarranted and unwise. In this regard, oncology nurses can draw from research that cautions against any simple linking of sociodemographic variables with needs or decision role preferences. Bruera, Willey, Palmer, Tolley, and Rosales (2001) advocated that oncology professionals speak with each patient about her or his preferred role in decision making early in the process and revisit the topic over the course of treatment and follow-up care. In a more general way, careful initial history taking and ongoing interaction with the oncology healthcare team are essential to understand, for each patient, the particular and potentially shifting ways that older age may be relevant to cancer care.

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