PORTFOLIO TITLE: Cancer and the Older Person

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Signed statement:

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I wish to acknowledge the time and willingness of those who participated in these studies and did so without expectation of personal benefit.

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Overview of research field

This portfolio focuses on cancer in people 65 years and older. It incorporates two research studies conducted at different time-points in the healthcare trajectory: early detection and treatment of cancer. Cancer was chosen from the many chronic illnesses that affect older people because it is feared almost universally as a potentially life threatening illness, has a greater incidence in this population and was an area of professional interest for an oncology nurse practitioner as researcher. The cancer experience was firstly explored with respect to early detection of the most common cancers in a solid organ. The second time point of research documented a lived experience after diagnosis and during treatment for people with newly diagnosed cancer. The selected participants/subjects were people 65 years and older who represent a complex patient population. Compared with younger people, their likelihood of a cancer diagnosis in the setting of co-morbidities is higher and greater longevity allows for a twenty or more year survival span. As a result, they are not a homogeneous group when presenting for cancer screening or with a cancer diagnosis.

Although the cancer experience was studied at two time points, detection and treatment, the studies were conducted in the reverse fashion, the treatment experience studied first. This was because a review of medical and nursing literature pertaining to older people and cancer revealed the research to be fragmented across age groups and cancers with little qualitative research in the newly diagnosed patient. A qualitative approach was chosen as it can reveal aspects and nuances of a healthcare experience that empirical inquiry cannot capture and in the case of this study allowed the study group opportunity to describe their experience of diagnosis and treatment. Hearing about an experience ‘first hand’ from a study population can provide caregivers with a better understand of healthcare needs and highlight need for improvement in care during treatment.

This research portfolio commences with documentation of a lived experience of older people newly diagnosed with cancer after treatment was initiated. One sub theme identified in this study was misinformation about age as a risk factor for cancer. This sub theme and a subsequent literature review revealed little research about the state of cancer knowledge among older people. This concept was used to develop the second study in older people with no prior history of cancer. This study measured knowledge about cancer, attitude to cancer and self-reported personal history of early detection tests for the most common cancers, and then utilized correlation tests to explore positive or negative relationships between health beliefs and health behavior. The findings from both studies have been used to present a viewpoint about and recommendations for further research about cancer, older people, their healthcare and healthcare providers.

The portfolio is structured as follows; section 1 introduces the portfolio with overviews of each study and the conclusion. Section 2 contains the qualitative study titled 'The Lived Experience of Elderly People Receiving Conventional Treatment for a New Cancer Diagnosis'. Section 3 presents the quantitative study titled 'Knowledge, Attitudes and Perceptions about cancer risk in the 65-year and older population. Is there an influence on screening behavior for breast, prostate and colorectal cancers?' while section 4 contains the conclusion to the portfolio.

SECTION 1

Chapter 1: Introduction to the Portfolio

Overview of study 1

Introduction

This section of the portfolio introduces the first study by presenting the state of literature uncovered during the review and how this contributed to development of the study. This is followed by description and discussion of methodology and methods used to conduct the study. The themes that emerged are discussed with respect to their uniqueness and relevance to current literature about the older cancer patient. Avenues for further research are discussed including areas related to the sub theme used to develop the second study.

Literature Review

The literature review revealed a subject discussed with respect to the enormity of the problem, that is, the emerging elderly population likely to present with new cancer diagnoses over the coming years. The most common cancers are lung, breast, prostate and colorectal cancers where the elderly represent more than half of all new diagnoses.[1] Search of the electronic databases MEDLINE, CINAHL and EMBASE uncovered a gradual increase in the volume of literature pertaining to the elderly cancer patient over the last few decades, however the quality of literature was weak in a number of areas. Reliable information on demographics and prevalence was well documented; lacking was a solid body of empirical studies to inform treatment protocols as well as qualitative studies in newly diagnosed patients. Current medical and nursing knowledge revealed that the older population had not been sufficiently studied as a group, rather part of other age groups, albeit in small numbers.[2, 3] Furthermore, studies conducted in the elderly that were located had not used consistent age groups. The age considered elderly varied from one study to another, so studies have included people over the age of 70, 75 or 80 years.

The literature revealed that elderly cancer patients do not appear to receive care equivalent to that of younger patients throughout the care trajectory.[4] They are more likely to be diagnosed in the setting of comorbidities,[5] with more advanced cancer and a poorer prognosis.[4] Likelihood of inclusion in clinical trials is lower than younger patients,[6] and they are more likely to feel uncertain about their future when treatment is completed.[7] In addition, they are at higher risk for treatment related toxicity due to age related pharmacokinetic changes that affect drug absorption, distribution, metabolism and excretion.[8] Finally, a cancer diagnosis in the elderly may correlate with poorer quality of life compared to elderly without cancer.[9]

Nursing literature was found to be largely non-experimental, the majority of studies either descriptive or correlation designs sporadic across cancers with a predominance of breast cancer studies. While issues such as illness, uncertainty, survivorship, fear of recurrence, type of treatment and extent of disease as variables that affect quality of life in cancer survivors have been studied,[3] few studies have included large numbers of older patients. One study documenting the lived experience of older cancer patients was located but not conducted in the newly diagnosed older person, rather those with a cancer diagnosis in the prior five year period.[10]

Methodology and methods

Although a qualitative approach had already been considered when the literature review was initiated, the state of the literature as well as fragmentation and gaps were factors that influenced the choice of a qualitative approach with phenomenology as methodology to document a life experience. In particular, this was seen as an opportunity to give the study group a voice by which to speak to healthcare providers about their health experience.

Six participants newly diagnosed with cancers of the lung, breast and colon were interviewed twice, all shortly after diagnosis so their stories were captured during the treatment experience. The research findings were not intended to be generalizable, rather the hope was that uniqueness of the experience would reveal a previously undocumented world and possibly open new avenues for further research.

The purist approach of descriptive phenomenology was rejected in favor of the hermeneutic or interpretive approach since this provided opportunity to draw on the researcher’s experience to interpret findings rather than solely extracting the essence of the phenomena. Moreover, the processes of gathering data, interpreting and exploring emerging concepts while working in the clinical area of oncology allowed for a degree of daily reflection on the research and this reflection was captured in a written diary used in conjunction with interviews.

Max van Manen’s method of hermeneutic phenomenology was chosen from several methods described by researchers conducting phenomenology. This method involves a series of activities undertaken during the research that can occur individually or simultaneously and result in a created text describing the participants’ lifeworld. The activities in the method are not rigid steps, nor intended to be carried out consecutively. This fluidity and flexibility aided the decision to employ the method allowing involvement by the researcher as opposed to descriptive phenomenology where ‘bracketing’ restricts the researcher to extraction of data and excludes interpretation.

After the interviews were completed and transcribed, examination of narrative data commenced using the ‘highlighting’ approach to isolate statements that suggested relevance in the world of an older person undergoing the first episode of cancer treatment. A narrative text was created using emerged statements and themes that described the lifeworld of participants through the four structures of body, space, time and relation to others. Balance and relevancy of sub themes that created the lifeworld structures were tested by removing one at a time and comparing the importance of the sub theme for the study group to other groups of cancer patients such as younger people. This was done to ascertain if the sub theme would change the degree of relevancy for each lifeworld structure. Relevant sections of narrative text were woven together to present the findings under each sub theme that contributed to each lifeworld.

Data Analysis and Interpretation

The world of the participants incorporated all aspects of the lifeworlds however; some were more relevant with a greater number of contributing sub themes. The lifeworld of space was the structure that most demonstrated a process of transition for participants, although the lifeworlds of body and time were also relevant. As participants found themselves in a new and unfamiliar world, most had never considered a cancer diagnosis and some believed that older age protected them from cancer. Nonetheless, once diagnosed, they accepted changes in their lives, participated and complied with treatment although explicit details of diagnosis, prognosis and treatment were not paramount for them. All participants described transition from the unknown and unfamiliar that they negotiated mostly without fear or dread. Age and greater life experience meant the cancer world was one they had previously encountered through family members who had been diagnosed and treated for cancer however, now they were experiencing it personally.

Some questioned whether to accept treatment, but finally the majority deferred treatment decisions to their physicians, learned new skills and adjusted to the demands of treatment. Noteworthy was the degree to which most deferred to their physicians who they trusted to decide their treatment course, behavior many of them recognized younger patients did not do.

Universally, participants verbalized that cancer at an older age was easier psychologically than they thought it would be for younger people or would have been for them when they were younger. Physically, adverse effects were tolerable for this group and despite their older age, all maintained positive attitude and looked forward to the future with or without cancer.

Discussion

This life experience of cancer and cancer treatment for the six participants in the study revealed that for this group the diagnosis was not an overwhelming experience or a shock but rather taken in stride as it was seen to be part of older age. Several participants were misinformed or unaware of age being a risk factor for cancer. Some experienced coexisting illnesses that required treatment simultaneously with their cancer, and this was an additional burden. Despite this, few experienced treatment side effects and all participants were able to adjust and learn new information and skills required for treatment. A number of participants noted they asked few questions about diagnosis and treatment and were less involved in decision-making, preferring to defer decision-making to their physicians who they trusted. Although the findings were not intended to be generalizable, the sub theme related to misinformation and lack of awareness about age as a risk factor for cancer was used to develop the research question for the second study.

Overview of study 2

Introduction

The second study was undertaken to explore what older people know about age as a risk factor for cancer. The significance of the finding from the first study was not simply limited knowledge, but belief that cancer was less likely to occur and age offered some protection against cancer. In developing the study, a broader set of variables was included so correlation studies could test for relationships between health beliefs and health behavior such as tests that detect cancer in the early stage. A quantitative approach was chosen as the best way to collect data and conduct correlation tests. The variables were knowledge about cancer, attitude to cancer and self reported participation in screening tests for cancers of the breast, prostate or colon among people 65 years and older who had never been diagnosed with these cancers. These cancers were targeted because the older population represents a significant proportion of new diagnoses of these cancers and early detection tests are recommended.

Literature Review

The literature review from the first study was updated and built upon for the second study to include the research variables of knowledge and attitude to cancer, cancer-screening utilization in the older population and cancer-screening guidelines. The electronic databases of MEDLINE, CINAHL and EMBASE were searched in addition to a number of governmental and non-governmental databases such as the National Institute of Aging, the Centers for Medicare and Medicaid Services (CMS) and the American Association for Retired People (AARP). These databases were utilized because they collect health utilization data for the population over the age of 65 years and this information was relevant to the study to demonstrate comparison utilization data.

The literature review revealed that people aged over 65 years experience the highest incidence of some cancers while continuing to be under screened for breast and colorectal cancers. Few surveys had been conducted exclusively in the elderly over the past twenty years with respect to the research variables. A substantial amount of literature related to barriers to cancer screening tests in all populations was uncovered and this was reviewed for relevance to and comparisons with the older population.

One survey relevant to the research question was located, The Cancer Knowledge Survey for Elders (CKSE) and some questions were adapted for this study.[11] A national survey about cancer knowledge and cancer survival was reviewed.[12] A combination of findings and criticisms from both these surveys was used in development of the data collection tool for this current survey. In addition, the CKSE was located a second time in 1997 when used in a Canadian study,[13] this allowed comparison of test scores from 1983 when the survey was developed, 1997 and this present survey. Finally, care of the older person presenting for cancer screening was considered from the position of the healthcare provider who is responsible for initiating referral. Literature pertaining to attitudes and educational preparedness, both initial preparation and continuing education was reviewed. Although little literature was located, the findings revealed decreasing interest in cancer screening among oncology nurses,[14] and wide knowledge disparity among nurse practitioners with respect to cancer screening guidelines.[15] General practitioners appear well educated about geriatric care although not oncology education specifically.[16] Only one paper was located pertaining to attitudes of healthcare professionals caring for older oncology patients, this revealed negative attitudes across medical and nursing personnel irrespective of experience.[17]

Methods

Since the study sought to collect information on specific variables and examine for strength of relationship, a non-experimental approach with a correlation design was employed. The data collection tool was a self-report survey that included demographic information, multiple-choice questions and two questions requiring a written response. Information collected was knowledge about cancers of the breast, colon and prostate with respect to myths and misconceptions, early warning signs, risk factors and lifestyle modification that could decrease risk. In addition, questions measured attitude to cancer and self-reported participation in early detection tests such as mammogram, colorectal screening tests and prostate specific antigen (PSA) tests as recommended by the American Cancer Society (ACS).[18]

The data collection tool utilized a number of questions exactly as they had been tested in a prior survey (CKSE) so these scores could be compared across three time points to evaluate knowledge over time. Open-ended questions required a written response; these were adapted from CKSE and used as a second measure of knowledge. The open-ended questions were added in an attempt to ensure more accurate knowledge measurement and avoid overestimation that can occur when responses are provided.[12] The remaining questions were adapted from a survey developed for older people about knowledge of colorectal cancer.[19] These adapted questions were not in the exact format when originally developed, so scores between surveys were not compared.

Apart from questions requiring written responses, all questions were Likert scored and generated ordinal measurements. Questions requiring written responses allowed several possible answers, so all responses were documented verbatim then counted collectively by age group as number of responses generated and frequency with which the response occurred. Scores for questions adapted from CKSE were scored as percentages of correct responses and comparison scores shown in the relevant section (chapter 12).

The study population was people 65 years and older with no prior history of cancers of the breast, prostate or colon stratified into three age groups 65-74; 75-84 and 85 years and older to total sixty subjects. This was to ensure equal numbers for each sex and age group so comparisons could be made across groups and all age groups were represented. Recruitment of subjects was conducted at a senior citizen center in a large metropolitan area, inclusion criteria being no prior history of breast, prostate or colorectal cancers, those who agreed to participate when approached and could complete the survey independently at the center on days of recruitment. Attendance at the center was voluntary; most programs free and included a range of cultural, educational and social events so the prospective study group did not appear to be restricted by socioeconomic status.

The study was approved by the ethics committee at the university where the researcher was a doctoral student. No formal approval process was required by the senior center, although documentation pertaining to the survey including the approval letter, recruitment flyer, information sheet and survey were reviewed by the center director. No consent was required to participate; to ensure and demonstrate eligibility criteria for no history of cancer an additional question was included requesting this information. All surveys were anonymous; demographic information collected was sex and age to demonstrate quota sampling. None of this information could be used to trace subjects who completed the survey and returned it directly to the researcher in a sealed envelope.

Statistical analysis included descriptive statistics of mean, range and standard deviation. The Spearman's Rank Order Correlation (rho), a non-parametric test was used to correlate variables for relationship. This non-parametric test was used because measurements were ordinal not interval or ratio so it was deemed the most appropriate test.[20] All data was transferred from the surveys to a spreadsheet, and then applied to Statistical Package for the Social Sciences software Program (SPSS) version 15.0 to generate statistics.

Results

The study results are reported as descriptive statistics and correlation results as well as comparison scores for adapted questions and collective data by age groups for questions that required a written response. Tables illustrate findings and are located in the appropriate section (chapter 12).

Descriptive statistics revealed knowledge scores were lowest for women in the middle age group (75-84), attitude scores for women decreased with age, whereas no trend was demonstrated for men. Mean utilization scores showed mammography decreased with age, PSA remained stable and colorectal test scores were higher for men than women and decreased with age for women but not men. Correlation studies did not demonstrate a relationship between knowledge and self-reported participation in any cancer-screening test in any age group however; a strong positive relationship was detected between attitude and mammography in the oldest group of women and the oldest men and women for colorectal screening tests that was statistically significant.

All questions from CKSE scored higher than previous scores with some questions scoring significantly higher. The question testing knowledge about age as a risk factor for cancer, scored higher than both prior surveys however, about half this study group either answered incorrectly or did not know. Knowledge about early warning signs for cancer was greater than ten and twenty years ago, but limited to breast changes and lumps, and bowel and bladder changes. Questions that required a provided response when measured collectively revealed an inverse relationship between age and number of responses Knowledge about early warning signs for cancer was limited; few people demonstrated knowledge of constitutional symptoms and knowledge of lifestyle modification was even lower across all groups.

Discussion

Although this small study produced findings consistent with the literature and raised a number of issues about screening and patient education, there were limitations to the study that might have affected results. These included location of the study, in a large metropolitan area with the recruitment site proximal to a medical center where healthcare is provided to veterans. Both these factors may have contributed to better access to medical care as well as other services such as transportation that can facilitate better compliance. In other words, the study group may have had better availability and access to screening. With respect to screening utilization scores, this information was self-reported so unable to be verified. Furthermore, reasons why subjects had tests or did not have tests was not explored in the survey and this might have uncovered age or gender specific barriers to screening. Nonetheless, the findings raised a number of issues for patients and healthcare professionals around the issues of screening and education.

First, with respect to screening, multiple guidelines have been issued from several organizations in the U.S. and all organizations except the ACS indicate when to discontinue screening although this is not uniform. In addition, interpretation of guidelines is further complicated by application and interpretation for some sectors of the population such as very old or very frail people or those with co morbidities. Other factors also appear to influence screening such as patient request and expectation for referral and time constraints during physician office visits that preclude in-depth discussion about risks and benefits of ongoing screening. There is some evidence that over screening is related to some tests but not others, for example PSA is screened routinely when other screening tests have been discontinued.[21] This may be due to the nature of the test, a simple blood test however, beyond the simplicity of the test is the complexity of further workup should the test be abnormal.

Despite this, under screening continues among some population sub groups. Mammography screening declined with age in this survey, although among the oldest women a positive relationship was detected between attitude and self-reported mammogram screening. This poses the question about why screening utilization was so low since the probability of compliance appears high. When comparing colorectal scores across sexes, women scored lower than men in all age groups with the middle group of women also demonstrating the lowest knowledge scores that were far lower than scores for men. Gender differences in screening practices are found in the literature with men often more compliant and receptive to information about cancer and attendance at screening programs than women[22] and higher screening among men was seen in this survey. One further issue about screening the oldest sector of the population is risk versus benefit ratio with a greater incidence of complications likely to occur during procedures such as colonoscopies.[23]

Knowledge level of older people about cancer although higher than ten or twenty years ago remains low. More especially, knowledge about lifestyle modification that can decrease risk for both cancer and heart disease was low and limited to one or two interventions. Some sub groups of the older population may derive more benefit from health education than other groups. Women in the middle age group with reasonable life expectancy demonstrated the lowest knowledge scores and much lower colorectal screening scores than men so could potentially be considered greater beneficiaries of education programs about risk and early detection of cancers.

In summary, cancer screening among people 65 years and older is complicated by longevity where this age group could span a thirty-year survival period and include very fit and very frail people. Implications for practice suggest ongoing under screening and over screening of some sectors of the population for some cancers, inadequate public education about cancer and cancer prevention and a wide range of barriers to screening as well as inconsistent implementation of screening guidelines.

Overview of the Portfolio's conclusions

Introduction

The portfolio's conclusions are based on the findings of both studies. Conclusions were developed from the most relevant and pertinent findings from each study drawn together and examined for common themes then discussed as broader points within the context of current literature. Conclusions are summarized with a statement of position about older people and cancer.

Summary of findings

The conclusion to the portfolio is approached from the perspectives of the patient and the healthcare provider. The discussion was developed from the following study findings.

Study 1

- Misinformation about age as a risk factor for cancer
- Deferred decision-making to physicians
- Contribution of age to coping with a new cancer diagnosis and treatment
- Treatment tolerance and adjustment to cancer and cancer treatment

Study 2

- Under screening and over screening for cancer
- Lack of knowledge about cancer and lifestyle modification to decrease cancer risk
- No relationship between knowledge and self-reported participation in cancer screening tests
- Attitude to cancer positively related to self-reported screening for breast cancer in women 85 years and older
- Attitude to cancer positively related to self-reported screening colorectal cancer among men and women 85 years and older.

Discussion

When examining the findings from both studies, one needs to consider that the findings related to patients do not stand alone, but are intertwined with issues surrounding healthcare providers. The sub theme of misinformation about age as a risk factor for cancer is not solely an issue for the older person who is seen with reasonable frequency by healthcare providers, therefore presenting opportunity for education. Studies in older people indicate that despite frequent visits to physicians, discussion about cancer risk and referral for screening tests occur infrequently.[19] Furthermore, sources and accuracy of information is paramount since the media not physicians are often the primary source of medical information for many older people.[24] With respect to the finding that participants were more likely to defer decision making to physicians, there is little literature documenting physician views about their role in decision making for patients. Moreover, research about the nature and content of communication between patients and healthcare providers is limited to physicians only.[25] Literature although limited, suggests oncology healthcare providers including nurses hold mostly negative attitudes to older patients[17] and oncologists do not always inform older patients about their condition and prognosis to the same degree they do younger patients.[26]

The intention of the life experience study documented in this portfolio was to report a unique experience not a generalizable finding. Nonetheless, it revealed the positive contribution of older age and greater life experience to coping during a new cancer experience. This has been reported numerous times in the literature over a period of twenty years, so appears to be a consistent finding as is tolerance to treatment.[27-29]

If one considers the older population as a whole against the backdrop of cancer screening tests available, a number of findings from the survey were confirmed in the literature. Some cancer screening tests are readily available and done almost routinely such as PSA,[30] although this test is likely to find fewer cancers that will cause cancer deaths in the oldest men.[31] On the other hand, older women continue to be screened for breast cancer at lower rates than younger women and screening appears to decline at an earlier age than other screening tests such as PSA and colonoscopy.[21] Decision to participate in screening programs for any cancer is complicated by multiple barriers cited in the literature including personal and environmental.[32] The second study revealed that the oldest women demonstrated strong positive attitudes to participation in breast cancer screening but were the least screened compared to the other groups of women. This suggests that if referred for screening they would likely be compliant. Colorectal screening for women was lower than men for all age groups, and declined with age for women but not men.

Review of screening data from 1987 to 1998 revealed older women under screened more frequently than older men and participation of men in screening programs increasing more rapidly than women.[33] These findings combined with misinformation about cancer risk, early warning signs and lifestyle modification suggests a need for patient education among this group.

Educational preparedness of healthcare providers themselves is also at issue. Few studies have evaluated education level of oncology nurses working with older patients and positive attitudes of nurses towards older cancer patients have been shown to correlate negatively with knowledge.[34] With respect to family physicians, geriatric medicine knowledge appears high[16] although this has not been demonstrated in oncologists. It is unclear from the literature if lack of continuing education about care of older cancer patients is related to lack of interest or lack of program availability. While complexity of healthcare for older people is recognized, these two studies raise a number of questions for future research among healthcare providers. Little is known about attitudes to older patients, cognizance of verbal and non-verbal communication with patients or healthcare provider views towards sole or joint decision-making.

In summary, people over 65 are a diverse group when presenting for cancer treatment and early detection of cancer. Although older people are better informed about cancer risk and early warning signs than two decades ago, they lack knowledge about cancer and cancer screening and particularly benefits of lifestyle modification. As cancer patients, they appear to cope adequately although differently from younger patients. Care may require a different approach to details such as decision-making and communication. Their reluctance to question every detail of diagnosis and treatment should not be interpreted by healthcare providers as a less aggressive attitude to treatment.

SECTION 2

STUDY 1

THE LIVED EXPERIENCE OF ELDERLY PEOPLE RECEIVING CONVENTIONAL TREATMENT FOR A NEW CANCER DIAGNOSIS

A HERMENEUTIC PHENOMENOLOGIC STUDY

Chapter 2. Introduction

Context of the study

This interpretive study using hermeneutic phenomenology as methodology was embarked upon in the setting of increasing longevity in the population and a greater proportion of cancer diagnoses in the 65-year and older age group where research is fragmented across the trajectory of care. The study gave a sample of elderly people a voice by documenting their life experience shortly after a new cancer diagnosis as they were undergoing treatment. Documentation of a life experience can bring into focus a world the healthcare provider does not see through the same lens affording insights into aspects of care relevant to the patient population. In this way, healthcare providers are educated by patients and this can result in improvement or changes in practice.

Research problem

Compared to other age groups, the elderly represent the largest number of new diagnoses in the most common cancers such as lung, colorectal, prostate and breast.[1] In addition, there is the least amount of research-based evidence to guide care, they are more likely to have co morbidities at diagnosis[5], to be diagnosed with more advanced cancer[4] and receive diagnosis in the setting of shrinking social support, declining financial resources or the patient may already be a caregiver for an ailing spouse.[7] Furthermore, care of the elderly is more complex as providers must attend to both cancer related and patient related factors when they plan treatment since these factors can be predictive of outcomes.[35] Research to date has been fragmented because older people are often only included in studies in small numbers and not in all cancers or all aspects of care. In addition, scant qualitative research exists on the newly diagnosed older person with cancer who is undergoing treatment.

Research question

Since little was known about this group and how they experience a new cancer and treatment, the research questions posed were:

- What is the experience like for an older person who is diagnosed with cancer in his or her latter years?
- How does that experience unfold as they undergo treatment?

- What can healthcare professionals learn from these participants' experience?

Significance of the study

The literature review prior to the study revealed only one lived experience in older people with cancer that had been conducted within a five-year period prior to diagnosis.[10] This study was significance because it was conducted shortly after diagnosis and during treatment therefore capturing feelings, thoughts and experiences as they unfolded rather than documenting from recall when the experience was over.[36] The hope was that this timing would be more complete with respect to physical and psychosocial feelings during treatment. Moreover, no lived experience is likely to produce the same findings, even in the same group. In summary, this current study captured all participants during the same period, approximately two to three months from diagnosis when they were receiving treatment and this differed from the study conducted by Thome, Dykes, Gunnars and Hallberg.[10]

The approach for this study was used because the focus of the study was:

- What is the experience like?
- What occurs in this world that we do not know and have not considered in the care of older cancer patients?

Using hermeneutic phenomenology as methodology allows for discovery and understanding of the participant's experience. It does not explain this experience but rather brings us into closer contact with the participant's world, therefore allowing us insight and knowledge. This can result in better understanding and different action, in the case of healthcare providers to change practice.[36]

Assumptions about the study population

Little literature exists on educational preparedness and attitudes of healthcare providers to the elderly cancer patient. One study located revealed negative attitudes among several groups of healthcare professionals to older cancer patients.[17] As healthcare providers we often have positive and negative perceptions about elderly cancer patients and their suitability for treatment.[37] Given, Given, Azzouz and Stommel in their study of physical functioning in the elderly cancer patient were surprised by the finding that treatment was only partially responsible for decline in physical functioning, age was not related and decline could occur any time during treatment, and was due to symptoms such as pain, fatigue or insomnia.[38] In other words, poorly managed symptom clusters were responsible for physical decline not age. While literature about attitudes of healthcare providers to older cancer patients is scarce, what exists reveals negative attitudes raising concern that treatment decisions made for older patients might be based on assumptions about age affecting tolerability of treatment and treatment either not offered or less effective treatment offered.

My personal assumptions about the study population were developed from my work as an oncology nurse practitioner. Increasingly people presenting for cancer treatment were older, frequently wanted treatment and appeared to manage treatment well. They learnt names of medications, followed instructions about care and maintained a positive attitude and outlook. In summary, they were mostly a joy to care for, in some ways, they appeared easier to care for than younger cancer patients. My hope was that this study would allow a deeper look into their world and uncover aspects in their care I had not considered.

Definition of terms

Elderly is defined as 65 years and older because this is retirement age in many countries and the age used by several organizations to define the beginning of older age. In addition, traditionally people older than 65 have been excluded from clinical trials and this has contributed to a lesser body of knowledge about them.

Chapter 3. Literature Review

Introduction

In this section, a review of literature pertaining to elderly cancer care is presented. The purpose is to establish previous research conducted in the area and comment on that research. Reviewing and critiquing existing literature about the elderly cancer patient with respect to guidelines for medical treatment and nursing care as well as psychosocial needs from the time of diagnosis forward, allows for identification of good practice, gaps in the research or appreciate this as an area where little nursing knowledge has been generated.

Search strategy

The literature search was commenced in June 2004 when the research protocol was developed for this study. The strategy commenced with the search terms 'older adults with cancer' and 'geriatric oncology' using the electronic databases MEDLINE, CINAHL and EMBASE for the period 1966 to present. These terms were chosen because they appeared frequently in papers published in medical and nursing journals, so it was expected that they would best capture the bulk of literature available on the subject. Together, the databases MEDLINE, CINAHL and EMBASE located 18, 116 and 75 papers respectively. Occasionally the phrase 'senior adults with cancer' was found, this is the term used in the US by the National Comprehensive Cancer Network (NCCN) whose task force issue guidelines for care of the older cancer patient, however this search term did not locate any papers. To broaden the search strategy, the term 'elderly cancer survivors' was applied and uncovered a further six papers.

The quantity of articles uncovered was considered lower than expected for an area of care the literature suggested as an almost insurmountable problem for the future.[39] Consequently, the search was updated in October 2004 using the term 'elderly cancer'. This term located 158 papers in MEDLINE, 148 in EMBASE and 48 in CINAHL. In reviewing these papers, many had already been located; some were duplicate entries or overlapped from one database to another. This was particularly the case with the search findings from EMBASE, where several duplicate papers existed or had already been located in other databases. The search term 'experience of cancer' was also entered and located two further papers in CINAHL. The first was an unpublished doctoral dissertation only available as an abstract. This explored the cancer experience for the elderly and developed the concept of integration of a cancer diagnosis when the greater part of life had been lived. The second was an interpretive study exploring the experience of older people diagnosed with cancer within five years prior to the study. Review of the reference list of the latter paper failed to uncover any further papers. The database of the Joanna Briggs Institute (JBI) was also searched but yielded no results for any of the search terms. All EBM reviews located only one paper pertaining to the elderly cancer survivor, review of this paper found it was not relevant to this study.

In addition to the above strategy, a combination of descriptors such as ‘quality of life, hope, cognitive dysfunction and anxiety’ was used with the original keywords. The reason for choosing these descriptors was they appeared frequently in nursing oncology literature for cancer patients in general, so perhaps would uncover work conducted with the elderly. This search uncovered thirteen articles, many of which had been located or did not apply specifically to the elderly.

In 2004, the term gero-oncology appeared in the nursing literature. Two articles using this term were located in CINAHL; both articles were overviews of geriatric oncology nursing research. In addition, combination of terms ‘nursing research’ and ‘elderly cancer’ was entered in the databases. This strategy did not locate any articles in any of the databases. Medical subject headings (MeSH) were also reviewed throughout the search as they can suggest other terms to use as keywords. In the case of this search, MeSH terms were broad, for example ‘elderly cancer’ mapped to ‘aged’ and other similar terms as well as ‘neoplasm’ which led to uncovering many papers not specific to the research subject.

Relevant time span

The literature review spanned from 1966 to October 2004. Although it is recognized that literature more than five years old might no longer be current, the rational was to locate any landmark papers published as well as indicate when literature about the elderly cancer patient was first acknowledged. Reviewing papers throughout a time span also allows the reader to view how the evidence in the most current literature evolved. Not all databases are available from 1966 as MEDLINE is, EMBASE is available from 1980 onwards and CINAHL from 1982.

The first comprehensive geriatric assessments were conducted over thirty years ago, so there was the possibility that literature about care of the elderly cancer patient may have appeared sometime after. The earliest papers located dated 1970 in MEDLINE, 1980 in EMBASE and 1985 in CINAHL. All databases demonstrated an escalation in articles as time progressed. For example, using the search term 'elderly cancer' in CINAHL where the bulk of nursing articles are listed, located 5 articles in the 1980s, 16 in the 1990s and 27 since 2000. Likewise, the same term in MEDLINE located 2 articles in the 1970s; 22 in the 1980s; 59 in the 1990s and 75 from 2000-2004. All other search terms were consistent with the above examples, the earliest articles appearing in the 1980s with gradual increase through the 1990s but the majority from 2000 to the present.

Results

The largest number of articles located in any single database was in MEDLINE (158) using the term 'elderly cancer'. The titles and abstracts of these papers were reviewed for content, then grouped together to evaluate level of evidence presented. The criterion for level of evidence is based on what is accepted in the evidence based medicine (EBM) and evidence based practice (EBP) movements.[40] The movement initiated by David Sackett led to the development of a classification system that grades evidence from weakest to strongest. It has been adopted by a number of organizations including Oncology Nursing Society, (ONS) and the National Comprehensive Cancer Network, (NCCN) in the US, as well as The Joanna Briggs Institute for Evidence Based Nursing and Midwifery in Australia. For example, ONS divides evidence into two categories; non-research and research based evidence, and then grades each group from weakest to strongest. Case studies and expert opinion fall into non-research based evidence with research-based evidence ranging from systematic reviews at the highest level followed by experimental designs such as randomized controlled trials (RCT), then non-experimental designs including descriptive, correlation and qualitative studies. Published evidence based practice guidelines are graded at the lowest level of research-based evidence.[41] This hierarchy guided the evaluation of the literature located during this literature review.

The bulk of 'elderly cancer' papers in MEDLINE were surveys, retrospective data analysis, chart reviews, literature reviews and phase II studies with the latter being the only experimental design apart from one systematic review located. Thus, the majority of articles fell into the lowest category of evidence. When grouping the papers into general subject areas they included patient care guidelines, position papers, assessment and discussion of treatment toxicity and morbidity.[8, 35, 42-47]

The systematic review located explored the relationship between age and risk of neutropenia requiring hospitalization during treatment. The study conclusion was recommendation that colony stimulating factors be administered routinely to the elderly to decrease morbidity during treatment.[46] This recommendation has been adopted by NCCN in guidelines for care of the older cancer patient.[48] In other words, this is an example of the different approach to clinical care needed for elderly cancer patient receiving treatment.

One RCT was located that compared need for and utilization of specialist care for newly diagnosed community dwelling elderly over 70 years during cancer treatment. This large study of over 400 subjects revealed intensive primary care including patient education, teaching and supervision by homecare nurses for symptom management resulted in lower hospital admissions and intervention by specialist physicians.[47] In other words, aggressive care and attention to detail although not at specialist level cost less but did not compromise care. These two studies together suggest care of the elderly cancer patient requires a different approach to avoid complications of treatment. More studies are needed to replicate these findings as well as explore a variety of scenarios. For example, whether all age groups of elderly benefit from all interventions or whether variables such as lack of social support or co-morbidities are relevant to all age groups of elderly or more relevant for those 75 and older when age related physiologic changes impact more significantly.[10] Since both these studies were conducted during treatment, the findings were reviewed at the completion of the lived experience study for relevancy and significance.

Repetitive documentation reports demographics of aging, its relationship to cancer incidence and future societal implications in terms of economic burden.[5,49, 50] Complexity of care of the elderly cancer patient is frequently cited in the literature, with limited evidence from clinical trials to guide treatment decisions and a significant amount of evidence that the elderly are more likely to be offered clinical trial participation when cancer is more advanced as opposed to early stage.[43, 51] It is reasonable to state from literature that ageism may not afford the elderly the same chance of treatment as younger patients.[4, 52, 53] Yancik, Wesley and Ries in a large retrospective chart review of over 1800 patients found the elderly received a more limited workup and less than standard treatment resulting in earlier mortality.[54] Although this chart review was conducted only in breast cancer, the results are significant for the elderly because they comprise over two thirds of new breast cancer diagnoses.[5]

With respect to level of evidence, Yancik's study demonstrated that RCT is not always appropriate or the only research method to reveal significant findings. It would not be acceptable to randomize a group to less than standard treatment or suboptimal diagnostic workup or incomplete diagnostic staging, all of which were findings of this chart review. Yancik et al., published this paper in 2001 and reviewed charts in the years preceding the publication, therefore these findings are now several years old. Follow-up studies are needed to demonstrate if there has been a change in practice since this initial study. In addition, studies in other cancers such as lung and colorectal where the elderly also represent a high proportion of newly diagnosed cases should be conducted to evaluate if similar findings exist across these malignancies.[5]

The nursing literature contained multiple review articles attesting to longevity and increasing cancer incidence in the elderly population and highlights changes nursing should consider to adequately care for this group.[39, 50, 55, 56] Nursing acknowledged the special needs of the elderly cancer patient in 1982 when the first nursing abstract was presented at the annual conference of ONS. Ten years later, it became the first professional oncology organization to publish a position paper on care of the elderly cancer patient.[56] In 2004, ONS and Geriatric Oncology Consortium (GOC) a multi-disciplinary group of physicians, nurses and pharmacists across community oncology practice sites jointly developed a position paper on care of older adults with cancer that was based on the 1992 ONS paper.[57]

In the ten years from 1982 to 1992 when the position paper was developed fewer than 20 papers published by nurses and located in CINAHL focused on older cancer patients, with 50 from 1985 to 2004.[55] Since the majority of nursing papers were located in CINAHL using the search term 'elderly cancer', the abstracts of these papers were reviewed individually then categorized to evaluate where nursing interest was concentrated. Less than half the articles located were specific to the topic of the elderly cancer patient. In general, the papers were non-research based evidence, mostly of expert opinion as well as several descriptive correlation studies. There were no randomized controlled trials.

Although the level of evidence was lower, questions asked by some researchers were those not well explored or documented. Given et al., in a large cohort study of 826 sixty five year and older newly diagnosed cancer patients explored the issue of physical function in the elderly.[38] The questions asked were:

- Did the patients notice a change in physical function prior to diagnosis to signify that something was wrong?
- Did their level of physical function decline during and after treatment and if so, what influenced the decline?

It should be noted pre treatment physical functioning data was patient self-report, so dependent on the patients' memory of several months prior to a diagnosis that for many people is distressing. With this approach, there is the chance patient recall may not have been accurate. In fact, patients reported no noticeable significant change in physical functioning prior to diagnosis. Although the authors recognized this weakness in the study, there was no attempt at symptom correlation to support pre treatment physical functioning level. For example, was there a medical record available that documented weight loss, cough, pain or fall history that may have indicted something was wrong?

Despite this, it is one of the few studies to evaluate physical function at any stage of treatment in the elderly. The finding that symptom clusters such as pain, fatigue and insomnia were predictors of physical decline irrespective of age and co-morbidity built on the findings of one prospective study.[58] Chen, Cantor, Meyer et al., in their study of newly diagnosed elderly cancer patients receiving chemotherapy, demonstrated correlation between degree of functional decline and treatment side effects but overall there was limited impact on independence, co morbidity and quality of life.[58] Other studies have shown a cancer diagnosis can affect physical performance but to a lesser degree than other co morbidities.[38, 58, 59] For healthcare providers these findings are pertinent to care during treatment since cancer at an older age could cause a decline in physical function and increase the risk for ongoing decline after treatment is initiated if symptoms are not well controlled. Because data collection in these studies occurred during and at the conclusion of treatment, the findings were considered in the light of the emerged themes from this current life experience study.

Since the intention of this current study was to document a lived experience, the two papers located using the search term ‘lived experience’ were reviewed. One an unpublished doctoral dissertation was only available in abstract,[60] the other, an interpretive study by Thome, Dykes, Gunnans and Hallberg[10] was reviewed in detail. In this study, the authors chose a subset of elderly, 75 years and older who had experienced a cancer diagnosis five years prior to the study. Latent content analysis was used to interpret the text to formulate categories of themes. Although this was a large study, 64 persons, not all the interviews were analyzed (41 were analyzed), some were conducted by telephone not face to face interview and some ‘only vaguely focused on living with cancer’ so were discarded by the researchers as were some interviews of poor sound quality or language problems that prevented analysis of the text.

There are few qualitative studies in this age group in cancer patients, and while the authors clarify why they chose this subset of elderly, it was not clear why they chose the five-year time interval from diagnosis. The fact that some participants had been diagnosed with cancer for up to five years, raises the issue of whether the experience for them was the same two, three or up to five years later as it might be for someone newly diagnosed with cancer. Individuals living with cancer for several years may have adapted so the symptoms of illness blend with those of older age. The study finding that daily life of the participants was influenced by disabilities from cancer, old age or co morbidities or the three combined did not seem so surprising. Therefore, the question of impact of a new cancer diagnosis and its effect on daily life of elderly persons may be better understood if asked early in diagnosis or during treatment.

With respect to the unpublished doctoral dissertation, this explored how elderly integrate a cancer diagnosis into their lives. It was only available in abstract, so unable to be fully appreciated and critiqued. In the dissertation, Kagan coined the phrase ‘a life mostly lived’ as a concept she drew from interviews with the elderly for whom a cancer diagnosis was not so much a disruption to life as a constant in it.[60] In other words, they had come to terms with cancer so it did not consume their lives. It should be noted that in the mid 1990s when this dissertation was completed, treatment of the elderly person with cancer was not widespread or well documented as is demonstrated by escalation in literature in the databases that really did not appear until the end of the 1990s. It is difficult to say more about this study since only the abstract was published. Certainly it was one of the earliest qualitative studies conducted in elderly cancer patients during treatment, and because some of the themes drawn from it were discussed by Kagan in one of the two opinion papers located using the search term ‘gero-oncology’ this paper was reviewed.[55] Ten years had elapsed between the dissertation and the opinion paper so the author (Kagan) had a strong background from which to build such a review.

In summary, the paper is a critical review of the current state of knowledge, research and guidelines for elderly cancer care. Kagan argues that the road forward should be through establishing new terminology, leading with the term ‘gero-oncology’ that would re-focus the research approach away from demographics to a higher more sophisticated level. The language or terminology, she argues would become the structure to guide the ‘value, vision and approach of the research’.[55] In other words, scientific discourse would follow in much the same way that the term ‘quality of life’ led to the development of a body of research and literature.

Presently, only two papers using the term ‘gero-oncology’ were located. Should the term become established, then the findings from this current study documenting how the newly diagnosed older cancer patient experiences cancer and treatment could help build a body of literature. To date, the focus has been centered on the issues of recurrence, advanced disease and end of life care.

Gaps in the literature

The level of evidence in nursing was largely non-experimental consisting of descriptive and correlation studies sporadic across cancer groups without repetition of findings. One explanation may be education level of oncology nurses caring for elderly patients. An unpublished doctoral dissertation revealed nurses were well prepared in oncology, however this did not include elderly cancer care since more than half the group had not completed any continuing education on elderly cancer care in the prior two year period.[34]

Overall, medical and nursing literature revealed the elderly have not been consistently studied in standard age groups. That is, studies of the elderly have included participants over 60, over 70, over 75 and 80 years and older.[2, 6, 7, 10, 53, 61] As a result, no strong body of evidence exists to guide recommendations for the elderly. It has been suggested by Given et al., the elderly be divided into young-old (65-74), mid-old (75-84) and old-old (85 and older).[38] This would seem a reasonable approach but to date is scant in the literature.

Some aspects of patient care are well represented in the literature, as are some cancers. For example, breast and prostate cancer have been studied from screening to survival. Quality of life, social support, pain management, fatigue and physical function have been studied by a number of investigators mostly in the long term survivor but occasionally during treatment.[2, 7, 38] Qualitative studies in the newly diagnosed are sparse as well as across the trajectory of care from diagnosis to treatment and survivor. Kagan notes in the case of the elderly, who do not look towards another 20 or 30 years of life, quality of life has focused too heavily on the future rather than quality of life being lived.[55] These factors were considered when the final report for the qualitative study reported here was finalized.

Conclusion

Literature pertaining to the elderly cancer patient attests to the increasing incidence of new cancer diagnoses that will likely continue and result in larger numbers of older people presenting for cancer treatment. Although there has been a gradual increase in the quantity of literature in all databases over the last few decades, it is fragmented across cancers and there appears to be no consensus about how to study older patients whose ages span more than twenty years during which time physical decline and co morbidities are likely to develop. Many studies have included older people, but only as a minority of the study group and not all cancers. No lived experiences have been published in the older cancer patient newly diagnosed with cancer and undergoing treatment. Literature examining attitude and education of healthcare providers in geriatric oncology care is sparse.

Chapter 4. Methodology

Introduction

In this section, methodology for the study is described. An overview of phenomenology is followed by outline of the theoretical perspective that favored hermeneutic over descriptive phenomenology. Description and rationale for choice of van Manen's method of hermeneutic phenomenology is discussed using examples from the study to illustrate how the method was applied.

Tradition of Phenomenology

The idea of studying human experience was first introduced at the end of the 19th century when Edmund Husserl recognized validity of human experiences as worthy of scientific study but rejected the notion that positivist science could adequately study subjective experiences.[36, 62, 63] He developed a human science called phenomenology that could explore life experiences when little was known about such an experience so that understanding could be gained. Understanding the experience requires extracting the bare truth and presenting a clear perception of the experience through structures that make up the lifeworld.[64] In other words, the researcher as the tool draws out essential details of the experience and presents the world of the participant in as pure and unbiased a form as possible therefore allowing the uniqueness of the life event, not intended to be reproducible in either time or person, to speak for itself. Because phenomenology is a philosophical movement, change and modification of the original concept have resulted in two main approaches: descriptive or eidetic and interpretive or hermeneutic.[63]

Descriptive Phenomenology

Descriptive phenomenology arose from Husserl's philosophical ideas and is centered on several beliefs. First, everyday life experiences are valuable, yet we reflect upon them very little as we go about our daily routines. This is the lifeworld, a world we experience but have not reflected upon or labeled. Second, it is the responsibility and role of human science to identify and bring to consciousness the essential elements of a human life experience and third, features of any lived experience are common or universal to all who share that experience and are referred to as eidetic structures or universal essences.[63] This search for stark truth that is considered universal to those who share any experience studied by descriptive phenomenology implies generalizability rather than uniqueness of findings making it more akin to the theoretical perspective of positivism rather than phenomenology.[64]

There is little role for researcher flexibility in Husserl's view. The researcher must forget or separate personal knowledge and preconceptions of the experience under study, a process known as 'bracketing'.[65] It was this idea of extraction of essence and distance from the experience by bracketing that led Husserl's student Heidegger to move away from this philosophy towards one of exploration and understanding of the different possibilities a text could present.[36] These activities and ideas such as seeking out descriptions, meaning and interactions of life are central to the philosophy of interpretive or hermeneutic phenomenology as described by Heidegger.[36, 63]

Hermeneutic Phenomenology

Following in Heidegger's footsteps, Gadamer favored a merger of participant and researcher, the participant contributing the dialogue, the researcher the language by which to express it. While focus for Heidegger was understanding relations between individuals and their world, focus for Gadamer was means through which the researcher gains understanding.[66] For Gadamer, the most advantageous position to gain understanding was within the world of the participant, allowing merger or fusion of both worlds.[63] Thus, the researcher enters the participant's world with a perspective of what has happened in the past, in the case of this study, cancer knowledge based on professional experience and current literature. Positioning the researcher within the research validates and draws on the personal background of the researcher who can see more clearly what questions need to be asked thereby augmenting the meaning of the undertaking.[65] This methodology grounded this study.

Theoretical perspective

The research question delving into the world of the elderly cancer patient was chosen after literature review revealed little qualitative research about how the elderly manage life during treatment for a new cancer diagnosis. This literature review was undertaken partially because my role as an oncology nurse practitioner involved caring for increasing numbers of elderly people with cancer and I sought guidance with practical aspects of clinical care. By far the bulk of literature uncovered was repetitious as to increasing incidence of elderly people undergoing cancer treatment with fewer specifics about treatment and almost no qualitative research in newly diagnosed older people. It was in this setting that I began to explore what research question to pose and what philosophy and methodology would best guide this pursuit.

Because little qualitative nursing research about the newly diagnosed elderly cancer patient was located, gaining an understanding and studying the experience from the participants' point of view seemed the first logical step into this world.[67] I favored a greater degree of participation and considered my knowledge an asset in locating meanings in the narratives as opposed to being merely the instrument to extract the data. Therefore, in rejecting bracketing, a required component of descriptive phenomenology, I turned instead to an approach that would augment my understanding of the elderly cancer patient's experience in their new world. Assumptions I specifically considered as the study commenced were based on my professional observations; that older people with cancer appeared to cope well physically and psychologically. My interest lay in exploration of the nuances and depth of the experience that I hoped the narrative data would reveal.

In balancing descriptive versus hermeneutic phenomenology, choosing the former meant that I would bracket my knowledge, conduct interviews and extract meaning from the narratives. While this would not be wrong or detrimental to the research topic, the choice of hermeneutic phenomenology offered much more. First, as interviews were conducted there would be opportunity to explore and understand the possibilities the texts presented and this could be explored more fully during repeat interviews.[36] Second, as exploration of the text moved forward, there was the possibility that aspects of elderly care not well researched could emerge and lead to a second study as part of this doctoral thesis. Third, hermeneutic phenomenology acknowledges the significance of the researcher's world in as much as prior assumptions are recognized as part of the hermeneutic circle included not excluded as bracketing does in descriptive inquiry.[68] Finally, hermeneutic phenomenology allows for overlap in the process of interviews while viewing the emerging interpretation.

Van Manen's framework for hermeneutic phenomenology

Although Husserl, Heidegger and Gadamer developed and described their philosophies, they did not develop clear research methods.[66] This absence of method has led to attempts by later researchers such as Spiegelberg, Colaizzi and Giorgi to devise step-by-step approaches as method in descriptive phenomenology [36, 64] and van Manen, Ricoeur and Fleming, Gaidys and Robb to do likewise in hermeneutic phenomenology, although van Manen with less precision.[36, 66, 69]

After determining hermeneutic phenomenology would best suit the purpose of the study, the issue became which method. Gadamer did not develop a method for phenomenology, so review of frameworks oriented to the lived experience was undertaken. This led to the method described by Max van Manen. Although van Manen is a teacher and his method is grounded in pedagogy, he does attempt to be relevant to those in other professions such as nursing and nursing researchers have adapted his method.[65, 70, 71]

Van Manen's approach to hermeneutic phenomenology was chosen for a number of reasons. First, it describes an outline for activities that are linked and interplay and was developed with the lived experience in mind.[36] Second, this method was appealing to me as an experienced oncology nurse practitioner because the first step in the activities described by van Manen is the choice of research topic that 'seriously interests us and commits us to the world'.[36] While it is unlikely many researchers would chose a research topic that does not interest them, a particular group one interacts with on a daily basis denotes a higher level of interest and concern and is in line with the philosophical assumption underlying hermeneutic phenomenology.[63] This refers to the value placed on the expertise of the researcher that increases not decreases how meaningful the inquiry is and how it proceeds.[69] Third, interpretation of the experience by the researcher is accomplished by creation of a text achieved through a number of approaches. In the case of this study, the text was presented by balancing the life worlds of the participants against what the life world of younger people with cancer might be like.[36]

Beyond the choice of a phenomenon of interest, the sequences of activities that comprise this method are as follows: investigating the experience as lived; reflection on emerging themes; description of the phenomenon through writing and re-writing and balancing the context of emerging themes.[36] Each of these activities will be discussed with respect to this study. It should be noted that van Manen warns against using these activities as a set of procedures to be followed consecutively,[36] suggesting instead the activities be considered as a whole, done simultaneously or intermittently therefore linking the activities.

The phenomena of interest and commitment

While this may seem straightforward, the issue goes beyond simply a topic of interest. If one intends to delve into the experience of another, then investigating it by survey would not yield the same data. An interview affords opportunity to question and clarify, can reveal more that intended but also risk going astray unless well prepared. Therefore the idea of investigating another person's experience is a delicate one requiring closeness to the subject itself as well as clarification that the experience is a true phenomenon.[36]

With respect to this study, responsibility lay with the researcher to draw out the meaningful aspects of the cancer experience by the elderly person. While as a clinician I would see elderly patients for less than half an hour during an office visit, the question remained in my mind as to the impact of cancer on an older person. Did it alter their lives and those of their families to the degree that I imagined? The one point about the phenomena of interest that van Manen stresses repeatedly is degree to which one must be oriented to the original question because failure to do this can derail the project. Although this point of topic of interest needs to be on firm ground before proceeding, the researcher needs to become virtually embedded in the topic.[36] It was with this in mind that a field diary was introduced as both a data tool and a means by which I could demonstrate closeness and evolution of the study as it moved forward.

Closeness to the research question can be a double-edged sword, one that descriptive phenomenology avoids through 'bracketing'. Hermeneutic phenomenology requires balance, holding assumptions in check while exploring the phenomena that could prove the assumption that drove the research in the first place, to be wrong.[36] The field diary aided this, if participants revealed information that made me question a belief I held, then notations were made after interviews. In this way, my assumptions that led to the research were exposed by what the research revealed. For example, prior to conducting this study I believed, and there was some literature to support this, that a cancer diagnosis for an elderly person often occurred in the setting of shrinking social support and declining health.[7] Notations made in the field diary at the conclusion of interviews however led me to question this as more than one participant described how they overcame logistical hurdles to receive treatment and manage their lives during the course of treatment. They described strong social support and ingenuity in negotiating new skills. Clearly, this may not be the case in all elderly patients but was apparent in this study group.

Investigating the experience as it is lived

The idea of investigating and delving into another's experience is a learning experience for the reader. That is, what is the significance of the experience for those experiencing it and what does it teach those reading about it? For this study, the choice to investigate the experience as it unfolded was influenced by timing of one of the 'lived experience' papers located.[10] The study was conducted among people living with cancer for up to five years and it seemed this extended period of time could possibly reflect vastly different experiences.[10]

Gaining access to the world we wish to learn about can be achieved through verbal interaction or written description. While the latter may provide us with information, written skills do not come easily to many, nor is there opportunity for drawing out aspects of the experience as it is documented. We have all experienced writing an essay or letter and later upon reflection wondering what one phrase or another referred to or meant. Furthermore, in written description burden rests largely with the participant to describe the experience. In an interview, burden is placed on the researcher to delve into and explore the experience. Because this study was conducted in the elderly population, the choice of interview was made because it was felt that a cancer diagnosis and treatment was a burden in itself and recruitment for a study where participants were required to document their descriptions would be problematic. In addition, interviews would allow for deeper exploration of the research question by re-focusing pointers as the interviews proceeded and new information revealed.[36]

Reflecting on the essential themes

Before the process of reflection can begin, as with the research question, the researcher must be closely oriented to the notion of what a theme is. With respect to this study, the 'highlighting approach' was used to isolate statements in the text that revealed something about what it was like to be older, diagnosed with cancer and receive treatment. As the interviews proceeded and more statements were isolated, the existential 'lifeworld' themes were drawn upon to give order to what was emerging and enhance the process of reflection. Initially the significant statements were labeled by concept. As interviews proceeded and more statements collected, a sub theme descriptor was allocated to each group of concepts. This continued until no new sub themes were created and the interviews were completed. At this point, allocation to the lifeworld structures began.

After all sub themes were categorized, the relevancy of the sub theme, its strength and contribution to the lifeworld was tested. This was achieved by removing one sub theme at a time, to determine if and how this changed the overall weight of the lifeworld structure. In other words, was this an incidental or essential sub theme? Four categories of lifeworld exist, in this study all four lifeworlds were represented. The categories will be briefly described using examples to illustrate the relevance of sub theme to the category of lifeworld.

Lived space

Four sub themes contributed to this lifeworld, one that describes our place and level of comfort in the world; how we experience everyday life affairs and the resources we draw upon to negotiate life. Space is complex; we all have a favorite space that provides us with a sense of well being as well as spaces where we are uncomfortable. If we are uncomfortable in a space, we can leave it. This latter option was more difficult for participants in this study who found themselves in a new space because of their diagnosis, a space they could not leave. Space can be large or small; in a large space one could feel dwarfed or lost whereas claustrophobia can occur in a small space. In addition, the space we find ourselves can affect how we feel. The sub themes in this category described all these aspects of space, including unfamiliarity, attempts to find a comfortable place in the large space of cancer and treatment, learning new skills, adjustment and finding a place of comfort.

Lived body

Three sub themes drawn from the narratives fell into this lifeworld, one that allows for our bodily existence in the world and it is through our physical presence we experience this world so bodily changes can affect our physical presence in the world. The experience of having all eyes upon us can cause us to feel more conspicuous. Illnesses prior to a cancer diagnosis can mean physical changes to the body such as weight loss as can bodily changes during chemotherapy and this can influence how we feel physically and spiritually in the world. When a person is older, there is more likely contemplation of death, and a cancer diagnosis can augment worry and concern about bodily deterioration. All participants described their degree of comfort with diagnosis at an older age, several commenting that if treatment were not successful then a peaceful, painless death would be acceptable to them. Within this category, several entries were made in my field diary as to how easily all participants spoke of their lives passing into death.

Lived time

Two sub themes contributed to this lifeworld of subjective time, one with much significance for the elderly who had already lived the greater part of their lives when diagnosed with cancer and were more likely to have had prior positive or negative cancer experiences that could influence their outlook. The concept of time when one is receiving treatment for a serious illness often means time seems to pass more slowly and it may be difficult to look forward to the future. These aspects of lived time were explored in the interpretation of the narratives.

Lived relation

This lifeworld relates to how we perceive others and maintain relationships with those in our personal space. For the participants, it was new space they were experiencing and this affected those around them. This was the least influential structure with one sub theme describing support as well as dependency.

Describing the phenomena through writing and re-writing

Together with balancing the text, describing the experience is probably the most essential part in van Manen's method. This is the part of the research where orientation to the aims, purpose of the study and the presentation of the intricacies and depth of the participants' experience though language used in the constructed text is most vital. It is at this point all can be lost if one is not immersed in the narratives and the research question that began the project. It is here that responsibility of the researcher to the participants is greatest so the created text is a true representation of their experience.

Apart from choosing a topic of interest and commitment, the activity of describing the text was the activity in van Manen's method that drew most heavily on my experience as an oncology nurse while simultaneously challenging it. This was because the process of writing led to re-thinking parts of the transcribed texts, reflecting on what I knew as a nurse and saw in the texts, re-examination, that is re-reading the transcripts prior to new interviews, conducting interviews, transcribing these interviews, isolating concepts then re-writing the existing text.[36]

Balancing the text

This creation of balance speaks to the process of organizing the text so that it does not result in a collection of multiple excerpts of the transcripts. In some ways, this is tied into writing and re-writing since it is through re-writing that the text is woven together. Balance is created in the final structure by the degree to which all parts contribute to the final text and the part of the van Manen method where the hermeneutic circle is most evident. It is here that the researcher goes back and forth between parts and whole of the text, reading and writing to ensure a 'good fit'. According to van Manen there are five approaches to creation of structure and balance in the text. In this study, the phenomenological descriptions in the narratives are presented existentially.[36] This refers to presentation of descriptions within the lifeworld of the elderly compared to another patient population in the case of this study, younger people with cancer. For example, descriptions are drawn upon to demonstrate how elderly people with cancer experience lived space, lived time, lived body and lived relation differently from how younger people with cancer might experience these worlds.

Methodological Rigor

In addition to the framework described by van Manen, a number of activities were employed to ensure methodological quality. The criteria most commonly used in qualitative research were outlined by Lincoln and Guba over two decades ago; credibility, transferability, dependability and confirmability.[72] These criteria were applied to the study.

Credibility

In this study, believability of the data was tested by repeat interviews with participants when thematic statements drawn from their interviews were discussed. During this second interview, participants were given opportunity to correct, clarify or expand on what had been said, a process known as member checking.[20] These repeat interviews were also tape recorded and transcribed verbatim.

Transferability

The question of whether the data could be transferred to another setting or group was addressed by adequacy and depth of the narrative text included in the final report. The 'thematic construction' document that was created included small excerpts of narrative with a key concept descriptor as the themes were gathered together. However, when the final report was created, original transcripts were used to include longer excerpts from the text. This was done to provide detail and therefore one that could be applied to another setting.

Dependability and Confirmability

Other researchers have described use of a diary on a daily basis to record their feelings and thoughts during data collection.[67] This was not done; the diary was used primarily at time of interviews and during transcription of interviews to note positive and negative influences during the interviews and some of my comments from a professional standpoint such as my assumptions. In addition, all interviews were conducted, transcribed and analyzed by the researcher.

Summary

A number of factors were considered in selection of methodology and method for this study. A qualitative approach allowed illumination of the study population's world and the flexibility and fluidity of van Manen's method of hermeneutic phenomenology allowed my professional experience to enhance and enrich the findings through creation of text drawn from narrative data.

Chapter 5. Methods

Introduction

In this section the study design and setting is described, discussion of the sample, selection of participants, development of the interview tool, interview process, ethical considerations and data analysis are provided. The methodology is briefly described with respect to difficulties encountered while conducting the study.

Study design

The study approach was non-experimental because subjective rather than objective material was being explored. A descriptive design with purposive sampling was used with data collected across different time points in treatment for each participant. The inclusion criteria meant that participants shared certain similarities and therefore was a purposive sample.[20] Van Manen's method of hermeneutic phenomenology was chosen because it is specific to the purpose of studying a lived experience.[36]

Qualitative data was collected in the form of narrative interviews. An interview tool was developed around the objectives of the study and consisted of five core questions. These were pre-tested in the first interview after which locational pointers were inserted. A diary was kept and notations made to reflect ease or difficulties of interviews as well as specific points about each participant and my reactions and feelings. The latter related to my personal assumptions about older people receiving cancer treatment that I had identified at the commencement of the study. Analysis of narrative data consisted of manual isolation of relevant statements, development of themes, reflection on the themes to ensure they were essential not incidental, then textual description of the phenomena using participants' stories to illustrate the themes.[36]

Study setting

The study was conducted in the ambulatory setting. An outpatient facility together with a 34-bed inpatient cancer unit comprised the cancer services at a 700 bed academic institution in a large metropolitan area. Doctoral students were not permitted to recruit participants directly, so an oncologist became the physician sponsor and principle investigator who recruited the participants. Recruitment was undertaken in the cancer center where participants were referred for diagnosis, treatment and follow up care. Care included administration of chemotherapy, intravenous fluids and medications, and transfusion of blood products.

Participants were given a choice for the interview setting, either at the cancer center while receiving chemotherapy or in their home. All participants chose to be interviewed at the cancer center, several stipulating that the interview should not last longer than their treatment since they did not wish to spend more time than necessary at the center. All interviews were conducted face-to-face and tape-recorded. The interviews were conducted after the diagnosis was made and treatment was initiated. For all participants interviews were conducted during the first few months of treatment. No participant had undergone diagnostic testing to evaluate treatment effectiveness or experienced treatment failure, progression of cancer or required change in treatment. Interviews were conducted over a span of a several months.

Interview Tool

The interview tool (Appendix I) was developed around the aims of the study to explore the experience and create narrative data. Initially, five semi-structured questions were developed to draw out the participants' stories. These questions focused on what they knew at diagnosis, feelings about diagnosis, how they negotiated this new territory, what their experience was like and their thoughts and feelings about how this diagnosis at an older age compared with how they might have felt at a younger age. The first interview was used as a pre-test of the interview tool. Based on this interview that lasted approximately twenty minutes, during which the participant did not elaborate on the subject matter and many responses were short, locational pointers were added to each question that could be utilized to facilitate more expansive replies as well as explore the experience to the fullest. Subsequent interviews were between thirty and forty minutes in duration with fewer short responses.

The rationale for prior formulation of interview questions and prompts was to maintain focus of the interview. While some participants answered several questions together, other participants required pointers to elicit their story. Other researchers have described the situation of voluminous data that is difficult to analyze or is discarded due to poor interview quality or technique.[10, 36] It was this possibility that led to formulation questions, however, it was recognized that in the course of interviews new information could be revealed requiring verification by other participants. Pointers were adjusted as the interviews proceeded but original questions were not altered.

Selection of participants

Inclusion criteria for study participants were no prior cancer history and recent diagnosis undergoing conventional treatment for cancer of a major solid organ such as lung, colorectal, prostate or breast. Rationale for targeting these cancers was occurrence as the most commonly diagnosed in the elderly who also comprised the largest proportion of new diagnoses in breast and lung cancers.[5] No prior history of cancer ensured the experience was equally new to all. Although findings were not expected to be generalizable to the elderly population newly diagnosed with cancer, the choice of the most common cancers and high proportion of elderly likely to be treated for these cancers meant that if change in practice was suggested by the findings then it could apply to a larger rather than smaller group. Likewise, if future research were conducted, then a large group would likely benefit.

The number of participants recruited for the study was based on current literature that suggested a small number of participants would sufficiently highlight the experience to the point of thematic saturation.[73, 74] Other researchers have documented the point of saturation or repetition occurs after five or six participants have been interviewed between one to three times.[75] This was the reason why a large sample was not required. There was no attempt to ‘choose’ a representative group of participants because the qualitative approach was intended to illuminate a unique situation not produce generalizable data. Because the study required a small number of participants, it was important none of the interviews be discarded for poor quality or failure of participants to understand and communicate adequately in English. For this reason, non-English speakers and those with only a few months to live who might find such an interview physically and emotionally exhausting were excluded.

The inclusion and exclusion criteria could be viewed as purposeful sampling because it selected participants that fit the aims of the study. This type of sampling is commonly used in a qualitative approach because it intentionally selects as suitable a participant as possible for the needs of the study.[74] This narrowed the sample group to any person older than 65, probably retired who had lived the greater part of their life, newly diagnosed with cancer and physically and psychologically able to describe their experience of cancer diagnosis and treatment. In this way, participants were as close to the subject matter as possible.

After meeting inclusion criteria, participants who agreed to participate were consented and enrolled in the study on a first come basis. The minimum age requirement of 65 years was based on accepted age for retirement as well as age used by a number of policy making institutions.[5] There was no age cut off for inclusion in the study. This was to ensure any elderly person cognitively intact who met the inclusion criteria was given the opportunity to describe their experience.

The study included those receiving treatment for palliation as well as cure. This was because significant numbers of people receive treatment to control symptoms and disease without curative intent and in some cancers can live another one to two years.[76] Since this can be the case in colorectal and breast cancers where the elderly are more often diagnosed with advanced disease and receive treatment for control rather than cure, their experiences were considered appropriate for this study.[54, 76] Although unlikely that other clinical trials would collect the same information as this study, those already enrolled in clinical trials at the institution were not recruited for this study.

Enrolment

A number of difficulties were encountered. There was delay in enrolment with two-month intervals between the first, second and third participant interviews. Several participants were recruited who did not meet the inclusion criteria for first cancer diagnosis or were referred to other cancer centers for treatment. Because there did not appear to be sufficient elderly participants in the physician sponsor's practice, recruitment broadened to the general elderly cancer population at the cancer institute but excluded the practice where I worked. Enrolment resumed and the remaining four participants were recruited from the breast cancer population. Enrolment, interviews and second interviews were then completed over a two-month period.

Interview process

At the commencement of the interview, each participant was allocated a pseudonym that was recorded along with time, date and location of the interview. The reason for recording information such as the date and location was to correlate any information documented in the field diary with aspects of the quality of the interview. Demographic data such as age, ethnicity, education level, work history, marital status, social support, type of cancer and treatment were collected on a demographic data sheet before the interviews commenced. To ensure accuracy, the type of cancer and treatment was verified from the medical record. Although none of this information was used in the interpretation of data, it was included in the final report.

Once delay in enrolment was resolved, interviews, transcriptions and isolation of significant themes were done simultaneously. As themes became more apparent, pointers were adjusted to better focus the questions and explore more deeply information revealed by one or more participants. After the sixth participant was enrolled, second interviews began.

All participants were interviewed twice with the exception of the first participant where this interview served as a pre-test. During the second interview, the first transcript was reviewed with the participant to allow opportunity to clarify or expand the contents in the original transcript before further questions were posed. The process of clarification of meanings is recommended as part of study credibility in qualitative research.[20] All participants with the exception of the last participant were asked between one and three further questions related to concepts verbalized by other participants but not themselves. The last participant did not raise any new concepts; no further questions were addressed to her as pointers in the questions had been adjusted prior to the interview to allow for inclusion of recently emerged concepts.

Two interviews were not included in the data analysis. The first because the participant had a recurrence of cancer from 20 years prior, so was not newly diagnosed. In this case, the interview was completed, transcribed and the tape stored but no data analysis was included. The second exclusion occurred because the participant experienced adverse effects to treatment during the interview, there were a number of interruptions and there was little meaningful narrative captured. This participant declined a second interview, the interview tape was stored but not transcribed and description of the interview documented in the field diary.

Ethical issues

Approval

Because the study was conducted by a doctoral student from a university not affiliated with the medical institution where the study was to be conducted, preliminary approval was required by the university peer review committee at The University of Adelaide, Australia (RAHDS). In addition, research conducted in cancer patients required approval by a Peer Review Committee (PRMC) at the cancer institute in a separate approval process from the Institutional Review Board (IRB) that supervises all research at the medical institution. PRMC approval included review and approval by the department of biostatistics. After approval from the PRMC, the study was reviewed and approved by the IRB (study # H 12585) for an initial period of one year with option of yearly renewal with further approval. This was not required because the interviews were completed within the initial one-year period.

Informed consent

The physician sponsor identified eligible participants who agreed to participate. Participants were provided with an information sheet outlining the study then contacted via telephone. During the initial contact, eligibility criterion was again reviewed and interview time and location arranged. The second review of eligibility was introduced after the second participant recruited to the study was found ineligible after being consented and the interview was in process. At the first face-to-face meeting, participants were given an opportunity to ask questions about the study prior to completing the IRB approved consent form.

Privacy

All interviews were conducted in individual cubicles in the cancer institute after treatment had commenced and the medication would infuse over at least one hour. This was to minimize the number of interruptions and maintain privacy. If nurses needed to enter the cubicle for a prolonged period, the tape recorder was turned off until the nurse left the cubicle. On several occasions, interviews were interrupted for technical difficulties with chemotherapy infusion or adherence to institution policy checking guidelines for safe administration of chemotherapy. If the interruption occurred to check chemotherapy, the tape recorder was turned off to avoid recording the participant's name. After all interruptions, the participant was reminded of their prior statement and the question that prompted it to allow for continuation of the dialogue.

Anonymity

All participants were given pseudonyms used from the beginning of the first interview onwards and recorded in the field diary, the digital file and the transcripts. The participants' identities were only documented on the demographic sheet. Although I worked at the cancer center, none of the participants recruited to the study were known to me nor did I participate in their care at the cancer institute. The physician sponsor was not my collaborating physician. No reference was made either before or after the interviews to any aspect of the participants' care. If participants requested answers or information about treatment, they were directed to the appropriate resources. After transcription of interviews all references to names and geographic locations were removed.

Confidentiality

During second interviews, aspects of sub themes raised by other participants were addressed. The source of key concepts and sub themes, or any details of other participants in the study were not revealed to any participant. In addition, I did not reveal any information from the interviews to the MD sponsor or any other healthcare providers, participant pseudonyms were not revealed to anyone.

Beneficence

The research proposal included a statement of counselor support should any participant become distressed during interviews. This did not occur, no participant requested termination of the interview due to emotional distress. No advice or any personal involvement with participants occurred.

Storage of data

The IRB policy of the medical institution required documentation be stored for a period of three years after completion of the study period, and then discarded. All digital files and transcripts were stored on my personal computer that has the appropriate security safeguards such as unique identification of authorized users, password protection, anti-virus controls, firewall configuration, and scheduled and automatic backups to prevent against data loss or theft. The diary, demographic sheets and all paper copies of transcripts were stored together in a locked file cabinet at my home and I alone have access to this cabinet.

Data Analysis

All interviews were transcribed verbatim by me either the same day or days following the interviews. This was to minimize the time lapse between interview and transcription and allow for closer reflection on the interview, recalling any difficulties or problems and documentation of such in the field diary. In addition, because I was an experienced oncology nurse practitioner, some professional and personal observations were included in the diary, in particular how my assumptions evolved during the study. As previously stated, I thought many older cancer patients coped reasonably well with the diagnosis and treatment. I found myself constantly surprised at how resilient, resourceful and strong these participants were as they received treatment and told their stories.

After transcription, text lines were numbered and isolation of thematic statements commenced using a 'highlighting approach'.[36] As the text was read and re-read, the question asked to isolate themes was 'is this phrase relevant to the experience of being older, having a new cancer diagnosis and undergoing treatment' (p.30).[36] During this process, relevant phrases were identified and labeled by concept then grouped together according to common concepts then assigned a sub theme definition. For example, 'Dealing with cancer at an older age' was a sub theme definition that included the relevant phrases about what participants thought it was like having cancer at their age compared to when they were younger. A separate document titled 'thematic construction' was created for this purpose.

As data analysis continued, highlighted phrases were grouped into an existing sub theme or a new one created. Interviews and thematic isolation continued until no new sub themes were created. After the fourth participant, no new themes emerged but enrolment continued until six participants were interviewed because this was the criteria documented in the study proposal and approved by the various ethics committees and there was still the possibility that new themes could emerge. All relevant phrases entered into the thematic construction were labeled with the first initial of the participant's pseudonym, the interview number and the corresponding line number in the text. This allowed for ease of identification and contributed to the audit trail that demonstrates dependability.[20]

Sub themes were then drawn together into themes that make up the structure of our 'lifeworld'.[36] These four lifeworlds are 'lived space' or the place one finds oneself during a life experience. 'Lived body' or one's physical and/or spiritual being during a life experience; 'lived time' or how one reflects on past and present events and experiences to negotiate the future and 'lived relation to the other' or how one interacts and shares space with those around us during a life experience.[36]

The themes were then re-examined by asking the question 'is this theme incidental or essential to the study question'. This was determined by considering the phenomena of an older person with cancer receiving treatment then removing one theme at a time to test whether the meaning of the experience would be lost or diminished.[36] After this period of reflection on the themes, a written text was created using the participants' words and stories. This served to illustrate the themes and answer the question whether the stories revealed what it was like for this group of elderly people to experience a new cancer diagnosis and undergo treatment.

Methodological Issues

From the beginning of the study, a number of issues arose and these were documented in the field diary. The initial problem I grappled with was interview technique and this remained a challenge throughout the study. Interview difficulties have been described by other researchers who felt disappointment and frustration with interviews that did not seem to yield voluminous data or produced volumes of unwieldy data with little meaning to the topic.[36, 68] This occurred at the commencement of the study and although it improved as time passed, it remained a challenge to re-focus an interview that was moving away from the topic and becoming unmanageable.

The first interview yielded many short responses thought due to poor interviewer preparation and inadequately prepared questions. This improved after revision of questions and addition of pointers that could be used to re-focus the interview as well as elicit more of the participant's story. Because interviews were conducted at the cancer center, I would break from work to conduct an interview so there was often little time to reflect and prepare for the interview. These issues were addressed by a number of rehearsals, listening to the first interview and self-critiquing interview techniques as well as re-reading the completed transcripts the night preceding the next interview. Although subsequent interviews were easier and seemed to flow better, the process of self-critiquing and reflection continued until all interviews were completed.

A further issue was that I worked at the cancer center where the participants received treatment. In an attempt to appear as little as possible as a staff member, I dressed in casual attire and ensured no work related interruptions occurred at any time during the interviews. Because the interviews were conducted during infusion of chemotherapy, care was taken to ensure patients had received non-drowsy anti-emetics prior to interviews. This only occurred on one occasion. At no time did any participant become emotionally distressed and request termination of the interview.

Chapter 6. Data Analysis

Participants: Catherine, David, Francis, Helen, Karen and Janice
Key to coding: First initial of participant followed by Interview # then Line # in transcript e.g. C1: 34 (Catherine interview 1, line 34)

THEME-LIVED SPACE: *the world or landscape in which we find ourselves at home; the way we experience the affairs of our daily existence.*

1. SUBTHEME-knowledge: old, new, incorrect

Key phrase	*Concept*
The cancer always gets you it seems D1:171	No hope with cancer
My sister had breast cancer...for some reason it seemed to me that I wasn't going to get it F1:23-25	Surprised about diagnosis
Very little if anything (knowledge about lung cancer) D1:40	Knew nothing about lung cancer
I had no idea that so many people over 50 had cancer F1:15-16	Didn't know age was a risk factor
I simply don't know (knowledge about breast cancer) F1: 28	Knew very little
I think of cancer of the breast and cancer of the prostate gland...they seem not to be as awful as the other kind of cancers F1:181-183	Some cancers worse than others
I thought I was too old to get cancer F1:141-142	Misconception about risk
Actually not too much, though I've known a few people who have had breast cancer K1: 26-27	Knowledge of breast cancer
I've known people who have had it but to be informed on it, no, I would say I'm not, no K1: 41-42	Little knowledge of cancer
I thought maybe up to seventy only and I was seventy seven when I got it, I thought I would not have it any more J1: 13-14	Misconception of age
I know that some are different and that some are more aggressive but I guess that is all I know about it J1:48-49	Little knowledge of cancer
When the doctor suggested the chemo I said no I don't like chemo because of that feeling that I don't like J1: 93-94	Pre conceived idea about treatment
I think it is more slow growing their tumors are, more slow growing so they have a longer life span (older people) C2:41-42	Cancer grows slower in older people
I think the oncologist told me that it was not as strong a chemotherapy so I would assume, I don't know...maybe an aggressive therapy wasn't called for. H2:72-73	Unsure about rationale for treatment

2. SUBTHEME-negotiating degree of knowledge, trusting doctors

Key phrase	*Concept*
I am kind of cowardly, she (daughter) asks all the question when I am not around C1:35	Don't want to know too much
These markers, I'm not too sure what they are C1:50-51	Limited knowledge
Didn't ask any really pertinent questions C1:25-26	Didn't want to know
I'm trusting him [doctor] that he knows what he is doing C1: 67	Trust doctor to take care of me
I didn't know exactly what was going to happen...you do what you do H1:50-51	Naive about treatment plan
I never thought about side-effects so I am still encountering them H1: 106	Lack of knowledge
My feeling is that if I go to a doctor, I trust their years of experience F1:101	Trust doctor
There is just no way that whatever I read could make a big difference F1:103-104	Defer to doctor
I didn't ask any questions.....I trust the people I am being taken care of by F1:204/219	Trust
She was the breast doctor that was recommended to me by my gynecologist who I trust so I didn't question F1:95-97	Trusted recommendation
I felt confident in him and that it was discussed with other doctors. I couldn't say what I should have, I just don't know K1: 81-83	Trusted doctor's decision
I just left it to the doctors what ever they said that I needed J1: 15-16	Deferred to doctor
I left it to the doctors, you know, to see if they could do something about it with this treatment J1: 41-42	Decision made by doctors
I thought oh Jesus I never asked any questions (about what kind of radiation I should have) F1:200-204	Didn't ask questions that younger people were asking

3. SUBTHEME-impact of diagnosis, decisions about treatment

Key phrase	*Concept*
I keep wondering well what if I had never....no, I couldn't have done that, not had the chemo, I just couldn't have done that, I think that is probably asking for death F1:294-296	Pondered not having treatment
I was just thinking that maybe I should get this for six months only instead of a year of treatment J1: 75-76	Considering less treatment
I thought gee, if I can go on like this for another ten years or so I wouldn't want to be bothered doing this (chemotherapy) H2:14-15	Considered not having treatment
One of the reasons they gave it to me was because of my age, not to have some of the side-effects that the more aggressive ones F1:40-41	Easier treatment
I didn't expect it to be in stage 4 C1:6-7	Advanced cancer
At my age, lung cancer, I would not have a much longer time to live D1:12-13	Die soon
I thought that when I did go, when I died it would be the heart, I never dreamed it would be from cancer D1: 25-27	More likely die from heart disease than cancer
I don't know if I could say that I was really terribly upset, I thought it was a nuisance H1:19-20	Not upset
Furious, I mean I am 75, I thought I was beyond that(reaction to diagnosis) F1: 10	Age protected against cancer
Being 73 I have lived most of my life, I am not going to be around forever, I am very lucky that I have reached 73 and I am just finding out about it now D1: 194-196	Grateful for life lived prior to diagnosis
I shouldn't say I am resigned to it, I'm still upset, not happy about it but I think I am handling it well K1:13-14	Accepting
I don't need it, spoiling my next year now, but I wasn't depressed over it, I can't say that K1: 56-57	Inconvenience but accepting
It was cancerous, my first thought was why at this age J1: 9-10	Age protection
They asked me if I wanted reconstructive surgery I said no, at my age who cares J1: 31-34	Didn't care about reconstruction
I never thought I would get cancer J1:66	No idea of risk
If I had a lumpectomy then I would have radiation. I don't know, so I said better take it all off J1:28-29	Less concerned with appearance

4. SUBTHEME-Adjustment

Key phrase	*Concept*
I go home with chemo, I have to disconnect it myself, it’s awkward C1:86-87	Burden of self care
It has changed my life in the time it takes to get the treatments, I am always going to the cancer center and the hospital D1: 83-88	More time taken with healthcare
Physical therapy...I just found I couldn’t do that and deal with the breast stuff F1:66-67	Burden of two illnesses
I used to go down to [place] with my family for a week and I didn’t go this past summer I had the knee done and the summer before I had the other knee done so now this summer again I don’t think I will be going down there K1: 172-174	One illness after another
I give myself three shots a week to build up my white blood count...I never gave myself a shot in my life. K2: 4/7	Learnt new skills for treatment
I said no, no I don’t need anyone driving me, I tried it once and it wasn’t necessary...sometimes that annoys me more than helps me when I hear that. K2: 68-70	More independent than people think
I’m not good on the internet C1:40	Limited resources
Asked them (son and nephew) to look it up on the internet F1:121	Depend on younger family to use resources
My children, they got pamphlets and they said Mummy read this. J1:50	Some information

THEME-LIVED BODY: *physical interaction with the world, how we exist in the world physically and spiritually, the part we present to the world while holding a part in reserve.*

1. SUBTHEME-older body, existing health problems

Key phrase	*Concept*
I felt like I was coming down with pneumonia, having terrible trouble breathing D1:5-7	Seriously ill
I don’t usually do self examination, I never did F1:3-4	Limited health maintenance
I had a knee replacement in May F1: 64-65	Prior health problem
I’ve had both my knees replaced and the last one was just in June and then this comes along like eight or ten weeks later K1:51-53	Consecutive health problems
I had mammograms taken two years ago and I was told to come back. I was never able to come back J1: 5-6	Didn’t follow-up

2. SUBTHEME-Physical effect of treatment

Key phrase	*Concept*
I just have no energy C1:74	Fatigue
The nausea that we haven’t seemed to be able to control C1:78-79	Feel sick all the time
It’s really not been all that bad C1:83-84	Overall OK
I am kind of beat afterwards C1:118	Wiped out
The only side effect I have had from all of this chemo is my hair falling out D1:107-8	Tolerating well
I tolerated it very well; I had very few side-effects. D2: 2	Well tolerated
The treatment itself is fine H1:95	Easy
I have swelling in my feet and if we go out to maybe dinner I get pretty uncomfortable H1:200-201	Discomfort
I do get tired F1:265	Tired
The fatigue is just awful, it’s very hard. F2:6	Debilitating fatigue
I am starting occasionally to feel a little tired, but I think I’m going along well K1: 19-20	Occasionally tired
Different from what I expected and easy too because anything I have heard before was how sick people were and it has not been that way K1: 140-142	Easier than expected
I am active, I go out a lot J1:120	Still active

3. __SUBTHMEME-spiritual strength of older age__

Key phrase	*Concept*
I've lived a long life, you know, so it is more acceptable C1:219-220	Older age at diagnosis
If I was much younger I probably would have been......angry probably, but I'm not. C1: 221-222	Acceptance with older age
I actually don't mind dying, I don't want to suffer C1:304-305	Accept what happens
If I was diagnosed thirty years ago I might be very angry about it D1: 206-7	Easier when older
I think when you are older you can accept this a little bit more as part of the aging process H1:146-147	Accepting as part of old age
If I thought that I could have a death that wasn't painful I would never have followed up, I would have just enjoyed my health as long as it lasts H1: 29-31	Accepting of situation
They (younger women) were much more frantic about it than I am F1: 162	Accepting
If I had gotten it when I was younger? I have no idea; it probably would have changed my life much more than now F1:156-157	Less impact on life when older
I hope this works and I hope if it doesn't I'd go quickly F1:220-221	Hopeful but accepting
I don't worry as to whether the chemo is going to work or not F1:298	Not worried about chemo working
Having cancer is dreadful, having to deal with it is hard, in some ways being older is easier F1:349-350	Easier when older
Thirty years ago I would have been I think a complete wreck for a while, but at this age, no K1: 97-98	More accepting when older
If I had to have it, it's better at this age than it would have been then K1:100-101	Easier when older
If I had to have cancer yes, as I get older it is better K1:159-160	Easier when older
When you are young you are not supposed to be ill and that makes a big difference K1: 221-222	Less peer support when younger
I think as you go along and get older, more and more of your friends come down with something which includes them too and makes them more tolerant K1: 216-217	Older friends are better support
If I had it when I was younger I would be mad because my children would be younger and I wouldn't want to leave my children when they were young, but now they are older and I am seventy eight J1: 148-150	Difference between cancer at an older age
I think I would be devastated you know if I were younger, with small children J1:67-68	More upset if younger
..Treat us old folk as equal and important and they do the best for us...I don't think at all that they are giving me a less aggressive treatment. C2: 17-19	Treated the same as younger people
At our age if it is not them it is someone they know so I guess would be more understanding C2: 24-25	Older friends more understanding

THEME-LIVED TIME: *how past and present influence the future we live towards.*

1. SUBTHEME-Personal experience

Key phrase	*Concept*
My father died of cancer and I thought about how he died C1:13	Seen it before
My mother died of cancer D1:65	Cancer death of a parent
My sister has had three different cancers D1: 59-60	Sibling living with cancer
My mother had breast cancer H1:32	Recent experience
I did have an aunt that did have stomach cancer and had a horrible death H1:34-35	Painful cancer death
My sister had breast cancer F1: 23	Close prior experience
I had an aunt who had cancer of the breast J1:11	Witnessed cancer
Chemo and nausea, my brother had that, cancer of the prostate J1: 99-102	Witnessed treatment side-effects

2. SUBTHEME-attitude to present and future

Key phrase	*Concept*
This sickness makes me more grateful C1:195	Appreciate what I have
I don't think I'm so old that death is acceptable C1: 219	I could die from this
I don't really see the future as positive C1:263	Negative outlook
I have to be content with each day C1:276	Content
Angry...I'm not. I'm kind of accepting of it C1:222-223	Acceptance
I am not angry about this D1: 202-203	Accepting
I'm not staying at home dwelling on this D1:82	Getting on with life
I may die of this someday but I don't think it is going to be soon D1:95	Acceptance
In stage 4 I don't think you have that much of a chance C1:269	Thoughts about prognosis
As soon as I know what the prognosis is, then I will be planning more trips D1:231	Tentative plans for the future
If I get through with this cancer and I'm OK I will be delighted and just hope that the next thing doesn't F1:148-149	Greater risk of illness with age
I'm 75 years old, I've got three grandchildren who are quite young and both my daughter and son and I would love to hang out with them more and stuff like that F1: 164-166	Would like more time but realistic
It would be lovely if I could have a few more good years F1:196	Accepting of what future may bring
I do worry about...can I get my body back together and get on with another life F1:305-306	Wants to get on with life
I have got to live with it and do what I am told is the best for me and that is what I am trying to do K1: 12-13	Willing to follow instructions
It's really not changed my life that much, no, I would say it hasn't K1:191-192	Life not really changed
I have the cancer yes, but what can I do, it is there. I am having treatment for it. I don't know, I think that is the best way to look at it, what can you do? I cannot brood, and worry and worry, it won't help me J1: 153-155	Accepting attitude

THEME-LIVED OTHER/RELATION: *interactions we have with those in our personal space, how we maintain relations with those in the space around us.*

1. SUBTHEME-levels of dependence

Key phrase	*Concept*
Burden everybody, driving me here all the time C1: 114	Dependent
My family worries, I can't tell them if I am sad, I want to tell them C1:140-141	Lack of support from family
He goes out all day, I think he doesn't want to face it C1: 150	Isolation from husband
Telling people...it's not been that difficult C1:247	Not difficult telling people
I have good friends, if you say I want to sit down and complain for an hour they say go ahead and complain and if it gets to be too much, I'll stop you K1:210-211	Support from friends
I have a hard time coming and going, they have to get off from work to come with me J1: 78-80	Depend on family

Chapter 7. Data Interpretation

Introduction

This section presents demographic and medical information of participants followed by data analysis and interpretation. Lifeworld structures are illustrated by sub themes drawn from the participants' statements. The phenomenological descriptions illustrate the lifeworlds of space, time, body and relation and how worlds may differ between younger and older cancer patients. Woven into the presentation of themes are appropriate notations from my field diary and experience to illustrate the world of these elderly cancer patients as they were diagnosed and treated for cancer.

Demographic and medical data

The six participants were five women and one man ranging in age from 68 to 78 years old; five Caucasians and one Asian. They are referred to by their pseudonyms of Janice, Helen, Frances, Catherine, Karen and David. Four participants were diagnosed with breast cancer; one with colorectal cancer and one with lung cancer. Four participants received chemotherapy alone, one received chemotherapy followed by radiation therapy and one received radiation followed by chemotherapy. Four participants had completed university level education; two had completed high school. One participant was still working at the time of diagnosis, four were retired and one had never worked. Four lived alone, one was married and lived with a spouse and one was widowed but lived with family.

Interpretation

The participants in this study described experiences across the four everyday lifeworld structures of space, time, body and living in relation to others. Each lifeworld will be presented through sub themes using excerpts of participants' stories to illustrate and describe the lifeworld.

1. Living in a space with cancer

For the participants in this study this was a highly relevant world. Four sub themes contributed to this lifeworld, the most for any lifeworld. With a new cancer diagnosis, the participants found themselves in a new and different space where they confronted an experience many of them realized they knew little about and did not always accommodate them. The four sub themes in this new space began with an unfamiliar world where they recognized their limitations and lack of information, made discoveries, learned new skills, adjusted to change and personalized this new place.

Knowledge: old, new, incorrect

Frances had only just begun to realize that older people also developed cancer yet felt the world of the cancer sufferer was not her world.

'I had no idea that so many people over 50 had cancer. I thought I was through....too old to get cancer......much of the cancer, the discussion about cancer and so forth is related to younger people, I guess mostly because they are the ones who have kids and are young'. F1: 13-16

In an attempt to negotiate their new world both Frances and Helen attended support groups neither of them found helpful. Thus, in their attempt to find a place of comfort and understanding as well as improve knowledge about their new world, they found themselves in a space that negatively affected how they felt.

Helen spoke about demographics of the group she attended that consisted mostly of younger women who were living with their cancer in a different place from her.

'They didn't relate to me...... I found it upsetting too because I heard of all the different side-effects at this meeting that I wasn't aware of that could happen and I thought maybe I don't want to know these things, what will happen will happen'. H1: 156-162

Frances also felt anxiety after attending a support group with mostly younger women.

'Actually I got frantic because they were carrying on about all this reading and stuff, about what kind of radiation I should have and whether they should have 20 days or 30 days or this or that and I am well you know, the surgeon said we will do this and that is what we are doing and I thought oh Jesus I never asked any questions' F1: 200-204

Like Frances, Janice realized that she had much to learn in this new world and was not aware of the cancer risk for older people.

'My first thought was why at this age..... I had an aunt who had cancer of the breast but she was younger not in her seventies so I didn't know what to think. I thought maybe up to

seventy only and I was seventy seven when I got it, I thought I would not have it anymore'. J1:10-14

Both Frances and Janice had a family history of breast cancer. Unlike other cancers, a number of risk models have been developed in breast cancer to calculate risk. The Gail model was developed to calculate risk in the general population, while several other models predict for high-risk families and genetic mutations. Although the Gail and Claus are the most commonly used models, both have limitations including exclusion of distant relatives and number of relatives with cancers.[77] The application of risk models was not intended as part of this study but their existence is noted because it would appear that although breast cancer is highly publicized, all four participants in the study diagnosed with breast cancer knew little about their personal risk.

Frances seemed unaware of risk of age and family history:

'Well my sister had breast cancer, but I hadn't really thought about it, for some reason I it seemed to me that I wasn't going to get it, I mean it had just never been something that I had thought about' F1: 23-26

While all participants mostly adjusted to changes diagnosis and intended treatment brought to their lives, many were less comfortable questioning the oncologist about medical aspects of care and all except David preferred to be told what was going on rather than initiating questions and discussion.

<u>Negotiating degree of knowledge, trust in doctors</u>

Catherine spoke about her fear of asking what was happening and was reluctant to seek more information.

' I couldn't really think of anything else....it is new to me so I didn't know what to ask and to tell you the truth I really didn't want to know too much. C1: 23-25

'I am kind of cowardly; my daughter does it all, she takes care of everything, she asks all the questions when I am not around, she calls the doctors she does that, looks at the records, I don't want to see the records'. C1 34-37

Strong trust and dependence on physician decision-making and information sometimes resulted in lack of information. If questions were not initiated by participants, they were not always fully aware of what could happen as they progressed through treatment. Helen had almost completed treatment at the time of interviews and despite weekly physician visits was still unsure of treatment toxicity.

'I guess I never thought about side-effects so I am still encountering them and I am surprised at things. I hope that they will be all be gone when the treatment is gone, you know when it is completed, I don't know'. H1: 106-108

She previously noted this was in sharp contrast to younger women in the support group she attended who knew a great deal about side effects of treatment.

'They (support group) talked about a lot of side effects and I thought oh my god am I going to face all of this, on one hand I was interested, but the reality of the things that could happen was kind of shocking so to me. I want to know what the side effects are but I had no idea that there could be so many and such a variety of them so maybe in certain cases you don't have to know all that' H2:110-114

Overall, participants were comfortable with the level of trust and decision-making they placed in their physicians. Frances, Catherine Janice and Karen all preferred to defer to their physicians for decision making often without questioning on their part as these excerpts illustrate:

'I'm trusting him [oncologist] that he knows what he is doing, I didn't have to make any decisions' C1: 67-68

'I just left it to the doctors, whatever they said that I needed' J1: 15-16

'There is no way that whatever I read could make a big difference. F1: 103-104.

Frances recognized younger women at her support group were much more involved in decisions regarding their care than she was.

'She was the breast doctor that was recommended to me by my gynecologist who I trust so I didn't question' F1: 95-97

'I thought I had better get started with this group....these people, they were younger, they were frantic, they have a whole life and are making decisions for them in terms of this therapy or that therapy and everything and my thing is well, what the hell I trust the people I am being taken care of by and I hope this works and I hope if it doesn't work I go quickly and that's it'. F1: 213-221

Impact of diagnosis, decisions about treatment

As the participants learnt about their diagnosis and found themselves in new surroundings, two of them considered not receiving treatment and one considered a shorter rather than longer treatment course. No participants expressed anger or devastation about their diagnosis; something they all recognized would have been the case if diagnosis occurred at a younger age.

Helen and Frances both considered not having treatment at all, although Frances only transiently. Consideration of treatment refusal may be more likely among people who have lived longer lives, rather than those in the prime of life.

'I don't know if I could say that I was terribly upset, I thought it was a nuisance. I actually asked the doctor if I ignored this how long would I have to live and what type of death would it be. I thought if I could have a death that wasn't painful I would never have followed up, I would have just enjoyed my health as long as it lasts' H1:19-31.

I keep wondering well what if I had never....no, I couldn't have done that, not had the chemo, I just couldn't have done that, I think that is probably asking for death F1:294-296

Janice considered shortening her course of treatment due to transportation difficulties.

'I was just thinking that maybe I should get this for six months only instead of one year of treatment because I have a hard time coming and going. They (family members) have to get off work to come with me'. J1: 75-80

Multiple times after interviews, I made notations about how relaxed and comfortable participants appeared in their situation even though aspects seemed grim to me. I was continually reminded by the participants' words how they should not be underestimated. David was particularly calm and expressed his feelings in this new world of cancer, one that he had not anticipated but accepted.

'Being 73 I have lived most of my life, I am not going to be around forever, no one is, so in that sense I am very lucky that I have reached 73 and I am just finding out about it now. I am not angry about this...if I was diagnosed thirty years ago I might be very angry about it...so it is different when you are 73' D1: 194-210

He was seriously ill with other health conditions when diagnosed and experienced cardiac arrest twice during his initial hospitalization.

'I was having trouble breathing, I couldn't lay down, I would have to sit up. If I lay down I had terrible time breathing, that is how it was discovered. I figured at my age, lung cancer I would not have a much longer time to live. I died twice in the hospital from the heart, they had to bring me back twice, they used the shock, that was hard. I thought when I did go it would be from the heart, I never dreamed it would be from cancer' D1: 6-27

Following this interview, I made a long notation in my diary describing how calm David was when telling me about his resuscitation, something that I felt certain would be more difficult for a younger person. This attitude of 'deal with it and get on' seemed to pervade this group and is aptly described by Karen. These words had shown me that healthcare providers might assume cancer treatment too rigorous in older people however; these narratives spoke contrary to such beliefs.

'Well, I can't sit here and cry, I've got to just follow through and see what the doctor is saying...I've got to live with it and do what I am told and what is best for me and that is what I am trying to do' K1: 10-13

Although Janice deferred to physicians for most decision-making, a major decision she made herself with little fuss. As I noted in my diary she was a quietly spoken woman who I had to strain to hear at many times during the interview. Her daughter was present in the cubicle, albeit several feet from us, so I was reluctant to ask Janice to speak up to maintain her privacy. Still despite her quiet demeanor, she was very clear about some things.

'At first they asked me if I wanted a lumpectomy on the left and a mastectomy on the right but I said what for, better to remove it. If I had a lumpectomy then I would have radiation so I said better take it all off. They asked me if I wanted reconstructive surgery... I said no more, at my age who cares, now I have the prosthesis' J1: 26-35

Adjustments

Karen, aged 74 years old, spoke of the multiple changes diagnosis and treatment had brought to her life. Although living alone she was highly resourceful, on the day of our first interview there was a transportation strike but she overcame the minimum car passenger limit into the city by inviting three of her neighbors for a shopping day while she received chemotherapy after which she drove everyone home. In addition, she participated in her care in a way that surprised her.

'I give myself three shots a week to build up my white blood count so that I will be doing that. I never gave myself a shot in my life, actually it was very easy, the girls here gave very good instructions and a little mock demonstration and it went fine' K2:4-9

Catherine also spoke of the new skills she had to master in order to receive chemotherapy as well as the anxiety associated with participating in her care.

'I have a port, I see some people get it just in their arm for the day and go home. I also go home with chemo, portable chemo for two days and I hate that because I have to disconnect it myself and it is awkward. I was petrified the first time, my daughter had a nurse come and do it for me and then she hired a nurse again to come and I did it with the nurse watching me and then the first time alone I was really scared, I am always a little nervous that things aren't going to work'. C1: 85-94

More specific to the elderly with cancer is their higher likelihood of co-existing illnesses and this was the case for three participants whose daily lives were affected for a protracted period of time, something they had not anticipated and less likely to occur in younger people when they are diagnosed with cancer.

David and Helen verbalized the impact of medical care on their lives.

'It has changed my life in the time it takes to get the treatments...my days are pretty much taken up at the hospital and that is one thing I don't like. I am always going to the cancer center and the hospital' D1: 83-88

Helen also felt that a great deal of time was taken up with treatment.

'I used to exercise, now I do doctors' H1: 79-80

2. Living in a body with cancer

For people receiving chemotherapy, bodily changes are demonstrated through change in physical appearance as well as general well-being. Many participants were aware of changes in their physical appearance and some changes could not be easily concealed such as weight changes and hair loss. While in the physical world we are able to reveal and conceal something of ourselves at the same time, this became either lost to the participants or more difficult. Such is the situation of awkwardness in the world when all eyes are upon you. This lived body world for the elderly in this study was by their report less difficult for them for a number of reasons. All participants verbalized acceptance and adjustment to physical change something they felt they might not have done so easily at a younger age. Many received support from friends who also experienced health problems, a more likely situation for older rather than younger cancer patients. Three sub themes were drawn from the narratives that demonstrate how the group dealt bodily and spiritually with cancer and the impact of co-existing health problems prior to diagnosis.

Older body, existing health problems

David, Frances and Karen all had other health problems prior to their cancer diagnoses. For David, diagnosis was made during management of other problems so the issue became priority and severity of illness.

'I felt like I was coming down with pneumonia, my whole body was full of fluid, my ankles were swollen, my wrists and I was having terrible trouble breathing, I couldn't lay down, I would have to sit up. If I lay down I had terrible trouble breathing so that is how it was discovered' D1: 5-9

Both Karen and Frances had undergone knee replacements just prior to their diagnoses. Although they were not as seriously ill as David was, they had recently experienced symptoms of pain and limited mobility for several weeks before diagnosis. While Karen had completely recuperated, Frances had not.

Frances explains how she struggled to manage both diagnoses and treatments.

'I had a knee replacement in May...I had to kind of back up, I was doing pretty well with the physical therapy but I just found I couldn't do that and deal with the breast stuff so I have been doing some physical therapy but not as much as I would have been. This week I am very tired so I skipped physical therapy......had I known I was going to have breast cancer I certainly wouldn't have done the knee' F1:64-71

Karen felt that she had experienced one medical problem after another, a more likely situation for older rather than younger cancer patients.

'I've had both my knees replaced and the last one was in June and then this comes along like eight or ten weeks later and I thought oh gee. I was all set to go and run around the city and this came up' K1:51-56

Physical effect of treatment

Overall, participants in this study tolerated treatment well. The most common side effects were fatigue, nausea, hair loss and swollen feet but in general, many continued in their daily routines.

Karen was somewhat surprised how the treatment was progressing.

'Different from what I expected and easy too because anything I have heard before was how sick people were and it had not been that way, so yes I would say it is easy' K1:140-142

Catherine was also aware of the possibility of side effects, but had experienced few when interviewed.

'It is not bad really, I get slightly nauseous and have some little problems, I just have no energy, I mean I think years ago people were very sick and threw up and so on but that has not been happening. I see people lose their hair and that has not been happening, so it's not a quality of life but it's doable, definitely doable' C1: 73-77

Spiritual strength of older age

Participants did not verbalize significant physical side effects from treatment nor were they spiritually disheartened by their diagnoses and treatment. In this group, all participants considered a cancer diagnosis easier and more acceptable in older age than younger age and many spoke freely about the consequences of failed treatment.

Helen thinks about a cancer diagnosis at an older age.

'I think when you are older you can accept this a little bit more as part of the aging process so maybe you are a little more accepting of it.' H1: 146-147

Karen too spoke about dealing with a cancer diagnosis when older.

'I think I would be much more upset at that age, what am I, 74.....thirty years ago I would have been a complete wreck for a while but at this age, no.....if I had to have it, it's better at this age than it would have been then......I wouldn't have been as relaxed about it...I would have been I think, much more upset for a longer time' K1:94-10

Catherine expressed positive and negative feelings about her diagnosis, treatment and outcome.

'I don't think I am so old that death is acceptable but on the same token I've lived a long life so it's more acceptable, it's more acceptable if things are not going to work out but if I was much younger I probably would have been.... angry probably, but I'm not. I'm kind of accepting of it........I actually don't mind dying, I don't want to suffer' C1: 219-223/304

Janice repeatedly expressed an accepting attitude to her cancer diagnosis considering how diagnosis at a younger age would have affected her children more than herself.

'If I had it when I was younger I would be mad because my children would be younger and I wouldn't want to leave my children when they were young, but now they are older and I am seventy eight' J1:148-150

Karen received a great deal of support from friends and spoke about better support from friends in older age because illness is more a part of older age than younger age.

'I think as you go along and get older, more and more of your friends come down with something which includes them too and makes them more tolerant. A younger person is impatient, you don't feel well go to the doctor and be quiet something like that, but no you get more tolerant as you get older, more aware of what is going on around you, more accepting of illness, when you are young you are not supposed to be ill and that makes a big difference I think'. K1:216-222

This issue of better psychosocial support in older age discussed by Karen was not verbalized by the other participants so in second interviews this was addressed. Catherine was the only other participant who agreed that older friends might be more understanding.

'I don't know you have been around and you have been around people who are sick and at our age if it is not them it is someone they know so I guess would be more understanding' C2: 23-28

3. Living in time with cancer

Two sub themes were allocated to this lifeworld structure, one of strong significance for the elderly who were more likely to have witnessed death and illnesses in both friends and family. There is also greater likelihood that past events and memories both positive and negative could influence a cancer experience. In the past, cancer and death from cancer were not discussed by the medical profession or in society as openly as today. Therefore, the elderly who witnessed a cancer experience many years ago could be more likely misinformed or recall negative experiences compared with younger cancer patients. Four participants had experienced death of family members from cancer, yet overwhelmingly they maintained positive outlooks during their own experiences.

Personal experience and impact of cancer experience on life attitude and the future

David spoke about his sister as a cancer survivor and the death of his mother from cancer although neither situation appeared to negatively influence his outlook.

'My sister has had three different cancers....my mother died of breast cancer' D1: 59-61

Despite this, David remained pragmatic and positive during treatment, something he recognized would have been more difficult if he were younger.

'I'm not staying at home and dwelling on this.....I may die of this someday but I don't think it is going to be soon...as soon as I know what the prognosis is then I will be planning more trips' D1:82/95/231

Janice had also experienced the death of an aunt with breast cancer and her brother was living with prostate cancer, yet these experiences did not negatively influence her attitude or outlook.

'I don't think about it, I have the cancer yes but what can I do, it is there. I am having treatment for it. I don't know I think that is the best way to look at it, what can you do? You cannot brood and worry and worry, it won't help' J1: 153-155

Likewise, Catherine had experienced the death of her father from cancer many years earlier and was now undergoing treatment herself.

'My father died of cancer, I thought about how he died and it frightened me and then you start to accept it.....I'm adjusting and actually this sickness makes me more grateful.....I

just have to live for the day, I don't know if I have a year or not, or six months or another day so I have to be content with each day' C1: 13/195/275-276

Frances was highly realistic about cancer diagnosis at an older age.
'I've got a lot more still to go and I see and feel much more now that I am at the end of my life, it would be lovely if I could have a few more years....I'm 75 years old, it would be nice, I've got three grandchildren who are quite young and both my daughter and son and I would love to hang out with them more and stuff like that, but if not that's it' F1:196/164-166

4. Living with cancer in relation to others

One sub theme contributed to this lifeworld, one that speaks to relations we maintain with those in our interpersonal space. While we may be surprised by our initial impression of a person, we may also be equally surprised by the reactions of those with whom we are well acquainted, especially when an unexpected life situation is confronted.

Dependency

Catherine describes relations with both her husband and her sister who in their own way did not support her during treatment. Her husband became isolated and spent little time with her, her sister was reluctant to listen to her fears of treatment failure.
'My family worries...I can't tell them if I am sad, I want to tell them, I can't really tell them, they want to hear all positive things, they worry and sometimes I am not positive' C1:140-142

In addition, she felt dependent on her family for transportation to treatment.
'I wish it were closer so I wouldn't have to burden everybody driving me here all the time...my daughter and my sister are taking turns' C1: 113-115

Most participants described little difficulty revealing their diagnosis to friends but more difficulty telling family. Helen considered not telling her adult children but then did not regret it when she did.
'I really toyed with that, I hated to tell them I really did but I felt that I had to and they were supportive, very supportive more so than I anticipated and they got right into it, they

were on the computer looking up everything, more aggressive than I was about the care, so it is hard to tell the children' H2: 52-55

Summary

The sub themes drawn from the narratives describe all facets of the lifeworld for these older people newly diagnosed with cancer. In all lifeworld structures, older age and greater life experience influenced thoughts, feeling and reactions to the experience they were living. The lifeworld 'living in a space' more than any other structure demonstrated a process of transition and adaptation for participants. They moved from a position of little knowledge about cancer as their new health problem to finding their individual level of comfort as they considered treatment at an older age. This was followed by encountering treatment and adjusting to changes their new situation brought.

The sub themes that demonstrated the experience of living in a body with cancer were highly influenced by age. Overwhelmingly, the participants considered diagnosis in older age preferable with less impact on their lives compared with how the same situation might have affected them at a younger age. Coping with cancer treatment is more likely to occur in the setting of other co morbidities for older people and this was the situation for some participants. Treatment side effects did not appear to be age related.

Age and longer life experience influenced the two sub themes represented in living in time. Older people are more likely to have witnessed death of a family member and this was the case in this group. Because all but one participant had experienced the death of family members from cancer, it might be expected this negatively affect their own experience. This did not appear to be so, all the participants described acceptance of their situation and were cautiously optimistic about the future.

The lifeworld of lived relation was the one structure that did not demonstrate multiple sub themes with strong relevance for the elderly. While two participants described dependency on family for transportation to treatment, this was not the case for the remaining participants. Furthermore, negative statements about support were only voiced by one participant, as was difficulty disclosing the diagnosis to family members. In summary, while each participant said something about their interactions with others, there was no single strong statement in this theme as there were in the other themes. Since this was apparent after the first series of interviews, it was addressed with further questions in second interviews however; additional sub themes did not emerge.

Chapter 8. Discussion

Introduction

This chapter presents an overview of rationale for the research subject and methodology chosen for the study. Findings are highlighted and discussed with respect to significance for the elderly cancer patient as well as their caregivers. The results and implications for practice are situated within the current literature with recommendations made for further research.

Purpose of the study

This study was initiated to provide a voice to a group of newly diagnosed elderly cancer patients receiving treatment. The purpose was to explore what it was like for them to be diagnosed with an illness like cancer that carries negative connotations and requires prolonged treatment. The reason to study this population subset was their current and future high proportion of new cancer diagnoses within the general population and limited documentation of their experience. A qualitative approach was chosen because this was deemed the best approach to broadly research a topic where current literature was fragmented across cancers and age groups. Hermeneutic phenomenology was chosen as methodology because it allowed for interpretation of the life experience of the treatment-naive cancer patient by an experienced oncology nurse as researcher. The time point of new diagnosis was chosen because the elderly represent the largest proportion of new cancer diagnoses so if recommendations for further research were made it would be applicable to a large group.

Summary of findings

Expressed through the lifeworld themes, the participants in this study coped well with a new cancer diagnosis and treatment. Overall, having lived through multiple life experiences both positive and negative contributed to their ability to cope and adjust in the world of a cancer patient where there is often much uncertainty. In addition, because a greater part of their lives had been lived, cancer appeared to have lesser influence on their lives psychologically. All the participants stated they would not have coped as well emotionally if they were diagnosed with cancer at a younger age.

The lifeworld of ‘space’ best demonstrated a transitional period for participants. They found themselves in an unfamiliar world that now included cancer and recognized their limitations as they faced new challenges, learnt new information, participated in decision-making within their own comfort level and finally adjusted to this new space. What was significant for the elderly in this lifeworld was misinformation about cancer risk, and preference to defer decision-making to their physicians. For many participants in this study, it was notable how fearless they were facing cancer, providing someone else asked questions, made decisions or was informed of exact details that were not paramount for them. Many noted this was not the case for younger people with cancer, who delved into every detail. In addition, many participants spoke nonchalantly about the possibility of treatment failure and facing death, something that may come more easily to one who has lived a greater part of life.

Although this group was realistic and practical in their approach to cancer, this did not mean they had no psychosocial needs during their experience and some attended support groups in an attempt to adjust to their new space. Without exception, those who attended support groups found themselves in a world not suited to them. Rather, the groups were dominated numerically by younger people whose needs seemed different from theirs and this created more not less stress and defeated the purpose of participation in the group for them. Nonetheless, many recognized benefits of a support group if among their contemporaries who they felt would support their position and views instead of setting expectations as the younger group members had done.

The lifeworld of ‘living in a body’ with cancer was expressed through the sub themes of physical side effects of treatment or prior co-existing illnesses. With the exception of one participant who experienced extreme fatigue as treatment progressed, treatment was well tolerated. Of significant impact on the elderly in this lifeworld was existence of co morbidities that made the cancer diagnosis and treatment more difficult as participants received treatment for illnesses simultaneously. This was the case for three participants, all of whom verbalized the physical and mental burden of consecutive health issues as well as the time consuming aspect of their healthcare. ‘Living in a body’ with cancer at an older age brought a degree of calm reality to the situation for all participants. All spoke about how a cancer diagnosis and the experience they were living made them grateful for the lives they had had, and diagnosis at an older age preferable to a younger age.

Greater life experience and longer lives meant greater likelihood of prior personal contact with cancer and this wholly represented the lifeworld ‘living in time’ for these older participants. It did not however appear to worsen the experience, rather they expressed the attitude of getting on with life and if life was not long for them, they were accepting.

Although the remaining lifeworld ‘living in relation to others’ was not significant for all participants, it represented a high level of significance for one participant who felt isolated yet supported by family although the support she received was not always what she wanted and this left her feeling isolated. Because this theme was not verbalized by other participants during the first interviews, this theme was raised in second interviews with other participants. None of the other participants shared her experience so this remained an isolated sub theme in the lifeworld of ‘living in relation to others’.

Significance of findings

A significant finding from this small study was misinformation about cancer risk. Although this was a small group, several participants thought they were not at risk for cancer because they were older. Two people stated they thought they were protected from cancer because they were older or that cancer would not occur in someone over a certain age. Knowledge of a population’s health belief system such as this is important for those who plan, co-ordinate and deliver health care since health beliefs and health behavior are related.[78] The elderly are more likely to receive regular healthcare,[79] so there is ongoing opportunity to address lack of knowledge and misinformation about cancer risk and benefits of early diagnosis and treatment.

Literature suggests the elderly require a different approach to care and may need more aggressive education, management and guidance since they may not pose questions or be as assertive as younger patients.[46, 47] Findings from this small study would concur with this. The majority of participants deferred to physicians to make treatment decisions and were comfortable doing so. Furthermore, the majority did not question aspects of their diagnosis and treatment. Several participants were not fully aware of side effects they would encounter from treatment and some considered either not having treatment or discontinuing treatment without fully understanding the consequences of doing so. In other words, the elderly may need greater involvement from health care providers during treatment to ensure they receive adequate treatment and appropriate management of adverse effects.

Previous studies that included small numbers of newly diagnosed elderly patients found they experience a satisfactory quality of life and manage a cancer diagnosis well as they undergo treatment.[7, 80, 81] This current study supports these findings, and while participants did not always request details of information about their diagnosis and treatment plan they noticed younger patients did, they were able to adjust to rigors of treatment and learn new skills required for treatment. Most had witnessed death of family members from cancer or had family members living with cancer yet this did not appear to affect their attitude towards their personal cancer experience or prevent them from looking to the future. In fact, unanimously this group was accepting of their diagnoses and grateful for the lives they had led. They did not appear panicked when contemplating treatment failure but nor did they question their physicians about that possibility.

It is important for health care providers to be aware of how older cancer patients cope since they are likely to care for them with increasing frequency as the population ages. Little is known about attitudes of health care providers to older oncology patients and what is known reveals negative attitudes and stereotypic views.[17] Kearney, Miller, Paul and Smith found negative attitudes towards the elderly cancer patient were widespread among nurses, physicians and ancillary staff irrespective of gender or years of experience.[17] This raises concern about adequate psychosocial support during treatment for elderly cancer patients if such ageism exists.[82] Although not a finding, there was little mention in the narrative dialogue of nurses' contribution to care. This was despite the fact that all participants spent the majority of time in the cancer center under the care of nurses.

While not all participants attended support groups, those who did were not satisfied their needs were met. Some reported increased levels of anxiety due to pressure from younger members in the group to question and challenge physicians about treatment decisions, something these older cancer patients did not see the need to do. Participants who attended support groups unanimously felt their issues were not shared by younger cancer patients but thought their needs might have been met if the group was attended by their contemporaries. None was able to locate support groups for older cancer patients, suggesting that in the large metropolitan area where this study was conducted there are few psychosocial supports specifically for the elderly cancer patient.

Implications of findings on clinical practice

No lived experience studies among the elderly cancer patient receiving treatment for newly diagnosed cancer were located during the literature review. This study could then be considered unique in its attempt to capture a time point for older cancer patients and bring their world into view for healthcare providers. Based on the findings from this study, a number of implications for practice can be considered.

Misinformation about cancer risk

The surprising aspect of this finding was not that participants thought they had some risk for cancer but they thought they were not at risk for cancer because they were older. In other words, they thought age protected them. A few studies have shown the elderly know little about their risk for cancer.[11, 13, 83] Two surveys over the last twenty years have shown that while knowledge levels has increased, the elderly are still largely unaware of their cancer risk.[11, 13] During these twenty years, the elderly have become the largest group presenting with newly diagnosed cancers of solid organs such as breast, prostate and colon; all cancers for which early detection results in significantly better outcomes.[1]

Currently in the U.S. the elderly do not participate in recommended cancer screening for these cancers at optimal levels.[84] Evidence now suggests that breast cancer screening continues to be cost effective until age 80 years,[85] and screening for prostate cancer is recommended for men with an expected lifespan of at least ten years.[18] The elderly as a group receive medical care reasonably regularly; therefore, opportunity exists for re-enforcement and discussion of benefits of early detection of cancer.

There are few studies in the elderly that include information about utilization of cancer detection tests. In 1992, Weinrich, Weinrich, Boyd, Johnson and Frank-Stromberg measured colorectal cancer knowledge among the elderly and found that approximately half the study group had not received any information about colorectal cancer in the previous year. This was despite at least one physician visit during this time. Just as concerning was the fact that one-third of those screened either did not know or did not understand the purpose of the screening test.[19] Although the Weinrich study is over ten years old and knowledge may have improved, the findings from this current study suggest the elderly still do not question aspects of their medical care and may need details of care explained to them differently and/or more frequently.

Treatment tolerance

The finding that participants in this group coped well with diagnosis and treatment should be noted because frequently health care providers develop opinions about patients that influence the care and hope they give or do not give.[82] Healthcare providers' perception of elderly cancer patients is poorly researched as Kearney et al., found in a literature review prior to their survey of oncology staff measuring attitudes to the elderly cancer patient.[17] The majority of staff, across three groups of healthcare providers with an array of oncology experience held negative and stereotypic views and opinions about caring for older cancer patients. Knowledge that this current study group coped well physically and psychologically with treatment and was able to learn new skills is important for healthcare providers.

Patient advocacy and the healthcare provider

In this current study, some participants were more accepting of treatment failure or terminating treatment prematurely. Patient misinformation about treatment outcomes and negative attitudes of healthcare providers towards older patients risks being a combination of factors that could lead to sub optimal care for this population. The opportunity exists for nurses and other healthcare providers to be proactive rather than reactive in uncovering obstacles to treatment in the elderly population that may in the long-term impact their care.

While this was a small study group, the issue of health care decision-making was prominent. Not all but the majority of participants stated they did not want to 'know too much'. This raises issues around informed consent for current treatment as well as decision-making for future treatment should the treatment plan be modified. In the U.S. the introduction of the federal Patient Self-Determination Act (PSDA) that led to development of health care proxies (HCP) by each state, addresses decision-making at a time when patients no longer have decision-making capacity but have discussed his or her wishes in advance.[86] When patients accept treatment, this implies informed consent. Yet, there may be a murky area of uncertainty about details as this study showed among a number of participants with decision-making capacity receiving treatment but deferred to physicians.

From a legal perspective, there is no provision for surrogate decision-maker when the patient has decision-making capacity. Furthermore, it is likely older patients have multiple family members, namely their children who wish to participate in their healthcare decisions. There may be potential in some families for conflict over decision-making that risks increasing tension rather than decreasing it. The implication for practice may well be advocacy on the part of healthcare providers to initiate discussion about treatment with the elderly as opposed to waiting for them to advocate for themselves, something they may not do.

While participants in this study were not approaching the end of their lives, they had been diagnosed with what is considered a serious chronic illness at an age when it is reasonable under normal health conditions for physicians to initiate discussion of advanced directives.[87] It was notable that many of participants deferred to physicians who may not always present the overall situation realistically, rather, hopelessly dismal or overly optimistic.[88] Equally notable was the scant mention of nurses' contribution to their care. This was despite time spent with nurses amounted to hours as opposed to minutes spent with physicians. While this would seem discouraging, it may suggest existence of opportunity for change by nurses, especially at the institution where the study was conducted.

Study limitations

When little is known about a subject or when literature is fragmented, a good research approach is a qualitative study because multiple themes can emerge and any one of these can direct research in a more focused way. The disadvantage of the qualitative approach is the small number of participants and the lack of generalizability of the findings.

One disadvantage of this study was location, in a large metropolitan area where better availability of services such as transportation, delivery of medications and meals exists compared to suburban or rural areas. One participant lived in a suburban area and was dependent on family members for transportation to treatment. She also required assistance with shopping so felt her level of dependence burdened her family. In other words, independence for elderly requiring treatment may be geographic and lack of services may deter some elderly people from receiving treatment or completing treatment. This was partially an issue for another participant who considered terminating treatment early because she was dependent on her children for transportation to treatment and uncomfortable with this level of burden.

Overall, participants were from a high socio-economic group and coped well with cancer and treatment. However, this may not be the case if the same study were conducted among a lower socio-economic group with less support and fewer resources or in a rural area where patients have no choice but to travel distances to treatment increasing stress and fatigue.

A further limitation was the upper age limit of this group. Although there was no age cut off as part of the inclusion criteria, no one older than 78 years was recruited for the study. Increasingly, the elderly are not considered homogeneous as their ages could span across thirty years and include very healthy people as well as those with multiple co morbidities. While this study group received different treatments and overall tolerated treatment well, this may have been different if more participants were over 80 years old.

Recommendations for further research

The elderly cancer patient is treated for cancer with increasing frequency, often without clinical trial evidence to guide or support treatment decisions.[89] While there is increasing discussion in the medical community with respect to conducting clinical trials exclusively in older populations, the reality is that these will take several years to be conducted and reported. Nursing was the first group to publish a position paper on care of the elderly in 1982, but since nursing research has been fragmented with small numbers of elderly included in studies.[2, 83, 90]

Creating a body of research in the elderly cancer patient may require division of the population into age groups such as 65-74; 75-84 and older than 85 since they are not a homogeneous group.[38] There is some evidence that physiologic decline accelerates more rapidly after age 75, therefore allocating the elderly to older or younger than 75 also seems a reasonable first step to organizing research and care guidelines for the elderly.[10] Whatever age division is chosen would be acceptable, the first step is acknowledgement of the rationale for doing so. The next step could be research conducted in each age group across the most prevalent cancers. While lung, breast, prostate and colorectal cancers are the most commonly diagnosed cancers in the elderly, the impact of treatment and symptoms varies among cancers. For example, symptoms in lung cancer are far worse and prostate cancer far better as found by Given et al., in their study of physical functioning changes after cancer diagnosis in the elderly.[38] In other words, the elderly as a group are not homogeneous nor are the cancers they are most commonly diagnosed with, therefore research by age division in each cancer seems a reasonable approach to building a body of research.

One finding of this study was misinformation about age as a risk factor for cancer. A suggestion for future research could be assessment of knowledge about cancer and cancer risk across age groups, then development of educational programs targeting those likely to benefit from early detection. For example, benefits of early detection of breast and prostate cancers are enormous with respect to survival[18] when compared with lung cancer, yet the elderly may not be aware that benefits of early detection and treatment or prognoses and outcomes differ from one cancer to another.

While it is recognized that clinical trial data and care recommendations in the elderly continues to be limited in a number of settings,[89] there is some evidence oncology nurses are poorly prepared to care for older people with cancer.[34] A survey of 247 registered nurses across the U.S. revealed over 60% had completed no continuing education in geriatric oncology for two years.[34] Furthermore, there is little literature about attitudes of healthcare providers to the elderly cancer patient and what exists shows negative attitudes among nurses, physicians and ancillary staff.[17] Further research is required to evaluate educational preparedness and attitudes of those who care for older cancer patients. Results of such research could support the introduction of mandatory continuing education programs or perhaps minimal requirements for geriatric oncology education in continuing education programs. Changing negative attitudes of healthcare providers who care for elderly cancer patients represents a greater challenge that may need to be addressed by national oncology organizations.

Conclusions

The literature review conducted prior to initiation of the study established that evidence guiding care of older cancer patients is increasing but remains fragmented across cancers and age groups. Older adults continue to be studied as one group despite evidence that those over age 75 have a higher likelihood of co morbidities and physical decline.

Older people may not be fully aware of their cancer risk and this requires further research. When the elderly are diagnosed and treated for cancer, they appear to cope adequately although differently from younger patients. Issues such as participation in decision-making and assertiveness when seeking information about treatment may require more involvement on the part of healthcare providers. This is some suggestion in the literature that ageism is apparent and educational preparedness of oncology nurses caring for older cancer patients low. The elderly are and will continue to be a significant proportion of cancer patients receiving treatment. As healthcare providers, we will need to be more proactive to meet their needs and assist them through their cancer experience.

SECTION 3

STUDY 2

KNOWLEDGE, ATTITUDES AND PERCEPTIONS ABOUT CANCER RISK IN THE 65-YEAR AND OLDER POPULATION.

IS THERE AN INFLUENCE ON SCREENING BEHAVIOR FOR BREAST, PROSTATE AND COLORECTAL CANCERS?

Chapter 9. Introduction

Context of the study

This study was developed to investigate a finding from the first study in this portfolio suggesting people 65 and older might be unaware or misinformed about age as a risk factor for cancer. This concept was broadened to include knowledge, myths and misconceptions of the most prevalent cancers as well as attitude to cancer and correlate against utilization of early detection tests for breast, prostate and colorectal cancers. For healthcare providers, information about population's knowledge and screening patterns allows for planning of interventions such as education programs and facilitating easier access to healthcare by identification and elimination of barriers.

Research question

The study aimed to answer a number of questions.

1. What do older people know about risk and early warning signs for cancers of the breast, colon and prostate?
2. Do the elderly know more about breast, prostate and colorectal cancers than those tested 10 and 20 years ago with the same questions?
3. What do older people know about lifestyle modification to decrease risk for these cancers?
4. Is there a relationship between what older people know and believe about cancer that influences their decision to participate in early screening?

Statement of the hypothesis

Higher levels of knowledge and positive attitude to cancer are related to higher self-reported compliance with screening tests for breast, prostate and colorectal cancers. Knowledge is defined as being informed about what is true or false about cancer, cancer risk and cancer treatment. This includes myths, misconceptions, group specific risk factors, early warning signs and benefits of early detection. Definition of the dependent variable is adherence to the ACS guidelines for early detection of cancers of the breast, prostate and colon. Recommendations are yearly mammogram starting at age 40, annual PSA testing from age 50 for all men with a life expectancy of at least ten years and fecal occult blood test (FOBT) and flexible sigmoidoscopy every 5 years or colonoscopy every 10 years starting at age 50.[18]

The null hypothesis states there is no relationship between knowledge and attitude to cancer and self-reported compliance with screening tests.

Significance of the study

Few studies have been conducted in older people exclusively with respect to knowledge and attitude to cancer and none located had included self reported participation in cancer screening tests. In addition, this study included all age groups of older people equally, that is sex and age quota sampling to ensure equal representation as well as opportunity for comparison of scores across age groups. Another significant point of the study was adaptation of some questions from a previously used survey developed specifically for older people so scores could be compared across time points.

Assumptions

There is the assumption and some evidence to suggest knowledge about health and healthcare is a greater influence on healthcare behavior than attitude.[91] Attitude has been found to be a strong predictor for seeking follow-up for other cancers[92] which was the rationale for inclusion of both variables in this survey. Because cancer screening in the elderly population has lagged behind the younger population, there is the assumption they continue to be under screened and experience more barriers to screening than the younger population. This was explored at the completion of the survey by comparing utilization patterns not only across age groups but also to the most recent available data in the U.S.

A further assumption in healthcare relates to gender differences, that men hold different health beliefs and are less involved in their healthcare than women.[93] For this reason, men were included in this current survey in equal numbers to women and findings compared to the limited literature available.

Summary

This study was developed in the context of a number of factors. First, to investigate a finding from an earlier study in older cancer patients, some of whom did not recognize their age as a cancer risk factor. Second, an aging population more likely diagnosed with cancer in a more advanced stage than younger people,[4] suggesting they were not screened at similar rates for major cancers. Third, few studies conducted in older people evaluated their knowledge of cancer and cancer risk. Finally, opportunity to compare knowledge about cancer and cancer risk at three time-points since 1983 in people 65 years and older.

Chapter 10. Literature Review

Introduction

In this section, a review of literature pertaining to the research question and research variables is presented. Prior surveys are critiqued and reviewed for suitability and adaptation in this current survey. Findings related to relationship between health beliefs and health behavior are presented and commented on with respect to significance to the elderly. In addition, gaps in the literature are identified and discussed as opportunities for further avenues of research in this population.

Search strategy

The search strategy for this current study built on a literature search conducted for a previous study in newly diagnosed elderly cancer patients undergoing treatment. This was reviewed and updated to determine if any papers were relevant for this second study, particularly those that would demonstrate current demographics and cancer incidence in the elderly compared to other age groups thus establishing the sub group as one numerically significant to warrant and benefit from ongoing research. The search strategy was then directly towards reviewing the literature with respect to the research variables in the proposed hypothesis as well as identifying gaps in the literature.

The initial step was locating evidence of recommended guidelines for early detection tests in the general population. A focus of the literature search was demonstrating whether early detection remained beneficial as people aged and if not, did the literature suggest when early detection was no longer beneficial. In addition, documentation of current utilization rates of early detection programs was reviewed to demonstrate if underutilization existed, degree of underutilization and if this was changing or remaining stagnant. The strategy also included searching for any prior surveys conducted in the elderly using the same or similar research variables. In the case that other surveys were located, did the survey remain current and was there a possibility of adapting questions and comparing results. Finally, because the proposed study was to be conducted in a population sub group and the study question was one of relationship between health beliefs and health behavior, literature about other sub groups such as ethnic minorities, their health beliefs and influence if any on health practices and behavior was also included in the search.

Search time span and databases

The literature review for this study was performed from March to May 2006 to include the period from 1966 to present. Since the study population was the elderly, several other resources were utilized in addition to electronic databases of MEDLINE, CINAHL and EMBASE. The additional resources were those that collect data specifically about older and retired people in the U.S. such as the National Institute of Aging, the Centers for Medicare and Medicaid Services (CMS) and the American Association for Retired People (AARP). CMS is the central database for those covered by Medicare health insurance system that includes almost all people 65 years and older so has the most recent and complete information on utilization of early detection programs reimbursed by Medicare. In addition, the Journal of the American Cancer Society was utilized as the source for current demographics about all age group cancer incidence and is one group that has established evidence based early detection recommendations.[1, 18]

Search terms

The search terms used were those that would cover all aspects of the study including the population, terms related to knowledge of cancer and cancer risk, early detection and screening, surveys related to cancer in the elderly as well as health beliefs, attitudes, awareness and behavior.

The keywords used were ‘health knowledge, health attitudes, health practice, health beliefs, health behavior, fatalism, knowledge of cancer, misconceptions about cancer, perception of cancer risk, misinformation about cancer, cancer awareness and determinants of cancer stage’ as individual terms then in combination with ‘aged, elderly and cancer’. In addition, evidence of utilization of detection programs was located in the governmental database of the Centers for Medicare and Medicaid Services.[84, 94] The electronic databases were used to locate papers related to cancer screening and early detection of cancer in the elderly. Since recommendations for early detection in the general population have only been established since 2000,[95] the literature search was performed from 2000-2006 using the keywords ‘cancer screening’ in combination with ‘elderly’.

Six hundred and fifty eight papers were located from the search. Of these, 331 were from the combined databases related to cancer screening and the elderly and 328 related to knowledge, attitude and health beliefs as well as surveys. All studies identified during the database search were assessed for relevance to the review based on the title of the papers prior to reviewing the abstracts. For example, all the relevant studies located in MEDLINE with respect to cancer screening and the elderly were located in EMBASE however, many of the papers in EMBASE were not relevant to either the elderly or cancer screening as judged by titles that did not include any of the keywords.

The studies identified from titles and abstracts were retrieved and reference lists were reviewed for any further relevant papers. For example, the search term 'knowledge of cancer' identified the second paper to use the survey 'Cancer Knowledge Survey for Elders'[13] but not the original paper when the survey was developed and results published in 1983.[11] This original survey was located from the reference list of the second paper. In addition, the keywords from relevant papers were reviewed to ensure no keywords were omitted in the search, although a large number of papers located did not list keywords. Many of the papers retrieved overlapped from one database to another so the total number of relevant papers retrieved was smaller.

Results

Three hundred and twenty eight papers were identified from the search that included some reference to health beliefs, knowledge, attitudes, perception, fatalism, misinformation and their influence if any on health behavior with or without cancer in different minority groups and the elderly. Of these, only three surveys retrieved were relevant to the elderly with a further study, a national survey that included elderly people. The surveys tested knowledge of risk and early warning signs for the most common cancers, two studies utilized the same survey, a third study had developed a survey about colorectal cancer only and the fourth study was a national survey about all major cancers.[11-13, 19] Multiple references from the national survey were reviewed because the titles included words such as 'age, cancer knowledge, attitudes or utilization'. None of these studies had been identified in the search nor did they list keywords. On review, the studies were either surveys of screening utilization for one or two cancers such as breast and cervical [96] or included a minority of older people within a larger group.[97-99] Several studies were identified from reference lists that included but were not exclusively conducted in elderly people. As noted, many papers did not include keywords so although some surveys were located from reference lists the possibility exists that studies have been missed. In any case, the last study retrieved specific to knowledge and early warning signs of the most common cancers in older people was conducted almost ten years ago in 1997.[13]

From the 331 papers retrieved during the search relating to cancer screening and the elderly, eighteen focused on the emerging and controversial issue of screening, challenges related to decision-making and when benefit from early detection begins to decline. Demographic data and utilization of screening programs was retrieved from the electronic database of the Centers for Medicare Services. The findings of the retrieved studies were grouped together around different aspects of the research variables and are now presented.

Demographics

The identification of an increasing cancer incidence that led to development of surveys as early as 1983[11] has not decreased.[1] In other words, as early as the 1980s, literature had documented a higher incidence of cancer in the 65 year and older population with increasing age a risk factor.[11] This has not changed, nor have the cancers namely breast, prostate and colorectal, where the elderly comprise the highest number of new diagnoses.[1] Early detection tests for these cancers are reimbursed by the health insurance program for the elderly in the US, so as a group the elderly have better health insurance and less out of pocket expenses for these tests than other age groups.[18] Despite these factors, no recent cancer knowledge surveys in the elderly population have been conducted.

Early detection: Utilization and underutilization

Use of early detection tests such as mammogram, colorectal screening tests and PSA tests are tracked by the Centers for Disease Control and Prevention[84, 94] but utilization remains suboptimal. As recently as 2004, only about half of all eligible older women had yearly mammograms and about one-third of older men and women had colorectal screening as recommended[18] with only small yearly increases. What is unclear in the literature is the duration for which testing should continue. For the general population, the benefits of early detection of breast, prostate and colorectal cancers are multiple including greater treatment options, less aggressive treatment, reduced risk of dying from cancer as well as being cost-effective.[18] For older people, utilization of early detection tests has been questioned with respect to when and if to discontinue screening as well as how decision making is achieved and by whom.[85, 100, 101]

Demonstrating benefits of early detection in older people can be approached from the viewpoint of safety, cost-effectiveness and yield from the screening tool. Several studies have demonstrated safety of colonoscopy and flexible sigmoidoscopy in age groups ranging from 70-94 years.[23, 102, 103] Diagnostic yield is more controversial, some studies diagnosing a higher percentage of malignancies in those 75-years and older compared to those aged 50-74 years[102] with another study demonstrating low yield in asymptomatic older people.[103] Reduction in mortality from early screening by mammogram has also been demonstrated across age groups[104] and continues to be cost effective until age 80.[85] Compared to prostate and colorectal cancers, utilization of breast cancer screening has been shown to peak and decline at an earlier age. For example, one large self-report survey comparing screening patterns of three cancers, found PSA screening increased until age 79 before decreasing compared to mammogram that peaked at age 59 and then declined.[21] This raises the question about factors contributing to the decline in screening, could this be physician or patient driven or a combination of both.

There is some literature to suggest the elderly may not receive education or referral for screening tests despite frequent physician consultations.[19, 96, 99] A study testing knowledge of colorectal cancer in older people by Weinrich, Weinrich, Boyd, Johnson and Frank-Stromberg reported that although almost their entire study group of 211 people had consulted a physician within the prior year, only about 5% had received information about colorectal cancer and cancer screening.[19] Lack of physician referral has been shown to be a strong barrier to participation in mammography and other cancer screening.[97, 98, 105]

Some literature although limited, suggests healthcare providers including physicians, nurses and ancillary staff do not view older cancer patients positively when caring for them.[17] Lack of continuing education about care of older cancer patients[34] may be partially responsible for nurses' lack of knowledge about benefits of programs such as early detection tests. In addition, there is conflicting and limited evidence with respect to guidelines for ongoing cancer screening in older people for the most common cancers. Some of the conflict relates to disparity between patient and physician priorities for decision-making. One study showed physicians were strongly influenced by such factors as current health status whereas patients did not consider this a relevant factor.[101] Several approaches to guide decision-making have been proposed, however, both discussion and decision-making can be complex and time consuming.[23, 101, 106]

Relevant surveys

Although the keywords 'cancer risk' and 'cancer awareness' had been used in the search, very few surveys measuring knowledge of cancer risk were located in the oncology or general population. All surveys located were reviewed, however because the focus of this current study was the most common cancers, it was more relevant to review surveys that had tested knowledge about breast, prostate and colorectal cancers in the elderly as was the intent of this survey.

National survey

To date, one national survey has been conducted across the U.S. measuring knowledge of risk factors for major cancers and survival after early detection.[12] This survey conducted among 12,000 subjects aged 18 years and older revealed low levels of knowledge about risk factors with two-thirds failing to recognize age as a risk factor and negative knowledge correlation between increasing age and perception of risk for breast and colon cancer among women surveyed. Age was only recognized as a risk factor for prostate cancer. Moreover, half the subjects held pessimistic views about survival from breast and colorectal cancers where 5-year survival exceeds 90% when diagnosed and treated in the early stage.[12] It is probable knowledge levels have increased over the last ten years since this study was published because access to technology and improved computer literacy have increased information availability, however increased availability of information may not translate into increased knowledge about cancer risk and survival.

Findings from the national study were reviewed when developing the survey for this current study. With the exception of prostate cancer, increasing age correlated negatively with recognition of age as a risk factor for breast and colorectal cancers. This finding was considered when developing this current survey and supported the decision for quota sampling so comparisons across age groups could be made. Comparison between studies was not intended because age groups differed between the national survey and this current survey. Review of the test method utilized in the national study led to the decision to include questions where written responses were required. Cancer knowledge was tested in the national study by respondents choosing from provided answers. Knowledge scores from these questions were low but they might have been even lower if respondents were required to provide answers, therefore knowledge might have been overestimated.

Cancer Knowledge Survey for Elders

With respect to surveys developed and tested exclusively in the elderly, the self-report questionnaire Cancer Knowledge Survey for Elders (CKSE) was the only survey located that was developed to test cancer awareness of the most common solid organ cancers in the older population.[11] CKSE was developed in conjunction with an education program targeting older people for whom the risk of cancer was recognized as higher than the general population. When reviewed for this current study, CKSE remained both relevant and current in some but not all aspects. Incidence of the cancers it addressed: breast, prostate and colorectal continue higher among the elderly compared to younger age groups and all have cost-effective early detection methods that result in better outcomes.[18] In addition, this survey was employed a second time in 1997[13] so there would be the opportunity to compare knowledge scores at three time points. The disadvantage of this survey was it was developed over 20 years ago, so some questions tested information that has likely become common knowledge such as 'Is cancer contagious?'[11] Despite this, the principles that guided development of the survey, that is, examining myths, misconceptions and knowledge of warning signs of cancer remain current.

During development of CKSE, the survey was administered twice, initially a pre-test then a post-test two weeks after an education program. Although some knowledge levels changed, the scores were not statistically significant.[11] This may have been for several reasons. The post-test was conducted using a sample group of 63 drawn from the pre-test group of 204 so knowledge scores might have been different if the entire group was post-tested. In addition, how the post-test group was chosen was unclear. Proportionally, the 71-80 age group represented a larger proportion of the post-test group than the pre-test group (48% versus 31% respectively) with fewer young elderly in the post-test group. It is possible the older age group did not retain information compared to the younger subjects resulting in lower scores. It is unclear from the paper why the entire group was not post-tested or why age divisions were proportionally different. No information about the dropout rate was documented in the paper. Percentages of correct and incorrect responses were not divided by age groups in either the pre or post-tests scores, only total scores were reported, so it was not possible to determine if one group was responsible for lower scores or lower scores were equivalent across all groups.[11] AAAlthough the paper stated the difference in pre-test and post-test scores was not statistically significant, it did not describe statistical analysis performed on the data beyond calculation of correct, incorrect and do not know responses to each question.

Some scores improved after the education program, while others did not change at all. The questions where scores did not change did not represent one single category of information. For example, the survey tested knowledge about myths, misconceptions, and early warning signs of cancer. Improvement in post-test scores about early warning signs for cancer were markedly improved for some questions, but not for others. Likewise, with questions related to misconceptions about cancer, some were dispelled almost completely (is cancer contagious?) yet others remained a belief held by 50% of the group (can a bump or a bruise to the body cause cancer?). Although scores for the question testing age as a risk factor improved, less than half of the post-test group answered this question correctly. Furthermore, scores for questions testing knowledge about improved survival after early detection and personal risk reduction did not change either. The survey did not collect information about personal use of early detection tests, but since these were not clearly established until 2000 [95] the authors of this paper did not have benefit of such guidelines.

In summary, following an education program about the most common cancers, the older population tested in this survey improved their knowledge about cancer and cancer risk but for unclear reasons continued to hold incorrect beliefs about cancer and a large proportion of the group did not recognize age as a risk factor.

Fitch adaptation of CKSE

One additional paper was uncovered that used CKSE unaltered but translated. In 1997, a large multi-ethnic Canadian study used the survey in English and seven other languages as part of a cancer awareness program.[13] The impetus for developing an education program and using this survey was three-fold; recognition of the high incidence of new cancer diagnoses in the elderly, a greater number of elderly diagnosed with more advanced cancer and a higher proportion of cancer deaths in older people compared to younger people.[13]

Although this was a large study of 513 subjects, the group consisted of seven other ethnic groups besides 271 English-speaking Canadians; therefore, many groups were small. For example, five groups consisted of between 18 and 32 people. In addition, although the entire ethnic population was born outside Canada, duration of time lived in Canada varied from group to group. The 56 Italians surveyed had lived in Canada for over 15 years yet 22% of the remaining ethnic group had lived less than 4 years in Canada. A further disparity existed across sexes in some groups. While the English-speaking group was 75% female, among 21 Punjabi subjects, 74% were male and 26% female although five of the seven ethnic groups were heavily skewed towards females comprising 61% of the group.

Initially, results of the survey were reported as total scores for the entire group then scores for ethnic groups scored together and compared to the English language group. Compared to English-speaking Canadians, the scores for ethnic groups were lower for nine of the 12 questions and this was statistically significant. No statistical significance was demonstrated for the remaining three questions where test scores differed. Mean scores for women were slightly higher than scores for men, 6.2 versus 5.1.

With respect to the ethnic groups, total scores did not reveal the true knowledge levels for each group or provide any information about where knowledge was lacking with respect to a single group. The question ‘can blood in a bowel movement be a sign of cancer?’ was answered incorrectly by 84% of the non-English speakers however scores were not reported for each group. It might have been more advantageous to compare small group to small group or across groups based on time lived in Canada therefore comparing knowledge levels as assimilation increased and people could better access healthcare and healthcare information.

Three questions did not demonstrate a statistically significant difference in scores between the two groups. One question related to age as a risk factor for cancer in older people and scored similarly for both groups and almost equally to the scores in the original survey in 1983. In other words, the belief that older people are no more likely to develop cancer than younger people are might be a firmly entrenched belief across time and ethnicities.

In summary, although this was a large study, a number of factors should be considered in the findings. The ethnic groups consisted of many small groups with varying degrees of assimilation and unclear language skills however, were evaluated as one group. In addition, both the English-speaking group and the ethnic groups were predominantly women. These disparities might be more relevant in the ethnic group and perhaps responsible for lower knowledge scores, since it is likely ethnic women experience more difficulty than Canadian women when assessing healthcare due to language and unfamiliarity with the system. Since the survey was translated into native languages, it was unclear what the English literacy level was among the ethnic groups as healthcare and healthcare information may not always be available in all languages. It might have been more advantageous to compare the ethnic groups who were more equally matched for length of time in the country and degree of assimilation as well as numerical size of the group.

Other surveys

Occasionally, older people have been included in surveys measuring knowledge about certain cancer risks but with variable representation in the study population.[83, 97, 99] The importance of adequate representation in a study may only become apparent when the results are examined. For example, in their survey measuring hereditary and sporadic breast cancer risk factors, Katapodi & Aouizerat included 54 subjects aged 50-69 but only 10 subjects aged 70-85 years and found that as age increased, the likelihood of recognizing age as a risk factor decreased.[83] Since there were far fewer subjects in the older age group compared to the younger group the comparison is somewhat unequal. Similarly, a large study measuring knowledge and attitude to breast cancer found knowledge decreased with age however, so did the number of subjects older than 60 years.[99] The numerical difference of subjects from one age group to another suggests that including equal numbers of subjects in each group might provide a better comparison. This supported the rationale for age and sex quota sampling in this current survey.

Health beliefs

From the large volume of papers located using the multiple keywords around health knowledge, attitudes and perception, the titles were scanned for papers where correlation with health practice and behavior was a focus of the study. The majority of studies located were conducted in ethnic and minority groups who share some similarities to the elderly with respect to health care and health outcomes. For example, those presenting with later stage cancers resulting in higher mortality are more likely from ethnic or minority groups compared to the Caucasian population[49, 107] or the elderly compared to the younger population.[4, 78] Therefore, rationale for reviewing the literature about health beliefs and health behavior among ethnic or minority populations was examination for existence and consistency of correlation, and if comparisons could be drawn with the elderly population.

The relevance of health beliefs to screening behavior was found to be both a prominent and complex finding among ethnic groups where misconceptions about screening often results in delays or failure of care delivery.[78, 90] Moreover, despite similarities such as language and customs within ethnic groups, people held incorrect and widely different health beliefs that influenced their health behavior with respect to prevention and screening for cancer.[78, 91] In other words, although different nationalities spoke the same language and had access to the same information, some nationalities were deeply fatalistic and negative towards participation in early detection programs for cancer while others were not.

In some ethnic groups, knowledge of cancer guidelines has been found to be a significant predictor of participation in early screening programs when attitude to cancer did not appear to be an influence.[91] This suggests education about early cancer detection may be beneficial because knowledge of cancer might be a stronger predictor for participation in early detection programs than attitude to cancer cure.

Among minority groups such as African-American men, prostate cancer deaths are twice those of the Caucasian population.[1] Factors influencing participation in screening programs in this group were shown in one study to be multi-factorial. Subjects were not reluctant to comply with screening guidelines if instructed by physicians, however about half the study group did not believe they were at risk and one-third did not wish to be informed of a cancer diagnosis.[108]

Gaps in the literature

Although the increasing incidence of cancer in the elderly population was recognized in the 1980s, and this led to a cancer education program and survey, few surveys have been conducted since and none located after 1997. The elderly as a group continue to be studied as one group despite their ages spanning a thirty-year survival period and the possibility of significantly different levels of physical function and decline. In other words, the elderly are more heterogeneous than other age groups. One objective of this study was to employ quota sampling and compare knowledge, attitude scores and self-reported screening utilization scores across age groups. Participation in some cancer screening tests requires physician referral so there knowledge and application of guidelines is relevant. There is scant literature about attitudes and educational preparedness of healthcare providers to care of the elderly. Limited literature reveals negative attitudes among many professionals as well as inconsistent continuing education.

Conclusion

Since development of an age and cancer specific education program and survey in the 1980s, age has remained a risk factor and the elderly now comprise a larger proportion of the population than twenty years ago. Early detection of cancer by screening tests results in better outcomes with less aggressive treatment for several cancers. Compared with other age groups, the elderly have better health insurance coverage and less out of pocket expenses but continue to underutilize recommended tests. Discontinuing screening tests in the elderly is a complex issue requiring consideration of ongoing benefit versus risk. Lack of physician referral for screening is a significant factor across many cancers and age groups, physician lack of continuing education might influence lack of referral. Literature about educational preparedness and attitudes of healthcare providers to the elderly is scant and what exists shows mostly negative attitudes. Although a national survey in the general population demonstrated low knowledge levels about cancer prevention and survival and lack of recognition of risk factors including age, educational programs to correct this knowledge deficit have not yet been developed nationally.

Chapter 11. Methods

Introduction

In this section, the research design, population and recruitment process is presented. The variables are defined and the data collection tool is described. Type of measurement scale, instrument validity and reliability and ethical issues specific to the study are discussed. This is followed by description of data extraction and statistical tests used to analyze the data. Tools used to conduct the study are included as appendices II, III and IV.

Research design

The design was a non-experimental correlation study that used a survey as data collection tool to measure variables of knowledge, attitude to cancer and treatment and self-reported utilization of recommended screening tests for breast, prostate and colorectal cancers. The study population was cognitively capable adults aged 65 years and older at the time of recruitment with no upper age limit who were capable of completing a written questionnaire in English without assistance and had no prior history of breast, prostate or colorectal cancers. These cancers were targeted because they are the most common cancers in this age group and benefits of early screening have been established.[18]

The hypothesis tested was higher levels of knowledge and positive attitudes to cancer were related to increased participation in cancer screening programs as measured by self-report. This hypothesis was developed after a prior qualitative study exploring the experience of a new cancer diagnosis in a small study of people 65 years and older revealed a belief that older people were at lower risk for cancer than younger people did and this current survey sought to explore this belief further.

The surveyed group was a quota of 60 subjects, 10 men and 10 women in 3 stratified age groups, 65-74; 75-84; and 85 years and older. Because the group shared characteristics such as sex, age and no prior history of cancer this can be considered a convenience sample. Subjects were those present on recruitment days who agreed to participate and the quota for their age group had not been filled.

Recruitment process

Recruitment was conducted at a senior center in a large metropolitan area where programs for people 65 years and older were offered. Subjects were independent living adults voluntarily attending the program open to all individuals 65 years or older without charge and included a variety of recreational and educational programs. A flyer (Appendix II) was posted in advance of recruitment, requesting volunteers and describing the purpose of the study, recruitment times and time commitment required of the subjects.

On recruitment days, the researcher approached the subjects, referred to the flyer then requested permission to review the information sheet (Appendix III) with the prospective subject. After reviewing the information sheet, subjects were offered the option of reviewing the information sheet alone before deciding to participate, or if they agreed to participate, provided with a survey in an envelope with instructions to complete the survey alone, and then return it to the researcher in the sealed envelope. Record was kept of the number of surveys distributed each recruitment day in order to track the returned surveys. While not all subjects approached agreed to participate, all distributed surveys were returned.

The tool was piloted on the first day of recruitment to evaluate and determine if the instrument required refining or if respondents encountered difficulty understanding or completing the survey. Five surveys were piloted and evaluated before further surveys were distributed. All subjects completed the survey in less than 15 minutes, there were no missed responses and no subject reported difficulty interpreting the questions. Because all five surveys were completed correctly, that is all subjects answered NO to the screening question about cancer history, all questions were answered with a single response and no questions were voided, these five surveys were included in the final tally. Surveys were numbered for tracking purposes and as an identifier when scores were calculated.

Some difficulties with recruitment were encountered. Many potential subjects refused participation due to time constraint and did not wish to choose between attending programs and completing surveys. This was overcome by attempting recruitment at lunchtime and approaching those who had exited the dining room first since they would have additional time to complete the survey. In addition, a number of people refused participation citing concern about developing cancer; this was the most common reason for non-participation. Since this appeared to be a strong belief among those who verbalized it, no attempt was made to dispel this and these subjects were not approached again.

As the quota for each age group was completed, the advertising flyer was amended to reflect the age group of subjects still required. It was expected that younger age groups would be easier to recruit so early in the recruitment process, those who appeared to be older were approached. Despite this, those 85 years and older were the last group to complete recruitment so the flyer was updated to reflect this. To avoid embarrassing those who appeared older than their actual age, the flyer with the age requirement prominently displayed was used when approaching people who would either respond by saying they were in that age category or not. Occasionally people stated they were not in the required age group but directed the researcher to others who they thought were in the recruitment group. This occurred on three occasions and although this aided recruitment these subjects may have been recruited without assistance since they were in the same room. This process was repeated weekly over approximately a two-month period until each age group quota was achieved.

Data Instrument

The data collection tool (Appendix IV) was a self-administered questionnaire consisting of 17 questions in addition to demographic information including age, gender and education. Since there was no written consent, an additional question was included as a screening question to demonstrate eligibility criteria for no prior history of breast, prostate or colorectal cancers. If this question was not answered or if subjects answered YES, the survey would be discarded. One survey was discarded because this question was not answered but none was discarded because of prior cancer history.

The tool was developed to test knowledge, myths and misconceptions about the most common cancers as well as attitude to cancer, early detection of cancer and self-reported personal utilization of screening tests. Distribution of questions was 14 each for men and women, 9 questions related to knowledge of cancer (8 each for men and women), 4 questions examined attitude to cancer, early detection and treatment, (3 each for men and women) and 3 questions each for men and women asking about utilization of cancer screening tests. Some questions were adapted from two prior surveys. Six questions were taken from Cancer Knowledge Survey for Elders[11] (CKSE), questions 1-4, 12 and 16 and were multiple choice questions with provided answers of YES, NO or DON'T KNOW. Two statements from Knowledge of Colorectal Cancer Questionnaire were adapted into questions for this survey, questions 5 and 8.[19]

Questions 1-5 were multiple-choice questions with provided response of YES, NO or DO NOT KNOW.
Question 1 tested knowledge of age as a risk factor for cancer
Question 2 tested knowledge of myths about cancer
Questions 3 and 4 tested knowledge of warning signs
Question 5 tested knowledge of benefits of early detection of cancer

Questions 6 and 7 collected data about self-reported personal utilization of tests for colorectal cancer as recommended by the American Cancer Society guidelines[18] and were Likert scored with five for correct utilization, four for lower level of utilization, three for less than adequate utilization, two for no further testing and one for never being tested.

Question 8 examined attitude and knowledge of the impact of early detection of colorectal cancer.

Question 9 tested attitude to diagnosis and treatment of a new cancer. Both were Likert scored with five for positive attitude, four allocated to less positive attitude, three for no opinion, two for a degree of negative attitude and one for a completely negative attitude towards early detection and treatment.

Question 10 asked about prevention of any type of cancer by lifestyle modification and required a written response instead of choosing a provided answer. Accepted answers were those recommended by the American Cancer Society for which sufficient evidence exists for their recommendation to decrease the risk for several cancers and are as follows.[109]

- Avoiding obesity and weight control throughout lifetime
- Regular moderate to vigorous exercise
- Moderation of alcohol intake
- Limited intake of red and processed meats, daily consumption of fruits and vegetables
- Consumption of recommended levels of calcium
- Avoidance of tobacco and tobacco products
- Use of sunscreen and limited sun exposure

Question 11 also required a written response about warning signs for breast, prostate or colorectal cancers with accepted answers of fatigue, pain, weight loss, change in bowel or bladder function, unusual bleeding or discharge including blood in the stool or urine and thickening or lump in the breast or other part of the body.[110] Some of the information subjects were required to provide had already been tested. For example, pain, breast lumps and blood in the stool were all signs included in the first four multiple-choice questions. The rationale for required written responses was to better evaluate what subjects knew, since multiple choice responses can over estimate knowledge[12] and testing knowledge levels by prompting has been shown to elicit higher scores than unprompted answers.[111]

Questions 12-14 were for men only with respect to prostate cancer.
Question 12 was a multiple-choice question adapted from CKSE and tested knowledge of warning signs of prostate cancer.

Question 13 was Likert scored testing attitude to benefits of early detection of prostate cancer with five for positive attitude, four for lower level of positive attitude, three for no opinion, two for a degree of negative attitude and one for a completely negative attitude.

Question 14 asked about personal utilization of PSA screening and was Likert scored with five for recommended utilization according to the ACS guidelines, four for lower level of utilization, three for inadequate utilization, two for no further utilization and one for never tested.

Questions 15-17 were for women only and were the same as the questions for men; one question testing knowledge versus myths about breast cancer, attitude to early detection and personal utilization of screening mammogram.

Instrument reliability and validity

The survey consisted of 17 questions, 14 each for men and women that measured cancer knowledge, attitude to cancer and self-reported screening history for cancers of the breast, colon and prostate as recommended by the American Cancer Society.[18] Questions measuring knowledge scores were adapted from two separate surveys, questions 1-4, 12 and 16 from Cancer Knowledge Survey for Elders[11] and question 5 from Knowledge of

Colorectal Cancer Survey.[19] While this current survey was not tested for content validity or reliability, the adapted knowledge questions were from surveys that had been repeated with consistent results over a time span of a decade and were not modified for this survey.[11, 13] Stability and consistency of results can be considered measures of reliability.[20] Furthermore, the number of questions in this current survey was comparable to other surveys located that were developed specifically for older people with one survey demonstrating reliability for a 12-item survey.[19]

With respect to content validity of questions developed specifically for this survey, these questions asking about personal utilization of recommended screening tests as per the guidelines developed by the American Cancer Society, therefore content had been established and validated.

Ethical Issues

Coercion

The subjects were approached by the researcher and the study explained to them. Those who did not readily agree to participate were given the option of reviewing the information sheet again either alone or with the researcher. Those unsure about participation were not approached again by the researcher who reiterated the voluntary nature of participation. These subjects were encouraged to retain the information sheet that included contact information for the researcher and given the option of approaching the researcher either the same day or the following week if they wished to participate. No attempt was made to coerce subjects to participate if they were unsure about participation. Informed consent was not obtained because completion and return of the survey implied consent.

Anonymity

Surveys were numbered for tracking purposes since the center was large, over several floors and subjects often moved to other areas of the center to complete the survey. Although the survey collected demographic information such as age and education, there was no way to identify those who returned the survey since names were not documented on the surveys. In addition, subjects were not asked their names or any other personal information when the surveys were distributed.

Confidentiality

I was the sole person responsible for distribution of surveys. Although it was agreed that staff members could temporarily retain completed surveys in sealed envelopes until I collected them later the same day, this did not occur as all subjects returned the surveys directly to me. Subjects completed surveys in any area they chose within the center. While I may have been present in the general area, I was not in the same room where subjects were completing surveys. No discussion about the survey occurred in the same vicinity where surveys were being completed. In addition, no detailed discussion about the survey content occurred prior to subjects completing the survey.

The completed surveys were taken to my home, the sealed envelopes were broken and surveys deposited in an opaque envelope then chosen at random for data extraction as each group of 10 surveys were completed. This was to maintain the anonymous nature of the process. The surveys or results of any individual survey were not shown or discussed with anyone.

Storage and access to data

Hard copy and electronic data related to this survey was securely stored at my home to prevent unauthorized access, disclosure or loss and will be for a period of seven years after completion of the study according to The University of Adelaide requirements. Electronic data was saved on a device that has appropriate security safeguards such as unique identification of authorized users, password protection, anti-virus controls, firewall configuration, and scheduled and automatic backups to prevent against data loss or theft.

Data extraction

Data was extracted from surveys in a stepwise manner and some steps were duplicated to ensure accuracy. Surveys were discarded if more than one response was chosen for the same question making it unclear what the intended response was. Only one survey was discarded for this reason, in addition, one survey was discarded because the cancer-screening question was not answered so inclusion criteria could not be demonstrated. No other surveys were discarded, although several surveys were not counted in the statistical analysis because they were completed and returned after the quota for the age group was filled.

Data extraction commenced with documentation of responses to adapted questions (questions 1-4, 12 and 16). Responses were tallied by response of YES, NO, DO NOT KNOW or MISSED responses and then calculated as a percentage of the total. Each survey was then allocated knowledge, attitude and utilization scores with utilization further divided into mammogram, PSA and colorectal testing so five sets of scores were generated for each survey. The scores were initially recorded on a Microsoft Office Excel spreadsheet (Appendix V). Surveys were recorded on the spreadsheet by survey number, age group and gender followed by the scores. After all surveys were recorded, the surveys were then re-scored manually and scores documented on individual surveys then compared with the spreadsheet to ensure no errors occurred in manual calculation of scores or recording of data on the excel document. Knowledge scores were based on the number of correct answers to multiple-choice questions with one point allocated to each of the six questions, the highest score being 6. Mean scores were calculated and difference in distribution of knowledge score between age and genders were tested by contingency table analysis.

The questions where respondents were required to provide written responses (questions 10 and 11) were scored collectively by age group not individually, because a single score could not be allocated to a question that allowed for several possible responses. These responses were counted collectively by age group. The provided answers were tallied and represented as quantity of responses and number of times each response occurred. Recording of these responses commenced with verbatim documentation for each answer provided for each age group then categories created and these documented on a spreadsheet. For example, responses such as ‘healthy diet, low fat diet, high fiber diet, moderate red meat, fresh fruit and vegetables’ were all initially recorded as individual answers then counted collectively under the heading of ‘balanced diet’ on the spreadsheet. This was done because they could be categorized as diet modification recommended by the American Cancer Society Guidelines. Likewise, responses such as ‘trouble passing urine, blood in the urine, urinating too often’, were categorized under a single heading of ‘change in bladder function’. A number of respondents documented answers such as breast lumps and changes in the skin such as dimpling so this was counted as two responses; this explains response number of 21 in the 65-74 age group seen in Table 3-16.

Attitude and utilization questions were Likert scored with the highest possible score being 15. The utilization scores were totaled, and then separated into scores for each test, 5 for correct utilization of mammogram and PSA and 10 for colorectal screening.

Statistical methods

Statistical Package for the Social Sciences software Program (SPSS) version 15.0 was used to calculate descriptive statistics and correlation co-efficient. Level of significance was set at p=0.05 with number of paired observations (N) for each age group = 10 or 20 depending on the test. For example, when calculating women's knowledge scores and use of mammogram for each age group, the number of paired observations was 10, but when correlating knowledge scores with colorectal tests, scores for men and women were counted collectively in each age group so paired observations was 20. Spearman's Rank Order Correlation (rho) was used to detect relationship between the following in each age group:

Men

- Knowledge and PSA screening scores

Women

- Knowledge and mammogram scores

Women and Men

- Knowledge and colorectal scores
- Attitude and PSA, colorectal and mammogram scores

The critical value was 0.450 for 20 paired observations and 0.648 for 10 paired observations.[112] The final report also compared knowledge scores for the six questions from the CKSE survey (questions 1-4, 12 and 16) to scores from the two previous reports generated from this survey. The purpose was to demonstrate if knowledge about cancer and cancer risk among the elderly had increased over the last two decades. Scores for questions requiring written responses (questions 10 and 11) were scored collectively and shown in the final report in chapter 12 as tables 3-15 and 3-16.

Chapter 12. Results

Introduction

This section presents findings of the study including descriptive statistics, correlation results, and comparison of scores for questions adapted from a prior survey as well as responses to questions requiring written answers that resulted in collective data. Tables have been used to demonstrate comparison scores, descriptive statistics, correlation studies and collective data.

Demographic data

Age and sex data were collected as part of demographic data to demonstrate quota sampling for twenty men and women in each of the 3 age groups, 65-74, 75-84 and 85 years and older. Education level was also collected but not used in any statistical analysis.

Discarded surveys

One survey was discarded because it contained more than one response to several of the questions so was unclear what the intended response was. One survey omitted the response to the question about PSA testing; this survey was not discarded as it met inclusion criteria. No surveys were ineligible because of prior cancer history.

Descriptive statistics

Descriptive statistics were generated using SPSS version 15.0 for all sexes and age groups across the variables of knowledge, attitude and each of the three utilization test scores (Table 3-1). The scores for these variables will be discussed with respect to mean, range and trends across sexes and ages. The possible range of scores was from one to six for knowledge, one to fifteen for attitude, one to ten for colorectal tests and one to five for both mammography and PSA. Range of scores from low to high indicates less to more knowledge, attitude and frequency of screening. The scale of measurement for all variables was ordinal.

Table 3-1

Descriptive Statistics

Age	Sex	Variables	N	Minimum	Maximum	Mean	Std Deviation
65-74	F	Attitude	10	11	15	13.70	1.252
		Knowledge	10	2	6	4.40	1.265
		Mammo	10	5	5	5.00	.000
		Psa	0				
		Colorectal	10	2	10	6.70	2.830
		Valid N listwise	0				
65-74	M	Attitude	10	10	15	13.30	1.418
		Knowledge	10	3	6	4.30	1.160
		Mammo	0				
		Psa	10	1	5	4.40	1.265
		Colorectal	10	4	10	7.80	1.932
		Valid N listwise	0				
75-84	F	Attitude	10	9	14	12.30	1.567
		Knowledge	10	3	4	3.70	.483
		Mammo	10	2	5	3.90	1.370
		Psa	0				
		Colorectal	10	2	10	6.10	2.807
		Valid N listwise	0				
75-84	M	Attitude	10	7	15	11.30	2.452
		Knowledge	10	3	6	4.40	1.174
		Mammo	0				
		Psa	10	2	5	4.40	.966
		Colorectal	10	6	10	8.50	1.581
		Valid N listwise	0				
85+	F	Attitude	10	9	15	11.60	2.171
		Knowledge	10	3	5	4.20	.919
		Mammo	10	1	5	2.70	1.567
		Psa	0				
		Colorectal	10	2	10	4.40	3.204
		Valid N listwise	0				
85+	M	Attitude	10	9	15	12.60	2.011
		Knowledge	10	2	6	4.00	1.155
		Mammo	0				
		Psa	10	2	5	4.56	1.014
		Colorectal	10	5	10	6.80	1.874
		Valid N listwise	0				

Knowledge scores

Knowledge scores ranged from two to six as the maximum score. All groups scored across this range with the exception of 75-84 year old female group where score range was three to four (Table 3-1). In other words, this group exhibited little range in knowledge scores about cancer and the lowest mean knowledge score of 3.70 (SD=0.483) as seen in Figure 3-1. The other groups, regardless of age demonstrated higher mean scores of 4.0 (SD= 1.155) to 4.4 (SD=1.265) so there was no clear trend across age and sex groups for knowledge scores. This is represented in the figure below with age groups displayed on the x-axis and response on the y-axis. (Figure 3-1).

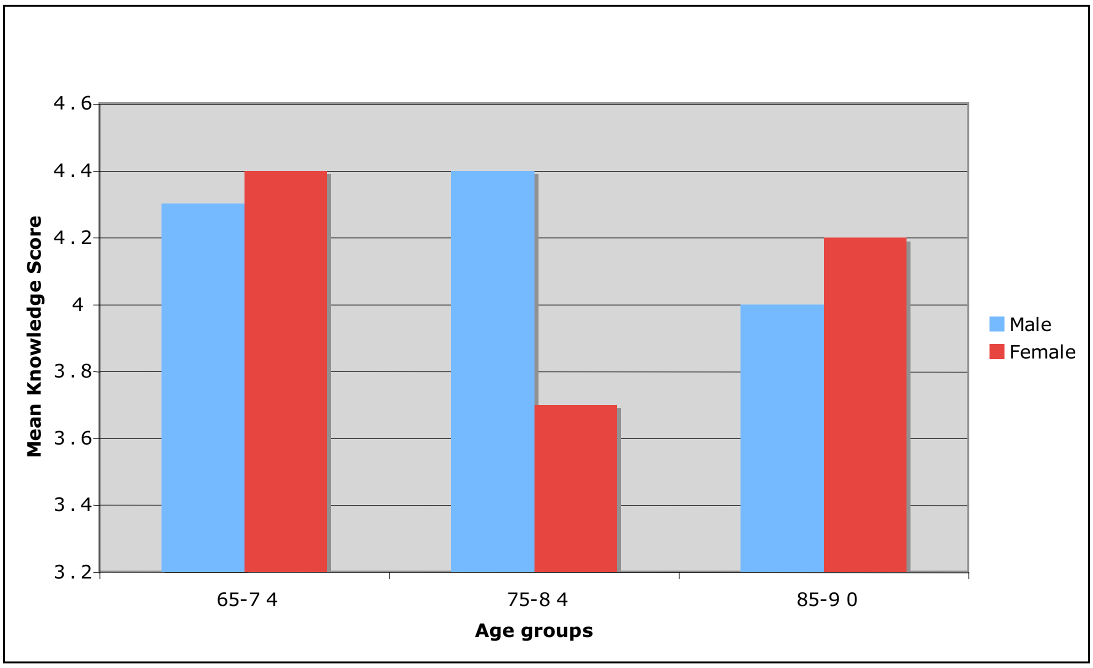

Figure 3-1 Age groups and mean knowledge score.

Attitude scores

As shown in Figure 3-2, attitude scores fell slightly with age for women, 13.7 (SD=1.252 range 11-15) to 12.3 (SD=1.567 range 9-14) to 11.6 (SD=2.171 range 9-15) although this trend was not seen in men where mean attitude scores for the oldest group were higher than the middle group. This middle group of men also exhibited the largest range of scores for attitude from seven to 15 whereas all other groups scored between 9 and 15. This is demonstrated in Table 3-1.

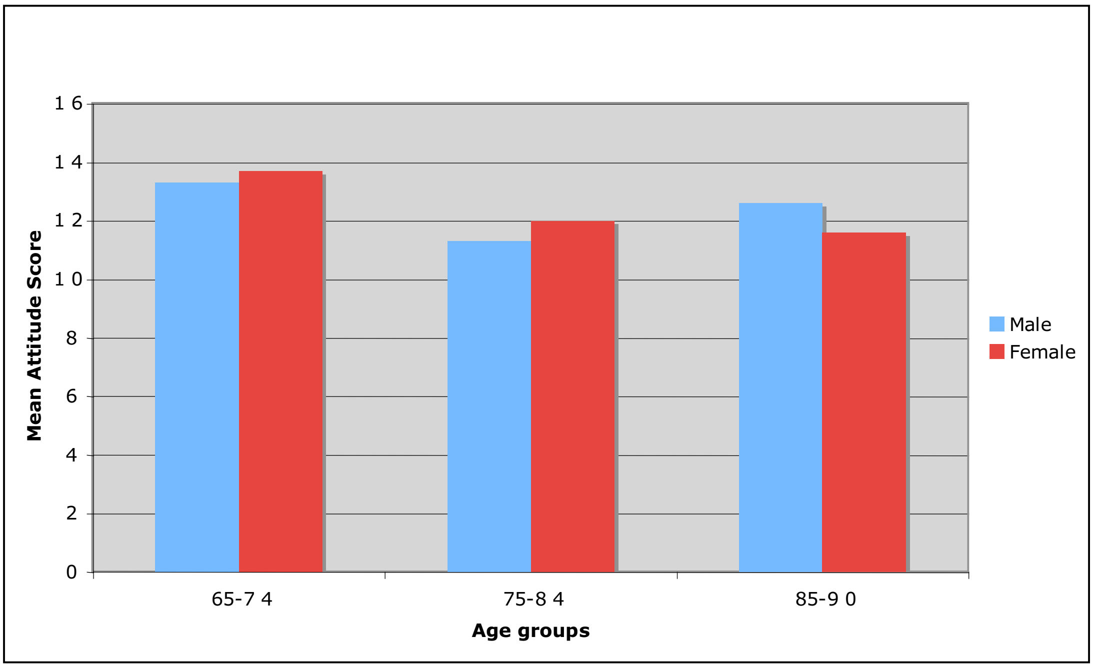

Figure 3-2 Age groups and mean attitude score

Utilization scores

Mean scores for utilization tests were calculated for each individual test and compared across age groups (Table 3-1). While mean PSA scores remained stable across age groups, 4.40 (SD=1.265 range 2-6) for 65-74 and 75-85 year old men with 4.56 (SD=1.014 range 2-5) for the 85 and older group, mammography scores decreased as age increased. Reported utilization of mammogram in the 65-74 year old women was fully compliant with a mean score of 5.0 but decreased to 3.90 (SD=1.370 range 2-5) for 75-84 year old women and further to 2.70 (SD=1.567) for women 85 years and older. In addition, the range of scores became wider as age increased indicating reported less frequent mammogram testing.

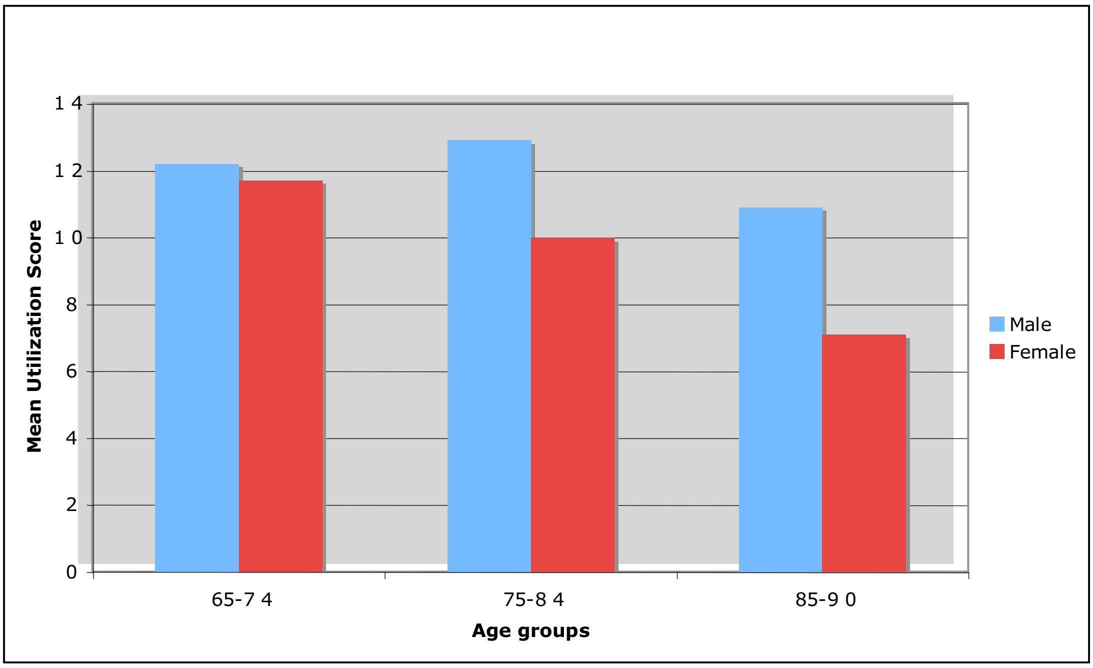

Figure 3-3 Age groups and mean utilization score

Colorectal scores were more complex. As shown in Table 3-1, all age groups displayed large ranges in scores from two to 10 across both sexes and age groups. Mean scores for women progressively declined with age from 6.7 (SD=2.83) to 6.1 (SD=2.807) to 4.4 (SD=3.204) men scored higher for all age groups, the oldest men scored the lowest at 6.8 (SD=1.874) which was slightly higher than the highest female group score.

Correlation studies

Correlation results will be presented for the variables of knowledge and attitude with each of the utilization tests, PSA for men and mammogram for women where n=10. Colorectal scores were combined for men and women in each age group so the number of subjects was n=20. Spearman's Rank Order Correlation (rho) was used to calculate strength of the relationship between the variables, the critical value for n=10 was 0.68 and 0.450 for n=20 with p value significant at 0.05. The 65-74 age group of women self-reported complete compliance with mammogram testing; no correlation studies were conducted between the variables of knowledge or attitude and mammography.

PSA

Knowledge

Positive correlation between knowledge and reported use of PSA was demonstrated for two age groups with the middle age group demonstrating a negative relationship between knowledge and PSA (-0.662) that was statistically significant, p value 0.037 (Table 3-3). The other two age groups demonstrated positive correlation 0.443 for the 85 and older group (Table 3-4) and weaker positive correlation for the youngest group (Table 3-2) at 0.220 but neither was statistically significantly. Correlation co-efficient was calculated on nine subjects in the 85 and older group due to 1 missed response in this age category.

Attitude

Only the youngest age group 65-74 year old men demonstrated strong positive correlation between attitude and reported use of PSA tests 0.577 although not statistically significant, p value 0.081 (Table 3-2). The middle group of men demonstrated only very weak positive correlation 0.059 not statistically significant, p value 0.870 (Table 3-3) while the oldest men showed negative correlation between attitude and reported use of PSA -0.106 not statistically significant, p value 0.786 (Table 3-4).

Table 3-2

Correlation between knowledge, attitude and PSA in all age groups

Age groups = 65-74 Men

			knowledge	attitude	Psa
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	.220
		Sig. (2-tailed)		...	.541
		N	10	...	10
	attitude	Correlation Coefficient	...	1.000	.577
		Sig. (2-tailed)	...		.081
		N	...	10	10
	Psa	Correlation Coefficient	.220	.577	1.000
		Sig. (2-tailed)	.541	.081	
		N	10	10	10

Table 3-3

Age groups = 75-84 Men

			knowledge	attitude	Psa
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	-.662*
		Sig. (2-tailed)		...	.037
		N	10	...	10
	attitude	Correlation Coefficient	...	1.000	.059
		Sig. (2-tailed)	...		.870
		N	...	10	10
	Psa	Correlation Coefficient	-.662*	.059	1.000
		Sig. (2-tailed)	.037	.870	
		N	10	10	10

*Correlation is significant at the 0.05 level (2-tailed)

Table 3-4

Age groups = 85 and older Men

			knowledge	attitude	Psa
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	.443
		Sig. (2-tailed)		...	.232
		N	10	...	9
	attitude	Correlation Coefficient	...	1.000	-.106
		Sig. (2-tailed)	...		.786
		N	...	10	9
	Psa	Correlation Coefficient	.443	-.106	1.000
		Sig. (2-tailed)	.232	.786	
		N	9	9	9

Mammogram

Knowledge

The youngest age group self-reported complete compliance with recommended mammogram screening as well as the highest mean knowledge score of 4.40 (SD=1.265) as seen in Table 3-1. Correlation co-efficient was not computed for mammography and the independent variables because of perfect compliance (Table 3-5). The other two age groups demonstrated very weak positive correlation between knowledge as a predictor for reported use of mammography, neither statistically significant (Tables 3-6 and 3-7).

Attitude

The oldest group of women was the only group to demonstrate a positive relationship between attitude (0.861) and mammography that was statistically significant, p value 0.001 (Table 3-7). The middle age group demonstrated weak positive correlation (0.174) not statistically significant, p value 0.630 (Table 3-6).

Table 3-5

Correlation between knowledge, attitude and mammography in 65-74 age group

Age groups = 65-74 women

			knowledge	attitude	mammo
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	....
		Sig. (2-tailed)		...	....
		N	10	...	10
	attitude	Correlation Coefficient	...	1.000	...
		Sig. (2-tailed)	...		...
		N	...	10	...
	Mammo	Correlation Coefficient	....	...	....
		Sig. (2-tailed)	....	...	....
		N	10	...	10

Table 3-6

Correlation between knowledge, attitude and mammography in 75-84 age group
Age groups = 75-84 women

			knowledge	attitude	mammo
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	.165
		Sig. (2-tailed)	.	...	.649
		N	10	...	10
	attitude	Correlation Coefficient	...	1.000	.174
		Sig. (2-tailed)	...	.	.630
		N	...	10	10
	Mammo	Correlation Coefficient	.165	.174	1.000
		Sig. (2-tailed)	.649	.630	
		N	10	10	10

Table 3-7

Correlation between knowledge, attitude and mammography in 85+ age group
Age groups = 85 and older women

			knowledge	attitude	mammo
Spearman's rho	knowledge	Correlation Coefficient	1.000	...	.141
		Sig. (2-tailed)		...	.697
		N	10	...	10
	attitude	Correlation Coefficient	...	1.000	.861*
		Sig. (2-tailed)	...		.001
		N	...	10	10
	Mammo	Correlation Coefficient	.141	.861*	1.000
		Sig. (2-tailed)	.697	.001	
		N	10	10	10

*Correlation is significant at the 0.05 level (2-tailed)

Colorectal testing

Unlike other tests where the subject number was 10, series of correlation were conducted on 20 subjects in each group because men and women were combined (Tables 3-8, 3-9, 3-10, 3-11, 3-12 and 3-13).

Knowledge

As shown in Table 3-8, only the youngest age group demonstrated strong positive correlation (0.425) between knowledge and reported use of colorectal tests however, this was not statistically significant, p value 0.062. The middle age group demonstrated only very weak negative correlation with weak positive correlation for the oldest age group but neither was statistically significant (Table 3-9, Table 3-10).

Table 3-8

Correlation between knowledge and colorectal scores in 65-74 year age group

Age groups = 65-74 Men and women

Spearman's rho	knowledge	Correlation Coefficient	1.000	.425
		Sig. (2-tailed)	.	.062
		N	20	20
	colorectal	Correlation Coefficient	.425	1.000
		Sig. (2-tailed)	.062	.
		N	20	20

Table 3-9

Correlation between knowledge and colorectal scores in 75-84 year age group

Age groups = 75-84 Men and women

Spearman's rho	knowledge	Correlation Coefficient	1.000	-.062
		Sig. (2-tailed)	.	.794
		N	20	20
	colorectal	Correlation Coefficient	-.062	1.000
		Sig. (2-tailed)	.794	.
		N	20	20

Table 3-10

Correlation between knowledge and colorectal scores in 85+ age group

Age groups = 85+ Men and women

Spearman's rho	knowledge	Correlation Coefficient	1.000	.277
		Sig. (2-tailed)	.	.237
		N	20	20
	colorectal	Correlation Coefficient	.277	1.000
		Sig. (2-tailed)	.237	.
		N	20	20

Attitude

In addition to strong positive correlation between knowledge and self-reported use of colorectal tests, the youngest age group (65-74) also demonstrated positive but weaker correlation between attitude and reported use of tests, however this was not statistically significant, p value 0.228 (Table 3-11). The oldest age group demonstrated positive correlation between attitude and reported use of colorectal screening tests (0.591) and this was statistically significant, p value 0.006 (Table 3-13). The middle age group demonstrated negative correlation between attitude and reported colorectal testing (-0.170) p value 0.473 (Table 3-12).

Table 3-11

Correlation between attitude and colorectal scores in 65-74 year age group

Age groups = 65-74 Men and women

Spearman's rho	attitude	Correlation Coefficient	1.000	.282
		Sig. (2-tailed)	.	.228
		N	20	20
	colorectal	Correlation Coefficient	.282	1.000
		Sig. (2-tailed)	.228	.
		N	20	20

Table 3-12

Correlation between attitude and colorectal scores in 75-84 year age group

Age groups = 75-84 Men and women

Spearman's rho	attitude	Correlation Coefficient	1.000	-.170
		Sig. (2-tailed)	.	.473
		N	20	20
	colorectal	Correlation Coefficient	-.170	1.000
		Sig. (2-tailed)	.473	.
		N	20	20

Table 3-13

Correlation between attitude and colorectal scores in 85+ year age group

Age groups = 85+ Men and women

Spearman's rho	attitude	Correlation Coefficient	1.000	.591(**)
		Sig. (2-tailed)	.	.006
		N	20	20
	colorectal	Correlation Coefficient	.591(**)	1.000
		Sig. (2-tailed)	.006	.
		N	20	20

Comparison scores

Questions adapted from ‘Cancer Knowledge for Elders Survey’ were tabulated and compared to scores from 1983 and 1997.11, 13 The 1983 survey was tested twice, the second time after an education program so two sets of scores were generated. Neither this current survey nor the 1997 survey was related to an education program so score comparisons were made with1983 pre test scores and 1997 scores (Table 3-14).

Table 3-14
Score comparisons from Cancer Knowledge Survey for Elders[11]

NOTE: This figure is included on page 122 of the print copy of the thesis held in the University of Adelaide Library.

In examination of scores, a number of points can be made. All questions scored higher in this current survey compared with scores from 1983 and 1997 surveys. Some questions scored substantially higher than previously tested such as questions 1, 2, 4 and 5. Despite higher scores, a large number of older people in this survey were unaware of their age as a risk factor, approximately half of this survey group. In addition, the myth that cancer can be caused by a bump or a bruise to the body although believed by far fewer people in 2006 was only answered correctly by 47% of this group. The remaining group either answered the question incorrectly or did not know.

The question that demonstrated the most dramatic improvement in knowledge was with respect to warning signs for colorectal cancer where 88% of the group answered the question correctly. Only one subject answered this question incorrectly, the remainder did not know. The myth that all breast lumps are cancerous appears to have been dispelled with a high percentage of correct scores in the survey. No subjects answered this question incorrectly; the remaining 12% either did not know or did not answer the question.

Recognition of urinary difficulty as an early warning sign for cancer was not recognized by a third of the men in this group with half answering incorrectly, the other half did not know. Pain as a warning sign for cancer is still not completely clear as evidenced by the scores of this group. Only one person answered the question incorrectly, the remainder, almost 30% did not know the answer.

Collective response questions and results

Two questions (10 and 11) required written responses that allowed more than one possible answer. This data was documented collectively for each age group and results presented in Table 3-15. These two questions asked about lifestyle modification and early warning signs. Both questions demonstrated the youngest group the most knowledgeable with decline in number of responses and frequency of response as age increased.

Table 3-15

Comparison of collective responses for lifestyle modification across age groups

LIFESTYLE CHANGES TO REDUCE RISK	65-74	75-84	85+
Balanced diet	12	9	4
Smoking cessation	9	7	5
Sunscreen	6	4	2
Exercise	5	2	1
Moderate alcohol	3	1	0
Stress reduction	1	1	0
Fewer sexual partners	1	0	0
Weight control	0	1	1

With respect to the question about early warning signs for cancer, although the oldest age group demonstrated the lowest response rates, they were knowledgeable about bladder and bowel changes and breast lumps as early warning signs of cancer. In fact, bowel and bladder changes, breast changes and lumps were the most frequently provided responses across all age groups (Table 3-16).

Table 3-16

Responses for early warning signs of cancer across age groups

SIGNS OF CANCER	65-74	75-84	85+
Breast lump or changes	21	8	12
Blood in the stool	18	12	11
Bladder changes	12	12	6
Bowel changes	8	0	2
High PSA	3	0	1
Pain	1	0	2
Fatigue	1	0	2
Digestive problems	1	0	0
Swelling	0	1	0
Weight loss	0	0	1
Loss of appetite	0	0	1

Summary

The survey was conducted for several reasons. First, exploration of relationships between knowledge, attitude and self-reported participation in cancer screening tests in older people. Second, to compare scores for adapted questions testing knowledge, myths and misconceptions about major cancers over three time points to evaluate if knowledge had improved. Third, comparison of self-reported compliance with early detection tests by a subset of older people in a large metropolitan area to national estimates. Finally, consideration to what recommendations for care and further research in the older adult at higher risk for developing cancers of the breast, prostate and colon.

From the data, a number of points can be made. Women in the middle age group 75-84 were the least knowledgeable; this could make them an ideal target group for education programs. Reported mammogram screening among women decreased progressively with age even though the oldest women demonstrated strong positive correlation between attitude and mammogram that was statistically significant. This suggests older women may view mammography positively if they were referred however; their low knowledge scores raised the possibility that they may not be adequately informed to request referral.

Unlike mammography, PSA testing for men remained high across age groups despite the middle group of men demonstrating an inverse negative relationship between knowledge and PSA that was statistically significant. This might indicate it was not knowledge about prostate cancer and early detection that was responsible for these men being screened, but rather other factors such nature of the test, a blood test that can be included with other routine tests and does not require referral and appointment as mammogram does. What argues against this in this group were high scores for colorectal screening such as colonoscopy, a test requiring appointment and preparation. In addition, men self-reported higher scores for colorectal screening than women whose scores declined progressively as they aged, whereas men did not.

One explanation for higher reported colorectal and PSA scores among men in this survey could have been location of the study. Recruitment for the study was at a senior center in a large metropolitan area where many such centers exist. Those who attended this center probably lived in the immediate area where the largest Veteran Hospital in the city is located. It is likely that a large proportion of the men surveyed received health care at the Veteran Hospital and therefore had good access to care.

When examining correlation studies between age groups, the middle group of men and women demonstrated weak negative correlation between both knowledge and attitude to colorectal testing although neither was statistically significant. Only the oldest group of men and women demonstrated positive correlation between attitude and colorectal testing that was statistically significant. While the youngest group also demonstrated strong positive correlation between knowledge and colorectal testing this was not statistically significant.

With respect to adapted questions from prior surveys, comparisons across three time points demonstrated improved scores for all questions. Despite this, approximately half of this group did not recognize age as a risk factor for cancer. Furthermore, the belief that a bump or a bruise to the body causes cancer still appears prevalent with about half of the group retaining this myth. It could be speculated that the wording of the question might not have been fully understood by subjects because more subjects answered ‘Do Not Know’ than incorrectly.

Pain and urinary difficulty as symptoms of cancer seem to be incompletely understood as approximately one third of the group answered incorrectly. With respect to pain as a warning sign for cancer, the majority of the incorrect responses did not know rather than answered incorrectly. This raises the question of whether it was lack of knowledge about the symptom being a warning sign or confusion about when the symptom occurs. It is possible that subjects were unsure about early versus late onset of the symptom and this explains why many subjects indicated ‘do not know’.

None of the women believed all breast lumps are cancer; there was a high correct response rate with the remaining 13% answering ‘Do Not Know’. Blood in the stool as an early warning sign was known by the majority of the group with this knowledge increase being the largest percentage gain for all compared scores.

Early warning signs were tested a second time by question 11 that required a written response. The youngest age group was the most knowledgeable, however, all age groups knew that breast changes and lumps, bowel and bladder changes could be early signs of cancer. Beyond this, there was little knowledge of constitutional symptoms. As previously noted, the question about pain might have been unclear with a large number of ‘do not know’ responses however, when given the opportunity to provide information, pain was only documented by three subjects indicating that this symptom is not well known as a warning sign.

With respect to lifestyle modification to prevent cancer, knowledge was low with fewer answers provided and again there was an inverse relationship between knowledge and age. The most common answer was balanced diet; this was known by approximately half of the youngest group with smoking cessation known by less people with few people aware of benefits of application of sunscreen or participation in exercise programs.

In summary, the hypothesis that a relationship exists between knowledge and better utilization of cancer screening tests was not demonstrated for any group. There was a negative relationship between knowledge and reported PSA testing in men aged 75-84. Positive attitude was positively related to self-reported use of mammography in the oldest women and colonoscopy in the oldest men and women. When compared with prior surveys tested, knowledge levels have improved but there is still considerable lack of knowledge about age as a risk factor as well as limited knowledge about lifestyle modification and early warning signs.

Chapter 13. Discussion

Introduction

This chapter reviews the purpose and aims of the study then presents findings from descriptive statistics and correlation studies in the context of current literature. This is followed by discussion of implications for clinical practice with respect to screening practice and education for both patients and healthcare professionals. Study limitations are discussed and recommendations made for further research.

Purpose of the study

The study was conducted for several reasons. A prior qualitative study conducted with a group of older people with cancer revealed several participants were misinformed about age as a risk factor for cancer. It was considered that this finding in a subset of the population with the largest proportion of new cancer diagnoses merited further investigation. A literature search confirmed a paucity of literature related to cancer knowledge and cancer risk in the older population, so the study was pursued. A quantitative approach using a non-experimental descriptive design measured knowledge, attitude to cancer and correlated these scores against self-reported participation in early detection tests for breast, prostate and colorectal cancers in subjects who had never had these cancers. A limitation of the earlier study was those over 78 years were not represented because none was recruited. In order to ensure all age groups were equally represented, this study used age and sex quota sampling with stratified age groups. Since knowledge about breast, prostate, and colorectal cancers had been previously tested in the elderly, a further point of the study was comparison of knowledge scores from two earlier time-points. Finally, additional questions were added to measure knowledge about early warning signs and lifestyle modification where the subjects were required to provide answers not choose a response in order to avoid overestimation of knowledge.

Summary of findings

Comparison of utilization test scores across ages revealed reported use of mammogram declined with age, PSA remained stable and colorectal test scores were higher in men than women but women's scores declined with age whereas men did not. With respect to mean knowledge scores and correlation effect, the middle group of 75-84 year old females scored lowest 3.70 compared with their male counterparts who scored 4.40, although for this group of men a negative relationship between knowledge and PSA was detected that was statistically significant. While several groups demonstrated strong to weak positive correlation between knowledge and the three screening tests, none was statistically significant.

The oldest women scored lowest for reported mammogram testing, however, a positive relationship between attitude and mammogram was detected that was statistically significant. In fact, the only groups to demonstrate positive correlation between attitude and testing that was statistically significant were women 85 years and older with mammography, and men and women 85 years and older with colorectal testing. Strong positive correlation between attitude and testing was found in several other age groups but none was statistically significant.

Although questions adapted from the Cancer Knowledge Survey for Elders[11] revealed knowledge about cancer had increased in all compared questions, approximately half this group did not recognize age as a risk factor for cancer. The myth that all breast lumps are cancer was not held by anyone in this survey group although several subjects did not know. Bowel changes, as a warning sign for colorectal cancer was known by almost the entire group. This question demonstrated the largest percentage increase in knowledge for all adapted questions. One question testing knowledge of myths about cancer 'Can a bump or a bruise to the body cause cancer?' was not known by about half of this group. The remaining half was divided almost equally between incorrect responses or they did not know. While this question scored higher in this survey group than when previously tested, it seems surprising that this has not become common knowledge. The two remaining questions about warning signs for cancer, pain and urinary difficulty were not known by about one third of the group.

With respect to questions testing knowledge about early warning signs for cancer and lifestyle modification that required written responses, knowledge levels as evidenced by the number and frequency of responses decreased with age for both questions. Knowledge about early warning signs for cancer was mostly limited to bowel and bladder changes and breast lumps that all age groups knew. The question about pain as a warning sign for cancer had been tested as a multiple-choice question with about half the group answering correctly, however in the provided response section about early warning signs, pain was only provided by 5% of the group with even fewer people aware of other symptoms such as weight loss and fatigue.

Knowledge about lifestyle modification to prevent cancer was lower with fewer provided responses compared with early warning signs and again, knowledge levels decreased as age increased. The most common responses across all age groups were balanced diet followed by smoking cessation, use of sunscreen, exercise and moderate ingestion of alcohol although few people knew the last two responses 13% and 6% of the group respectively.

In summary, in this study group the hypothesis that greater knowledge about cancer was related to participation in early detection tests was not found in any age group, although the youngest women demonstrated perfect reported compliance with recommendations for mammogram screening so correlation studies were not conducted. Positive attitudes correlated with reported use of mammogram in the oldest women and colorectal testing in the oldest men and women. Knowledge levels about cancer have increased over the last ten years when compared with prior testing however, knowledge about early warning signs of cancer is limited to breast changes, lumps, and bowel and bladder changes. Knowledge about lifestyle modification to decrease risk is even more limited.

Significance of findings

A number of significant findings were revealed from the survey with respect to the variables measured, screening practices across age and gender as well as increased knowledge over time.

Screening tests

High self-reported utilization of mammography demonstrated in the youngest group of women is consistent with U.S. data from the 1980s to the 1990s where dramatically higher adherence among women 40 years and older was reported.[33] The inverse relationship between mammogram testing and age as demonstrated here is also consistent with national utilization data in the U.S.[84] This suggests that while mammography use has increased, older women are screened at lower rates than younger women are. The survey did not collect information about why people did or did not have tests, especially one that is reimbursed by insurance for women 65 years and older.[84] Multiple barriers to mammography have been cited including fear, discomfort, lack of knowledge, uncertainty about benefits[113] or lack of physician recommendation[32] and any of these barriers could be applicable to the older women in this group. Furthermore, the older women in this survey with the lowest utilization scores were also less informed so lack of knowledge and expectation for referral may have existed and expectation is a strong positive predictor for cancer screening referral.[114]

Lack of physician referral as women aged could also be an explanation since decline in mammography was progressive. Several studies have shown older women to be less concerned about developing breast cancer compared to younger women and consequently under screened.[98, 99] In the case of the oldest women in this survey, attitude scores correlated positively with use of mammography, which may suggest that should they be referred, they would be compliant.

Continuing mammography in the oldest women is a complicated issue with limited literature about risk and benefit to guide both physicians and patients who appear to see the situation differently, physicians using health status as a deciding factor whereas fewer patients considered it to be so.[101, 115] Ongoing screening has been evaluated from the point of cost-effectiveness suggesting that biennial screening after the age of 65 even among women with clinically stable co morbid conditions reduced mortality and was cost-effective.[85]

With respect to the other groups of women, the youngest women self-reported 100% compliance with recommended yearly mammograms. In addition, they demonstrated the highest knowledge and attitude scores. The 75-84 year old women scored lowest for knowledge and mean colorectal utilization scores demonstrated the greatest disparity when compared with their male counterparts. Scores were 6.10 (SD2.8 range 2-10) for women and 8.5 (SD1.58 range 6-10) for the middle group of men. This suggests these women might likely benefit from education about cancer and benefits of early detection. In addition, men scored higher than women did across all age groups with respect to colorectal screening tests suggesting this specific area of patient education, women and colorectal cancer and screening could be targeted.

Literature comparing utilization of any cancer screening tests across genders in the older population is sparse. One study in the U.K. found men were more likely than women to attend colorectal screening programs.[22] Likewise, in the U.S. where colorectal screening over recent years has increased for both genders, increases were greater for men than women.[33] In this current survey, correlation studies comparing colorectal scores with knowledge and attitude were combined for men and women. Positive correlation between attitude and colorectal screening tests was demonstrated in the oldest age group suggesting that if they were referred for screening they would likely be compliant, although may not have adequate knowledge to request referral.

Although men demonstrated higher colorectal screening scores than women did across all age groups, it was unclear why the middle group of men scored far higher than the other two groups. An explanation may have been the close proximity of the senior center to a medical center where veterans receive medical care including routine cancer screening tests such as colorectal screening tests.[116] If this were the case, it should apply to the youngest group of men as well, although it is possible that there were fewer veterans in this group.

Comparison of mammogram scores with PSA scores showed differences in reported utilization as mean utilization scores remained high across all male age groups. Several reasons could explain the decline in utilization of one test while not in another. The nature of these tests could influence compliance; one a blood test that is done during a routine physician visit, whereas mammogram requires referral and appointment. In addition, there may be discomfort as well as other deterrents associated with mammogram[117] that are not a concern with PSA testing.

With respect to the finding that the middle group of men demonstrated negative correlation between knowledge scores and PSA but mean utilization scores were high, this suggests that knowledge may not have contributed to screening but might be screening practice of their healthcare provider. Literature about physician screening practices with respect to PSA suggests that it is aggressively ordered by physicians.[118] One large study revealed PSA continues to be tested until age 79 before declining, which is longer than other screening tests for cancer and in the case of mammography twenty years longer.[21]

PSA screening is recommended by the ACS but this recommendation is not followed universally by other organizations including the Department of Veteran Affairs (VA) where war veterans in the U.S. receive medical care. The ACS recommendation for colorectal screening however is followed by the VA.[116] While the median age for diagnosis of prostate cancer is older than other cancers,[119] there is no clear consensus about routine screening beyond the age of 75 years.[120] With respect to the oldest group of men in this survey, they reported PSA testing as frequently as the other two groups of men. Although this was a small survey, this finding raises the question about screening the oldest men**.** If PSA is elevated then the dilemma of how meaningful the finding is and the subsequent pursuit of diagnostic work-up and treatment if cancer is diagnosed needs addressing. Few studies about treatment benefit for prostate cancer in the oldest men are available. One observational study showed benefit of treatment, however the upper age limit of the study group was 80 years.[121]

Cancer Knowledge Survey for Elders questions

When comparing cancer knowledge from adapted questions, the most significant knowledge improvement was that of early warning signs for breast and colorectal cancers. The question testing pain and urinary symptoms was answered correctly by two thirds of the group, which was higher than previous surveys. Although knowledge about cancer had increased over the last decade when the survey was last tested, half of this surveyed group did not recognize age as a risk factor. In evaluating the responses to this question across the three age groups, there was little difference in correct, incorrect or do not know responses from one age group to another. This suggests the two youngest groups might benefit most from education about this risk factor.

Knowledge about cancer risk and prevention

Two questions required written responses rather than selecting a provided response. One question tested lifestyle modification to prevent any cancer, the second tested knowledge of early warning signs of breast, prostate and colorectal cancers. There were several possible answers to each question, so responses were tabulated collectively for each age group and compared by quantity and frequency of responses across age groups.

Few studies have measured knowledge about cancer risk factors; to date only one national survey in the US has been conducted.[12] This study revealed little knowledge about lifestyle modification even though respondents chose from provided answers. Diet and smoking cessation were identified by approximately one third to less than one-half of the group in the national survey. In this current survey, balanced diet was the most common response but provided by less than half the group with fewer responses as age increased. The next most common response was smoking cessation documented by approximately one third of the group. Data about risks of tobacco was documented as early as 1964 by the US Surgeon General[122] and most recently in 2004 when the report detailed the extent of tissue damage to multiple organs as well as risk factor for multiple cancers.[123] Given the quantity of information that has been generated about smoking over the last four decades, it is unclear why so few subjects could provide this information in this current survey.

Obesity has been associated with increased risk for developing several cancers[109] however, lifestyle modifications such as weight control was identified by very few people in this survey group. Only eight people documented exercise and two documented weight control as part of lifestyle changes to decrease cancer risk. It should be noted that many evidence based lifestyle modifications that can reduce cancer risk also decrease risk for heart disease.[124]

Implications for practice

Although this was a small study, several findings emerged with respect to cancer screening practices and lack of knowledge in the older population that have implications for clinical practice.

Screening

Early detection of cancer is a complicated issue with some sectors of the population including the elderly under screened[21, 91] while there is emerging evidence that some age groups of elderly may be over screened for some cancers.[115] The impetus to screen older people could be partially consumer driven with significant media influence on patients who increasingly request test referrals from physicians.[125] None the less, the decision to screen or not remains largely controlled by physicians.[118] While the ACS guidelines are clear when to initiate screening for cancers of the breast, colon and prostate, these guidelines do not indicate when screening should cease. From a physician perspective, life expectancy, age, co morbidity and functional status have been suggested as factors to consider when making the decision to stop screening.[126] Patients appear to prioritize these factors differently, even the oldest women appear to view screening mammogram as important, despite other more serious health problems and their risk of dying from heart disease greater than cancer.[1, 101]

In this current survey, self-reported PSA testing remained constant across all groups of men, whereas colorectal testing declined in the oldest men. The ACS recommends offering PSA tests to men 50 years and older with a life expectancy of at least ten years. While PSA testing has dramatically increased over the last few years, such aggressive screening has diagnosed a far lower number of new cancers compared to the number of PSA tests conducted. One study reported 9,410 tests conducted in 1997 but 23,684 in 1998 even though only an additional 31 new cancers were diagnosed in 1998.[30] In other words, the test may have been indiscriminately ordered and this might be due to its simplicity. Public enthusiasm for complete and painless screening tests was shown in one survey to be staggering, 85% of the survey group preferred to undergo total body CT scan rather than receive $1000 in cash even if they were not experiencing symptoms and understood that false-positive results could lead to unnecessary testing.[127]

Despite this, benefits of cancer screening are well established. With respect to the older population, there is some evidence that procedure related risk such as colonoscopy increase after the age of 70 when a greater number need to be screened to diagnose one new cancer.[23] In other words, aggressive screening may increase risk of procedure related complications for a greater number of people without diagnosing new cancers. This does not imply the oldest old should not be screened, rather risk versus benefit ratio carefully considered. Moreover, although the potential number of new cancers found in the elderly increases with age, transformation of a polyp to colorectal cancer takes approximately 5 to 10 years, which may be longer than the life expectancy of many older people.[100]

In this current survey, self-reported utilization of both colorectal screening and mammography decreased with age in women. Although reasons for this were not explored in the survey, it could be speculated that discomfort, lack of referral or logistic difficulties such as travel and test preparation contributed. In any case, the only group where a relationship was established between the independent variable and participation in screening that was statistically significant was the oldest group. Positive attitude towards early detection of cancer has been measured in the general population in the U.S. where enthusiasm for testing was found to be high across all age groups including the oldest members of the population although they were proportionally underrepresented.[127] One finding from this study was that a significant proportion of the group thought people over the age of 80 irresponsible for non-participation in cancer screening. This was not the elderly themselves, who were underrepresented in the study, but those 55 years and younger. This finding may indicate potential influences the elderly may encounter from younger family members who hold different views about ongoing cancer screening.

Patient education

From this survey and consistent with a national study in the U.S. women participated in colorectal screening at lower rates than men.[33] In addition, when comparing mammogram with PSA and colorectal screening, there is some evidence to suggest that mammogram screening declines at an earlier age than either PSA or colorectal cancer screening.[21] In this survey, women aged 75-84 demonstrated the lowest knowledge scores with utilization scores for mammogram and colorectal tests lower than the 65-74 year old women. From a cost-effectiveness perspective, this middle age group continue to benefit from breast cancer screening[85] and therefore could be targeted for cancer screening education.

Across all age and sex groups, knowledge about organ specific early warning signs has increased, although little is known about constitutional symptoms. Knowledge about lifestyle modification was also low across all groups. Literature pertaining to population knowledge of lifestyle modification benefits that decrease cancer risk is scant. One study found no correlation between knowledge of modifiable risk factors for melanoma and behavior such as sun protection and sun avoidance across five groups including lay people, medical students, nurses, training oncologists and oncologists.[128] It would seem somewhat discouraging that oncology professionals demonstrating higher knowledge levels than lay people did not change detrimental behavior. Melanoma is a model for cancer where a causal link between behavior and incidence is well established and behavior modification programs have been developed in many countries, although evaluation and success of these programs has been limited.[129]

To date, public education has focused largely on improving disease awareness rather than education of modifiable risk factors to prevent cancer. While lack of awareness remains a significant barrier to all cancer screening tests[32, 113, 130] little literature exists about public education programs to decrease modifiable risk factors for cancer beyond smoking cessation. Few studies were located using the search terms education, diet and exercise, in combination with 'modifiable risk factors for cancer' in both MEDLINE and CINAHL. One small study to promote cancer awareness and prevention demonstrated the program was effective even among participants with little formal education.[131] Although positive findings, the study was small, only thirty-one people and the program conducted in participants' homes that would be impractical if the goal was public education.

Study limitations

A limitation of this study was location, in a large metropolitan area with close proximity to a medical facility where veterans receive healthcare. Due to the regional nature of senior centers in the metropolitan area, it is almost certain the majority of those attending the senior center lived in the vicinity with a high likelihood that male subjects received healthcare at the Veteran Affairs Hospital a short distance away. Veteran Affairs Hospitals are the largest integrated healthcare system in the U.S. and offer health care and prevention programs including cancer screening to veterans 65 years and older.[116] If this were the case, availability of healthcare for male subjects may have been better than other areas in the city or rural areas, therefore reported utilization scores may have been higher in this surveyed group.

A further limitation was source of cancer screening utilization data. This was self-reported with no means to verify the data so the possibility of overestimation of testing exists as well as dependence on the subject's memory to recall when tests were done. In addition, the survey did not collect data about why participants did or did not participate in screening programs. This might have revealed what and who prompted screening and identified of screening barriers. Since there is some evidence that men are more compliant with screening for some cancers than women are, identification of gender barriers may have been helpful.

Although the study size was comparable to the original post-test study group in 1983, because quota sampling was used the sex/age groups were small so a larger study may have yielded different results. In addition, the statistical tests utilized were limited by both the size of the study and ordinal level of measurement that meant tests such as multiple regression analysis or logistic regression could not be calculated. This statistical analysis could have provided more information about the relationship between the independent variables and the dependent variable.

Recommendations for further research

When developed, the Cancer Knowledge Survey for Elders was an appropriate test and remains so as a test of knowledge about the most common cancers; it is limited by length and relevancy of some questions. In addition, screening information and barriers to testing are not included in the survey. Further research could be conducted in the elderly to include measurement of knowledge, use of screening tests as well as exploration why older people do or do not have screening tests. Knowledge about reasons for and against participation in testing is equally important. While barriers to participation in screening programs are well documented in the literature, the fact that there is discrepancy from one test to another and screening declines at different ages for one test compared with others, suggests the issue may be more complicated. Furthermore, knowledge about factors influencing screening compliance is important for healthcare professionals when developing education programs.

Qualitative studies in the oldest old related to their opinion of ongoing cancer screening are non-existent. A national study about enthusiasm for cancer screening revealed strong opinions among younger people towards non-compliance of the oldest members of the population. This suggests older people could be at risk for interference in decision-making by younger family members with different opinions about screening. In addition, there is some discrepancy between influences on physicians and very old people about ongoing screening. There are few studies comparing patients' views to physicians' views and those studies located had only been conducted among the oldest people among the population.

Literature across genders is sparse, further studies may reveal why men participate in screening programs with greater frequency than women do or if different barriers to testing exist for women and men. Literature about lifestyle modification to decrease cancer risk is limited for any age group as are studies documenting successful education programs. Healthcare professionals developing education programs should emphasize the self-help aspect of lifestyle modification as well as additional benefit of decreasing heart disease.

Conclusion

The research reported here produced findings consistent with literature pertaining to cancer screening and older people. Comparisons in this small study of people 65 years and older, stratified into sex and age groups, revealed reported mammogram screening declined with age, PSA remained stable and colorectal screening was higher in men than women with declining compliance as women aged. In addition, only attitude positively correlated with self-reported participation in screening and was statistically significant among the oldest age group. Cancer screening in this population is complicated with evidence that the elderly are both under screened and over screened. Few decision-making guidelines have been developed for physicians screening the oldest sector of the population.

The findings raise a number of issues for clinical practice with respect to screening and patient education. Knowledge about risk factors such as age have improved over the last two decades but remains low as does knowledge about lifestyle modification and early warning signs for cancer. As with other aspects of healthcare in older people, the decision to continue cancer screening is based on limited literature, consideration of multiple factors and discussion with the patient.

SECTION 4

Portfolio Conclusion

Chapter 14. Introduction

As the population ages and people over the age of 65 comprise a greater proportion of the general population, a number of healthcare issues have emerged with respect to early detection and treatment of illnesses such as cancer where this population represents more than half of all newly diagnosed cancers. This portfolio consists of two studies conducted using different methods and methodologies to study cancer screening and the cancer experience in people 65 years and older. The first study was conducted in older people with a new cancer diagnosis receiving treatment, while the second examined the relationship between knowledge and attitude to cancer and self-reported participation in screening for breast, prostate and colorectal cancers. The findings from each study are briefly summarized, then issues central to both studies discussed with respect to implications for practice in the context of current literature. Conclusions are drawn and recommendations made for further research.

Chapter 15. Summary of study findings

Using a phenomenological approach, the first study revealed participants newly diagnosed with cancer undergoing treatment were both prepared and unprepared for the experience. Many were unprepared and misinformed about age as a risk factor for cancer however their life experience contributed positively to coping in their new world. Although they adapted and learnt new skills, they often relied primarily on their physicians and sometimes family to negotiate the finer details of decision-making in their medical care. Overall, findings from this lived experience suggest that despite knowing little about cancer and their risk they coped well with diagnosis and treatment. They appear to require a different approach to care from healthcare providers, since most participants were reluctant to question many aspects of care and most expressed great trust in their physician to make decisions for them. Moreover, many noted they did not experience the anxiety level or need for details about diagnosis and treatment they observed younger patients did.

In the second study, although participation in testing was self-reported and unable to be verified, compliance varied from one group to another and one test to another suggesting under screening and over screening. Cancer knowledge was not related to participation in any screening test but the oldest subjects demonstrated attitudes to early detection tests for breast and colorectal cancers that positively correlated with reported testing and was statistically significant. While knowledge of early warning signs and cancer risk has improved over the last one to two decades, about half the study group did not recognize age as a risk factor for cancer. Knowledge of modifiable risk factors for any cancer was lower than recognition of myths, misconceptions and early warning signs.

Central to both studies are issues of approach to care for older people and attitude and educational preparedness of healthcare professionals who deliver care to this group. Approach to care refers to application of knowledge across the spectrum from cancer screening to cancer treatment among a diverse and heterogeneous population in the setting of incomplete evidence that may not change for many years to come. Attitude and educational preparedness of healthcare professionals will influence interpretation and application of evidence that directly affects patient care and health outcomes from screening to cancer treatment.

Chapter 16. Approach to care of older people

The approach to care of older people will be discussed in this section with respect to time points in the care trajectory. First, issues related to screening will be presented followed by discussion of approach to care of older cancer patients receiving treatment.

Screening

Although cancer screening in the general population in the U.S. has increased dramatically over the last two decades,[132] historically people 65 years and older have participated less frequently in early detection programs.[94, 133] Evidence now suggests that older people continue to be under screened for some cancers, namely breast[134] and colorectal[21] but may be over screened for prostate cancer.[30] Moreover, there is a strong belief in the U.S. among the general population that they should never stop routine screening, and older people who do are irresponsible.[127] Several organizations in the U.S. issue guidelines for screening, all are age based with conflicting recommendations.[106] What exists here is a dichotomy of beliefs and practices that could result in older people on one hand undergoing unnecessary screening and work-up, while on the other at risk for diagnosis with late stage cancers that could have been detected and treated in an earlier stage.

Under screening

Factors influencing under screening in the older population include availability of services, geographic isolation, physician office procedures for reminders as well as lack of awareness and referral.[32, 134-136] Barriers to screening in rural communities have frequently focused on availability of services, but inadequate reminder systems also account for lack of attendance at breast cancer screening programs in some rural areas compared to urban areas. Predictors for referral in physician practices include use of flow sheets and size of practice, that is group practices report better referral histories than smaller practices.[135] The implications for nurses in non-group rural practices are that evaluation of their practice reminder policy and implementation of flow sheets have been shown to improve cancer screening in older people. Despite urban areas reporting higher rates of cancer screening than rural areas, barriers still exist and strategies such as same day availability of mammogram have demonstrated increased compliance especially in women over 65 years.[136] Lack of awareness about need for cancer screening tests has been shown to be related to lack of knowledge[113] or lack of symptoms[137] as well as issues of fatalism. Cancer fatalism, the belief that death is inevitable when cancer is present, is more likely found in older people than younger people but lack of knowledge also predicts higher levels of fatalism.[138] In fact, knowledge is the only modifiable predictor for fatalism, which could be changed whereas other predictors, age and formal education cannot.

Greater knowledge about cancer in addition to other factors such as high functional status and regular medical care by consistent providers have been shown to predict earlier stage cancer diagnosis as opposed to later stage when prognosis is worse.[139] As demonstrated in the cancer survey in this portfolio, knowledge about cancer and cancer risk has improved over the last two decades but knowledge of age as a risk factor and especially knowledge about lifestyle modification was low. This presents a great opportunity for nurses working in the community as well as physician practices to address lack of knowledge and emphasize the positive benefits of diet, exercise and avoidance of unhealthy lifestyles such as smoking and sun exposure.[109] Population health education has long been considered a nursing domain, especially that of public health nurses, however, there is some evidence to suggest public health nurses lack educational preparedness for this role and only a minority of their interventions target the general population.[140]

Few intervention studies have addressed the relationship between lack of awareness and improved screening. One study found people under the age of 66 years welcomed information about cancer awareness and screening for colorectal cancer without increasing anxiety about cancer.[141] The study did not include people over the age of 66 years so results may not be applicable to them. The second study in this portfolio demonstrated high positive attitude to cancer scores across all age groups, although only the oldest groups demonstrated a positive relationship to participation in some screening tests. This suggests that results might be similar in those older than 66 years however, this would need to be demonstrated by further research.

Lack of physician referral remains a screening barrier for breast and colorectal cancers.[32, 137] Older women continue to be referred for mammography at lower rates than other groups of women[134] and less than one third of the eligible population receive recommended tests for colorectal cancer screening.[142] The findings from the survey conducted here were consistent with these national figures with respect to mammogram testing. Nurses working in physician practices are well positioned to identify whether these deficits exist within the practice where they work. In addition, it is important to remain current with cancer-screening guidelines, underserved populations and the health beliefs of patient population in a practice. Nurses may not be aware of differences in health beliefs between men and women with better responses of older men to health intervention programs compared to women[92, 131]and male gender but not female predicting screening adherence.[137] These findings may not be common knowledge among healthcare professionals who often believe the situation to be opposite.[143] The implication is that women risk being overlooked in health care education due to the assumption that they are more informed and involved in their health care than men.

Over screening

Nurses are considered with high regard and trusted by the public[144] so likely to be asked their opinion about cancer screening tests in and out of the workplace. This means they need to be aware of current guidelines as well as the limitations these guidelines present for the oldest population[106] including potential for over screening that can lead to further work-up when false-positive results occur.[145] Knowledge of guidelines presents a dilemma in itself, since several organizations in the US issue guidelines. This survey used American Cancer Society guidelines that do not indicate an age cutoff to stop screening whereas other guidelines do.[18, 106] Moreover, all guidelines are age based without consideration of other factors such as co morbidities.

A survey of nurse practitioners testing knowledge of breast cancer screening guidelines demonstrated a wide range of knowledge scores suggesting further education was needed.[15] With regard to nurses, their knowledge of cancer screening guidelines is unclear. A recent needs assessment of research priorities revealed nurses ranked screening, early detection of cancer, prevention of cancer and cancer risk reduction lower in priority than they had previously ranked these topics.[14] It is unclear if this change in ranking was due to perceived adequate knowledge or lack of interest in the topics.

The over screening demonstrated in the second study in this portfolio was among the oldest group of men who self-reported PSA tests at the same rate as younger men. Over screening the oldest men and women in the population has been demonstrated in some surveys of physicians for mammograms, Pap smears, PSA tests and colorectal screening tests.[115, 118, 146] The consequences of over screening is how to approach treatment for an early cancer that may not cause symptoms during the remaining life expectancy of the individual.[100, 106]

Autopsy reports in men with no history of prostate cancer have been conducted in several countries with consistent findings of the presence of prostate cancer in the prostate gland in close to 90% of men over the age of 80 years.[31] In other words, prostate cancer may be present in tissue for many years before causing clinical evidence of cancer and aggressive screening of older men may lead to unnecessary biopsies for cancers that may never cause illness and cancer is currently not the leading cause of death in this age group.[147] In addition, the oldest men demonstrated lower utilization scores for colorectal testing than the youngest men, but attitudes were positively related to participation in screening that was statistically significant. More recently, men have recorded better attendance than women at colorectal cancer screening programs[22] however, this could be a double-edged sword more especially in the case of men over the age of 80 who may derive little benefit from ongoing colorectal cancer screening.[148]

It is important for nurses and other healthcare professionals to remain aware of the risks of all causes of mortality for people 65 years and older. While cancer is the leading cause of death in the U.S. for men and women 60-79 years old, it causes less than half the deaths compared to heart disease for those 80 years and older.[147] This suggests education targeting the oldest men and women might be more beneficial if it focused on the benefits of healthy lifestyles through diet and exercise which decreases risk for some cancers and cardiovascular disease.[109, 124] Although younger men and women will derive greater benefit from cancer screening, they should also be targeted for education especially given the lack of knowledge deficit about early warning signs and modifiable risk factors seen in all age groups in the survey reported here. Evaluation of older people should include patient's knowledge of risk and early warning signs, benefits of diet and exercise that decrease risk for cancer, and discussion of benefits of ongoing screening on an individualized basis.

There are few studies in the oldest members of the population exploring their interactions with physicians about discontinuation of cancer screening. One study found older women could be categorized into three groups: one highly enthusiastic about screening, the second opposed and the third who deferred to the physician's decision.[101] While it may be more time-consuming, physicians and nurses working with physicians will need to consider the value system of their older patients during discussions of cancer screening before proceeding with referrals.

As healthcare professionals, we need to consider patients' knowledge levels as well as health information sources. One small Canadian study showed the media was the primary source of information for older people although this information was often unclear.[24] Cancer and fear of cancer is prominent in the media with reports often presenting negative statistics and contradictory information rather than emphasizing importance of lifestyle changes.[149] Physician office visits although time constrained, should allow opportunity for discussion of inaccurate beliefs verbalized by older patients as well as provision of alternative resources other than the media where patients can access accurate and reliable information.

Approach to care during cancer treatment

Despite the fact that age remains a negative predictor for receiving any cancer treatment,[150] from a clinical perspective, age specific treatment guidelines and less toxic chemotherapy including oral agents now exists for the older cancer patient.[151] From a patient perspective, aspects of care such as decision-making could be considered far more complex than one or more decades ago as could availability and increased volume of disease and treatment related information that patients often feel obliged to comprehend.[152, 153]

Decision-making and communication

One of the findings from the lived experience study in this portfolio was decision-making about treatment and other aspects of care. Many participants preferred to defer this to their physicians and were comfortable doing so. It was not that they did not wish to know what was happening, but did not need involvement in every detail of their care because they trusted their physicians. Moreover, they considered the physician better informed to make decisions than they were, although many noted younger patients were more assertive with decision-making than they were.

There is limited research about patient decision-making. One small study in women both newly diagnosed and cancer survivors found the oncologist was the principle decision-maker for older women but not for younger women.[154] A study of colorectal cancer patients showed women preferred to share decision-making with physicians more frequently than men, while older people preferred the physician to make decisions whereas younger people did not.[155] Another study using a qualitative approach revealed the burden older women felt when decisions about treatment were designated to them by physicians leaving them confused about how to proceed and overwhelmed about making the right decision.[153]

With respect to decision-making in newly diagnosed older people with cancer, Sinding, Wiernikowski and Aronson's study about older women's interactions with their physician when they refused treatment were difficult interactions for patients. Many experienced lack of support from physicians and did not appear to receive adequate explanations of benefits of treatment that may have altered their decision.[153] How frequently this scenario occurs is unknown however, decision-making such as this leaves older people at risk for confusion about healthcare professionals' intentions as well as leaving them at risk for alienation from the healthcare system if they do not agree with physician recommendations.[153] Other factors such as co morbidities at time of diagnosis or during a cancer experience can influence decisions older people make about treatment. This was found in the life experience study in this portfolio where three participants experienced coinciding health problems although this did not result in forgoing treatment as found in another study.[153] In addition, two participants in the life experience study considered either not having treatment or terminating treatment prematurely, one due to lack of knowledge about treatment benefit, the other due to lack of transportation.

The challenge here for healthcare professionals is recognition of factors that influence decision-making for patients. By virtue of time allocated to patients compared with physicians, oncology nurses are at the forefront of communication with patients so should be aware of the context of patient physician relationships. While it is important that older people make fully informed decisions, it is equally important they be supported not rejected if they decide against treatment. The nurse's role here is twofold, early and complete evaluation of barriers to treatment including physical, psychosocial or environmental and support and referral to other levels of care if patients decide against treatment. Moreover, nurses should be mindful of recent high level evidence revealing older people are less likely to be referred to palliative care services compared with younger people with terminal illnesses.[156]

Assertiveness and communication between patients and physicians can be complex. There is some suggestion the greater the number of better-informed patients in a physician practice, the greater the benefit for the less-informed because the physician responds to information needs of well-informed patients and changes behavior towards the practice population.[157] Few studies have compared associations between age or gender with assertiveness in medical care however, younger women appear more assertive than older women in interactions with their physicians and this appears to result in a higher level of healthcare for a longer duration.[158] In other words, patient assertiveness at the beginning of a patient-physician relationship seems to ensure a higher level of referral practice on the part of the physician for the duration of care. This information may be useful for nurses working with oncologists because facilitating communication early in the care trajectory may benefit older patients throughout the care period even if others are not present to advocate for them.

In the first study in this portfolio, none of the participants mentioned the nurses' role in their care although why this was so did not emerge from the narrative dialogues. Research on patient communication with any healthcare professionals is almost exclusively patient-physician although clearly patient-nurse communication exists. Oncology nurses may not be comfortable, feel confident or prioritize the importance of decision-making discussions with patients; however, this may be changing. A 2004 needs assessment of research priorities among oncology nurses in the U.S. ranked the topic 'Participation in decision making about treatment' fourth in priority when four years earlier it had ranked forty-three and 'Participation in decision making about treatment in advanced disease' ranked second compared to previous ranking of eighteen.[14] These topics were not specific to older patients but to cancer patients in general. Research in the area of geriatric oncology was not ranked among the top twenty topics of priority.

Life with Cancer

It is important for health care professionals to understand how older people cope with a cancer diagnosis and live life from the point of diagnosis forward compared with younger patients. In the life experience reported here, none of the participants was shocked or unduly upset by their diagnoses and all attributed this to diagnosis at an older age when one has lived the greater part of life. This was in contrast to a qualitative study that included few older people where participants were overcome with shock of diagnosis to the extent they could not be positive at all.[159] There is some suggestion that older cancer patients have different expectations from treatment as well as fewer demands on their time compared with younger patients.[81] This too was a finding in the lived experience study reported here, where many participants considered treatment success almost an unexpected bonus, while being prepared for the possibility of treatment failure. Different treatment expectations should not be interpreted by healthcare professionals as lower expectations and result in delivery of a lower level of care.

Less psychosocial disruption and strong coping skills among older cancer patients was reported in the literature as early as twenty years ago when older men with cancer reported less cancer related psychological distress than younger men.[27] More recently, a literature review of the psychological impact of cancer on older people revealed that the elderly have either similar psychological distress or less compared to younger people.[28, 29] Similarly, older people who survived colorectal cancer appear to have a comparable quality of life one year after diagnosis compared with the same age group without cancer, whereas younger people experienced more psychosocial difficulties.[29] These consistent findings over time demonstrate that older people cope well at different time points in the cancer experience as well as in comparison to younger patients.

Life as one experiences cancer treatment as described by the participants in the life experience documented here reported reasonable treatment tolerance with fatigue being the main symptom experienced although this was not formally measured or a strong sub theme. Since this life experience study was conducted within approximately three to four months from diagnosis for all participants, this finding may have been different if the study were conducted later in the cancer course. Formal measurement of quality of life was not part of this study and few studies have measured quality of life of older patients within the first few months after a cancer diagnosis. One study located found little difference in quality of life within the first three months after diagnosis and treatment unless the older person was more dependent, less hopeful or experienced more financial difficulties.[160] For oncology nurses this highlights importance of initial and current psychosocial evaluation as well as importance of maintaining independence in older cancer patients.

Relatively few recent studies have explored factors contributing to positive attitude in patients or relevance of positive attitude during a cancer experience. An increasing body of qualitative research of all age groups of patients has highlighted the negative impact on patient attitude when nurses or physicians use medical terminology, statistics or appear judgmental about patients' treatment decisions.[153, 159] It is unclear whether healthcare professionals have insight into the strength of their words and demeanor during patient encounters. Certainly, patients remember the smallest of gestures and comments even when they no longer receive treatment and are facing death.[161] This is particularly important in care of older cancer patients who may sense ambivalence from oncologists whether to administer treatment because they are older and subsequently fail to follow-up with treatment.

Chapter 17. The role of healthcare providers

This will be discussed with respect to attitudes, educational preparedness and knowledge of healthcare professionals (HCP) in relation to care of the elderly population from cancer screening to cancer treatment.

Attitudes of HCP to elderly patients

Attitudes of HCP to patient populations have been shown to influence treatment decisions and healthcare when negative attitudes exist.[162] There is scant literature about attitudes of healthcare professionals to older cancer patients, but what does exist suggests a lower level of care for older people. One Italian study by Caruso et al., revealed older people with cancer were less informed about their diagnosis and disease progression than younger patients were.[26] One finding from the first study in this portfolio was several participants preferred their physicians who they trusted to make treatment decisions. This was not due to fear of worsening outlook or prognosis, but rather they considered their physician better prepared than they were, and did not feel the need to participate jointly in decisions they noted younger patients did. This finding in light of the Italian study is worrisome, because physicians may not inform patients about important issues such as worsening prognosis and extent of cancer. The Italian study did not explore reasons why physicians provided less information to older cancer patients; however, older patients in the study expressed a desire for clear information.

It could be speculated that older people require more time and attention than office visits permit or perhaps physicians wish to protect older patients from information about their disease and prognosis. Italian oncologists appeared well informed of the prevalence of older people among the cancer population, however their awareness did not result in more frequent utilization of age specific tools to guide care.[163]

In the first study in this portfolio, participants expressed positive feelings and attitude during their cancer experience and to the future. It was unclear what contributed to this since it did not emerge from the narrative dialogue and the purpose of this lived experience was not to explore a single concept that emerged. Few studies have examined what factors contribute to positive attitude of patients during a cancer experience. One study revealed physician attitude to be the most important factor influencing positive attitude in patients undergoing cancer treatment, although few patients in the study group were older.[159] Factors influencing positive attitudes in older cancer patients are unknown, however, if physician attitude is an important factor for older patients then the study reported by Kearney et al,. revealing negative attitudes to elderly cancer patients among physicians, nurses and radiology staff irrespective of years of experience exposes the older population to risk of ageism and a lower level of care.[17] Kearney's study was the only paper located evaluating attitudes of healthcare providers and was completed at a single institution. It is possible attitudes have changed or negative attitudes are the exception however, more studies at other institutions would need to be conducted.

Educational preparedness of HCP

There is some evidence that care provided by specialty educated nurses results in improved care, lower health care costs and lower mortality in the general population in some specialty healthcare areas.[164] While specially trained nurses care for cancer patients in some regions in the U.S. this is not national.[165] In other countries, many cancer patients receive care from generalist nurses with limited formal oncology training who undergo continuing education courses in oncology.[166] For older cancer patients, educational preparedness of their caregivers is even lower than the general oncology population. Education programs and curriculums do not as yet include geriatric oncology, although there has been progress in some European countries where new curriculums for nurses caring for older cancer patients are being developed.[167]

With respect to continuing education completed by oncology nurses, there is little recent evidence examining how nurses choose continuing education topics beyond availability. Only one large survey of geriatric education training in oncology nurses was located in the literature in the last ten years. This revealed life-long learning was not a priority for oncology nurses and about one-third had not completed any geriatric education for two years. Interestingly, attitude negatively correlated with knowledge, so better informed and educated nurses exhibited negative attitudes to older cancer patients.[34]

No literature about continuing education for physicians in geriatric oncology was located, so level of educational preparedness of oncologists caring for older cancer patients is unclear. Geriatric knowledge of family physicians appears to be reasonably high, although this has not been well evaluated. What is clear from high-level evidence is not all continuing education programs are equal, the most effective methods being combination of interventions that are more time consuming and more expensive although it is unclear if this approach results in care that provides better health outcomes.[16]

Chapter 18. Conclusion

This portfolio presented the results of two separate studies in older people. The view taken from this research is that older people pose a multiplicity of dilemmas and challenges to healthcare professionals around issues of cancer screening and cancer treatment. The difficulties facing healthcare providers are recognized, since never before has such a combination of factors been seen, including an aging population with increasing proportion of cancer diagnoses in the setting of co morbidities, a better informed public due to availability of information, albeit not always accurate, and limited and sometimes unclear empirical evidence to guide screening and treatment decisions. From a positive standpoint, better availability of less toxic treatments and age specific guidelines for older cancer patients now exists.

With respect to cancer screening, application and interpretation of guidelines requires consideration of functional status as well as discussion with patients about risks and benefits of testing should cancer be detected. It is unclear from the literature what cancer screening guidelines healthcare professionals utilize, since there are several organizations that issue guidelines in the US. American Cancer Society guidelines were used for this survey however, the American Geriatric Society and the American College of Physicians also issue guidelines, and all are age based and conflict about when to discontinue screening. Consensus on guidelines may not realistically occur for many years if at all, so healthcare professionals may need to approach such decisions based on the patients' position on decision-making, existence and severity of co morbidities, life expectancy and the cancer screening test in question.

The challenge for nurses is to develop innovative ways to overcome barriers to patient participation in early detection programs, identification of those most likely to benefit from early detection and treatment of cancer and evaluation of practice systems to enhance screening referrals. Education of older people should not focus entirely on benefits of screening but knowledge of risk factors and warning signs as well as lifestyle modification to reduce cancer risk and other chronic illnesses such as heart disease.

The older population has emerged as a complex group when presenting for cancer screening and cancer treatment. Multiple considerations may need to be considered including the patient’s desire for involvement in the decision-making process, the screening or treatment decision itself as well as management of co morbidities. Although more evidence and better treatment options for older people with cancer now exist, healthcare professionals including public health nurses, oncology nurses and oncologists are not well prepared from an educational standpoint for the challenges of caring for the emerging population of older people with cancer. While curriculums to incorporate increased geriatric oncology content may be on the horizon, realistically it will take several years for results of this intervention to become evident. Continuing education courses incorporating geriatric oncology content may be a more realistic approach to improve and maintain knowledge. It should be recognized not all continuing education programs are equivalent; an initial needs assessment combined with multiple teaching modalities may yield results that are more effective. Attitudes towards older cancer patients should be reassessed with further research since the only study located revealed widespread negative views among all healthcare providers at one institution.

In summary, care of older people during cancer screening and cancer treatment presents multiple challenges to healthcare providers who themselves do not appear adequately educated and may hold negative attitudes towards this patient population. Further research is needed among healthcare providers to assess educational preparedness and attitudes. Patient oriented research in older people may provide better understanding about issues such as decision-making, age and gender specific barriers to screening and care as well as education and psychosocial needs during cancer treatment.

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Appendices

Appendix I

Would you describe to me your thoughts were when you were told you had cancer?

Locational pointers

- Details of diagnosis
- Surprised by diagnosis?
- Prior experience or knowledge with cancer, need to learn more? How and where?

What type of things did you think about when considering the treatment that was offered to you?

Locational pointers

- Need help with finances, transport, around the house, assistance if sick?
- Feelings about the treatment
- Any options?

When you made the decision to have treatment, who or what helped you to make that decision?

Locational pointers

- Friends with cancer?
- Avoidance of talking to family and friends about your illness?

What has the treatment been like for you?

Locational pointers

- Easy? Difficult? Examples of what made it so
- Lifestyle changes, adjustments?
- Worries as the treatment progresses?
- Support received - from whom?

What do you think are the differences for you having cancer and someone younger?

Locational pointers

- Physical impact of treatment?
- Adjustment differences
- Plans for the future because of this illness?

Appendix II

VOLUNTEERS NEEDED

IF YOU ARE 65 YEARS AND OLDER AND
HAVE NEVER HAD CANCER

YOU CAN CONTRIBUTE TO A PhD THESIS

HOW............................COMPLETE A SURVEY ABOUT
CANCER, TREATMENT AND
SCREENING TESTS

WHY............................WHAT YOU THINK AND KNOW ABOUT
CANCER IS IMPORTANT.
IT HELPS OTHERS NOW AND IN THE FUTURE

WHEN......................... EVERY WEDNESDAY around LUNCHTIME

WHERE........................RIGHT HERE

HOW LONG................ABOUT 15 MINUTES

Appendix III

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

Information sheet for cancer questionnaire

Introduction

- You are invited to complete a survey for **people 65 years and older who have never had cancer.**
- The survey is to find out what you know and think about cancer, the tests that find it in the early stage and the treatment.
- Participation is voluntary and there is no payment to you for participating. This study is not affiliated with any organization or the center where you are doing this survey, so your participation does not affect any services you receive from the center.
- The study is part of a PhD thesis and has been approved by the University of Adelaide, Australia. The results of the survey will be published in a thesis and possibly professional journals but your identity will remain anonymous.

Why participate?

- The purpose is to find out what you think and believe and if this makes a difference to whether you have tests to find cancer when it is in the early stage.

What is involved?

- The survey should take about 10-15 minutes to complete.
- There is no need to put your name on the survey, your name is not important, only what you think.
- When you finish the survey put it in the envelope, seal it and place a cross over the seal. Completion of the survey is considered your voluntary consent to participate.

Who benefits from this questionnaire?

- What you think and believe about cancer, cancer screening tests and cancer treatment is very important for doctors and nurses to know.
- We constantly need to know what people think and know about their health so we can teach them what they need to know to take better care of themselves.
- By participating in this survey, you are keeping us informed about how you make decisions about your health and this helps us provide better healthcare to everyone.

Please be assured that...

- The survey is anonymous; there is no way to identify you from the survey.
- The surveys are numbered for tracking those returned.

Thank you for considering this survey

For further information contact:

Ann Cleary
Doctoral student from University of Adelaide, Australia.
Phone in New York: 212 5291245

This study is supervised by the Department of Clinical Nursing at the University of Adelaide, Australia by the following supervisors:

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Appendix IV

CANCER QUESTIONNAIRE FOR PEOPLE OLDER THAN 65

Before you start this survey, please answer these questions about yourself

i. Age ☐ 65-74 ☐ 75-84 ☐ 85 and older

ii. Sex ☐Male ☐ Female

iii. Highest education achieved ____

iv. Have you ever had cancer of the breast, colon or prostate?
☐ **YES** ☐**NO**

Questions 1-5 are general questions

Please answer Yes, No or Do not know to each question.

1. Do you think that older people are more likely to get cancer than younger people?	**YES NO DO NOT KNOW**
2. Can a bump or a bruise to the body cause cancer?	**YES NO DO NOT KNOW**
3. Is pain usually an early sign of cancer?	**YES NO DO NOT KNOW**
4. Can blood in a bowel movement be a sign of cancer?	**YES NO DO NOT KNOW**
5. Do you think that most people who get cancer could be saved if it were found and treated in the early stage?	**YES NO DO NOT KNOW**

Questions 6-7 ask about being checked for cancer of the bowel

There are several tests recommended to find cancer of the bowel in the early stage. The following two questions ask about what you do.

6. I have a bowel movement blood test to look for hidden blood.

☐ Every year
☐ Every 2 years
☐ Every 5 years
☐ I stopped having this test
☐ I have never had this test

7**. There are tests that show the inside of the bowel. Mark the box that best applies to you.**

☐ I always have **either** a flexible sigmoidoscopy every 5 years **or** a colonoscopy every 10 years

☐ I had either a flexible sigmoidoscopy more than five years ago, or a colonoscopy more than ten years ago; I plan to have one of these tests soon

☐ I had either a flexible sigmoidoscopy more than five years ago or a colonoscopy more than ten years ago; I am not sure if I will have this test again

☐ I stopped having these tests

☐ I have never had any of these tests

Questions 8-9 ask about your feelings and attitude to cancer

8. Please tell me what you think about the following statement by marking one of the boxes.

Having a test to find cancer of the bowel in the early stage instead of the late stage just means more worry for longer because bowel cancer is always a deadly disease.

☐ Strongly agree
☐ Agree
☐ Don’t know
☐Disagree
☐ Strongly disagree

9. If you found out you had cancer which of the following statements best describes what you think you would do.

☐ Definitely get treatment.
☐ Take some time to think if the treatment was worth it.
☐ Maybe not get treatment if the cancer was very advanced.
☐ Maybe not get treatment no matter what stage the cancer was in.
☐ I would not go back to the doctor if I found out I had cancer.

Questions 10-11 ask you to write information you know about prevention and early signs of cancer

10. There are some things people can do that may reduce their risk for getting some cancers. Please write down any cancer you know, and then say what a person can do that could help decrease their risk of getting this cancer.
You may answer I don't know if you can't think of an answer**.**

____

____

____

____

____

11. Please write down what signs someone may have that could indicate cancer of the bowel, breast or prostate. You may write down as many things as you know or answer I don't know if you can't think of an answer.

____

____

____

____

Questions 12-14 are for MEN only

Please answer Yes, No or Don't know to the following

12. Can difficulty when urinating be a sign of cancer? **YES NO DO NOT KNOW**

13. Please choose the answer that best describes what you think or believe about the following statement.

Most times, it does not matter if prostate cancer is found early, it doesn't change how long a man lives.

☐ Strongly agree ☐ Don't know ☐ Disagree
☐ Agree ☐ Strongly disagree

14. Please choose from the following answers about your PSA testing.

I have a PSA test done....

☐ Every year ☐ I stopped having PSA tests
☐ Every 2 years ☐ I have never had a PSA
☐ Every 5 year

Questions 15-17 are for WOMEN only

15. Please choose one of the following answers about your mammogram test.

I have a mammogram done..

☐ Every year ☐ I stopped having mammograms
☐ Every 2 years ☐ I have never had a mammogram
☐ Every 5 years

16. Are all breast lumps cancerous? **YES NO DO NOT KNOW**

17. Please tell me what you think and believe about the following statement by marking the box that best applies.

Looking for cancer by doing a mammogram is a good idea when you are younger but it hardly makes a difference when you are older

☐ Strongly agree ☐ Don't know ☐ Disagree
☐ Agree ☐ Strongly disagree

Thank you for completing this survey

Appendix V

Number	sex/age	age groups	knowledge	attitude	screening	mammo	psa	colorectal
1	M	65-74	4	14	15	XXXXXXX	5	10
2	F	65-74	5	13	13	5	XXXXXXX	8
3	F	75-84	4	13	4	2	XXXXXXX	2
4	M	75-84	3	11	11	XXXXXXX	5	6
5	F	65-74	4	14	7	5	XXXXXXX	2
6	F	75-84	4	14	13	5	XXXXXXX	8
7	M	85+	3	9	5		0	5
8	F	75-84	3	12	4	2	XXXXXXX	2
9	M	65-74	4	13	15	XXXXXXX	5	10
10	F	65-74	3	11	7	5	XXXXXXX	2
11	M	65-74	5	14	12	XXXXXXX	4	8
12	F	75-84	4	13	9	5	XXXXXXX	4
13	M	65-74	6	14	15	XXXXXXX	5	10
14	M	75-84	4	10	15	XXXXXXX	5	10
15	F	65-74	4	13	11	5	XXXXXXX	6
16	M	85+	5	15	12	XXXXXXX	5	7
17	M	65-74	4	12	12	XXXXXXX	4	8
18	F	75-84	4	13	10	5	XXXXXXX	5
19	F	85+	5	11	3	1		2
20	F	65-74	2	13	13	5	XXXXXXX	8
21	M	75-84	5	10	15	XXXXXXX	5	10
22	M	75-84	5	13	11		5	6
23	F	75-84	3	13	13	4		9
24	M	85+	5	13	15	XXXXXXX	5	10
25	F	75-84	4	13	13	5	XXXXXXX	8
26	F	65-74	6	15	13	5	XXXXXXX	8
27	F	75-84	3	9	15	5	XXXXXXX	10
28	F	75-84	4	13	9	2	XXXXXXX	7
29	F	85+	3	11	7	3	XXXXXXX	4
30	M	75-84	5	9	12		4	8
31	F	65-74	4	15	11	5	XXXXXXX	6
32	M	65-74	3	10	5	XXXXXXX	1	4
33	M	65-74	5	15	13	XXXXXXX	5	8
34	M	65-74	3	14	11	XXXXXXX	5	6
35	F	65-74	5	15	15	5	XXXXXXX	10
36	F	85+	5	13	14	4	XXXXXXX	10
37	M	65-74	3	13	12	XXXXXXX	5	7
38	M	85+	4	11	15		5	10
39	F	65-74	6	14	12	5	XXXXXXX	7
40	F	65-74	5	14	15	5	XXXXXXX	10
41	M	85+	4	12	9		2	7
42	M	75-84	6	13	13		4	9
43	F	85+	5	9	3	1		2
44	M	85+	4	13	10		5	5
45	F	85+	5	15	15	5		10
46	F	75-84	4	10	10	4	XXXXXXX	6
47	M	85-	4	12	10	XXXXXXX	5	5
48	F	85+	3	10	3	1		2
49	F	85-	4	11	4	2	XXXXXXX	2
50	M	85+	3	11	12		5	7
51	M	75-84	3	11	15		5	10
52	M	75-84	6	14	10		2	8
53	F	85+	3	9	4	2		2
54	M	75-84	3	15	15		5	10
55	F	85+	5	12	8	3		5
56	M	75-84	4	7	12		4	8
57	M	85+	6	15	11		5	6
58	M	85+	2	15	10		4	6
59	F	85+	4	15	10	5		5
60	M	65-74	6	14	12		5	7