



UNIVERSITY OF LEEDS

This is a repository copy of *Experiencing cancer in old age: a qualitative systematic review*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/83251/>

Version: Accepted Version

Article:

Hughes, N, Closs, SJ and Clark, D (2009) Experiencing cancer in old age: a qualitative systematic review. *Qualitative Health Research*, 19 (8). 1139 - 1153. ISSN 1049-7323

<https://doi.org/10.1177/1049732309341715>

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Closs and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Qualitative Health Research

Hughes et al. / Experiencing Cancer in Old Age

Authors' Note: This study was supported financially by Macmillan Cancer Support through a research fellowship grant to the first author. The sponsor played no part in the design or execution of the study.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes

S. José Closs

University of Leeds, Leeds, United Kingdom

David Clark

Lancaster University, Lancaster, United Kingdom

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José GLOSS and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Abstract

Our purpose in this study was to find, report, and interpret the results of qualitative studies which investigated the experiences of older people living with cancer. We conducted systematic literature searches, identified and extracted the findings from 11 studies, and analyzed them systematically. We interpreted the findings to suggest that living with cancer in old age is to live in a perpetual state of ambiguity. The experience is characterized by a sense of disintegration, diminished identity, suffering, and social retraction. These experiences are balanced by sources of comfort and strength found within the self and among diverse relationships. The results of our study illuminate the complex, multidimensional character of living with cancer in old age. They show that older people living with cancer are resilient as well as vulnerable. We argue for changes in attitudes and behavior that will enable health care professionals to foster older peoples' resilience.

Keywords: cancer; lived experience; older people; qualitative methods, general; systematic reviews

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

In this article we report the purpose, design, conduct, and findings of a systematic search and review of qualitative research literature that investigated older peoples' experiences of living with cancer. Cancer has its highest incidence in older populations. There is extensive literature reporting the incidence and prevalence of cancers in older age groups, along with approaches to treatment and the effects and management of comorbidity (Bennahum, Forman, Vellas, & Albarede, 1997; Extermann, Overcash, Lyman, Parr, & Balducci, 1998; Satariano & Silliman, 2003). However, the subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown. This review provides a basis for developing clinical health services that are based on older peoples' perceived and expressed needs.

To make the most effective use of research findings, approaches to synthesizing the results of many studies on the same topic have increasingly found favor and, in quantitative research, sophisticated methods of meta-analysis have been developed which aim to produce a definitive set of findings from a wide range of work. In qualitative research, also, such an approach is deemed to be an essential part of increasing the usefulness and relevance of findings (Sandelowski, Docherty, & Emden, 1997), though the methodology is at an earlier stage of development (Dixon-Woods, Booth, & Sutton, 2007; Popay & Roën, 2003) and there has been debate about whether the approach is epistemologically appropriate (Campbell et al., 2003; McDermott, Graham, & Hamilton, 2004; Sandelowski et al., 1997). This approach is termed variously "metastudy," "metasynthesis," and "research integration." It is an approach to the literature that is more than a critical review: it is an attempt to integrate findings across studies to arrive at new understandings.

Our reading of methodological literature in the field of qualitative reviewing and synthesis (Barbour, 2001; Booth, 2001; Britten et al., 2002; Campbell et al., 2003; Noblit & Hare, 1988; Paterson, Thorne, Canam, & Jillings, 2001; Sandelowski & Barroso, 2006; Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004) led us to describe the study reported here as a qualitative systematic review. This

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

seemed to us the most accurate rendering of our pragmatic combination of methods and concepts to be found in a field still under development and with ever-changing and sometimes conflicting terminology. There is continuing methodological debate about what exactly constitutes a synthesis, for example. Our purpose was not specifically to develop the methodology of qualitative metasynthesis, or to rigidly apply one set of techniques. Rather, we took a flexible and eclectic course (Johnson, Long, & White, 2001), applying techniques from different sources to examine in detail the findings of qualitative research that reports older peoples' experiences of living with cancer. We present new understanding based on our interpretation of those findings.

Systematic Literature Search

The question that guided a search for relevant studies was, "What qualitative research literature is available that reports experiences of living with cancer of adults aged 75 and over?" We conducted thorough and comprehensive searches of seven electronic databases (AMED 1985-2006; British Nursing Index 1985-2006; CINAHL 1982-2006; Embase 1980-2006; International Bibliography of the Social Sciences 1951-2006; Medline 1966-2006; PsycINFO 1985-2006) using a range of subject headings and keywords representing old age, cancer, experience, and chronic illness, and including a qualitative "filter" (Wilczynski, Marks, & Haynes, 2007) designed to maximize the retrieval of qualitative studies (see Figure 1).

INSERT FIGURE 1 ABOUT HERE

Limited results from this strategy, deemed in part to be the result of shortcomings in indexing of qualitative research reports in electronic databases (Barroso et al., 2003; Flemming & Briggs, 2007), led to a supplementary manual search of purposively selected journals considered likely to publish relevant articles. We identified and located 22 such journals and searched the content lists covering a period of ten years, 1996-2006, when available. In addition, we scrutinized reference lists of relevant articles retrieved by electronic and manual searching for titles that met the screening criteria of containing reference to

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

older people and cancer. We also decided to consult a range of experts ((authors of the articles included in the sample and members of the Cancer Experiences Research Collaborative at five United Kingdom universities) in the hope of identifying additional articles.

At each stage of searching, we retrieved abstracts if the title included reference to cancer and to older adults, but excluded them if it was clear from the title that the article was about cancer-related health promotion or screening. We also excluded titles if they were clearly not full reports of primary research; for example, conference abstracts, editorials or commentaries, or news reports. If it was not clear from the title or the abstract that the study reported primary qualitative research about older people and cancer then we retrieved the article and read it against the inclusion criteria. We included articles if they reported qualitative studies of older adults, investigating accounts of individuals' experiences of living with cancer.

Though we sought to be systematic and rigorous in our search of the literature, experience revealed that a sequential method of searching, however systematic, was insufficient to locate qualitative studies. Searching was iterative and reflective, informed by the metaphor of "berry picking" (Barroso et al., 2003). The process included false trails, frustrations, and subtle shifts in thinking and direction, along with surprises and rewards. Ultimately, a purposive sample of reports was obtained which represented a useful and workable sample for systematic review.

Search Results

Electronic searches yielded 214 records. One hundred and sixty four titles referred to aspects of chronic illness unrelated to older people, 39 titles referred to older people, eight titles referred to people with cancer, and just five titles referred to older people with cancer. Two of these articles met the inclusion criteria (Thomé, Dykes, Gunnars, & Hallberg, 2003; Thomé, Esbensen, Dykes, & Hallberg, 2004). Hand searching yielded 99 records, of which 11 met the inclusion criteria (including the two articles retrieved from the electronic searches). Scrutiny of reference lists from the 11 articles identified

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

48 potentially relevant citations. One of these studies met the inclusion criteria (Adler, McGraw, & McKinlay, 1998). No additional articles were retrieved from consultation with authors and the expert reference group. It should be noted that only two of the studies retrieved focused exclusively on people aged 75 or over (Thomé et al., 2003; Thomé et al., 2004); therefore, to broaden the study, we decided to accept authors' varying, and sometimes implicit, definitions of older people. Furthermore, we decided to include articles whose focus was not exclusively on older people (Harden, Northouse, & Wood, 2006; Navon & Morag, 2004), but whose study populations contained a substantial cohort of older people (defined as 65 years or older).

The provisional bibliographic sample comprised 12 studies. It is described as provisional because the analytic process allows for later exclusions (Sandelowski & Barroso, 2006). Of the 12 studies included at this stage, three were studies of men with prostate cancer (Harden et al., 2006; Hedestig, Sandman, & Widmark, 2003; Navon & Morag, 2004) and four were studies of women with breast cancer (Adler et al., 1998; Feher & Maly, 1999; Overcash, 2004; Roberts et al., 2006). One study investigated the experience of older women with a range of gynecological cancers (Sinding, Wiernikowski, & Aronson, 2005), and the remaining four articles reported studies of men and women with a range of cancers (Duggleby, 2000; Ryan, 2005; Thomé et al., 2003; Thomé et al., 2004). The studies were conducted in Canada (2), Israel (1), Sweden (3), and the USA (6). The total number of informants across all studies was 215; sample sizes ranged from 5 to 41, and the age range of participants was 51 to 99.

Methods

The analytic method used in this review was based closely on a framework presented by Sandelowski and Barroso (2003a, 2003b, 2006). This involves the processes of study appraisal and of identifying findings which are subsequently extracted, edited, grouped, summarized, and synthesized/interpreted. We derived a method for presenting summarized findings from Noyes and Popay (2006). Findings were interpreted using two methods. First, a working hypothesis, derived from close

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

familiarity with the review findings, was formed and investigated by exploring “dimensions of contrast” (Sandelowski & Barroso, 2006). Second, the concept of biographical disruption (Bury, 1982) was “imported” (Sandelowski & Barroso, 2006) and the core constructs of the concept applied to a reading of the studies’ findings. These methods are described and explained in more detail below.

Study Appraisal

We appraised studies by a process of close analytical reading using a reading guide (Sandelowski & Barroso, 2006) with which the relative proportion of “signal” to “noise” was assessed (Edwards, Russell, & Stott, 1998; Edwards et al., 2000). “Signal” refers to the clarity, relevance, and trustworthiness of a study’s findings, whereas “noise” refers to possible methodological flaws or reporting limitations which might obscure such clarity or make the credibility of the report questionable in some respects. We judged all the studies included to have more signal than noise. We made these judgments on the basis of two principal criteria: (a) the design and methods of the studies were appropriate to the research questions under investigation, and (b) methods and procedures (sampling, recruitment, data collection, data analysis, and ethical considerations) were reported in sufficient detail to enable a judgment that the research was conducted competently. Detailed descriptive notes and summary evaluative commentaries based on these criteria were written as each article was analyzed.

The principle underlying the appraisal of studies to be included was based on including and preserving logic (Sandelowski & Barroso, 2006). This means, for example, that perceived methodological limitations (for example, the lack of a substantive or formal theory in a grounded theory study) that might represent a degree of noise are not deemed in themselves to invalidate the findings of a study and are not used as a basis for exclusion from the review.

In the final analysis, the only reasons for excluding a report within the parameters of this framework were that a study appeared to have been conducted unethically or that on close reading and examination the report was discovered to contain no findings (defined below; Sandelowski & Barroso,

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

2003a, 2006). In this review, all original studies contained evidence of having been conducted according to sound ethical principles, and received ethical approval from an appropriate institution. We eventually excluded one study on the grounds that it was difficult to discern findings as defined in the review protocol, leaving a final sample of 11 studies.

Identifying and Extracting Findings

Findings from qualitative research reports form the raw data for a qualitative research integration project or systematic review (Sandelowski & Barroso, 2006). It is important, therefore, to identify all statements in a report that constitute the findings from the research. We defined findings in this review as “the data-driven and integrated discoveries, judgments or pronouncements which researchers offer about the phenomena, events, or cases under investigation” (Sandelowski & Barroso, 2003a, 2006). The following types of statements that appear in research reports are not findings within this definition and were not extracted:

- Direct quotations from interview data offered in support of findings
- Statements that indicate they are portions of interview data, even though they are not direct quotations
- Statements that offer researchers’ views on the clinical, educational, or research implications of the results
- Statements that refer to findings from other studies or from academic literature

The process for extracting findings was guided in this review in two ways. First, during the initial study appraisal, we identified and separated findings from the data that supported them (typically, though not exclusively, expressed as direct quotations from participants). Second, we devised a set of decision rules, based on the definition of a finding stated above, to guide the extraction of findings more clearly.

Decision rules reflected the complexity and subtlety of locating findings. For example: “Statements that

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

indicate they are portions of interview data, even though they are not direct quotations, are not findings and should not be extracted. These may begin, ‘One participant said that . . .’ or, ‘One participant described . . .’” (Decision Rule 4 of 7). Applying this rule led us to judge that, in the following statement from one of the studies, the first two sentences were classified as findings, whereas the third sentence was classified as supporting data and was not extracted as a finding:

Participants described past life experiences and attribution of meaning to their lives.

Relationships were often the focus of attribution of meaning. For example, one participant described the development of her relationships with God and others and how she was helping others in her church congregation.

To enhance trustworthiness of the process of extracting findings the first two (researcher) authors independently extracted findings from three articles selected at random from the bibliographic sample of 12 qualitative research reports. Each researcher used the written decision rules as a guide to extraction. Of 25 statements initially extracted as findings by one of the two researchers, but not by both, it was agreed to include 19 as findings and to exclude the remaining six (one was extracted as a simple oversight and five contravened a new decision rule). Discussion led to the writing of this new decision rule and to creating an exception to an existing decision rule. We reread all the reports in light of the new decision rules.

We located 414 findings in 11 reports and extracted them to word processing files. We edited findings, where necessary, to preserve the sense for readers who might be unfamiliar with the whole report (Sandelowski & Barroso, 2006). Subsequently, we copied all findings into one word processing file in preparation for the stage of analysis described as “grouping findings” (Sandelowski & Barroso, 2006).

Grouping Findings

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

We grouped findings by topic, in a process analogous to thematic analysis. Topics are recurrent patterns, subjects, themes, or motifs which are recognized through the close familiarity with the findings engendered by the previous stages of appraising, locating, extracting, and editing. For example, following repeated readings, we observed the topic of “empowerment” as recurring in the findings. Findings were initially grouped into 15 topics. Table 1 shows the variability of topic appearance by report.

INSERT TABLE 1 ABOUT HERE

Findings on the topic of relationships with family and friends appeared in all 11 reports; findings on the topic of assertiveness only appeared in one report (assertiveness was the major topic of this particular study). In a second phase of identifying topic groupings, an independent researcher (the second author) read all the study reports alongside the topic groupings identified in the first phase to check face validity, and with the intention of noting any potentially significant omissions from the original list. This process resulted in the identification of four additional topic groupings: age and aging; aloneness; meaning; and limited time. We interrogated the findings again to locate findings in each of these topic areas.

Abstracting Findings

The grouped findings comprised a dataset of approximately 20,000 words. To reduce the data in preparation for interpretation we explored the grouped findings to discover additional patterns, overlaps, comparisons, and redundancies. This process is referred to as “abstracting” the findings (Sandelowski & Barroso, 2006). This means that the findings are summarized, abridged, or reduced to a form that represents their essence. We used the authors’ original words except where findings were rewritten, according to decision rules, to maximize clarity. We rewrote findings to “render them more parsimoniously” and to produce a “set of statements that concisely but comprehensively capture the content of all the findings and preserves the context in which they appeared” (Sandelowski & Barroso, 2006, p. 159). In the process of abstracting, redundancies and repetitions in the grouped findings were

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

eliminated and finding statements refined to make them inclusive of the ideas the researchers conveyed in the findings (Sandelowski & Barroso, 2006). Abstracting the findings produced a dataset of approximately 6,000 words in five topic areas. All the previously identified topic groupings, from both phases of topic identification, were incorporated in the abstracted findings.

Results

Older people in these studies reported a range of complex impacts arising from their experience of cancer which related to (a) the bodily signs and symptoms of cancer, (b) decisions about whether to have treatment and the experiences of undergoing treatment, (c) the extent to which they felt empowered, (d) the states of mind induced by the experience of living with cancer, and (e) the effects of cancer on their relationships with partners, families, friends, and health professionals.

This might be considered a first-level analysis of the findings. At this stage the presentation is literally descriptive, with no attempt at interpretation, and stays very close to the language of the original reports. The only exceptions are where findings have already been edited or rewritten (Sandelowski & Barroso, 2006), according to the decision rules referred to earlier or where the narrative flow and clarity of meaning required the insertion of some linking phrases. It is important to emphasize this fidelity to the original language to preserve the credibility of subsequent interpretive moves performed with the studies' findings, which, to reiterate, form the data for this review.

Findings Relating to Bodily Signs and Symptoms

Older people in these studies experienced changes in their bodies that they attributed to cancer, the effects of cancer treatment, and age-related changes associated with normal aging or with comorbidities. Bodily experiences included fatigue, pain, nausea and vomiting, appetite loss, urinary and fecal incontinence, alopecia, and bodily feminization (as a result of hormone treatment). Older people could feel severely buffeted, worried, and anxious by these experiences but at the same time put in place strategies to manage the situation. Fatigue was managed by taking time to rest and by maximizing

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Closs and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

available energy. Analgesic medication for pain in terminal cancer was augmented not only by nonpharmacological means of pain relief but by a strategy of endurance based on finding hope and on adjusting to pain emotionally. Religious faith and the support of caring families provided essential underpinning support for the effectiveness of these psychological pain-relieving strategies. Adaptation to unwanted changes in physical appearance was achieved by simply avoiding the sight of the changed body or by reconstructing the difficulties to emphasize a positive side. For example, loving attention from family members sometimes compensated for the psychological pain of alopecia.

The experience of, and strength of reaction to, bodily change appeared to be heterogeneous according to age, stage of cancer, and comorbid disease. For some, effective cancer treatment that had minimal impact on the body or on the person's life proved to be encouraging and made things easier. For others, physical changes could be overwhelming ("excruciating"), could diminish physical and emotional strength unbearably, provoke revulsion and self-abhorrence, undermine a sense of normality, and transform life into a hopeless and lost situation.

Findings Relating to Treatment

Nine of the studies reviewed reported older peoples' experiences relating to cancer treatment. Decisions about treatment, including whether or not to have treatment, were affected by interpersonal, intrapersonal, and social factors. Relationships with health care personnel and family members affected treatment decisions. For example, the approach to decision making was seen as a collaborative venture by women undergoing radio frequency ablation (RFA) for breast cancer (Roberts et al., 2006), in which women perceived their role as being informed about available treatments but leaving the final decision to the medical team on the basis of a trusting relationship. This was seen not as a decision to opt out of decision making but as a decision to view oneself as only one part of the decision-making process. It is important to note that these women were receiving treatment as part of a research study and were highly motivated toward taking an active part in the management of their disease.

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

For older people in other studies, making decisions about treatment was sometimes felt to be burdensome, and they expected health care providers to make decisions for them, based on their superior knowledge. Conversely, older people who did want to be consulted, or wanted to decide against treatment, and who were ignored or unsupported in their decision, regarded their health care providers as paternalistic. Paternalistic attitudes and behaviors on the part of health care personnel caused ruptures in their relationships with older people. Whatever the decision, encouragement from family members was important.

Important intrapersonal factors in decision making about treatment included the ability to exercise personal control. In some studies (e.g., Thomé et al., 2003), some older people tried to get as much information and knowledge as possible to make independent decisions, whereas others chose not to be informed or to seek control and let other people make decisions for them. In the RFA study the decision to have treatment as part of the research study enabled participants to gain some personal control. For those aged over 75, decisions about treatment (for a range of different cancers) were not seen as discrete but were embedded in a wider context of the power to choose the approach to daily life with cancer (Thomé et al., 2003).

For older people, making decisions about treatment and living with the consequences was experienced as difficult in light of comorbid conditions. They sometimes chose to forego treatment (Sinding et al., 2005) explicitly in the context of their age, or age-related health problems and social circumstances. Careful thought preceded decision making. Readiness to undergo treatment showed itself in bargaining about the price to be paid in side effects in proportion to the beneficial effect of treatment. More broadly, willingness to undergo treatment was influenced by older peoples' values and their perceptions of their whole life situation.

Decisions about treatment were influenced by social context; that is, the general attitude toward cancer treatment in old age. Those in advanced old age felt that their age was a factor taken into account

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

by health professionals in deciding treatment options, which in some cases meant limited access to various methods of therapy. Suspicions about being treated less carefully owing to old age exacerbated feelings of abandonment and uncertainty. Contrary to these unmet expectations of high-quality treatment, some older people were challenged by their peers on the value of undergoing treatment at all at that stage of life.

Findings from these studies revealed a number of strategies employed by older people for managing the process of undergoing treatment for cancer. Strategies included placing trust in the oncologist; seeking comfort through prayer; maintaining an active life; concealing the illness from anyone outside the immediate family; keeping a sense of control by being well informed or, on the contrary, remaining passive and allowing health care professionals to be responsible for decisions about treatment and care; adapting and adjusting constructively to side effects of treatment and residual disabilities. For some women undergoing breast cancer treatment, maintaining an active life included sustaining a role as primary caregiver to others.

Positive and negative effects from treatment were reported. Women treated with RFA for breast cancer reported satisfaction with treatment, which reduced anxiety about the disease and improved quality of life. They were especially pleased with the amount of information they received before, during, and after treatment. Hormonal therapy for advanced prostate cancer allowed men to regain their strength, retain their masculine self-identification, and renew their relationships with their spouse and with social contacts. But there were psychosocial costs that affected their self-definition as healthy, sexually competent, and fully male. They lost a sense of closeness in their pretreatment relationships, and they felt deprived of a sense of continuity, excitement, hope, and coping capabilities (Navon & Morag, 2004). In a different study of men treated with hormone therapy for prostate cancer, men also spoke of disruption to their plans and of decreased energy and impotence caused by treatment (Harden et al., 2006). Impotence was a common result of disease (untreated localized prostate cancer) or treatment (hormone therapy for

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

advanced prostate cancer), but reactions to this varied. For some men sexual activity was less important because of old age. For others, advanced age did not reduce the importance ascribed to the role of sex in their lives.

Treatment effects for older people in the Swedish studies (Thomé et al., 2003, 2004) were experienced against a complex background of bodily disabilities and limitations resulting from the cancer disease, from the effects of aging (including comorbid disease), or from aging impaired by cancer. The effects of cancer and its treatment seemed to produce the greatest limitations in daily life, however, to the extent that life became “disintegrated”; that is, more or less fully occupied with traveling to undergo treatment, residing away from home for the duration of the treatment, then coping with the side effects of treatment, not only on the body but on social life and relationships. These experiences provoked existential, as well as physical and emotional, suffering.

Despite these difficulties, older people with cancer felt that it was possible to endure their experiences and to accomplish the tasks required of them to face the illness and its treatment. Illness experience presented an unexpected consciousness of the personal power and strength to have gone through a tough period of illness and treatment that forced them to reappraise their life. Despite its difficulties, the value of having undergone treatment was appreciated as time went on. In the anticipated future there was a reorientation and reentry to ordinary social life, but with a new experience added.

Findings Relating to Being Empowered

Eight of the studies reviewed contained findings relating to empowerment. A dichotomy or, rather, a continuum was evident over which older people were empowered or disempowered to varying degrees according to their own attitudes and actions, or the attitudes and actions of others. Participants in the studies were empowered by an attitude that represented an internal locus of control through their self-directed assertive behavior or through the supportive actions of others.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Self-empowered attitudes included a feeling of responsibility for one's own health, and the unexpected consciousness of the personal power and strength to have endured a tough period of illness and treatment. Self-empowered behavior included employing a range of assertive strategies in encounters with physicians, such as information seeking, insisting on comprehensive and efficient treatment and management of their illness and, as a last resort, changing to a different physician if they were not satisfied. Participants felt empowered by health professionals when they felt listened to and believed in, when they were given a choice to take part, or not to take part, in discussions and decisions about treatment. A contrary finding is that the invitation to make a treatment decision in the face of multiple health problems was seen as burdensome rather than empowering. It was seen as ironic that such a complex decision should be left to a patient, despite the physician's clearly superior knowledge.

Participants were disempowered by an attitude that represented an external locus of control, by their passive behavior, or by negative attitudes and actions of health care providers. Extreme feelings of disempowerment were reported by some participants from the point of diagnosis, as life was perceived as suddenly and wholly surrendered to the trust of health care personnel. This was experienced as a disintegration of the life situation. Passive behavior on the part of older people was seen as disempowering when it was enforced, rather than actively chosen, because they felt a lack of options because of their poor health. Passivity was not always disempowering; sometimes it was a route chosen by older people to get what they wanted. Health care providers reinforced feelings of disempowerment when participants felt they were being neglected on the grounds of their age.

Findings Relating to States of Mind or Feelings Associated With Living With Cancer

Nine of the studies reviewed contained findings relating to states of mind or feelings that accompanied older peoples' lives with cancer. The participants expressed a range of negative and positive emotions including uncertainty, fear, anxiety, insecurity, depression, and despair, as well as confidence, hope, safety, reassurance, and peace. Older people described fear and worry when they were first told that

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

they had a tumor and needed to have regular check-ups. An unsympathetic attitude from the physician at this early stage meant a violating experience leading to anxiety, sleep disturbance, and feelings of dejection. There was uncertainty about the relative roles of cancer, other illnesses, and age itself in producing symptoms and disabilities. Lack of information about the disease was discouraging and became a source of fear of progressive disease and death. Uncertainty was described as living in a “shadow land.” When older people wanted information but could not acquire it they felt insecure and out of control. Symptoms such as appetite loss, nausea, and vomiting caused them to worry about nourishment and about their dependence on others. They feared the physical side effects of treatment and worried about what would happen when side effects appeared.

It was not only the impact of the cancer on the body that caused negative emotions. Relationships with relatives, friends, and health professionals, in many ways sources of support, could also produce anxiety and fear; for example, fear of rejection by family and friends, or fear of retribution by physicians in response to assertive behavior.

Thoughts about the future hovered between hope and despair. Hope was important as a way to endure cancer and arose in the treatment phase from absence of signs of the cancer along with positive information from the doctor. At a later stage of disease, older people expressed hope that the end of life would come soon. Despair arose from feeling abandoned and uncertain about how future life would be affected by the cancer. There were fears of becoming dependent on help for daily living and expressions by couples of a nagging worry about their future together. A contradictory finding in the face of anxieties about the future was that, in regard to expectations of how much time was left, older people had realistic presumptions about future time and mostly met the probability of a foreshortened life with no fear. Death itself was sometimes feared and sometimes viewed as a release, but the process of dying was feared as older people anticipated excruciating symptoms, confinement to bed, and dependence on others.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Resources and strategies for replacing feelings of uncertainty, fear, and anxiety with feelings of confidence and assurance included older peoples' chosen attitudes, as well as specific behavioral strategies. Attitudes included acceptance of pain; acceptance, without fear or sadness, that a long and eventful life was coming to a natural end; hoping for relief of pain, an end to suffering, and life after death; endurance of suffering; trusting in a higher being, confidence in God, and belief in fate. Faith brought comfort, security, assurance, peace, tranquility, serenity, lack of fear, and thankfulness. Having a good understanding of their disease, effective treatment, and strong relationships with family, friends, health care providers, and other patients also played a role in boosting feelings of safety and confidence.

Behaviors to combat negative emotions included adjusting to pain by consciously diverting the mind from it; deciding to undergo a treatment that would kill the tumor; "binding" anxiety by focusing on others and praying for them; screening off or setting aside the experience of threat, denying that the cancer cells still existed; compensating for the threat by making lifestyle changes; remaining distanced from the disease by not talking about it; and presenting a picture of the self to family members and caregivers as safe, happy, and unafraid.

Findings Relating to Relationships

More than one third of all the abstracted findings related to study participants' relationships with their life companions, family, friends, communities, and health care providers. All the studies reviewed contained findings about relationships in the context of living with cancer.

Intimate relationships with spouses changed as a result of living with cancer, and adaptation to change was needed for couples to maintain the quality of their life together. Couples interviewed together about the experience of living with prostate cancer (Harden et al., 2006) expressed a deeper sense of closeness but noted that living with the disease required them to learn a new way of living together every day. Couples agreed that open communication was essential to adjusting to changes in their normal intimacy patterns. Being able to confront their problems and talk about them together helped them

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

overcome denial and move toward acceptance. Facing facts and talking about options seemed to make life easier to manage. Older couples referred to prostate cancer as a couples' disease.

Changes in sexual desire and function related to the cancer disease or its treatment had a variable impact on spousal relationships. For most men with untreated localized prostate cancer, the symptoms of the disease (i.e., impotence) had not affected their sexual relationships with their wives, but they often chose not to discuss their illness with their wives so as to protect them from worry. In a study comparing three cohorts (late middle age, young-old, and old-old), older (i.e., the oldest old) couples raised less concern about erectile dysfunction than late middle age or young-old couples (Harden et al., 2006).

Men treated with hormone therapy for advanced prostate cancer had dramatically different experiences. Referring to their partners' attitude toward their physical condition (i.e., feminized appearance resulting from hormone therapy), some of the research participants related that they had moved into separate bedrooms because of their spouses' revulsion, fear of infection, refusal to share the marital bed with them, and insistence on taking away their authority in running the household. Others, in contrast, reported that besides displaying care and affection, their partners had encouraged them to leave the division of roles unchanged, to participate in joint leisure activities and in noncoital sex (Navon & Morag, 2004).

Increasing disability and dependence made some older people worry about the strain put on their partners, and created anxiety about the spouse's future life alone. At the same time as awareness of vulnerability, however, there was a strengthened relationship between some spouses, which resulted in feelings of confidence in meeting future challenges together.

Changing relationships with family members had both positive and negative aspects. Participants identified caring family members as helping them with uncertainty and alleviating struggles in daily life by giving consolation, comfort, and confidence. They expressed a need to remain close to family members and enjoyed the more frequent visits that resulted from their illness. Even where geographical

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

distance precluded regular visiting, many participants considered family support, most often from their adult children, as being vital to their survival. They also valued contact with grandchildren, which gave them a sense of engagement with a world outside of their own limited life space.

Relationships with the family were interpreted in new ways. Families' capacity for loving care appeared to be unexpectedly great, and this was seen as something that would not have been disclosed if the person had not contracted cancer. The strength to handle life with cancer, derived from supportive family relationships, gave illness a new meaning and transformed it to a positive experience. In addition to receiving support from their families, participants sought to protect family members from the cancer, and relieve their sense of being a burden by not letting the cancer dominate in conversation, by preparing for approaching death by giving things away, putting things in order, and by praying for them.

Where misunderstandings arose concerning various changes caused by the disease, taking up an undramatic attitude toward the disease and talking openly about cancer reduced misunderstandings and fantasies. Some participants, however, hardly ever talked to their families about their situation. Though they expressed a need to share their experiences with other people and talked with other patients, they expressed sorrow that family members so seldom asked about their health. This made them feel even more alone with their experiences of the disease. Loneliness could also arise through dramatic challenges to the sense of self experienced in the "liminal" state induced by hormonal therapy for advanced prostate cancer. Loneliness was experienced, too, through widowhood or being the only survivor among family and friends. But solitude also brought positive feelings of independence and an appreciation that certain aspects of daily life could run more smoothly.

Participants frequently found support in their friends and social networks, including fellow sufferers. They also used their friends' health and states of life as comparisons to measure how they were doing, a process of "downward comparison" (Thomé et al., 2003). They usually compared their own situation favorably, no matter how bad they felt it to be, with their perceptions of others'. Church

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

communities offered a good amount of support to older people living with cancer. People felt connected to their church communities through prayer; both being prayed for and praying for others, including their health care providers, through a sense of belonging to something that had lasted for generations and through individual friendships. Church also played a significant role in socialization (i.e., having a social life) for many older people, particularly those living alone.

For some it was important to talk to other patients with cancer about their disease, the prognosis and their physician's comments on their progress. Sometimes, though, there was ambivalence about whether to involve other people. Some participants chose not to disclose their malignant disease to friends and relatives beyond the immediate family because they feared relationships would be negatively affected, believing that people prefer to stay away from cancer sufferers.

Relationships with health care providers were reported both positively and negatively. Health care professionals were said to be important by being easily accessible. Their efforts to treat older people with candor, honesty, and thoughtfulness led to feelings of security and hope. Positive relationships with physicians and oncologists were marked by a sense of trust. Some older people described their relationships with their physicians as close, like a friendship. Successful encounters with physicians and other health care providers were comfortably paced. Older people were affirmed in such encounters by being believed in and listened to. Being invited to participate in discussions and decisions about treatment was experienced as a respect for autonomy, which was supportive and affirming.

Relationships were damaged or ruptured, in contrast, when older people felt unsupported in their autonomous decisions (not to have treatment, for example). If the life situation aroused feelings of abandonment and uncertainty about how illness would affect future life, suspicions about being treated less carefully owing to old age added to those feelings. Unreasonably long waiting times and vague information from the physician were interpreted as a consequence of low priority because of age. When evident signs of a cancer disease were neglected and explained as age-related, it was felt to be insulting

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Closs and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

and unacceptable. Experiences of information being withheld and suspicions about dishonesty led to distrust of health care professionals.

Interpretation of the Findings

A positive–negative dichotomy relating to a range of reported experiences was detected in the findings from the studies reviewed. Close familiarity with the findings as a whole suggested the working hypothesis that to live with cancer in old age is to live with perpetual ambiguity. This hypothesis was investigated in the hope of producing more penetrating insights by exploring what Sandelowski and Barroso (2003b) called “dimensions of contrast” in the findings, or what Elofsson & Öhlén (2004) represented as “dialectical experiences.” Such contrasts were presented by authors using the stylistic phrasing “on the other hand”; “on the one hand . . . and/but on the other”; or, as a variant, “at the same time.” For example:

The patients interviewed said in their narratives that they were well informed about their cancers and their prognoses. They knew that their prostate cancers were localized and, together with their physicians, they had chosen watchful waiting because their tumors were “benign.” On the other hand, they spoke about a feeling that the cancer tumor might still run their lives and lead to death (Hedestig et al., 2003, p. 58).

The theme of ambiguity is represented by other linguistic and conceptual devices, as well. Metaphors of darkness (“shadow land”; Hedestig et al., 2003), fracture (“disintegration”; Thomé et al., 2004), and the concept of liminality (living on a threshold of “betwixt and between,” neither one thing nor the other; Navon & Morag, 2004) presented the experience of ambiguity at the heart of living with cancer in old age. Examples of this condition of profound ambiguity were found across the disease continuum and age range, including untreated localized disease, active treatment for various cancers, and the posttreatment state following hormone therapy for advanced prostate cancer.

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Even where specific findings presented an experience of unequivocal suffering—for example, excruciating bodily symptoms (Thomé et al., 2004) or spousal rejection (Navon & Morag, 2004)—other findings produced a similarly unequivocal account of a positive aspect of living with cancer—for example, the comforts provided by religious faith (Feher & Maly, 1999). Sometimes a single experience carried both positive and negative connotations; for example, hair loss from chemotherapy brought painful challenges to body image but at the same time renewed loving attention from the family (Thomé et al., 2003). Exploring dimensions of contrast across the findings as a whole, therefore, confirmed the ambiguity hypothesis.

We also interpreted the findings from this review in light of the concept of biographical disruption in chronic illness (Bury, 1982). Sandelowski and Barroso present the use of “imported concepts” as an interpretive device in the synthesis of qualitative findings (2006). Our reading of this is that review findings can be usefully investigated in light of concepts established in related fields of research. Bury (1982) articulated six features of the experience of rheumatoid arthritis that combined to disrupt normal life. Biographical disruption has since been investigated in relation to a range of disease and illness states (Green, Todd, & Prevalin, 2007; Hopkins, 2004; Rajaram, Hill, Rave, & Crabtree, 1997; Richardson, Ong, & Sim, 2006), and in some research the concept has been contested and modified (Carricarburu & Pierret, 1995; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004).

Because cancer is increasingly regarded as a chronic illness, the review findings were explored in light of Bury’s categories in an attempt to determine the extent to which living with cancer in old age represented a biographical disruption, conceptualized as comprising (a) the experience of pain and suffering, and the fear or anticipation of death; (b) the disruption of normal relationship rules of reciprocity and mutual support; (c) reexamined expectations; (d) disrupted assumptions, with a focus on new attention to the body; (e) fundamental rethinking of biography and self-concept; and (f) mobilizing resources as a response to disruption (Bury, 1982).

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Pain, suffering, and death. Pain, suffering, and death were apparent across the review findings. Physical pain was typically experienced toward the end stages of a cancer disease (Duggleby, 2000), or as a side effect of treatment (Thomé et al., 2003). Some older people were able to put strategies in place, in addition to taking prescribed medication, to effectively manage pain; for others, pain was excruciating and overwhelming.

Psychological pain comprising uncertainty, anxiety, and fear ran through the whole experience of living with cancer, from diagnosis, through treatment, to approaching death. With regard to death, these findings suggest that death, in itself, was not feared by the very old, especially when it completed a fulfilled life, but the process of dying, and leaving loved ones behind, was very much feared. Imminent death was feared if the cancer was experienced as sudden.

Disruption of normal relationship rules of reciprocity and support. With the exception of some startling examples of alienation in personal relationships brought about by the experience of cancer and its treatment (Navon & Morag, 2004), and some evidence of social withdrawal (Thomé et al., 2004), findings from these studies suggested the reverse of this kind of disruption, indicating rather a biographical flow (Faircloth et al., 2004). Relationships with family, friends, and other support networks were at the least maintained, and were sometimes enhanced, during the experience of living with cancer. Such relationships provided a vital means of continuing support—physical, emotional, and practical—for the studies' participants. Support did not always flow one way; the relationships could also involve reciprocity, with the cancer sufferer offering practical (Overcash, 2004) and spiritual (Feher & Maly, 1999) help to family and community members.

Relationships between patient and health care provider also proceeded smoothly in most cases. Physicians were seen as friends and partners in decision making (Hedestig et al., 2003; Roberts et al., 2006). Older people confidently sought information, or chose to remain in ignorance, according to their own perceived needs. There could be disruption, though, when participants made a decision against

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

treatment (Sinding et al., 2005; Thomé et al., 2003). This ruptured the unwritten contract whereby physicians offer treatment, sometimes recommend it, and patients accept the treatment. When older people decided against treatment the health care providers' response was sometimes unsupportive.

Reexamined expectations. Study participants reported changes in their expectations of present and future life, from alterations to daily activities necessitated by limitations caused by disease or treatment to the anticipation of a foreshortened lifespan. Variation in changed expectations could be seen even within one study population (Harden et al., 2006). For some participants in this study, cancer caused minimal disruption to their daily plans, whereas for others the effects of the disease and treatment, fatigue in particular, had a big impact on daily life. A positive finding in relation to reexamined expectations was also reported by Harden et al. (2006) to the effect that a cancer diagnosis helped couples set new priorities and more meaningful goals for themselves.

Disrupted assumptions, with a focus on new attention to the body. Cancer, inevitably though variably, brought a disruption of taken-for-granted assumptions about the body and forced a reappraisal of its capabilities and its relation to the self. Hormone therapy for advanced prostate cancer resulted in a feminized body which, for Israeli men who prided themselves on their masculinity, was deeply disturbing (Navon & Morag, 2004). A combination of cancer, cancer treatment, and old age led to the familiar body becoming transformed into a disobedient body, a vulnerable body, an unreliable body, a body forced to endure (Thomé et al., 2004). For some participants effective treatment, with limited side effects, softened the impact of cancer on the body and permitted the maintenance of an active lifestyle (Overcash, 2004).

Fundamental rethinking of biography and self-concept. Some participants in these studies had a strong self-concept that was not challenged by their disease but rather became a resource underpinning their adaptive response. Women with breast cancer who were self-empowered and assertive (Adler et al., 1998), or whose existing religious faith gave meaning to their illness (Feher & Maly, 1999), revealed biographical flow (Faircloth et al., 2004) rather than biographical disruption. For others, most noticeably

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

men treated with hormone therapy for advanced prostate cancer, the psychosocial effect of treatment was to place them into a state of “liminality,” which became a permanent, immutable state, leaving them in a condition of no longer knowing who they were (Navon & Morag, 2004). Renegotiation or reconstruction of their masculine identity did not seem available to them (Maliski, Rivera, Connor, Lopez, & Litwin, 2008).

Mobilizing resources as a response to disruption. Bury (1982) writes that “the disruption of friendship and community involvement arises not only because of functional limitations . . . but also because of the embarrassment which such disabilities create” (p. 175). There is certainly evidence in the studies reviewed that functional limitations and embarrassment acted to disrupt both family and social relationships (Harden et al., 2006; Navon & Morag, 2004; Thomé et al., 2003), though this could be temporary (Thomé et al., 2003). At the same time, study participants engaged in a wide range of coping strategies (Duggleby, 2000; Hedestig et al., 2003) in which they marshaled their inner resources as well as activating their community networks (church, fellow patients) to support them.

We conclude that the findings from the studies reviewed do reveal elements of biographical disruption, both to the life course and to the sense of self, in the lives of older people with cancer. But the effects of disruption were modified by the maintenance, and in some cases the enhancement, of family and other support systems and by the inner resources brought to bear by participants on their changed situations. Disruption was sometimes softened, too, by experiences of biographical flow (Faircloth et al., 2004), in which participants responded to their illness in a way that revealed continuity with their former selves. The central finding of this review, the experience of profound ambiguity at the heart of experiencing cancer in old age, applies also to the application of the interpretive concept biographical disruption: older people experienced both disruption and continuity in their lives with cancer.

Conclusions and Implications for Practice and Research

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

The analysis and interpretation of findings in the studies reviewed suggests that the experience of living with cancer in old age is characterized by profound ambiguity. Life comprised a sense of disintegration, diminished identity, suffering, and social retraction. At the same time, these experiences were balanced by sources of comfort and strength found within the self and among relationships with family, friends, health care providers, and community. These findings of ambiguity have been echoed in studies of older people living with diseases other than cancer (Elofsson & Öhlén, 2004), and in a mixed population of people (aged 39 to 79) living with cancer (Little, Jordens, Paul, Montgomery, & Philipson, 1998).

Although it might not be inherently surprising or novel to find that older people experienced, for example, a high degree of uncertainty when living with cancer, or that daily life comprised a fractured set of realities, the detailed accounts of what their experiences meant for them, and the ways in which they responded, have been clearly identified by this method of systematic review and shown in the description and interpretation presented here. The findings from this review reveal the multidimensional nature of older peoples' experiences of living with cancer, throwing into sharp relief both the sources of suffering endured and the resourcefulness and resilience (Nygren, Norberg, & Lundman, 2007) older people bring to managing a changed life.

The studies reviewed revealed both positive and negative findings relating to clinical practice. Some health professionals, for example, established strong caring relationships with older people who had cancer. In some cases physicians even came to be seen as friends by their patients. But sometimes it was reported that older people felt discriminated against because of their age. As a result of becoming familiar with these findings, then, some health professionals might need to learn how to think, feel, and act differently toward older people with cancer. They might need to internalize an attitude toward older people that is respectful of their unique personalities and life circumstances. This will help to enable a facilitative and empowering approach to discussions with older people about their diagnosis and about

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

available treatments. At the same time, some older peoples' wishes to receive direction and guidance from people they perceive to be the experts should be respected. Ascertaining older peoples' wishes in this regard requires careful and individualized assessment.

Health care professionals also might need to introduce flexibility into health care systems and processes to take into account older peoples' particular needs. For example, the debilitating effects of cancer treatments and of comorbid conditions might have implications for the timing of hospital attendance for treatment and follow-up, and for support of older people during their hospital visits. Finally, for health care professionals who are predominantly in younger age groups, a leap of imagination might be needed to enable genuine empathy with people whose life situation might be one of profound existential challenge.

We undertook this review because we discovered, to our surprise, that very little primary research has been conducted in this important field. There is scope for much more research investigating the subjective experience of living with cancer in old age. The first author is following this review with an empirical study, using narrative methods in a series of face-to-face interviews with a population of people aged 75 and older living in the northwest of England.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

References

- Adler, S. R., McGraw, S. A., & McKinlay, J. B. (1998). Patient assertiveness in ethnically diverse older women with breast cancer: Challenging stereotypes of the elderly. *Journal of Aging Studies*, 12(4), 331-350.
- Barbour, R. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal*, 322, 1115-1117.
- Barroso, J., Gollop, C. J., Sandelowski, M., Meynell, J., Pearce, P. F., & Collins, L. J. (2003). The challenges of searching for and retrieving qualitative studies. *Western Journal of Nursing Research*, 25(2), 153-178.
- Bennahum, D. A., Forman, W. B., Vellas, B., & Albarede, J. L. (1997). Life expectancy, comorbidity and quality of life. A framework of reference for medical decisions. *Clinics in Geriatric Medicine*, 13(1), 33-53.
- Booth, A. (2001). Cochrane or cock-eyed? How should we conduct systematic reviews of qualitative research? Paper presented at the Qualitative Evidence-based Practice conference, Taking a Critical Stance, Coventry University, May 14-16, 2001. Retrieved August 1, 2006, from <http://www.leeds.ac.uk/educol/documents/00001724.htm>
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta-ethnography to synthesise qualitative research: A worked example. *Journal of Health Services Research and Policy*, 7(4), 209-215.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4, 167-182.
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., et al. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 56(4), 671-684.

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

- Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: The case of HIV-positive men. *Sociology of Health and Illness*, 17(1), 65-88.
- Dixon-Woods, M., Booth, A., & Sutton, A. J. (2007) Synthesizing qualitative research: A review of published reports. *Qualitative Research*, 7(3), 375-422.
- Duggleby, W. (2000). Enduring suffering: A grounded theory analysis of the pain experience of elderly hospice patients with cancer. *Oncology Nursing Forum*, 27(5), 825-834.
- Edwards, A., Elwyn, G., Hood, K., & Rollnick, S. (2000). Judging the “weight of evidence” in systematic reviews: Introducing rigour into the qualitative overview stage by assessing signal and noise. *Journal of Evaluation in Clinical Practice*, 6(2), 177-184.
- Edwards, A. G., Russell, I. T., & Stott, N. C. (1998). Signal versus noise in the evidence base for medicine: An alternative to hierarchies of evidence? *Family Practice*, 15(4), 319-322.
- Elofsson, L. C., & Öhlén, J. (2004). Meanings of being old and living with chronic obstructive pulmonary disease. *Palliative Medicine*, 18, 611-618.
- Extermann, M., Overcash, J., Lyman, G. H., Parr, J., & Balducci, L. (1998). Comorbidity and functional status are independent in older cancer patients. *Journal of Clinical Oncology*, 16(4), 1582-1587.
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26(2), 242-261.
- Feher, S., & Maly, R. C. (1999). Coping with breast cancer in later life: The role of religious faith. *Psycho-Oncology*, 8(5), 408-416.
- Flemming, K., & Briggs, M. (2007). Electronic searching to locate qualitative research: Evaluation of three strategies. *Journal of Advanced Nursing*, 57(1), 95-100.
- Green, G., Todd, J., & Prevalin, D. (2007). Biographical disruption associated with multiple sclerosis: Using propensity scoring to assess the impact. *Social Science & Medicine*, 65(3), 524-535.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

- Harden, J. K., Northouse, L. L., & Wood, D. W. (2006). Qualitative analysis of couples' experience with prostate cancer by age cohort. *Cancer Nursing*, 29(5), 367-377.
- Hedestig, O., Sandman, P., & Widmark, A. (2003). Living with untreated localized prostate cancer: A qualitative analysis of patient narratives. *Cancer Nursing*, 26(1), 55-60.
- Hopkins, A. (2004). Disrupted lives: Investigating coping strategies for non-healing leg ulcers. *British Journal of Nursing*, 13(9), 556-558, 560-563.
- Johnson, M., Long, T., & White, A. (2001). Arguments for "British pluralism" in qualitative research. *Journal of Advanced Nursing*, 33, 243-249.
- Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science and Medicine*, 47(10), 1485-1494.
- Maliski, S. L., Rivera, S., Connor, S., Lopez, G., & Litwin, M. S. (2008). Renegotiating masculine identity after prostate cancer treatment. *Qualitative Health Research*, 18, 1609-1620.
- McDermott, E., Graham, H., & Hamilton, V. (2004). Experiences of being a teenage mother in the UK: A report of a systematic review of qualitative studies. Glasgow, UK: ESRC Centre for Evidence-Based Public Policy.
- Navon, L., & Morag, A. (2004). Liminality as biographical disruption: Unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science and Medicine*, 58 (12), 2337-2347.
- Noblit, G., & Hare, R. (1988). *Meta-ethnography: Synthesizing qualitative studies*. Newbury Park, CA: Sage.
- Noyes, J., & Popay, J. (2006). Directly observed therapy and tuberculosis: How can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *Journal of Advanced Nursing*, 57(3), 227-243.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

- Nygren, B., Norberg, A., & Lundman, B. (2007). Inner strength as disclosed in narratives of the oldest old. *Qualitative Health Research*, 17, 1060-1073.
- Overcash, J. A. (2004). Using narrative research to understand the quality of life of older women with breast cancer. *Oncology Nursing Forum*, 31(6), 1153-1160.
- Paterson, B. L., Thorne, S. E., Canam, C., & Jillings, C. (2001). *Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis*. Thousand Oaks, CA: Sage.
- Popay, J., & Roën, K. (2003). *Using evidence from diverse research designs*. London, Social Care Institute for Excellence.
- Rajaram, S., Hill, J., Rave, C., & Crabtree, B. F. (1997). A biographical disruption: The case of an abnormal Pap smear. *Health Care for Women International*, 18(6), 521-531.
- Richardson, J., Ong, B., & Sim, J. (2006). Is chronic widespread pain biographically disruptive? *Social Science & Medicine*, 63(6), 1573-1585.
- Roberts, J., Morden, L., MacMath, S., Massie, K., Olivotto, I. A., Parker, C., et al. (2006). The quality of life of elderly women who underwent radiofrequency ablation to treat breast cancer. *Qualitative Health Research*, 16, 762-772.
- Ryan, P. (2005). Approaching death: A phenomenologic study of five older adults with advanced cancer. *Oncology Nursing Forum*, 32(6), 1101-1108.
- Sandelowski, M., & Barroso, J. (2003a). Classifying the findings in qualitative studies. *Qualitative Health Research*, 13, 905-923.
- Sandelowski, M., & Barroso, J. (2003b). Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Research in Nursing and Health*, 26, 153-170.
- Sandelowski, M., & Barroso, J. (2006). *Handbook for synthesizing qualitative research*. New York: Springer.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Closs and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Sandelowski, M., Docherty, S., & Emden, C. (1997). Qualitative metasynthesis: Issues and techniques.

Research in Nursing and Health, 20(4), 365-371.

Satariano, W. A., & Silliman, R. A. (2003). Comorbidity: Implications for research and practice in

geriatric oncology. Critical Reviews in Oncology-Hematology, 48(2), 239-248.

Sinding, C., Wiernikowski, J., & Aronson, J. (2005). Cancer care from the perspective of older women.

Oncology Nursing Forum, 32(6), 1169-1178.

Thomé, B., Dykes, A.-K., Gunnars, B., & Hallberg, I. R. (2003). The experiences of older people living

with cancer. Cancer Nursing, 26(2), 85-96.

Thomé, B., Esbensen, B. A., Dykes, A.-K., & Hallberg, I. R. (2004). The meaning of having to live with

cancer in old age. European Journal of Cancer Care, 3, 399-408.

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis:

Reflections on methodological orientation and ideological agenda. Qualitative Health Research,

14, 1342-1365.

Wilczynski, N. L., Marks, S., & Haynes, R. B. (2007). Search strategies for identifying qualitative studies

in CINAHL. Qualitative Health Research, 17, 705-710.

Nic Hughes, MSc, RN, is a Macmillan Research Fellow and lecturer in nursing in the School of

Healthcare, University of Leeds, Leeds, United Kingdom, and a doctoral candidate in the International

Observatory on End-of-Life Care, Lancaster University, Lancaster, United Kingdom.

S. José Closs, PhD, RN, is a professor of nursing research in the School of Healthcare, University of

Leeds, Leeds, United Kingdom.

Hughes QHR final draft post-refereeing June 2009. The final, definitive version of the article is available at <http://qhr.sagepub.com/content/19/8/1139>

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

David Clark, PhD, is a professor of medical sociology and director of the International Observatory on

End-of-Life Care at Lancaster University, Lancaster, United Kingdom.

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Closs and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Figure 1

Example of Search, Including “Filter” for Qualitative Research

1. *HEALTH SERVICES FOR THE AGED/ or *"AGED, 80 AND OVER"/ or *AGED/ or *AGED, HOSPITALIZED/ or Aged.mp.
2. elder\$.mp. [mp=title, subject heading word, abstract, instrumentation]
3. geriat\$.mp. [mp=title, subject heading word, abstract, instrumentation]
4. gerontol\$.mp. [mp=title, subject heading word, abstract, instrumentation]
5. old\$.mp. [mp=title, subject heading word, abstract, instrumentation]
6. 1 or 2 or 3 or 4 or 5
7. exp neoplasms/
8. NEOPLASMS/
9. exp Attitude to Illness/ or exp Cancer Patients/ or exp Aged/ or exp Adaptation, Psychological/ or exp Adult/ or exp Patient Attitudes/ or exp Thematic Analysis/ or malign\$.mp. or exp Pain/
10. tumour\$.mp. [mp=title, subject heading word, abstract, instrumentation]
11. 7 or 8 or 9
12. exp chronic disease/
13. chronic illness.mp. [mp=title, subject heading word, abstract, instrumentation]
14. 12 or 13
15. experience\$.mp. [mp=title, subject heading word, abstract, instrumentation]
16. (living adj2 cancer).mp.
17. (living adj chronic illness).mp.
18. 15 or 16 or 17
19. 6 and 11 and 14 and 18
20. qualitative studies/
21. ethnographic studies/
22. phenomenological research.mp. [mp=title, subject heading word, abstract, instrumentation]
23. ethnonursing research/
24. grounded theory/
25. exp qualitative validity/
26. purposive sample/
27. exp observational method/
28. content analysis/ or thematic analysis/
29. constant comparative method/
30. field studies/
31. theoretical sample/
32. discourse analysis.mp. [mp=title, subject heading word, abstract, instrumentation]
33. focus groups/
34. phenomenology/ or ethnography/ or ethnological research.mp.
35. (qualitative or phenomenol\$ or ethnon\$).tw.
36. (grounded adj (theor\$ or study or studies or research)).tw.
37. (constant adj (comparative or comparison)).tw.
38. (purpos\$ adj sampl\$).tw.
39. (focus adj group\$).tw.
40. (emic or etic or hermeneutic\$ or heuristic or semiotics).tw.
41. (data adj1 saturat\$).tw.
42. (participant adj observ\$).tw.
43. (heidegger\$ or colaizzi\$ or spiegelberg\$).tw.
44. (van adj manen\$).tw.
45. (van adj kaam\$).tw.
46. (merleau adj ponty\$).tw.
47. (husserl\$ or giorgi\$).tw.
48. (field adj (study or studies or research)).tw.
49. (lived adj experience\$).tw.
50. narrative analysis.tw.
51. discourse\$ analysis.tw.
52. human science.tw.
53. life experiences/
54. convenience sample/
55. exp cluster sample/
56. or/20-55
57. 19 and 56

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Note. Search conducted on CINAHL October 13, 2006

Experiencing Cancer in Old Age: A Qualitative Systematic Review

Nic Hughes, S. José Gloss and David Clark

Qual Health Res 2009 19: 1139

DOI: 10.1177/1049732309341715

Table 1

Cross Comparison of Study Reports by Topic (Grouped Findings)

Topic	Article										
	Adler et al., 1998	Duggleby, 2000	Feher & Maly, 1999	Harden et al., 2006	Hedestig et al., 2003	Navon & Morag, 2004	Overcash, 2004	Roberts et al., 2006	Sinding et al., 2005	Thomé et al., 2003	Thomé et al., 2004
Assertiveness	*										
Choices	*				*			*	*	*	*
Control	*		*		*	*		*		*	*
Decisions		*			*		*	*	*	*	*
Power	*	*				*	*	*	*	*	*
Information	*		*		*	*	*	*	*	*	*
Relationships (HCP*)	*	*	*		*		*	*	*	*	*
Relationships (family, etc.)		*	*	*	*	*	*	*	*	*	*
Bodily symptoms				*	*	*	*			*	*
Pain		*				*		*		*	*
Treatment	*			*	*	*	*	*	*	*	*
Masculinity					*	*					
Mental impact	*	*	*	*	*	*		*		*	*
Religion	*	*	*		*		*				
Sexuality				*	*	*				*	

*HCP = Healthcare professionals