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Understanding functional health literacy in experiences with prostate cancer: older men as consumers of health information.

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ABSTRACT

This paper presents part of the findings of a doctoral study aiming to understand the construction of informational strategies for living and dealing with Prostate Cancer related information according to self-reported levels of functional health literacy. A qualitative modeling design framed the inquiry through the constructivist perspective. Older men recreate modes of living and attitudes toward information according to their social and cultural capital, as well as the intensity of their contact with an informational network. Self-reported levels of functional health literacy seem to be harmonious with distinct informational profiles/patterns despite differences in general literacy or formal education. This study implies a new understanding of functional health literacy and its role, the dynamics of social/informational networks, as well as the needs of redesigning communication strategies.

Key words: functional health literacy, qualitative modeling, prostate cancer, prostatic neoplasms.

INTRODUCTION

The specific health demands of older individuals and their misidentified ways of living with health information corroborate the importance of responding to the following question: "What is the nature of functional health literacy within a pragmatic and constructive dimension?" The ultimate goal is to develop a theoretical foundation regarding the strategies built by older individuals who admitted having literacy limitations for simultaneously interpreting, choosing, and deciding health information. The core of this inquiry dealt with the effects of older men's contacts with health and Prostate Cancer (PC)- related information while living in their natural social environments. The aim was to explore informational profiles based on their actions for gathering information, fulfilling informational gaps, and incorporating new pieces of information.

The phenomenon under inquiry

The phenomenon under inquiry was driven from two main observations. The first was made while attending a lecture composed of almost sixty participants, most of whom asked questions about cancer. The second was conducted in a Montreal university-affiliated hospital in the province of Quebec-Canada. This last observation focused on the identification of behaviors displayed by individuals who were hospitalized, regarding health information in care-giving situation and interactions with health professionals (Zanchetta, 1998). These are the thoughts that launched this inquiry: (a) social interactions-opportunities to build up or be engaged in a network of health information, (b) social interactions-enhanced ability to understand and incorporate cancer-related information, (c) cultural values within social

milieus-access to and circulation of cancer-related information, (d) social connections-enhancement of functional health literacy-understanding about cancer experiences.

Goals

The original inquiry (Zanchetta, 2001) aimed to describe, analyze, and understand the process of living and dealing with PC-related information through the construction and use of informational strategies by older men as a systemic, twofold process within their social and natural environments.

Question of inquiry

This paper only concerns with the answers to question IV of the original inquiry: "Do manifestations of profiles and patterns while living and dealing with PC-related information throughout self-reported levels of functional health literacy exist?"

Literature review

Despite a growing amount of contrary evidence in the literature, one's highest formal education and general literacy remain seen as preconditions to ensure needed skills to understand health information (Merriman, Ades & Seffrin, 2002). It is an ability to understand and use a dominant symbol system within a technological society (Centre for Literacy of Québec, 2004). The functional health literacy is known to be related to cultural, cognitive, and social and contextual features of having access, reading, framing, decoding, understanding, and acting on health information needed to make health decisions (Andrus & Roth, 2002). According to Doak, Doak, Friedell and Meade (1998), signs of dysfunctional literacy are

revealed by poor reading, literal understanding of words, slow reading, partial losing of the meaning, skipping words, and misunderstanding context. Other signs are easy fatigue while reading, reading within an inappropriate cultural context (Macario, Emmons, Sorensen, Hunt & Rudd, 1998), and inappropriate health behaviors such as misunderstanding medicine labels, hospitalization due to dosage errors, difficulty in following the physician's recommendations and instructions, misunderstanding of customers' rights (Gazmararian et al, 1999), and consciously giving informed consent (Merriman, Ades & Seffrin, 2002).

Such dysfunctional health literacy is due to a limited comprehension of written and spoken health information; lack of trust in written health information and preference for personal communication; inability to understand health-related words, categories, concepts and values; insufficient information about the health system; and shame and embarrassment in revealing limitations, use of complicated language by health professionals, lack of consideration of the unequal logic and experience between physicians and clients (Williams, 2002), poor recognition and acceptance of the problem by the general population, health professionals, researchers, as well as low literary abilities (Clough, 2002). Other explanations include difficulties in dealing with statistical information about ratios, probabilities related to the prognosis, or percentages while examining treatment-related facts, limited reading skills usually lower than one's education level (Albert & Teresi, 1999) affecting the understanding of medical messages (Parikh, Parker, Nurss, Baker & Williams, 1996), limited consultation of libraries and other formal sources of health information (Baker & Wilson, 1996) and use of the health services (The National Work Group on Literacy & Health, 1998).

Besides increasing access to information to overcome misconceptions of treatment limitations for controlling cancer progression, and protection against metastasis (Clark et al, 1997), a supportive network facilitates the processing of illness experiences (Lepore & Helgeson, 1998) reducing family uncertainty and facilitating men's adjustment to prostate cancer (Harden et al, 2002). The informational network is composed mainly of the urologist, radiation oncologist, spouse (Diefenbach et al, 2002), peers (Harden et al, 2002) and relatives including consultation of other informal sources (Davison et al, 2002).

In summary, a lack of research was found in the way PC-related information is incorporated according to the levels of functional health literacy, how social interactions in natural environments influence the way men live and deal with PC-related information, as well as the informational behavior of a less educated, less active or less interested consumer of health information and users of health facilities.

Philosophical and Theoretical perspectives

The constructivist and simultaneity paradigms formed the methodological and theoretical frames of this inquiry. Health experiences of the participants were understood as Newman's health vision of an expanding consciousness (Newman, 1995). Understanding the strategies linked to education and learning was based on Freire's theoretical approach about a critical awareness in education matters (Freire, 1999). In addition, Morin's innovative learning theoretical perspective (Morin, 1993) on adult education supported the understanding of actions toward a renewed learning within a social perspective. Constructivist view of learning (Schwandt, 1994) framed the method of rebuilding my personal and professional

knowledge and the collective construction of knowledge about the phenomenon under inquiry. Equal paradigmatic roots guided the method of inquiry because the qualitative modeling is inserted in this vision of science (Jaccoud & Mayer, 1997; Le Moigne, 1994).

METHOD

The qualitative modeling design is derived from the methods of naturalistic inquiry developed within the social sciences (Mucchielli, 1996). The core of this design is the conception of a simple representation of a complex process without losing its essence, thus avoiding the risk of an over simplistic view. Data are gathered grasping facts, actions, operations, context, agents, consequences, results and outcomes (Le Moigne, 1994), as applied in naturalistic inquiries (Creswell, 1998; Denzin & Lincoln, 1998). The typical analysis aims to reduce elements of a phenomenon to their important characteristics (Mucchielli, 1996).

A non-probabilistic method of purposeful sampling with multiple cases for contrast-saturation, network and stratified purposeful sampling (Pires, 1997) determined the minimum final sample of fifteen participants. Criteria of inclusion were: (a) having received a medical diagnosis of a localized or non-organ-confined PC; (b) childhood spent in Québec; (c) ability to define one's own level of functional health literacy; (d) effective communication in French; (e) normal time and space orientation, and (f) no reports of drug treatment for psychosis. Levels of functional health literacy were self-reported by each participant after listening to the following introductory explanation-question: "Health literacy means one's capacity to read, understand and use health related information. How could you assess your own?"

The sample was formed by thirteen French Canadians and two immigrant men, one from France and another from Algeria, aged from 61 to 83 years reporting high (n=8), middle (n=6), and low (n=1) functional health literacy. Their schooling profile associated with such levels revealed that 8 men reporting high level had 3, 4, 6, 8, 9, 10, 13 or 19 years of schooling, 6 men reporting middle levels had 4, 6, 9, 10 or 20 years of schooling, and 1 man reporting low level had 4 years of schooling. Regarding their reported socioeconomic level they were high (n=8), middle (n=6), middle/low (n=1). Their marital status was married (n=13) or widower (n=2). Their time since diagnosis varied from 1 to 11.5 years, with stages of cancer from stage D (n=5), stages A /B (n=5), unknown (n=4), to recurrence (n=1) having concomitant diseases such as cardiac, vascular, renal, metabolic, and respiratory.

Data were gathered by open-ended, semi-structured interviews, genograms, ecomaps, observation, personal logs of the researcher and the participants, personal documents, and other sources in an undefined methodological triangulation. The one-time interviews each had an average duration of 79 minutes. Participation was voluntary and unpaid. Participants were informed of the right not to answer questions and to interrupt the interview at any time. Copies of the recorded tapes were mailed to participants, if wished. Nine men who requested the tape received it 40 days post interview. A final version of the text containing all data was prepared for improving interpretation credibility as a situation-related interpretation (Lapadat & Lindsay, 1999). The coding procedure was performed by the software Atlas.ti version 4.1 for Windows 95, a standard qualitative analysis package (Muhr, 1991; Muhr & Scientific Software Development, 1997). The coding procedure was initiated by a list of first-level codes (Miles & Huberman, 1994) with "health

information” as the master code. Interviews and other findings were analyzed using a cross-case analysis (Miles & Huberman, 1994) with the grouping of responses by each question. The corpus was submitted to content analysis to the identification, codification, and categorization of the patterns existing in the data (Bardin, 1997).

The verification of the interpretation of the findings involved: (a) participant verification at the end of the interview; (b) confirmation of the general interview interpretation by six natural experts (four men reporting high level and two reporting middle functional health literacy level); (c) assessment of meaningfulness in the interpretations about the particular tendencies of each level. The main differences in the unfolding of the phenomenon were discussed jointly in a meeting with the group of natural experts. Varied contacts in the field, continuous observation, triangulation of sources and methods, and member checks ensured credibility and transferability of data, ensuring the trustworthiness of the findings. An all-encompassing description helped ascertain transferability (Lincoln & Guba, 1999). Ethical restrictions justified the dismissal of a confirmation criterion. As written in the signed informed consent forms no access was granted to external auditors. No code name was used to identify the verbatim quotes in the report.

Limits of this inquiry included (a) identification of medical conditions (stage of cancer and use of drugs) only by personal reports; (b) assessment of time and space orientation only by simple introductory questions; (c) possible interference in data quality due to interview interruption, recall bias and use of context and vocabulary unfamiliar or utilization of a specific language; (d) difficulty in reaching data saturation due to a non repetition of patterns; (e) poor representation of men reporting low functional health literacy; and

(f) minimal recruitment of men not enrolled in support groups. The aforementioned limits jeopardized the transferability of the findings to a population of older men reporting low functional health literacy, low socioeconomic class, and no involvement in a support group.

MAJOR FINDINGS

Informational profiles by levels of functional health literacy

Differences in the levels of functional health literacy tailored the creation of an informational network, and the mobilization of the informational resources. In addition, the intellectual processes used in dealing with PC-related information addressed the features of comparison, deduction, and hypothesis formulation. Professional dialect with no concern about language appropriateness and the silence among men who had little intention of talking to each other about PC-related issues were reported as the two major barriers to acquire PC-related information. Men explained both barriers as being natural features to avoid the disclosure of experience, feelings, and thoughts on masculinity and integrity. Moreover, perhaps due to a superficial social relationship, there was unwillingness to openly ask peers about health, resulting in not knowing what to speak about or how to ask others about the disease despite attentively listening to others’ stories about PC and health advice.

The particular informational strategies in high functional health literacy

Men who reported high functional health literacy revealed the contact with the informational network as being their major strategy to live with PC-related information.

The relationship with a formal source of health information occurred mainly with physicians because they needed a counselor on PC issues to justify multiple contacts to discuss clinical situations, learn more about the actual prognosis, and receive specific information by supplementary educational material. Altogether, a climate of partnership and trust was created due to the acknowledgment of professional competence, medical authority, and scientific knowledge about PC, trust was manifested through the critical evaluation of health education activities because some men emphasized that they were aware of their rights to health information and care.

Participants interacted with the Prostate Cancer Support Group (PCSG), friends, relatives, and peers who played complementary roles by exploring other informal sources and by acquiring further health information. Consequently, some men had access to specialized readings, while other men shared the reading of educational material (e.g., newspapers, books, and magazines) with their wives who helped with the complexity of technical words. Reading books on PC as a customary strategy for gathering information constituted the main strategy for consulting and using informal sources of information. The contents of interest were corporal anatomy and technical information about PC, giving an essential knowledge to its identification, reconstruction of one's self-identity as a man living with cancer, as well as launching an in-depth search for information.

Movies and specialized magazines, newspapers on PC were the second most common informal source of information to acquire instrumental information on PC treatment, often a precondition to decide a therapy modality as well as to take advantages in gathering information from multiple sources,

for example becoming critical, selecting higher quality information and knowing more about PC. As a result, men more actively requested physicians to clarify information by asking them direct questions externalizing a keen attitude to gather additional knowledge from an informational environment. According to them, they are open to accepting health information, readily recognizing the contribution of particular traits that place them in a more favorable position to deal with health information, as well as to accept external aid offered by other men from one's social network.

Knowing more about the in-depth nature of PC processes supported the major tendency to deal with information in this subgroup of participants: hypothesis formulation exclusively on metastasis and recurrence. Therefore, no concern about a non-favorable disease progression was revealed. Another way of dealing with information concerning a routine strategy for controlling one's health was through self-assessment of physical and emotional changes, and by looking for new or complementary information. Such assessment was usually related to unexpected findings and modifications, especially when no information was offered before or after procedures. Moreover, it also related to emotional conditions to define the necessity of taking medicine, often ascertained while avoiding overuse.

The particular informational strategies in middle functional health literacy

Men who reported middle functional health literacy tended to read about general subjects but not PC, despite an interest in understanding causes, as exemplified by the only man who recalled reading informative pamphlets. They tended to use nonspecific tools for gathering information. Moreover, none watched movies for gathering in-depth information on treatment, nor did they take advantage of learning

opportunities from the experiences of other men with similar health conditions. There was a tendency to be rather closed to new in-depth information, but a special interest in concrete factors of the therapy results. The tendency to formulate hypotheses on the PC treatment is associated with the notion of surgical “castration” as a definitive solution, continuous medical surveillance, as well as the technical principles of therapy modalities. Despite their interest on treatment-related issues, there remain misunderstandings regarding the treatment aims as well as its specific procedures.

Another tendency was to monitor inconspicuously the concrete responses to the therapy through the interpretation of the results of the tests. None of the participants in this subgroup adopted preventive behavior toward an early detection of any kind of cancer, despite family history of cancer, previous urinary symptoms, or other signs. Other tendencies included some communication about PC information to other men. Although in an intimate climate, they tended to share illness experiences with their sons. Preventive behavior was subtly suggested to friends through sharing information. The participants in this subgroup perceived this strategy as being helpful to other men, who could transmit PC-related information within their social milieu and benefit from sharing knowledge with other men.

There was a tendency to compare instantaneously new pieces of information with existing ones. For example, while watching television programs on PC, one man compared information on long-term consequences of the surgery with the information transmitted by his urologist. The strategy of applying information through the procedures of self-assessment was identified, although an unusual strategy. The less-often reported strategies seemed to define an in-depth personal style of dealing with PC

information as well as a unique trait, including a preventive behavior for handling unexpected or negative information, as well as the use of media as source of information.

The particular strategies in low functional health literacy

The one participant who reported low functional health literacy identified a tendency neither to reveal personal information to other men or to discuss sexual issues with his wife, nor to share illness experiences with his wife, daughters, and friends. This man did not identify an existing network for social support or contact with other men living with PC but was aware of several aspects related to the omitted information. He also recalled the existing barriers of silence among men in discussing the disease. No decision rationale related to treatment, exploration of information, or comparison with other men’s illness experiences was identified. For this man, the diagnosis was completely unexpected. The level of acceptance of the PC diagnosis was unclear in his narrative, since he seemed actually unconcerned with the possibility of having PC because he had no physical symptoms. However, once the diagnosis was confirmed, this man was also the only participant to openly require time to decide and accept a suggested therapy.

This participant also expressed his reluctance in accepting and undergoing long-term therapy because he was not convinced of its necessity. Moreover, he believed in the short duration of the side effects of hormone therapy. Regarding the strategies for acquiring information, this man described a tendency for reading but specifically for gathering specific content. In addition, this man was the sole participant who considered the possibility of receiving new information through contact with his urologist. He revealed the

perception that the urologist was the ongoing source of PC-related information. He recalled his request for the urologist's consent to apply the gathered knowledge.

The shared tendencies in high and middle functional health literacy

Before the diagnosis, they were rarely concerned with the disease since the absence of dysuria was assumed as being an actual sign of the absence of the disease. However, even those who had symptoms of dysuria did not think about PC. Reactions upon receiving the diagnosis indicated a negative moral and emotional nature with a reluctant acceptance, and feelings of panic and resignation. An intense impact was evoked because the representation of cancer brought forth images of life ending and affective memories of painful PC suffered by fathers and grandfathers. Living with another form of cancer increased the impact provoked by the diagnosis. Regarding the attitude facing the imminent danger of PC, men tended to be unconcerned about the danger of the disease because they received information that this disease was less invasive than others and not a mortal type of cancer.

No one sought a second medical opinion and they had no previous knowledge on PC treatment. Active search for information demonstrated some openness to receiving information since any available opportunity to read and learn about PC, as well as to explore scientific information of new discoveries related to PC and its genetic risk was considered. The use of informal sources of information (for example, magazines and television) was valued since they helped to understand unexpected tests results and treatments in conformity with their representation of cancer, and consequently better understood the stages of PC evolution.

Despite their struggles to learn, inadequacy

of PC-related information remains as shown by misinformation on the causality factors of PC such as beliefs about a consequence of abusive sexual activity or sexually transmitted disease, difficulty in recalling names of their treatment and diagnostic procedures, the prescribed medications with the complementary information on drug effects and usage, partially remembering the goals and procedures of surgical and clinical treatment, understanding the meanings of medical tests and examinations, and using this information in their daily lives. In addition, the need to deal with concepts related to statistics pushed them to tentatively associate the ideas of success/failure rates or percentages with favorable conditions to treatment success.

There was a high tendency to share and transmit PC-related information within their social relations by disclosing their personal condition, discussing their personal illness experience with peers, and sharing those experiences with their wives. One's intention to reveal his illness experience depended on the variability of his mood or emotional state, despite speaking often about his illness. The influence of masculine pride inhibited the disclosure of the illness experience and of the specific intentions when discussing health matters. Strategies to ensure the establishment of a favorable climate included the use of tests' graphical representations and drawings, talking overtly to couples, taking advantage of club meetings to reveal their personal condition, and a person-to-person approach. Conversely, other strategies were used to diminish other people's curiosity or discourage further questions about their personal condition. Frequent meetings with friends allowed easy-going conversations, mainly among those who also lived with PC and shared their own experience as well as others who were healthy who frequently asked for news about the improvement of the participants' health conditions.

Decisions and explanations related to the act of sharing illness experiences with their sons corroborated the idea of an existing “code of silence between men” that would either be kept or broken. The silence between fathers and sons was perceived from two opposite perspectives: for the sons’ protection, that is, from one’s feelings of fatherhood; and his perceived inherent responsibilities. The reasons for sharing information and illness experience with sons combined concerns about a possibility of another case of PC in the family, confidence in speaking about PC, the value of talking about illness experience to improve one’s own well-being, paternal responsibilities, as well as perception of being open-minded man. Reasons not to share illness experiences with sons included inadequacy of discussing parental subjects with children, not wanting to upset sons with daily problems caused by PC, sons’ lack of concerns about PC, and difficulties with revealing personal conditions provoking feelings of frustration and regret.

Another social environment shared among the participants was a support group where the core of the discussions concerned the experience of peers. Most of the discussions were based on questions concerning the advanced stages of PC and how to overcome the difficult symptoms of the illness. In response to these questions, the participants used a natural approach to transmit their actual experiences because the participants valued clear and precise information. Discussions with peers were favorable to direct questioning where feelings of optimism were reinforced and encouraged.

Deductive thoughts seemed to be a common strategy to deal with information because of its influence on understanding illness-related events. For instance, men deduced that the monitoring of PSA titration based on the factual indicator of the blood tests meant the compulsory restart of

the hormone therapy, or a clear sign of disease progression. The absence of pain symptoms meant certainty of being free of prostate cancer. Other examples of deductive thoughts were related to non-concrete aspects of the disease and its treatment. Another frequent strategy in decoding statistical information was mainly related to the probability of healing and survival, usually understood as being one’s time remaining to live.

The existing tendencies across levels of functional health literacy

The findings revealed some tendencies in the informational strategies to live and deal with PC-related information. First, there was a high tendency to perceive PC as an innocuous disease, justifying nonchalant reactions to the diagnosis. Second, there remained partial information and the lack of comprehension of clinical conditions and/or the evolutionary stage of PC. Third, enjoying reading was linked with the interest in reading books about the nature of the prostate gland, survival, prognosis, and various treatments and to learn about principles of chemotherapy, preparation for undergoing chemotherapy and its effects, and modes of adaptation to PC. Fourth, clinical conditions and treatment effectiveness were assessed through alterations on PSA titration. Fifth, it was less likely for men to seek a second opinion from another urologist to confirm the need for therapy, to seek out scientific evidence related to health information, or to correlate existing health information with new information. Sixth, there was recognition of the physician’s professional competence and trust between physician and client rendering information gathering from other informational unnecessary sources. Finally, there were feelings of embarrassment in revealing expectations of the prostate biopsy results and confirmation of the urologist’s PC hypothesis to their wives.

DISCUSSION

The inquiry revealed some contrary findings regarding the current state of knowledge about functional health literacy, despite the differences in formal education and self-reported level of functional health literacy. The participants commonly held misunderstandings, gaps, and inappropriate PC-related information. We identified the congruence between the self-reported levels of functional health literacy and the modes of dealing with PC-related information, and not with one's level of formal education with no necessary correspondence between one's level of formal education and functional health literacy (Merriman, Ades & Seffrin, 2002).

The ability to function well with health information included the notion of possessing the ability to treat health information and value the inner difficulties in order to understand medical language and discourse. Such functioning did not attain levels of general literacy as a precondition to ensure higher skills in mastering issues of health literacy as recalled by Andrus and Roth (2002). The main pattern to treat PC-related information included the use of deductive and hypothetical reasoning relied on the remaining state of uncertainty about personal behavior and attitudes before the PC diagnosis, medical decisions, events as well as other experiences along the PC trajectory. Equally the tendency to make social comparisons with other people living with cancer illustrated the most frequent profile of living with cancer related information (Bennenbroeck, Buunk, van der Zee & Grof, 2002).

The implications and recommendations for nursing practice

The main implication of nursing care for older individuals include the responsibility of establishing measures to create professional

links with family physicians and urologists to break the structural barriers of health care delivery to reach the older men (Greene & Adelman, 2003). Based on the findings of the present inquiry, the recommendations are the followings:

1. Considering that education level, years of schooling, and socioeconomic status, do not determine one's functional health literacy level, it is recommended that nurses be aware that functional health literacy is a result of a broad socially constructed process rather than a set of abilities comprising of reading, counting, and recognition of words.
2. Considering that the existence of an informational network is a favorable feature supporting functional health literacy, it is recommended that nurses be particularly attentive to the nature and extension of the social network, where the individual is involved.
3. Considering that older men perceive informative pamphlets, although written in medical language, as less credible than other sources of health information, it is recommended that nurses encourage their clients to work in collaboration with them and invite physicians to prepare educational materials to respond to knowledge gaps and misunderstandings on prostate cancer.
4. Considering that older men take a particular interest in prognostic information through social comparisons with other individuals living with cancer, it is recommended that nurses redesign with the clientele, innovative strategies to communicate others' experiences with cancer.
5. Considering that the findings of the present inquiry only identified the informational strategies of older men living and dealing with PC-related information, it is recommended that nurses register their

clinical observations of manifestations and general particularities of informational differences.

FINAL COMMENTS

The differences within the three levels of self-reported functional health literacy occurred in the sociocultural perception of PC, levels of awareness, intellectual managing of information, as well as the satisfactory level of information. Furthermore, the major manifestation of the differences within the levels of functional health literacy regarding the mobilization of one's informational network as a strategy to live with PC-related information seemed to be scattered and imprecise.

The main contribution of this inquiry relied upon the characterization of the autonomous process of learning about health as a long-lasting initiative of one's life. Knowledge is rebuilt within a frame formed by the support from beloved ones, the preservation of social roles, as well as the redefinition of self-identity. Further studies should describe the ways to face the lack of health information while living with the illness in natural environment devoid of or with limited educational resources in the community, explore the same phenomenon with those men reporting low levels of functional health literacy, having no contact with PCSGs in their communities, being of different ages, and having different socioeconomic status and cultural background.

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