

Discursive Meaning of Hope for Older Persons with Advanced Cancer and their Caregivers*

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RÉSUMÉ

Cette étude a utilisé l'approche du discours critique de van Dijk afin d'explorer le discours sociétaux actuel sur l'espoir, et d'explorer l'espoir des patients âgées avec cancer terminale, leurs soignants et leurs infirmières primaires. Quarante-trois articles de presse traitant de l'espoir et de cancer ont été recueillies et analysées pour explorer comment l'espoir est socialement construite par les médias de presse. Des entrevues individuelles de face à face, qualitatives et ouvertes ont été menées avec trois triades, constitués d'un patient de cancer palliatif âgé, un conjoint, et une infirmière primaire. Le discours prédominant de l'espoir et de cancer dans les articles de presse a été considérée comme discriminatoire à raison de l'âge; il a transmit le message que le seul espoir légitime qui existe pour les personnes atteintes d'un cancer est d'espérer un remède. Ce message a causé de la confusion et de la détresse pour les patients, leurs conjoints, et leur infirmières primaires, étant donné que leurs propre discours d'espoir ont été axés sur le confort, la paix et le maintien des relations à la fin de vie.

ABSTRACT

This study used van Dijk's critical-discourse approach to explore the current societal discourse on hope and to explore the hope of older terminally ill cancer patients, their significant others and primary nurse. Forty-three newspaper articles dealing with hope and cancer were collected and analyzed to explore how hope is socially constructed by print media. Individual face-to-face, qualitative, open-ended interviews were conducted with three triads, each consisting of an older palliative cancer patient, a significant other, and a primary nurse. The predominant discourse of hope and cancer in the newspaper articles was considered ageist, conveying the message that only one legitimate hope existed for persons with cancer: hope for a cure. The study findings suggested that this message caused confusion and distress for the patients, significant others, and their primary nurses because their own discourses of hope were focused on comfort, peace, and maintaining relationships at the end of life.

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Introduction

The majority of persons with cancer in Canada are over the age of 65; the median age at cancer diagnosis is between 65 and 68 years, and death most commonly occurs between ages 70 and 74 (Canadian Cancer Society, 2005). Older adults with cancer face the challenges of cancer along with those that accompany normal aging. Psychological resources such as hope become increasingly important to older adults (Cutcliffe & Herth, 2002) and are employed to deal with adversities in life (Westburg, 2003). Hope is the possibility of a positive future compared to a difficult present (Duggleby, Holtslander, Kylma, Duncan, Hammond, & Williams, 2010).

Each person's understanding of hope arises within a time and place, and with a specific nature, language, culture, and history (Baumann, 2004). Theories and definitions of hope have been developed without exploring how language is an outcome of meaning and a function of speech within a social context. The structure (e.g., words and sentence structure) and function (the way in which the words and sentences are used) of language give form to meaning, which occurs in a social context (Lahey, & Bloom, 1998). Media tends to reflect the current societal context and thus acts to shape the discourse of words (Teo, 2000). It also has an impact by reinforcing social trends (Baran & Davis, 2006). Therefore, the media can provide a reflection of the societal discourse of cancer and hope, which can potentially have an impact on older persons with advanced cancer and their significant other. Although societal values are promoted in mass media through discourse, the impact of this discourse on individuals with cancer is unknown (Seale, 2003). More specifically, the Western Canadian societal discourse of cancer and hope and its impact on individuals with advanced cancer and their caregivers has not been reported. A better understanding of the societal discourse and its influence on the meaning of hope for older adults with advanced cancer will provide a deeper and more holistic understanding of the meaning of hope in this population.

The purpose of this study was to explore the current societal discourse on hope as well as the hope of older terminally ill cancer patients, their significant other, and their primary nurse. The specific study objectives were twofold: (a) describe the social construction of hope for older adults with advanced cancer through the depiction of cancer and hope in regionally popular newspapers; and (b) explore the congruence of the newspaper reflection of one predominant societal construction of hope with the discourse of hope of older palliative patients, their significant other, and their primary nurse.

Background

The findings of hope discourse studies suggest that there are multiple versions of hope (Elliott & Olver, 2007; Elliot & Olver, 2002; Little & Sayers, 2004). In these studies, hope was focused on a positive future in a difficult present, and had multiple meanings. For example, in a study of 23 cancer patients attending an outpatient clinic, hope was objective and subjective, a burden or a resource (Elliott & Olver, 2002). The authors concluded that hope for participants had multiple meanings and discourses. Multiple discourses were also found in a study of 15 cancer survivors (Little & Sayers). For the survivors, the discourse of hope was hope for life over death, with life being a new and enhanced life. This hope was situated in two dominant discourses: one of life and death (cure), and a second discourse of meaning in life. The identification of two dominant discourses was also found in a study that explored how hope was discursively shaped for a population of dying patients in Australia (mean age: 61 years) (Elliott & Olver, 2007). A distinction was found between the discourse of life and death (hope for cure) and of meaning in life. The authors suggested that hope for a cure is narrowly defined and over-medicalized, whereas hope as meaning in life allows for a multifaceted discourse of hope that is situation specific. The authors also suggested the meaning of hope has been medicalized in western society, resulting in a narrow definition of hope as "hope for a cure" and thus impeding terminally ill patients from maintaining their own hope.

Previous research that studied hope of older adults with advanced cancer has been conducted using self-report and interviews without consideration that words of hope are not spoken in a vacuum but in the context of interaction with others and dominant cultural beliefs. Hope studies in older adults have been conducted after stroke (Bays, 2001), in community and institutional settings (Herth, 1993; Touhy, 2001; Westburg, 2003), in cancer patients in acute care settings (Fehring, Miller, & Shaw, 1997), and in advanced cancer patients receiving palliative home care (Duggleby & Wright, 2004, 2005; Duggleby, Degner, Williams, Wright, Cooper, Popkin et al., 2007). The majority of these studies are descriptive in nature yet their findings report the essential nature and importance of hope for older adults. Studies of older adults with advanced cancer suggest that these adults define hope as the possibility for a better future by conceptualizing the future as moments, hours, and sometimes days (Duggleby & Wright, 2004, 2005). In a qualitative, grounded-theory study of older adults with advanced cancer receiving palliative home care, participants described their hope for not suffering, for a peaceful death, and for their families' future (Duggleby &

Wright, 2005). These findings are in contrast to other older adult populations in which the focus of participants' hope is to get better (Hall, 1990), and the findings have suggested that hope in older adults with advanced cancer may differ from the hope of older adults in other populations.

These findings have major implications for health care professionals and families caring for persons who are dying. For example, if caregivers for someone who is dying define hope as "hope for a cure", this would conflict with how hope is defined by the terminally ill patient. The perception of hope maintained by health care professionals can have a negative influence on the quality of life of persons who are dying (Hall, 1990). Thus, if older adults with advanced cancer view hope differently than younger adults in an ageist society (Rozanova & Northcott, 2006), the culturally dominant view of hope may have an even greater detrimental influence on how older adults maintain their hope when they are dying. However, whether this is the experience of older adults with advanced cancer is not known.

Methodology

This study employed a qualitative, exploratory critical-discourse methodological approach as described by van Dijk (1991). Discursive methodological approaches explore talk as a form of action in relationship to social interaction and context. They provide a framework for examining and critiquing socially constructed values borders that impact individuals, in this case the societal discourse of hope. We conducted individual face-to-face, qualitative, open-ended audiotaped interviews with three triads, each consisting of a palliative cancer patient, a significant other, and a primary nurse. Caregivers (significant other and primary nurse) of older adults were interviewed to gain an understanding of the impact of the socially constructed hope discourse from multiple perspectives. We also collected and analyzed local and national newspaper articles dealing with hope and cancer to explore how hope was socially constructed by newspaper depictions to better understand one perspective of the dominant social context within which older palliative cancer patients define their hope. This study was approved by a university behavioral ethics review board, and operational approval was obtained from the health region.

Sample and Setting

Using purposive sampling, triads of palliative cancer patients (one male and two females), their significant others (one male, two females), and their primary nurses (three females) – resulting in a total of nine participants – were interviewed in their respective homes. The palli-

ative cancer patients had an average age of 75 (62 to 82) years and had been receiving palliative home care for 2 months. The significant others consisted of one friend and two spouses whose average age was 71 (range: 64 to 76) years. The average age of the primary nurses was 44 (38 to 51) years, and they had worked in palliative home care for an average of 15 (8 to 23) years.

The palliative care coordinator (PCC) in a rural health region in Western Canada identified potential patient participants based on the following selection criteria: (a) male or female; (b) English speaking; (c) 60 years of age and older; (d) having advanced cancer and receiving palliative home care services; and (e) able to participate as determined by the PCC. The PCC then contacted the potential patient participants to see if they were willing to speak to a researcher. If they were willing, a trained research assistant (RA) contacted the patient. The patient was asked to: (a) identify and provide contact information for a significant other who may be willing to participate in the study; and (b) identify their primary palliative home care nurse. The significant other and primary nurse were then contacted by the RA to see if they were willing to have the RA visit with them at their convenience to explain the study.

Data Collection

The *National Post*, the *Saskatoon Star Phoenix*, and the *Regina Leader Post* were searched using the Canadian Newsstand and CPI.Q databases available through the University of Saskatchewan library. These newspapers were selected as the most popular newspapers read by individuals in the geographic region on the basis of information from individuals living in the area. The most popular newspapers were selected so that study participants would have had a greater likelihood of having read them. Using the search keywords "hope + cancer" (where + is the Boolean search operator AND), 43 articles were collected in a 6-month time frame from January to July 2006, before the interviews began. The keywords *hope* and *cancer* were searched for in the entire article.

Following informed consent to participate and the completion of a demographic form, the terminally ill older cancer patient, their significant other, and their primary nurse were interviewed separately about their hope using open-ended questions such as: (a) tell me about hope; (b) what does hope mean to you; and (c) what influences your hope? Regarding influences on hope, the interviewer prompted regarding the influence of the media. The study participants were interviewed a second time to clarify what was said in the first interview insofar as possible.

Data Analysis

The interview data were transcribed verbatim by an experienced transcriptionist and managed using QSR International NVivo 7 software. In accordance with critical discourse analysis (van Dijk, 1991), analysis of the newspaper articles and the qualitative interview data involved two stages.

Stage One: A preliminary content analysis was performed to gain a sense of the patterns or trends of general themes. The interview data were coded into categories using the subject's own words as much as possible and then into themes. Representative quotations for each theme were identified. Variability and exceptions for each theme were noted.

The content analysis of the newspapers involved coding the articles for a number of standard properties: (a) name of the newspaper; (b) date of publication; (c) page number; (d) type of article (e.g., feature, brief news, letter to editor); (e) overall subject matter; (f) any interesting or unusual elements; (g) accompanying images (e.g., photographs, cartoons, drawings); and (h) the major and minor players discussed in the article. Once coding was complete, the macrostructure of each article was generally themed. This involved determining the general theme of the headline and first paragraph of the article: the "story in the microcosm" (van Dijk, 1991, p. 13). The standard properties within each article were then categorized within the general themes determined in the macroanalysis. Representative quotations illustrating each theme and category were chosen.

Stage Two: The chosen quotations from the newspapers and the interviews were critically analyzed using discourse analysis. Essentially, the structure and function of language in the interview data and the newspaper articles were identified. The researchers discussed the analysis through each stage.

Results

Discourse of Hope and Cancer in the Print Media

The focus of the newspaper articles fell into two categories: one category had 13 articles about groups of people and organizations; the second category had 30 articles about individuals. The articles describing individuals were comparable with regard to gender (12 males and 18 females). However, the majority focused on adolescents (Cutcliffe & Herth, 2002) and adults (Nelson, 2005); one article focused on children, and only three focused on older adults. The topic of two of the three articles describing cancer and hope for older adults was the older adults' inability to access an experimental drug. The third article focused on the

heroic actions of a celebrity appearing in public to help raise funds despite being ill.

Cancer prevention and cure represented the majority (35/43; 83%) of the newspaper article topics. These included stories of new drugs, new treatments, and how to prevent cancer through diet and avoiding the sun. The overall discourse emphasized the individual's responsibility to not get cancer; if they did, winning the battle with cancer was also the individual's responsibility. Some articles were stories of drugs and treatments providing miracle cancer cures leaving the individual unscarred (e.g., the title of one newspaper article about curing cancer was "Cancer survivors inspire hope for beating the disease"). In many articles, drugs and other cancer treatments were given the status of being the only source for hope (e.g., "...35-year-old has been fighting a seven-year-battle with colorectal cancer and recently started a new medication her doctor says is her last hope").

Nine (22%) of the articles were about individuals who were inspirations to others. For example, one article stated: "This year's campaign, carrying a single dream – a world of hope – was kicked off today by the personal story of a student [name] who lost her mother to cancer earlier this year" (*Leader Post*, 2006). The personal story went on to describe how the mother, who lost her battle with cancer, became an inspiration to her daughter to try to find a cure for cancer through participation in the Terry Fox Foundation campaign. The Terry Fox Foundation raises funds for research for finding a cure for cancer, which the article stated symbolized "hope in the fight against cancer". The discourse of this and other articles seemed to reflect the view that if you die from cancer, you then become an inspiration for others to fight for a cure. Moreover, the words "single dream" again imply the societal discourse of hope and cancer: that it reflects only one hope associated with cancer – hope for a cure.

Discourse of Hope of Older Persons with Advanced Cancer

The discourse of hope for older persons with advanced cancer was hope for their families: ("I hope the best for my family, my kids, that sort of thing ...") and for themselves to have little pain and a peaceful death. As one person said:

and I hope that it would go quietly, peacefully, with as little pain as possible ... and I've signed all the papers that I do not want to be put on systems ... and I would hope that more people look at what I'm doing as a ... second thought because if you're anywhere in the eighties – I've seen so many in [their] seventies and eighties who should never [have] gone through the chemo, because they've suffered through the chemo and [then] died.

Older persons with advanced cancer described multiple types of co-existing hope for themselves and for their families that did not reflect hope for a cure, but rather comfort and peace at the end of life and a positive future for their families. The discourse of hope was focused on quality of life, not life over death (hope for a cure).

Perceptions of Media

As the older persons with advanced cancer were not focused on hope for a cure, the participants described a tension between the social construction of hope for a cure and their own reality-based hope. They described confusion and distress related to the media depictions such as: "... [I] think they kind of mix you up more ... when the messages are inconsistent ... You're not sure ..." and "If you hear, like, someone's experience that, you know, they went through something, and you know it prolongs their life and it gives you hope to think ... Well, I am in that situation: that maybe it might help me ... But ...".

Discourse of Hope of Significant Other

Significant-other participants described hope related to them and to the person they were caring for. They described their hope to continue caregiving and to enjoy the time left: "[You] just hope [there are] days that you can ... enjoy, and help" They also had hope that their family member with advanced cancer would be comfortable and have a peaceful death. As one participant said: "My hope at that stage ... was that whatever [else], death would be gentle" The symptoms experienced by the person they were caring for decreased their own hope. Quality of life was important: "Hopefully, ... in the meantime she [person with advanced cancer] will have some quality of life" Similar to the discourse of older adults with advanced cancer, their hope discourse was quality of life.

Perceptions of Media

The significant-other participants also expressed a pattern of tension when others or the media dictated what they should hope for: "On certain literature on health topics, like I say, you know, it seems every doctor will have a different opinion Or, like you say, [their opinions are] inconsistent, sort of, with the information" They regarded information in the media as inconsistent and also incomplete: "Don't believe everything you read ... there's always some background that is missing." Their own reality was a world of uncertainty and lack of control: "There's so much that's out of your control."

Discourse of Hope of Primary Nurse

Primary nurse participants caring for older palliative patients and their families described their hope to help

their patients find hope. As one nurse said: "[My hope] is to work to find something in their life that will give them a bit of hope." The primary nurse participants counteracted the predominant societal discourse of hope (hope for cure as the only hope) by reminding palliative patients and their families that many kinds of hope exist. As one participant said: "Well, to me, hope means mostly when [we're] looking at palliative [care, that it] is allowing families to know that there is a lot of hope"

Perceptions of Media

The social construction of hope depicted in the media also had an impact on the hope of the primary nurses. Nurses reported a tension between the social construction of hope (hope for a cure) and their work with people who are seeking comfort (palliation, and not a cure for their cancer). In other words, restricting the concept of hope to only "hope for a cure" was contrary to the valuable work of palliative home care nurses. Due to this limited conceptualization of hope, individuals within society may perceive the work of palliative home care nurses to be "un-hopeful". One primary nurse participant indicated many people believe they must lose hope within their position:

Lots of people think that [for] people [who] work in palliative care it must be very depressing and very un-hopeful I think, if anything, that's where you see the hope, and you see the families coming together, and you see the positives that come with that ... I think that, if anything, it instills hope

Discussion

Our preliminary data indicate that the current societal discourse of hope and cancer, as depicted in the print media, is possibly ageist and cure-focused. Ageism is the discrimination of a person based on their age, and under-representation in the media of older adults is considered a form of ageism (Dahman & Lozma 2009). Our study reveals that seniors are under-represented in newspaper articles regarding cancer and hope despite older adults' constituting the majority of Canadians with cancer. The media has consistently been criticized for this overt ageism for approximately the past 30 years (Nelson, 2005; Rozanova & Northcott, 2006). The under-representation of seniors in the articles implies that older adults will not benefit from cancer prevention initiatives and should not be considered as examples of survivors. The current message regarding cancer and hope focuses upon curing young individuals or making an inspirational case of those who lose the battle. From an ageism perspective, this reflects a devaluing of older adults in our society.

The media discourse of hope and cancer currently presents hope as having a single focus: if a person has

cancer, then the person hopes for a cure. This narrow focus was also reported in a study of newspaper articles on cancer in the United Kingdom (Canter, 2006), which concluded that newspapers portray a self-willed victory over cancer and the limitations of the body. The articles we examined were about the cure of cancer and an unblemished view of survivorship, and again hope was framed within the context of a possible cure.

The evolution of the current conceptualization of hope can be traced through history. A discourse analysis of letters from the U.S. Food and Drug Administration in the 1950s suggested the message of hope as cure was instituted by the American Society for the Control of Cancer in 1913 (Canter, 2006). The message of hope was created to persuade people to stay away from “quacks”, to seek early diagnosis, and to continue with painful cancer treatments. This movement evolved to include the phrase “hopeless cases” when cancer treatments did not result in a cure, placing blame on the individual, not the treatment. From this movement evolved the belief that cancer drugs and treatments are the “only hope”. It also framed alternative therapies as offering “false hope”. From our findings, the discourse of hope in the current print media reflects the success of this movement in shaping our societal meaning of hope in the context of cancer. The discourse of hope in the cancer context (hope for a cure) underpins the entire enterprise of cancer research and treatment, serving to justify fundraising activities for research (Good, Good, Schaffer, & Lind, 1990).

The discourse of “hope for a cure” as the only single legitimate hope impacts older palliative patients, their significant other, and their primary nurse. Our data suggest it creates confusion and tension between the reality depicted in the media and the patients’ individual realities. Although our data are very preliminary, it showcases the discord between the current discursive meanings of hope; hope as currently used by the media is in the context of hoping for a cure. Many studies, however, suggest the meaning of hope for palliative patients is the hope for others, not suffering, and a peaceful death (Duggleby & Wright, 2005; Herth, 1990). This reflects a discourse of hope that is framed by quality of life, not life over death.

Our findings – demonstrating that the focus of the hope of family caregivers is to continue caregiving and to enjoy the time left with the older person – are similar to those of previous studies (Benzein, Norberg, & Save-man, 2001; Borneman, Stahl, Ferrell, & Smith, 2002). Moreover, our own mixed-methods study found that palliative nurses described their hope as offering hope to others (Duggleby & Wright, 2007). Thus, those caring for older palliative patients recognize multiple meanings of hope and do not focus on hope for a cure, which conflicts with the meaning of hope depicted by the print media.

Factors Influencing the Study

A small number of triads were interviewed for this study, and our findings are preliminary. The participants were identified by palliative care coordinators, and it is possible that others who may have been eligible for the study were not included and may have a different hope discourse.

The interviews with the older palliative patients, their significant other, and their primary nurse allowed us to collect in-depth data regarding the use of the word *hope*. However, the analysis of the printed newspaper articles was limited to what was written, and thus did not provide any opportunity to probe for an in-depth understanding of the meaning of hope. As well, newspaper media is a proxy for one dominant social discourse. Other media such as film, for example, may portray a different social discourse. The reported findings should be interpreted in light of these factors, and future research is needed to determine if the societal discourse of hope is similar in other forms of media and with larger samples.

Conclusion

Although several factors influenced the findings of this study, the use of discourse analysis allowed us to explore the meaning of hope as depicted by the print media as well as for older palliative patients, their significant other, and their primary nurse. The data clearly demonstrate that the meaning of hope differs significantly between the media and the participants. This may be due to the under-representation of older adults in the articles as well as the predominant focus on cancer prevention and cure; the palliative patients interviewed had made a decision to not seek treatment to cure their cancer, but rather for their comfort. Moreover, older adults have been shown to experience cancer from a different perspective than younger adults (Duggleby & Raudonis, 2006).

The media depiction of a single hope – hope for a cure – invalidates the multiple definitions of hope within society as well as the hope held by those who are dying and those who care for them. Our findings suggest the media reflects a narrow societal view on hope and cancer, which causes distress in those who are approaching death. In some cases, it causes individuals to lose hope as they are no longer hoping for a cure. Understanding the difference between the societal view of hope and that of older adults with advanced cancer has implications for those who are in contact with this population. Friends, family, and health care professionals should be aware of their own perception of hope, as it may be based on the current societal discourse and as such will differ from the perception of older adults who are dying. Hope is the possibility of a better future, and older palliative patients may define

better as being comfortable and *future* in terms of hours or days. Recognizing that “hope for a cure” is not the only legitimate hope will help foster hope in older adults and their caregivers at the end of life.

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